

Collaborating Center for Questionnaire Design and Evaluation Research

June, 2024

Findings from a Cognitive Interview Study of Survey Questions Administered with Adults with Intellectual and Developmental Disabilities

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1. INTRODUCTION

This report summarizes findings from a study designed to better understand the survey question response processes with people with Intellectual and/or Developmental Disabilities (IDD) within a population survey setting. The study was carried out by the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), using cognitive interviewing methods. The study was conducted on behalf of the Department of Health and Human Services (HHS), Administration for Community Living (ACL), Administration on Disabilities (AoD).

The main aim of the study was to provide an interpretive assessment of the way in which respondents taking part understood and formulated a response to relevant survey questions, covering different functional disability domains.

The assessment is intended to inform those designing survey questions for use with adults with IDD, and those managing the administration of those questions. In addition, it is hoped that this report will be of use to those making decisions about how to identify adults with IDD in population-based household surveys.

Additionally, population surveys sometimes allow for proxy responses to survey questions. This can occur when one person in the household is selected to respond on behalf of all other household members. A proxy respondent may also be sought when a sampled respondent is deemed incapable of providing their own responses. Therefore, for comparative purposes, in some cases, both the person with IDD (the reference person)¹ and a potential survey proxy respondent, took part in a cognitive interview to form a respondent-proxy dyad².

Suggested citation:

Wilmot, A., MacFadyen, A. Findings from a Cognitive Interview Study of Survey Questions Administered with Adults with Intellectual and Developmental Disabilities. National Center for Health Statistics – CCQDER. Q-Bank. 2024. <https://wwwn.cdc.gov/qbank/report.aspx?1250>

¹ For the purposes of this report the person with IDD may be known as the reference person when interviewed as part of a respondent-proxy dyad.

² All respondent-proxy dyads resided in the same household except in one case where they lived separately but close by.



Questions used in the study included those from the standard short set of disability questions used in the United States, to include functional domains covered by the Washington Group on Disability Statistics³ and the American Community Survey.⁴ The domains covered by this study included vision, hearing, cognition, mobility, communication, self-care and independent living, along with additional questions on the domains of learning and social participation. A question about age of disability onset was also included.

The study was iterative, involving a period of analysis and reflection between two rounds of face-to-face, one-on-one cognitive interviews. Round 1 interviews were conducted in-person during the latter part of 2019. Round 2 interviews were conducted during the latter part of 2022. The hiatus between rounds was considerably longer than expected due to the COVID-19 pandemic which began shortly after completion of Round 1. As a result of the pandemic, Round 2 interviews were conducted remotely using a CDC approved video-conferencing platform in order to comply with the CDC's recommendations of social distancing. No changes to the questions used in the study were made between rounds.

In total, 56 English-speaking adult respondents took part in cognitive interviews. Thirty-six respondents were considered to have IDD (see also section 3.2.2 for a more detailed explanation of how respondents were classified for this study). Twenty could be considered as not having IDD, and, of those, 16 were classified as potential proxy survey respondents for those with IDD, interviewed in tandem as respondent-proxy dyads. Four were self-reports not considered to have IDD. Sixteen questions were evaluated (included in Appendix 2). This study received OMB and CDC Human Subjects review and approval.

This report summarizes findings from both rounds of cognitive interviews. It includes a summary of general findings, along with interviewer experiences, and commentary on certain phenomena which influenced the way in which respondents with IDD were able to understand and answer the survey questions. Findings related to each question included in the study are presented as part of a question-by-question review.

2. BACKGROUND

CDC conducts nationally representative surveys that provide data on the health of adults and children in the United States. The National Health and Nutrition Examination Survey (NHANES)⁵ and the National Health Interview Survey (NHIS)⁶ collect information on developmental disabilities and delays in children.⁷ However, as Havercamp et al. (2019₍₂₎)⁸ note, current national health surveillance systems in the United States offer little or no information about the prevalence and health status of adults with IDD. Therefore, the American Association on Intellectual and Developmental Disabilities (AAIDD) convened a multi-agency, multi-stakeholder meeting which recommended that a workgroup be established, tasked to work with NCHS to determine what would be needed to identify respondents with IDD in the NHIS (Krahn, 2019).⁹ This study formed part of that task. CCQDER was asked to apply cognitive interview evaluation methods to selected survey questions, from different sources, covering different functional disability domains.

³ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com)

⁴ [How Disability Data are Collected from The American Community Survey \(census.gov\)](https://www.census.gov/programs-surveys/acs/data/questionnaires/how-disability-data-are-collected-from-the-american-community-survey.html)

⁵ <https://www.cdc.gov/nchs/nhanes/index.htm>

⁶ NHIS is an interviewer-administered (face-to-face and telephone) nationally representative household survey, providing information on the health of the civilian non-institutionalized population of the United States. NHIS is one of the major data collection programs of the National Center for Health Statistics, Centers for Disease Control and Prevention. [NHIS - National Health Interview Survey \(cdc.gov\)](https://www.cdc.gov/nchs/nhis/)

⁷ <https://www.cdc.gov/ncbddd/developmentaldisabilities/research.html>

⁸ Havercamp, S., Krahn, G., Larson, S., Fujiura, G., Goode, T., & Kornblau, B. (2019 (2)). Identifying people with intellectual and developmental disabilities in national population surveys. *Intellectual and Developmental Disabilities*, 57(5), 376-389.

⁹ Krahn, G. L. (2019). A call for better data on prevalence and health surveillance of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 57(5), 357-375.

The Washington Group on Disability Statistics Short Set on Functioning (WG-SS) was included in the study. The WG-SS is currently included on the NHIS and asks about the presence of difficulties in six core functional domains: vision, hearing, mobility, cognition, self-care and communication (these same domains are also covered by the American Community Survey¹⁰). Other questions included those from the Washington Group Extended Set (WG-ES)¹¹ on Functioning,¹² questions adapted from the Washington Group/UNICEF Child Functioning Module (CFM),¹³ or were derived from questions previously asked on the 1994-1995 NHIS Survey on Disability,¹⁴ the American Community Survey, the World Health Organization Disability Assessment Schedule 2.0,¹⁵ and the Diagnostic Adaptive Behavior Scale.¹⁶ The workgroup considered that questions about learning ability, independent living skills, and social participation may also help to establish IDD prevalence estimate. Some questions examined as part of this study cover the same or similar domains in an attempt to establish any differences in how the questions are understood or responded to by the IDD community.

A question about age of disability onset was also examined as part of the study. In population surveys, establishing age of disability onset is key to being able to determine whether a person has IDD (Havercamp et al., 2019₍₁₎).¹⁷ This is because clinical assessment is not feasible in a large population survey. Instead, reliance on self-report of developmental disabilities is needed. Developmental disabilities is defined as a group of conditions due to an impairment in physical, learning, language, or behavioral areas beginning before during the developmental period of life, before age 22.^{18,19} Intellectual disability is a type of developmental disability which is characterized by limitations in intellectual functioning and adaptive behavior that begin during the developmental period of a person's life, also before the age of 22.^{19,20,21} In a quantitative survey of the population, being able to establish age of disability onset before the age of 22 provides a way to differentiate adults with IDD and adults with other conditions, such as Alzheimer's disease or a stroke. A question about age of onset was therefore also included in this evaluation to ascertain, firstly, if respondents with IDD would be routed to a question about age of onset, in a similar way that was done in the National Health Interview Survey, a large population survey that routed respondents to the age of onset question based on responses of 'a lot of difficulty' or 'cannot do at all' to questions about functional disability, and secondly, how respondents with IDD who were asked the age of onset question interpreted and answered the question.

All of the questions included in this study, apart from the age of onset question, utilized a 4-point Likert scale of responses to provide more granular feedback on a respondent's ability to assess severity level. These responses were: 1. No difficulty, 2. Some difficulty, 3. A lot of difficulty, and 4. Cannot do at all. Further information about the items identified by the workgroup can be found in (Havercamp et al., 2019₍₁₎). The response options for the age of onset question were: 1. No, all of this happened after I turned 22, or 2. Yes, some of this happened before I turned 22. For the purposes of this study respondents who indicated any degree of functional difficulties were

¹⁰ <https://www.census.gov/programs-surveys/acs/>

¹¹ [WG Extended Set on Functioning \(WG-ES\) - The Washington Group on Disability Statistics \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com)

¹² https://www.washingtongroup-disability.com/fileadmin/uploads/wg/WG_Implementation_Document_4B_WG-ES_Question_Specifications.pdf

¹³ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com)

¹⁴ https://www.cdc.gov/nchs/nhis/nhis_disability.htm

¹⁵ https://www.who.int/classifications/icf/more_whodas/en/

¹⁶ <https://www.aaidd.org/dabs>

¹⁷ Havercamp, S.M., Krahn, G., Larson, S. and the National Health Surveillance for IDD Workgroup (2019). *Working Through the IDD Data Conundrum: Identifying People with Intellectual Disability and Developmental Disabilities in National Population Surveys*. Washington, DC: Administration on Intellectual and Developmental Disabilities.

¹⁸ [Facts About Developmental Disabilities | CDC](https://www.cdc.gov/ncbddd/iddis/factsheets/factsheet-developmental-disabilities.html)

¹⁹ [Criteria \(aaidd.org\)](https://www.aaidd.org/criteria)

²⁰ [FAQs on Intellectual Disability \(aaidd.org\)](https://www.aaidd.org/faqs)

²¹ [Historical Context \(aaidd.org\)](https://www.aaidd.org/historical-context)

routed to the age of onset question. In this way, the study evaluated whether and how respondents indicated if their difficulties began during the developmental period of life, before age 22, signifying IDD.

There is limited information in the literature comparing the ways in which proxy respondents and their reference person understand survey questions, particularly among adults with IDD. One exception is Massey et al. (2016⁽¹⁾),²² who compared and contrasted the response patterns of parent-child dyads as part of the evaluation of the Washington Group questions on disability. This report also examines differences in this way. Therefore, this study provides an examination of how differences in the constructs captured between proxy respondents and self-reporting respondents may affect the answers respondents provide.

In summary, this study utilized a question evaluation method to inform the wider aims of the workgroup. An evaluation of select relevant survey questions using cognitive interview methodology was made in order to inform the design and administration of survey questions with people with IDD. Some commentary is made on whether a false negative or false positive response to the questions may be likely in a quantitative environment, but the workgroup should consider further research to establish whether IDD prevalence rate estimates are possible from a quantitative survey of the general population, if that is indeed the intent.

3. METHODS

3.1. Cognitive interviewing

This study utilized cognitive interview evaluation methodology, face-to-face, one-on-one, over two rounds of interviewing. Round 1 interviewing was conducted in-person; Round 2 interviewing was conducted remotely using videoconferencing. The use of cognitive interviewing is intended to help gain a better understanding of the mental processes that respondents go through when answering the survey questions within the context of their individual life circumstances (Miller, 2011).²³ Using this method, researchers are able to explore construct validity and identify any difficulties respondents encounter in understanding and answering the survey questions (Miller et al., 2014).²⁴ In some cases both the respondent and their potential survey proxy were interviewed in respondent-proxy dyads. Findings from this sample of respondents therefore go further in informing the discussion on question administration with this particular group of people.

3.2. Study sample and respondent recruitment

For this study, a small-scale purposive sample of respondents was selected for interview. With a purposive, non-random sample, the characteristics of the individual are used as the basis for sample selection.

Across both rounds of interviewing, multiple methods were used by a CCQDER operations staff member to recruit respondents and their proxies for interview. Recruitment was mainly conducted through disability organizations supporting people with IDD, including charitable- and state-funded service providers. A few respondents were recruited from advertisements placed in Craigslist and CCQDER's internal respondent

²²Massey, M., Scanlon, P., Lessem, S., Cortes, L., Villarroel, M., & Salvaggio, M. (2016). *Analysis of Cognitive Testing of Child Disability Questions: Parent-proxy vs. Teen Self-report*. Hyattsville, MD: Questionnaire Design Research Laboratory, National Center for Health Statistics, Centers for Disease Control and Prevention. Retrieved from: https://wwwn.cdc.gov/qbank/report/Meredith_2016_NCHS_MCFD.pdf

²³ Miller, K. (2011). Cognitive Interview. In J. Madans, K. Miller, A. Maitland, & G. Willis, *Question Evaluation Methods: Contributing to the Science of Data Quality* (1st ed., pp. 51-75). Hoboken, NJ: Wiley.

²⁴ Miller, K., Willson, S., Chepp, V., & Padilla, J.-L. (Eds.). (2014). *Cognitive Interviewing Methodology*. Hoboken, NJ: John Wiley & Sons.

database,²⁵ as well as through word-of-mouth. It should be acknowledged that, for both rounds, the recruitment process took significantly longer than initially anticipated. Organizations were understandably protective of this potentially vulnerable group. A period of explanation and rigorous vetting of the study took place, often at governing board level, and involving CCQDER research and operations staff, before contact could be made with potential respondents.

A CCQDER operations staff member reached out to people who expressed an interest in taking part and administered a set of screening questions, and scheduled appointments with people who fulfilled the screening criteria. Screening criteria for this study included basic demographics such as age, gender, educational attainment, race and ethnicity, as well as questions about the disability status of the respondents. Answers to the screening questions, alongside the method of recruitment, helped the operations staff member to ascertain whether a potential respondent might be a person with IDD, but were not used to classify respondents by IDD status. The operations staff member also ascertained whether the respondent used any special communication aids or hearing aids, so as to inform the interviewer. In Round 2, provision was made for virtual set up prior to the interview, which may have required help from the respondent's support person or from the operations staff at NCHS.

Screening interviews were often carried out with the respondent. However, because the organizations contacted during recruitment work holistically, meaning they provide support to the family of the supported individual as well as the supported individual themselves, some calls were also received directly from a support provider such as a family member or case manager. In these cases, the study was explained to the support provider and the screening process only continued with their agreement. Only when consent capacity was considered impaired was the screening interview conducted with the legally authorized representative (LAR), on the respondent's behalf.

3.2.1 Respondent classification

The term Intellectual and Developmental Disabilities (IDD) is used in this report when referring to the community of people with developmental disabilities that is inclusive of people with intellectual disabilities.

To make a more nuanced comparison across sub-groups during analysis of the cognitive interview data, respondents were classified into three main categories:

- 1) Adults with intellectual disability (referred to in this report as respondents with ID).
- 2) Adults with developmental disability, but not an intellectual disability (referred to in this report as respondents with DD).
- 3) Adults without intellectual disability or developmental disability.

For this study, the classification was not made according to a clinical assessment of respondents. Instead, a classification was made based on information about a respondent's disabilities obtained during the interview directly from respondents, and verified during the discussion. That is, respondents told the interviewer that they did or did not have intellectual and/or developmental disabilities spontaneously during the interview discussion or in response to interviewer probing. For example, a respondent who was classified with developmental disability, but not intellectual disability, based on discussion with the respondent, explained that in her early life people had assumed she had intellectual disability because of her communication difficulties but that was not the case, "... lots of misassumptions were made about my ability to do things. This also included professionals assuming I had an intellectual disability...Of course people still make assumptions based on the way I communicate but I am able to share my thoughts, though not through speech." Alternatively, the classification may have been made based on

²⁵ Comprised of respondents to previous studies who have expressed an interest in taking part in future ones.

information obtained during a proxy interview on the respondent’s behalf. In a few cases respondents were in assisted living small-group homes because of their intellectual disability and under the care of the Department of Disability Services (DDS). Answers provided in direct response to the survey questions under evaluation were not used to make the classification. For example, a respondent under DDS care told the interviewer about his disability but when he answered the age of onset question indicated that his difficulties had not begun before age 22. During discussion, this respondent told the interviewer that his difficulties had begun as a baby. This respondent was classified as having intellectual disability.

3.2.2 Sample composition

In total, 56 English-speaking adults (aged 18 or over) were interviewed. Forty were self-reports and 16 were proxy-reports. Based on the classifications as described above:

Of the self-reports

- Thirty respondents had intellectual disability (ID).
- Six respondents had developmental disabilities, but not intellectual disability (DD).
- Four respondents did not have intellectual or developmental disabilities.

One self-report used an assistive device to communicate (discussed further in section 4.1.4).

Of the proxy reports

- Fourteen proxy respondents answered on behalf of someone with intellectual disability.
- Two proxy respondents answered on behalf of someone with developmental disabilities, but not intellectual disability.

Only three of the respondent-proxy dyads did not have a parent/child relationship (one was a caretaker of the reference person, the other two were couple relationships).

Table 1 shows this breakdown by disability status.

Table 1: Respondent type by disability status

Respondents interviewed						
Self-report				Proxy-report		
ID	DD	Without IDD	Total	ID	DD	Total
30	6	4	40	14	2	16

Table 2 shows the demographic breakdown for the achieved interviews (self-reports and proxy-report interviews) across both rounds of interviewing.

Table 2: Respondent demographic characteristics

Demographics	Number of self-report interviews (N=40)	Number of proxy-report interviews (N=16)
Age-group in years		
18-29	10	0
30-49	14	3
50-64	13	6
65 or over	3	7
Gender		
Female	14	16
Male	26	0
Education		
Less than HS Diploma/GED	9	0
HS Diploma/GED	23	7
2 or 4 year college degree	4	3
Graduate degree	4	6
Race/Ethnicity		
Non-Hispanic	39	15
Asian	2	1
Black or African-American	22	6
White	13	6
Multiple race groups	2	2
Hispanic	1	1

The sample for each round of interviews was similar in composition, with 27 respondents interviewed in Round 1 and 29 respondents interviewed in Round 2.

A good mix of ages was achieved for self-reports ranging from 19 to 70, but there were a disproportionate number of male (26) to female (14) self-reports, as well as those self-classifying as Black or African American (22) compared with White (13), Asian (2), or multiple race groups (2). One self-report and one proxy respondent self-classified as Hispanic. All proxy respondents identified as female between the ages of 33 and 81. The sample skewed towards respondents with a high school education only. Around a quarter of self-reports with ID did not receive a high school diploma. During probing a few said they had received a high school certificate instead, which became a more common public-school outcome for students with ID, beginning in the 1990s.²⁶

During Round 1 interviewing, conducted in-person, respondents were from the states of Maryland, and Virginia, and the District of Columbia. During Round 2 interviewing, conducted remotely, respondents were from the states of Colorado, Connecticut, Georgia, Maryland, New York, Texas, and Virginia, and the District of Columbia.

The sample also represented a range of types of disabilities with different levels of severity. Some respondents were reported as having more than one type of disability or impairment. A few had been diagnosed with rare conditions which are not named in this report for confidentiality reasons.

²⁶ Neubert, D.A., et al. (2001). Post-secondary educational practices for individuals with mental retardation and other significant disabilities: A review of the literature. *Journal of Vocational Rehabilitation*, 16, 155-168.

None of the respondents were unable to leave their home because of a disability. However, some were able to leave the home alone, some had to be accompanied on occasion, and others had to be accompanied at all times. This aspect was, of course, not only a reflection of the severity of their disability but also impacted on the recruitment process and interview location during Round 1.

3.2.3 Informed consent

It is important to note that an assessment of consent capacity was ongoing throughout the recruitment and interview process. If there was any indication of impaired consent capacity during screening, the recruiter was instructed to ask if the individual had a support provider or family member who they would like to attend the interview. The recruiter would then ask permission to speak with the support person to provide further details about the study. The individual's LAR would be sought to gain their consent for the prospective respondent to participate. In addition, the interviewer was instructed to review the consent form with the respondent and repeat where necessary the information contained in the form, and ensure the respondent had plenty of time to consider and ask any questions. A more formal and targeted assessment occurred if, at any point during the consent or interview process, it was suspected that consent capacity may be impaired. Specifically, the interviewer was instructed to ask the following questions, adapted from published instruments measuring consent capacity (Horner-Johnson & Bailey, 2013:²⁷ Jeste et al., 2007):²⁸

1. Please tell me, in your own words, what you will be asked to do if you take part in this study?
2. When I say your taking part is completely voluntary, what does that mean to you?
3. Do you have to answer all of the questions in this study?
4. What can you do if you start the study but don't want to finish it?

The interviewer was instructed to err on the side of caution and terminate the study session if they were in any way concerned. Although the consent capacity questions were administered by the interviewer prior to the start of the interview, in each of a small number of cases, the interviewer felt comfortable that the respondent understood, and continued with the interview without the need for further clarification. In addition, if during the interview the respondent appeared confused or upset the interviewer would ask the respondent if they would like to terminate the interview.

3.3 Data collection

Sixteen questions were included in the study. The identical question set was administered to both respondents and their proxies. During Round 1 in-person interviewing, cognitive interviews were conducted in a variety of locations selected for ease of access and convenience on the part of the respondent. Locations included CCQDER's cognitive testing laboratory, community establishments such as libraries, and the respondent's own home, including group homes. If the respondent or their proxy were unable to attend the interview at the cognitive testing laboratory an alternative location was offered. Sometimes the respondent's own home was not their preferred location when it involved in-person interviews. During Round 2, which was conducted remotely using videoconferencing, all but one of the interviews were conducted in the respondent's home, including some group quarters. One proxy interview was conducted while the respondent was sitting in their parked car.

²⁷ Horner-Johnson, W., & Bailey, D. (2013). Assessing understanding and obtaining consent from adults with intellectual disabilities for a health promotion study. *Journal of Policy and Practice in Intellectual Disabilities*, 10(3), 260-265.

²⁸ Jeste, D.V., Palmer, B.W., Appelbaum, P. S., Golshan, S., Glorioso, D., Dunn, L.B., Kim, K., Meeks, T., Kraemer, H.C. (2007). A new brief instrument for assessing decisional capacity for clinical research. *Archives of General Psychiatry*, 64(8), 966-974.

Each respondent, and where appropriate their proxy, took part in an interview lasting about an hour and received \$40 each for participating. All interviews were conducted on a voluntary basis, and informed consent was obtained prior to the start of the interview (as described above in section 3.2.1). Interviewers complied with OMB and CDC Human Subjects requirements for conducting this study. Standard protocols in place for handling any signs of distress during the interview were adhered to.

In order to achieve a balanced assessment of how a particular respondent went about answering the survey questions, cognitive interviewers asked expansive questions (or probes). The approach to cognitive interviewing used by CCQDER is interpretative. That is, it focuses on how respondents' own life experiences inform their answers to survey questions. As such, interviewers rely on non-scripted, verbal probing to illuminate the respondent's circumstances and inform how and why they answered the question the way they did (Cibelli Hibben & de Jong, 2020).²⁹ In anticipation of any time constraints, interviewers were initially instructed to probe retrospectively after administering the first nine questions about vision, hearing, mobility, cognition, self-care, communication, independent living, learning ability, and age of disability onset (Questions 1-9). Age of onset was asked of all respondents who reported having any degree of functional difficulties in order to determine when those difficulties began. Subsequent questions about learning and about social participation were probed concurrently (Questions 10-16). This protocol was not strictly adhered to as interviewers tailored their approach to the needs and abilities of the individual. Nevertheless, interviewers administered the questions orally (along with any probes) and respondents answered orally, as would be the case in an interviewer-administered population survey, such as the NHIS.

3.3.1 Respondent-proxy dyads

The respondent, or their proxy, may not feel comfortable disclosing certain information when another person, particularly their parent or child, is present. Additionally, the respondent's answers, or their proxy's answers, may be primed,³⁰ if they are present during the other person's interview. Because of this, during Round 1, in all but one case, the respondent and the proxy were interviewed simultaneously but separately, in different private locations. In this one case, the proxy had indicated difficulties with communication on the part of the respondent that would necessitate their presence..

During Round 2, it was not possible to interview the respondent-proxy dyads simultaneously due to the virtual environment. Respondents taking part in the dyad interviews required some additional support in accessing the cognitive interview via the videoconferencing platform used and/or there was only one laptop or computer available to use within the home. For Round 2, dyad interviews were conducted sequentially, one immediately after the other. Interviews were conducted in a private location and proxy respondents were asked not to be present during the interview with the reference person and vice versa. On a few occasions the interviewer became aware that the other participant was present in the room, or adjacent room, and asked for privacy. More often this occurred when the proxy was the respondent's caretaker. Nevertheless, in one case a respondent felt more confident when their relative was present. Indeed, that relative proved helpful in explaining the question intent when the respondent was unsure. This relative was able to provide concrete examples to the respondent to help them to understand. Since this relative had also taken part in the study as a self-report and were aware of the confidential nature of the study, the interviewer allowed them to remain while the interview took place.

²⁹ Cibelli Hibben, K., & de Jong, J. (2020). Cognitive Interviewing. In *Guidelines for Best Practice in Cross-Cultural Surveys*. Ann Arbor, MI: Survey Research Center, Institute for Social Research, University of Michigan.

³⁰ Influenced by another's responses.

3.4 Data analysis and reporting

Analysis of cognitive interview data follows a systematic process of synthesis and reduction from interview to report (Miller et al., 2014).³¹ Firstly, all interviews were video and audio recorded to allow the interviewer the freedom to concentrate on the interview and enable a more thorough analysis than could be achieved by simply taking notes during the interview. Interviewers created summary notes about the ways in which respondents interpreted and responded to the survey questions from the recordings, evidenced by verbatim statements made by respondents during the interview and observation of non-verbal behaviors. Where this report refers to verbatim statements, the accounts are italicized. The survey questions provided the framework for the interview summaries which, along with respondent's answers to the questions as they were administered, were entered into CCQDER's Q-Notes software.³² All notes were anonymized. That is, they did not contain any personal information that could identify those respondents who took part in the interviews. Respondent confidentiality was maintained throughout the analytical process. In line with the interpretive approach to cognitive interviewing mentioned earlier, any distinct occurrences or patterns of response were noted. The classification described in section 3.2.2 was used when comparing data from people with ID to those with DD or without IDD, as appropriate and irrespective of how they answered the survey questions under investigation. The findings presented in this report constitute those that emerged from the sample of people interviewed.

4. FINDINGS

This section of the report summarizes findings from both rounds of cognitive interviews combined. It first includes a brief discussion of the interviewers' experiences of conducting cognitive interviews with this particular population, both with respondents and proxies. Then, certain respondent characteristics which may influence question interpretation and response are highlighted, helping to frame the findings overall. Finally, in the 'Question-by-Question Review' section, a description of the way in which respondents understood and answered each of the functional disability questions, as well as the age of disability onset question, is provided, along with a summary of those findings. Equivalency between reporting by the respondent and their paired proxy is discussed, along with commentary on the performance of each functional disability question in terms of potential routing to a question about age of disability onset in a population survey setting (see also the Question 9 summary).

These findings, which describe the processes involved when interviewing people with IDD (of varying degrees of severity), alongside the way in which these respondents understood and were able to answer survey questions, are key to understanding how to design a questionnaire for adults with IDD. Also, the findings serve as a resource for those seeking to understand the feasibility of surveying respondents, with IDD, with varying degrees of severity, in a survey of the general population not specifically focused on the topic of disability.

As a direct result of respondents' intellectual disabilities, the survey question and answer process may carry greater cognitive burden, compared with those without intellectual disability. That is, question response process tasks, which may already be burdensome for those without intellectual disability, may be additionally burdensome, for those with intellectual disability that is not apparent for other populations. Yet, as with other populations, accuracy may be increased by reducing the burden of the tasks respondents are asked to perform (Krosnick and Presser, 2009).³³

³¹ Miller, K., Willson, S., Chepp, V., & Padilla, J.-L. (Eds.). (2014). *Cognitive Interviewing Methodology*. Hoboken, NJ: John Wiley & Sons.

³² Q-Notes is matrix-based approach for managing qualitative data that allows for both case and theme-based analysis. <https://www.cdc.gov/nchs/ccqder/products/qnotes.htm>

³³ Krosnick, J. A., and Presser, S. (2010). *Questionnaire design*. In J. D. Wright & P. V. Marsden (Eds.), *Handbook of Survey Research* (Second Edition). West Yorkshire, England: Emerald Group.

Herein, respondents with intellectual and developmental disabilities are reported on according to the classification described in section 3.2.2. When reporting on respondent-proxy dyad interviews the study participant with an intellectual disability, or those with a developmental disability but not an intellectual disability, is referred to as the respondent, or the reference person.

4.1 General findings

4.1.1 Interviewing respondents with IDD

The group of respondents interviewed was functionally diverse. Each person displayed different characteristics related to their disability and hence each interview presented different challenges and a different experience for the interviewer.

The main challenge of this study was utilizing the cognitive interviewing method with respondents who often had cognitive difficulties or difficulties with receptive language, the ability to understand and process information, or expressive language, the ability to get meaning across. The primary effect was that the pace of the interviews was relatively slow, and, at times, respondents had difficulty providing in-depth explanations. Respondents tended to fatigue and, in some cases, required longer than is typical to process questions and articulate responses. In response to these effects, interviewers employed the following techniques as needed: repeating questions and probes, simplifying or rewording probing questions, providing close-ended dichotomous probing, reverting to concurrent probing, and allowing for longer pauses. Inevitably the slow pace of the interview meant that sometimes questions that came later in the sequence were not asked due to time constraints, or the discussion required to ascertain why respondents answered the way they did was limited. Some respondents more often utilized non-verbal cues in answer to probes, providing an alternative avenue for communication during the interview. In essence, the difficulties that respondents with IDD experience in life, some of which the study questions are trying to measure, impact the cognitive interview experience as well. As a result, interviewers had to be flexible and adapt their cognitive interviewing techniques to suit the individual and the individual circumstances.

Disability awareness

Whether respondents were aware of their intellectual disability or were able to describe the way in which their disability affected their daily life, impacted the way in which the interviewer was able to conduct the cognitive interview and the depth of probing that could be carried out at each survey question.

Based on discussion with the respondent or their proxies during the interview, respondents with intellectual disability can be considered as follows: i) those who acknowledged and were able to describe their intellectual disability, ii) those who did not acknowledge their intellectual disability directly, but made reference to it during the interview, indicating that they were aware of their disability, and iii) those who were not aware of their disability or did not acknowledge their disability during the interview.

- i) Those who acknowledged their intellectual disability during the interview spoke about having an intellectual disability, albeit they may not have become aware of that fact until later in life. For example, one respondent explained that because his family had done everything for him when he was younger, he had not become aware of his disability until later in life when he was told he had intellectual disability. Others acknowledged the additional struggles that having intellectual disability brought:

“We learn the same way everybody else does. It may be a little different but it’s not fair that people tell you ‘you can’t do things’ when you know that you can do it...If you mess up the first time that’s okay just try it again and keep trying because eventually you’re going to succeed.”

ii) Some respondents did not acknowledge their intellectual disability directly but made reference to having a learning disability, receiving support, or being treated differently. Some spoke about taking special education classes in school, undergoing speech therapy or tests in school. Some made comparison to “regular people.” One respondent described being ridiculed by other people because of the way he communicated. Another expressed disappointment at having to be accompanied everywhere. In one case, a respondent who did not use the term ‘intellectual disability,’ indicated that she was aware she had a disability: *“Sometimes, I think a long time ago, I had a diagnosis with some disability that makes it more difficult.”*

iii) There were some who were not aware or who did not acknowledge an intellectual disability during the interview: *“Now that I don’t know.”* In such cases information about the diagnosis was obtained from their proxies who were also able to provide some insight. One proxy respondent said that she thought her son knew he was “different,” but in relation to understanding that he had a disability, she explained:

“No, I don’t think he thinks of himself that way. He has never indicated that something is wrong with him. He’s not a sad person. He’s not depressed. He’s not self-reflective. There’s things he loves and enjoys. He’s very much in the now. So he’s not reflective. It’s just part of his disability.”

Another told us, *“He doesn’t even act like a [age] year old adult male. He is still innocent from every age, from 2 to [age].”* However, it is interesting to note that proxy respondents were not always themselves aware of how respondents perceived their disability status: *“When I was scheduling for this interview...she [the respondent] reminded me. We are supposed to do that thing for persons with disabilities... I think that was the first time I heard her say that, know that it’s about her.”*

4.1.2 Interviewing proxy respondents

There were also challenges involved interviewing proxy respondents for this population. For this study, all proxy respondents were female and, in all but three cases, were the mother of the person with the disability. It was apparent across interviews that the mothers wanted the opportunity to tell their ‘story’ to the interviewer, to set the context in which they were answering the questions. But in some cases, the interviewer had to bring the proxy respondent back on track and to focus on the questions being evaluated.

Since the questions asked about difficulties their child experienced in life, proxy-respondent parents sometimes expressed concern over appearing to present their child in a bad light and wanted to take some time to let the interviewer know what the child could also achieve. As one mother said, *“I think it’s my own prejudice because I view [name of respondent] in a really positive light. I think of him for who he is, as being incredibly capable with the limitations he has.”*

Although the mothers were knowledgeable about their child’s disability and often were better able to report a medical diagnosis, some were less knowledgeable in a few areas covered by the series of questions, such as when answering questions that were more subjective about social participation. Proxies not related to their reference person, were more confident about answering questions about current difficulties but less so about the past. As one proxy respondent explained, *“I really don’t know a whole lot because I wasn’t with him then. I just know that he could do certain things on his own. He could do more things than he can do now. He had more independence when he was younger.”*

In addition, different care protocols, implemented by different companies or organizations providing adult caregiver support, may influence proxy responses to functional questions which may not necessarily reflect a respondent's ability. For example, it was interesting to hear from a caregiver for a person with ID that different contractors, who provide care and assistance to people living in group quarters, may have different safety protocols in place, which could restrict whether a respondent could do errands alone.

4.1.3 Nonresponse

None of the respondents or proxies refused to answer any question. Rather, occurrences of 'no response' were either because the interviewer did not ask the question due to time constraints during the interview or they were true reflections of the respondent or proxy's ability to select from the response options. At times, occurrences of 'no response' seemed to be due to fatigue, and at other times, they were likely due to the difficulties associated with IDD - such as slow processing speed (taking longer to process information) or difficulties with receptive and expressive language skills. Instances of 'No response' tended to be repeated from the same respondents across the series of questions. Less often, respondents, and in two cases proxies, provided a specific response of 'don't know.' Instances of 'no response' and 'don't know' are described in the question-by-question summaries for those questions where they occurred.

4.1.4 Method of communication

All but one respondent taking part in the cognitive interviews were considered verbal communicators. One respondent, who had a developmental disability but not an intellectual disability, communicated with assistive technology. This respondent was able to understand what the interviewer was saying without difficulty but was unable to provide an oral response. Instead, this respondent used an assistive device to communicate, such that the interviewer could hear a digital voice. The respondent described this device as an augmentative communication device. The cognitive interviewing process with this respondent was not dissimilar to that with verbal communicators, although there were longer pauses after questions had been administered while the respondent compiled a response. Because of restrictions on the length of the cognitive interview, the depth of probing typically associated with a cognitive interview was more difficult to achieve across all of the survey questions under investigation. To ensure that this respondent had the opportunity to provide her narrative, but without adding burden by extending the length of the interview, the interviewer focused probing on fewer questions. These questions, covering domains such as communication and learning, were perceived to be key to understanding the impact that this respondent's disability had on her life, and they revealed differences in question interpretation related specifically to the non-speaking aspect of this respondent's disability. Nevertheless, including the time taken to administer informed consent, with respondent permission, the interview overran by 10 minutes and was the longest cognitive interview conducted during this study.

In general, the interviewer found this respondent to be extremely articulate, although at times more literal in her interpretation of questions and probes. For example, when asked who she considered to be 'most people her age' during probing to Question 8, she gave her exact current age. It was important to be able to see the respondent during the cognitive interview, albeit this interview was conducted remotely using video conferencing. This was because, on occasion, the respondent used non-verbal cues to indicate her response to interviewer probes or points of clarification.

4.1.5 Conducting remote interviews

Among survey questionnaire designers it has long been accepted that cognitive interview studies should be carried out in-person rather than remotely over the telephone (Willis, 2005).³⁴ This is because interviewers are able to respond to both visual as well as aural cues, interviews can be longer, and respondents are generally more focused, receptive and open in a face-to-face environment, having greater rapport with the interviewer (Collins, 2015).³⁵ However, the COVID-19 pandemic brought with it many challenges with respect to in-person interviewing, in particular for people with certain health issues, some of which may be associated with having IDD. As a result of the pandemic, as mentioned in the introduction to this report, during Round 2 of this study, interviews were conducted remotely using video-conferencing software. This approach allows the interviewer and respondent to both see as well as hear each other, in theory still providing the richness of data afforded by in-person interviews.

For this study CCQDER was in the unique position of the same interviewers being able to compare their experiences of interviewing in-person in Round 1 and remotely in Round 2. For each interview, interviewers provided a comment in Q-Notes about their experience in conducting the remote interview, such that a systematic assessment could be made of the impact of conducting cognitive interviews in this way. Although subjective, in general, interviewers for this study did not consider that the remote nature of Round 2 interviews impacted the quality of the data collected from respondents and proxy respondents. While no technical issues were experienced for the majority of remote interviews, there were a few experiences worth noting from a methodological perspective.

Setting up the interview: Occasionally, there were some difficulties with the remote interview set up for people with ID who did not have a caretaker or family member for support. In these cases, a member of the CCQDER operations team provided that support, helping the respondent to navigate their email, finding the conference call link, and starting the call.

Technical issues during the interview: Occasionally, technical issues with using the videoconferencing platform affected the interviewing process itself. That is, where audio or visual connections faltered momentarily, or in one case where a respondent turned off her camera and microphone briefly to dismiss an incoming phone call. Interestingly, when these issues occurred, audio or visual issues experienced during the interview were more often associated with the proxy, than the respondent, where the respondent used a computer or laptop to take part in the interview, while the proxy used a mobile phone and moved around during the interview, which affected the quality of the audio and visual connection. In a couple of cases, the respondent used a stock video-conferencing background which meant it was difficult for the interviewer to know, without asking, if there were other people in the vicinity. In another case, the interviewer did not know that the respondent used a wheelchair because it was not visible during the interview. These situations illustrate a basic premise of conducting cognitive interviews, that is, that the interviewer did not make any predetermined assumptions about the respondent's difficulties when administering the question set.

The technical issues occurring during the interview are also those that have been observed when conducting remote-video cognitive interviews with the general population and are not specific to adults with IDD. However, during this study, a different type of technical issue was experienced, which is not necessarily related to remote interviewing, but did occur when interviewing a respondent who was using an augmentative communication device. Although easily rectified by the respondent, at one point during the interview the

³⁴ Willis GB. *Cognitive Interviewing: A Tool for Improving Questionnaire Design*. Thousand Oaks, CA: Sage Publications; 2005.

³⁵ Collins, D. (Ed.) (2015). *Cognitive interviewing practice*. SAGE Publications Ltd, <https://dx.doi.org/10.4135/9781473910102>

respondent's voice software was altered such that it was difficult for the interviewer to understand what the respondent was saying.

4.2 Respondent characteristics influencing the response process

Certain respondent characteristics, or phenomena, became apparent, when conducting the cognitive interviews, which affected question interpretation and response to the survey questions under investigation. Understanding these characteristics or phenomena, described below, may help survey designers to improve the quality of the data collected.

Experience-based understanding of the physical and social world

Answers to survey questions are always influenced by a respondent's own experiences and view of the world. This aspect was certainly apparent during the interviews with people with IDD and central to understanding how they interpreted and answered the survey questions. Indeed, respondents with IDD may have systematically different conceptions of time, and interactions both with the physical world and with people around them. For instance, some respondents in this study needed to be accompanied when leaving home or were otherwise restricted in independent activity. For people who were restricted in their ability to leave home, questions about errands were sometimes interpreted to include household chores, such as washing dishes or unpacking grocery bags. These different experiences meant that respondents did not always describe the difficulties in their daily life that their proxies indicated. Respondents interviewed for this evaluation study interpreted questions based on their own background, experiences, and knowledge, embedded in a world reflective of the social context of their disability. This even meant that, in the case of one respondent, an aide was required to provide context to the respondent's answers. The impact of respondents' experiences on their interpretation of the questions and their responses was important throughout.

The phenomena described below were compounded by difficulties some respondents had with receptive or expressive language skills. At times, respondents with more severe IDD had difficulty engaging with the questions on a fundamental level, limiting the cognitive interviewing process.

4.2.1 Understanding the question concept

This section outlines the phenomena which affected how respondents with IDD understood what survey questions were asking of them.

Literacy skills

Some respondents with IDD had poor literacy skills and a limited vocabulary which led to difficulty comprehending some of the terms used in the questions, such as the term 'errands' in Question 7 or 'analyzing' in Question 11. This led to either misinterpretation of the question or a shift in focus to other terms or examples used in the question stem in order to obtain meaning. A few respondents with ID stated they could not read or write, or proxies explained that although the reference person could read and write, they did not always comprehend what was read, nor could someone else read what they had written. One respondent with ID described himself as illiterate.

A few respondents did not appear to understand the term 'difficulty,' which is used throughout the question set and response options. In those cases, the interviewer asked follow-up questions using the words 'hard' and 'easy' to aid comprehension.

Focus on specific words or examples

Respondents sometimes focused solely on specific words or examples used in the question stem, and, in some cases, that led to a miscomprehension of the question intent. For example, focusing on the glasses clause in Question 1, or the hearing aid clause in Question 2, led some to take the questions to mean, ‘do you wear glasses?’ or ‘do you wear a hearing aid?’

Understanding complex constructs or abstract concepts

Some respondents demonstrated difficulty with understanding complex question constructs or concepts – such as time. Interviewers found this to be the case through the course of the conversation. For example, when answering Question 9 about the age of disability onset, one respondent answered ‘No, all of this happened after I turned 22.’ But when the interviewer asked when his difficulties did begin, he said they had started when he was a “*little baby*.” The respondent knew when his difficulties began, but he did not select ‘before age 22.’ Similarly, when discussing Question 8 on learning, one respondent with ID said that he had some difficulty learning to drive “*like regular people*,” but, he could not extrapolate what he did know to estimate when his difficulty learning things started.

Additionally, other questions that asked about abstract concepts were hard for some respondents, and at times, the respondents themselves asked for concrete examples to help make sense of the question concepts. Once an example was provided, respondents were then generally able to connect the question to something in their lives. The trade-off then, was that the resulting answer and explanations were typically focused on the specific examples provided rather than a respondent’s own experiences. For instance, when answering Question 11 (‘Do you have difficulty analyzing problems and finding solutions?’), one respondent with ID said, “*What’s that?*” When her husband mentioned that she works on puzzles, the respondent immediately described her strategy for completing a puzzle and for getting over interpersonal frustrations:

“Oh yeah, my puzzles, I guess. I solve my puzzles. Sometimes I stop and I say, ‘oh I’ll stop for a while and come back to it.’ That’s solving my puzzle. And, like my husband [laugh], I’ll say to him, ‘I’ll come back to you later.’”

Similarly, when another respondent with ID was asked Question 8 (‘Do you have difficulty learning how to do things most people your age can learn?’), he said, “*Can you give me an example, or what would be an example?*” When the interviewer asked about learning he might do at work, the respondent was able to provide an answer and in-depth reasoning and explanation. Proxy respondents, by contrast, were more readily able to extrapolate meaning from a question that did not provide examples, and the tended to view questions from within a disability framework.

Literal interpretation

Sometimes adults with ID appeared to make a more literal interpretation of questions rather than taking any inferential meaning. For example, in answer to Question 15 about getting along with people who are close to you, a respondent understood the question to be asking if he ever had difficulty being physically close to anyone as opposed to being emotionally close. Also, in some cases, respondents came up with examples to explain their responses from the immediate vicinity of the interview room or area itself. As one respondent discussed his response of ‘no difficulty’ to Question 3 on mobility, he pointed around the room in which he was sitting and said, “*I walk this way, I walk that way, I walk 2 times.*”

Difficulty with concentrating and/or poor memory

Because of their disability, some respondents had difficulty concentrating or had limited memory capacity which led them to have difficulty retaining information when thinking about a question. For example, a respondent with

ID showed signs of struggling to answer and resorted to saying, “*I forgot.*” In another case, a respondent with ID recalled the same scenario when considering most of the questions. His mother, the proxy respondent for him, explained that his short-term memory loss impacted him daily, requiring her to repeat things over and over for him. A few respondents appeared to have difficulty remembering the question content because the question was simply too long to process. For example, one respondent asked the interviewer to repeat nearly every question. The interviewer did not believe this was a hearing related issue because the respondent was able to process the question once it was broken down into smaller parts.

In some cases, respondents with ID also noted that they had difficulty concentrating on things that did not directly interest them, including, possibly, the cognitive interview itself. As one respondent said, “*It depends on what it is. If it’s something that isn’t interesting to me, I’ll probably forget it. You have to explain things to me in a different way. So that I can understand.*”

Slow processing speed

Interviewers occasionally witnessed what they believed to be question order effects whereby the preceding questions provided context or influenced answers to a following question.³⁶ Speculatively, this could have been because a few respondents experienced slow processing speed. The questions on social participation appeared more prone to these effects, perhaps because they asked about similar concepts, such as making friends or getting along with people. For instance, in answer to Question 16, about controlling behavior when together with other people, a respondent who was thinking about close relationships (Question 15) answered ‘no difficulty’ and explained, “*Maybe if I had a relationship with someone, something might change.*” Also, a respondent, who was unable to select a response to Question 16 said, “*When I’m with my friends? ... When I’m with my family I’m fine. With other people? If I’m used to them.*”

4.2.2 Response option selection

Once a survey respondent thinks that they have understood what a question is asking, they then attempt to provide a response that they feel represents their experiences. Ideally all respondents will do this on the same basis to ensure valid and reliable survey data. This section outlines the patterns that were found that emerged across questions as respondents in this study aimed to formulate their responses.

Accounting for accommodations

Respondents and their proxies, irrespective of whether they had IDD, sometimes did and sometimes did not take account of accommodations made to support daily living when selecting a response. Additionally, accounting for accommodations was sometimes inconsistent within one person’s interview. That variability was important because the use of accommodations may influence the perceived difficulty that respondents experienced with a given domain of functioning. Examples of such accommodations include a wheelchair assisting mobility or a family member or aide providing reminders or support with self-care tasks or errands.

Most commonly, respondents did not account for their aides or caretakers, for example when answering Question 7 about doing errands alone. The fact that respondents needed to be accompanied when going someplace outside of the home was often not taken into consideration. Indeed, a few respondents with ID did not acknowledge that they needed help despite having an aide. These respondents tended to answer ‘no difficulty.’ Similarly, in answer to Question 4 about remembering and concentrating, respondents did not account for their use of assistive devices to remember things, such as appointments. Such devices included their computers, smart phones or smart

³⁶ <https://methods.sagepub.com/reference/encyclopedia-of-survey-research-methods/n428.xml>

speakers such as Alexa. One respondent without IDD also did not account for the fact that he took medication to help him remember when he answered ‘some difficulty,’ to Question 4. He would have answered ‘a lot of difficulty’ if he had not been taking the medication.

Of note, however, is that when answering Question 5, about self-care activities like washing and dressing, respondents did acknowledge and consider any physical assistance received from aides or family members. Most respondents who utilized mobility accommodations likewise acknowledged assistive devices like wheelchairs when answering Question 3, about walking and climbing steps, though not unanimously. Question 3 and 5 both refer to concrete, physical activities that respondents could relate to in a tangible, active way. They were able to provide clear examples of walking, using a wheelchair, getting in and out of the bathtub, or brushing their teeth, for example. These discrete activities – as opposed to more complex things like learning how to get to a new place with the help of a digital assistant – may have made it easier for respondents to visualize their day-to-day difficulties and report their difficulty level accordingly.

Avoidance

Across the question set, respondents sometimes assessed their difficulties from within their chosen limitations and context. In that, some respondents said that they had ‘no difficulty’ with a certain function because they do not do it, or they avoid circumstances where that function would arise. For example, in response to Question 7 (errands) some respondents explained that they tried to avoid errands or tasks that they needed assistance with, and they would, for instance, choose to do banking online rather than going to the branch in person. As another example, in response to Question 13 about making friends, a respondent answered ‘no difficulty’ and said, *“No, I stay with myself and do what I need to do.”* In this case, the respondent was mistrustful of new people due to traumatic experiences in her past and avoided being with people she did not know.

Positive focus

Some respondents and proxies, particularly those who advocacy groups or organizations, tended to focus on the positive aspects of their ability to function in everyday life when assessing their difficulty levels. They thought about what they could achieve, everyday problems they had been able to resolve, and people they got along with well. Some respondents were very positive about their life generally, and that made assessing difficulties counter to their own outlook challenging which influenced the difficulty level chosen.

A recurring aspect of the ‘positive focus’ theme was that some respondents and proxies sought to account for improvement in respondents’ functioning over time, and that affected their response selection. For instance, when considering Question 4 (remembering and concentrating), a proxy answering on behalf of her son with ID answered ‘some difficulty’ rather than ‘a lot of difficulty’ because she had seen *“so much”* improvement over time. Similarly, some wanted to reflect the amount of effort that their child with ID applied to learning something. For example, one mother explained her answer of ‘some difficulty’ because she said her son did his best and would try even if he did not succeed: *“It would be ‘some difficulty’ because he is going to try.”* And another similarly said, *“I’m going to say ‘no difficulty’ based on what we have been working on for a long time...repetition, repetition, repetition.”* Likewise, one respondent with ID answered ‘no difficulty’ to Question 10 (learning) focused on his ability to do his familiar job tasks. He said, *“Once I learn the job, I’m pretty much good. And people who are familiar with you is good. I go down there and it’s like, ‘oh good to see you again.’”*

Proxy respondents occasionally determined the level of difficulty based on their reference person’s ability to perform the minimum necessary daily functions in life. This appeared to be true for those answering on behalf of people with more severe intellectual disabilities. For example, when responding to Question 1 (vision), one proxy

respondent selected ‘some difficulty’ rather than ‘a lot of difficulty’ because she said that although the reference person had difficulty with depth perception due to his disability, he could still function independently when wearing his glasses.

Focus on memorable events

In some instances, respondents’ answers to questions were influenced by specific, memorable, adverse events. For example, when answering about Question 3 (mobility), one respondent selected ‘some difficulty’ based on a memorable time he fell on an escalator in a department store. Likewise, a few based their response selection to Question 12 (learning in school) on just one significant event that stood out for them. For example, a respondent with ID answered ‘a lot of difficulty’ despite telling the interviewer *“I did pretty good on writing and reading in school.”* However, he based his answer on a time when his teacher had told him to stop looking out of the window and to pay attention in class: *“She was pretty angry that day.”*

Comparison with others

When formulating a response, sometimes respondents and proxies alike made comparisons with others. Sometimes comparisons were made to others without a disability and sometimes it was to others with similar disabilities. This was most apparent when answering the learning questions, Questions 8 and 12, where a difficulty level was selected in comparison to either those in mainstream education classes or those with similar disabilities, such as classmates from special education classes. One proxy respondent who answered ‘no difficulty’ on behalf of a person with ID explained her answer to Question 12 in the following way: *“Because he was in that special needs classroom, they gave him, he’s eight years old and they are giving him work for a five year old. It was his exposure...it was his exposure because he was in that enclosed classroom.”*

Self-awareness

Respondents with ID were not always aware of certain characteristics, as described by their proxy, which could influence their behavior. For example, when answering questions about social participation, proxies sometimes mentioned difficulties reading social cues, such as a respondent being overly friendly with strangers, which the respondents themselves were unaware of or did not factor into the assessment of their difficulty.

Lack of knowledge/difficulty remembering

Not all respondents or proxies had the knowledge to provide an answer to the questions under investigation. This was particularly evident when speaking with certain proxies about Question 9 (age of disability onset) and Question 12 (learning in school). For example, a proxy who had not known their reference person during their childhood answered ‘don’t know’ to Question 12. She explained, *“That one I don’t know. Like I said I didn’t know her when she was growing up.”*

Respondents sometimes did not have sufficient knowledge to respond, or they indicated that they were providing an answer as a best guess. For instance, a respondent with ID, who had grown up living in an institution, answered ‘a lot of difficulty’ to Question 12 because she remembered having a difficult time at school but did not know or remember much more about it. Likewise, when asked directly by the interviewer if she had taken special education classes, one respondent with ID said, *“I’m not too sure about that because I never see my mother and father, so I couldn’t tell you that. I was put in foster homes, so I couldn’t tell you nothing about that.”*

Difficulty generalizing experiences

Sometimes, respondents had difficulty selecting a response option, and provided an explanation of their experiences instead. Some relied on or expected the interviewer to make the classification. This tended to occur when the respondent had various experiences and could not generalize those experiences into a single response

option. For example, when one respondent with ID was trying to select a response to Question 8 (learning), he could not choose between the options. He told the story of his difficulties learning in school and his current difficulties managing money. He said, “*Reading, I still do – but some big words and stuff like that, I can’t get down. And then also the money thing, how to really spend, 20 dollars or fifty – different things. But I do make it [meaning he does well day to day].*” When the interviewer asked how he would answer, he said, “*Can I use two words?*” He ultimately wanted to select both ‘some difficulty’ and ‘a lot of difficulty’ because he felt both answers were true in different circumstances.

The difficulty lies with other people

Sometimes, respondents felt that the difficulty they had with something was due to other people not listening to them or not accepting them due to their disability and not because of a functional difficulty inherent to them. In those cases, respondents answered in a variety of ways: sometimes nonresponse, ‘no difficulty,’ ‘some difficulty,’ and so forth. This was particularly evident when discussing Question 6 about communicating. For instance, one respondent who did not provide any answer said, “*Well, I’ve had problems throughout my life when I’ve tried to voice my opinion, people just shut me out. They don’t want to listen to nothing I have to say.*” For a few, the issue they had was that other people not understanding or never having “*come to terms*” with their disability. When answering Question 15 (social participation), one respondent with DD, explained that she had answered ‘some difficulty’ because she was afraid to tell people she met about her disability for fear of how they might react.

Equivalency between respondent and proxy reporting

The questions with the highest levels of equivalency between the respondent and proxy were Question 2 (hearing) and Question 3 (walking and climbing stairs). These questions were both about tangible, physical difficulties, wherein both the respondent and proxy could point to clear examples.

Oftentimes, where the members of the dyad provided different responses, respondents reported a lower level of difficulty than their paired proxies. This was particularly evident for Question 4 (remembering and concentrating) and Question 11 (analyzing problems and finding solutions). However, in some cases, respondents reported a higher level of difficulty.

Where relevant, the question-by-question summaries below detail how proxies and respondents answered in relation to one-another.

4.2.3 Sensitive questions

In a few cases, some questions proved to be sensitive for certain respondents, dependent on their life experiences. Question sensitivity can arise in any study and cause respondents to feel different emotions, such as anger, anxiety or sadness. Though there are sometimes questions that are expected to be sensitive, sensitivity can arise unexpectedly, potentially affecting question responses. . In this study, certain questions triggered emotional memories of negative experiences related to some respondents’ disability. When certain questions prompted stronger emotional reactions in some respondents , they tended to either select a higher level of difficulty or they did not provide a response. The following are examples of situations where question sensitivity arose during the interview:

- Question 1 (vision): One respondent, with ID, described having vision problems because of a car accident his mother had been involved in during her pregnancy, and demonstrated distress and anger when answering the question.
- Question 3 (mobility): One respondent, without IDD, was upset by this question because he had recently suffered a stroke. Discussing his mobility difficulties triggered feelings about the changes he had undergone.

- Question 7 (errands): Some respondents reported negative experiences with the medical profession. The example of visiting a doctor’s office used in the question stem triggered memories of these experiences, which included being treated without respect, spoken down to, dismissed and ignored. One respondent with ID, described the difficulty he had in finding a doctor he could trust and who would treat him in a respectful manner because of his disability. He said, “*Some doctors when you ask them to break it down you get an attitude...Some doctors just tell you to do what they say because you have a disability.*” For another respondent with ID, the question brought up past experiences of doctors whom he had felt were communicating with his caretaker rather than talking to him directly. One respondent with ID was visibly upset during the interview when describing his bad experience during a hospital stay at the start of the COVID-19 pandemic. Because he had not been allowed visitors who could advocate for him, he had felt isolated and alone.
- Question 12 (learning): A few respondents, in particular people who were older, reported negative experiences associated with attending school. Some described a generally negative experience throughout their time at school while others described particularly stressful incidents which had occurred. The interviewer described one respondent as shutting down and disengaging from the interview process after being administered this question.
- Question 14 (social participation): A few respondents described being bullied, ridiculed in public and even physical abuse from strangers as a result of their disability. Hence, both respondents and proxies were not always trusting of people they did not know. Proxy respondents were less visibly upset than the reference person when describing negative encounters with people they did not know well.

4.3 Question by question review

Each question evaluated is reported on below. Question reviews include a summary of findings, a description of how respondents understood and answered the question, notes on the equivalency between respondents and their paired proxy, and commentary on the performance of each functional disability question in terms of potentially routing respondents to the age of disability onset question in a population survey setting, such as the NHIS. Each heading comprises of the question number and relevant domain. The question wording is presented prior to any commentary on the question.

Question 1: Vision

Q1. Do you have difficulty seeing, even if wearing glasses? Would you say...

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

Source

This question forms part of the WG-SS.³⁷ The question was designed to ascertain whether the respondent has any difficulty seeing, even with the use of glasses, and how much difficulty.

³⁷ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com)

Summary

As with studies that have examined the general population (Miller and DeMaio, 2006),³⁸ there was evidence of a comprehension problem because of the glasses clause included in the question stem. Respondents and proxies sometimes answered about difficulties seeing without wearing glasses, rather than with. This misinterpretation was evident among the study adults with and without IDD.

Understanding the question concept

Comprehension or miscomprehension of glasses clause

Some respondents and proxy respondents (irrespective of disability status) understood the question as intended and assessed their level of difficulty seeing when wearing their glasses (or contact lenses). For example, a respondent with ID stated that he had ‘no difficulty’ watching television when he wore his glasses. A proxy respondent, on behalf of a person with ID, answered, *“With his glasses, no difficulty.”* A respondent with DD answered, *“No real difficulty as long as I have glasses. I’m near sighted. I wear them all the time.”* A respondent without IDD answered, *“Some difficulty. I do have problems seeing even with the glasses.”*

On the other hand, some respondents understood the question to be asking about difficulty seeing without glasses (or contact lenses). Similar to studies of the general population (see, Miller and DeMaio, 2006), some heard ‘without the use of glasses’ rather than ‘even if wearing glasses.’ For example, one respondent with ID said, *“I wear contacts, so I would say if you are talking about without I would have ‘some difficulty.’”*

A few respondents with ID did not wear their glasses all of the time because their glasses had been misplaced or they simply didn’t want to wear them. This also led to an assessment of the respondent’s ability to see without their glasses. For example, a proxy respondent, on behalf of a person with ID, answered ‘some difficulty,’ explaining,

“He doesn’t like to wear them [glasses]. I know he needs them, but he tells me he doesn’t need them right now to do this or he doesn’t need them to do that. And then when I ask him a question that requires him to pinpoint something, he’s squinting.”

Another proxy based her response on the fact that the reference person with ID did not wear glasses all of the time when she was supposed to, and therefore had ‘some difficulty’ seeing. A respondent, without IDD, answered ‘some difficulty’ on the basis of his myopia, explaining that his glasses helped with seeing longer distances, but he was not in the habit of wearing them after losing *“a pair or two.”* He said, *“I don’t really need them [glasses] that much, but they definitely improve my vision.”*

A few respondents with ID initially understood the question as asking if they wore glasses or not: *“Yeah, I wear glasses.”*

Literal interpretation

A few responses suggested a more literal interpretation of the question. For example, a respondent with ID who answered ‘no difficulty,’ answered on the basis of what she could actually see in the moment, during the interview. She stated that she could see equally well with or without her glasses: *“I can see the same without my glasses.”* Only during probing did this respondent say that she needed her glasses to see long distance: *“I can see better long distance with glasses.”* Another respondent with ID explained that his assessment of ‘some difficulty’ was based on the fact that when he was having a seizure, which occurred almost daily, and for a period of time

³⁸ Miller, K., DeMaio, T. J. (2006). *Report of cognitive research on proposed American Community Survey disability questions*. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention. [Report of Cognitive Research on Proposed American Community Survey Disability Questions \(cdc.gov\)](https://www.cdc.gov/nchs/data/2006/20060601.pdf)

after the seizure, his vision was “*blurry*” irrespective of whether or not he was wearing his glasses. One respondent with ID made her assessment of ‘some difficulty’ based on the amount of time she wore her glasses: “*At night when I go to sleep, I remove them.*” In response to the formulation of the question ‘Would you say...’ one respondent with ID answered, “*No I didn’t say that.*” One proxy respondent initially questioned, “*With glasses? Uh, he wears contacts.*”

Response option selection

Can see well enough to cope with daily living

There was some evidence that the level of difficulty seeing was determined according to whether respondents were able to perform the necessary daily functions in life, and no more. This appeared to be true for those answering on behalf of people with more severe intellectual disabilities. For example, one proxy respondent said that she had not observed her son having any difficulties seeing when they were “*out and about*” and answered ‘no difficulty’ seeing, but she said that he used a magnifying glass to read newspaper print. Another proxy respondent selected ‘some difficulty’ rather than ‘a lot of difficulty’ because she said that although the reference person had difficulty with depth perception due to his disability and may need to get closer to a restaurant menu for example, he could still function independently when wearing his glasses. Another proxy selected ‘no difficulty’ stating that even though her son wore glasses he could probably function fine without them.

Accommodations

Some respondents described how they made accommodations for their visual impairment, such as by working in larger print either on paper, on their computer or their phone, and they made their assessment of difficulty based on these accommodations. As one respondent with DD explained. “*... I would not say ‘a lot’ I would say ‘some’ because I find ways to strategize and accommodate and overcome it...because of ... the advances in technology it’s easy to make accommodations.*” Another respondent with DD who also answered ‘some difficulty’ said, “*Now with phones, it makes it easy because you can make everything big.*” A respondent with ID answered ‘some difficulty’ explaining, “*I can see pretty good as long as it’s written big.*”

Positive focus

In a few cases respondents wanted to get across the fact that their visual impairment did not impact their ability to function or to be successful in life. Their positive focus may have influenced their level of difficulty assessment. For example, one respondent with ID, who described herself as partially blind in one eye, answered ‘some difficulty’ explaining to the interviewer that she tried not to let her vision problems have an impact on her life. Another respondent with DD, who said she had no depth perception, also answered ‘some difficulty’ stating that “*It has not stopped me from being a productive, successful, contributory person...*”

Equivalency between respondent and proxy reporting

Some proxy respondents provided a different difficulty rating to that provided by their reference person. These differences were mostly due to one or the other’s miscomprehension of the question. For example, one making an assessment wearing glasses; the other without wearing glasses. Where these types of question comprehension errors were not apparent there was some evidence that proxy respondents answering on behalf of a person with ID provided a higher level of difficulty rating than the reference person. This may in part be because they were aware of the reference person’s medical diagnosis. For example, one proxy answered ‘a lot of difficulty’ describing the respondent as being totally visually impaired in one eye following surgery for glaucoma, whereas that same respondent assessed themselves as having ‘some difficulty’ seeing. Another proxy answered ‘some difficulty’ explaining that the respondent needed to hold his cellphone or computer at a certain angle to see, even when wearing his contacts, whereas the respondent answered ‘no difficulty’ seeing when he was wearing contacts.

However, proxies were not always aware of visual difficulties experienced by respondents, as indicated by comments made, such as, “...as far as I can tell.” Indeed, one proxy stated that the reference person with DD had no difficulty seeing with glasses, whereas the person themselves said that small words and signs were difficult to read even with glasses and answered, ‘some difficulty.’

Sensitive question

This question proved to be sensitive for one Round 1 respondent with ID who answered ‘a lot of difficulty’ and described having vision problems because of a car accident his mother had been involved in during her pregnancy. Although this respondent said that he could see the interviewer, he demonstrated some distress when answering the question, saying “*I hate talking about this because it reminds me again ... I didn’t know I was going to go blind.*”

Age of onset

Almost all respondents answered ‘no difficulty’ or ‘some difficulty,’ even when some had experienced vision problems during childhood related to their disability. Respondents in the NHIS answering in this way would be unlikely to be routed to the age of onset question. Respondents answered in this way primarily because the question asks for an assessment of difficulty seeing when wearing glasses (which improve vision) and for the other reasons described below such as vision issues having been rectified. Only four respondents or proxy respondents answered ‘a lot of difficulty’ or ‘cannot do at all’ to this question and all of those said that their difficulty seeing had begun before age 22. However, respondents without IDD also said that their difficulty seeing had begun before age 22 which could lead to seeing difficulties being falsely associated with IDD.

Some respondents reported vision problems that began in childhood but were not associated with an intellectual or developmental disability, or respondents were not aware of whether they were associated with their disability. Some respondents were not diagnosed with vision problems until they reached adulthood, even though they may have had problems from an earlier age. For example, one proxy respondent, on behalf of a person with ID, answered ‘a lot of difficulty,’ explaining that it was not until age 25 that her son had been diagnosed with “*low vision*,” which meant he had difficulty seeing in poor light. She had, however, noticed his difficulty seeing during his childhood. Another respondent with ID, who answered ‘some difficulty,’ said that she had experienced vision problems during her youth but was not diagnosed as being “*partially blind*” in one eye until she was in her 20s or 30s. Furthermore, some vision issues were improved or rectified during childhood through surgery. One respondent with DD who answered ‘some difficulty,’ said that at age 15 she had had surgery so that her eyes could “*track together*” and she could see better. A proxy, who answered ‘no difficulty’ on behalf of a person with ID, said that at age 13 her son had received artificial lenses which had enabled him to see. A few respondents reported age related deterioration in their eyesight. One respondent with ID in his 50s described having “*superman eyes*” in his 20s and 30s “*...but my superman days are over.*”

Question 2: Hearing

Q2. Do you have difficulty hearing, even if using a hearing aid? Would you say

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

Source

This question forms part of the WG-SS of .³⁹ The question is designed to ascertain whether respondents have any difficulty hearing, even with the use of a hearing aid, and if so, how much difficulty. That is, whether they have any problems with their ability to hear sounds (including reduced hearing in one or both ears, or to their ability to distinguish sounds from different sources).

Summary

Most respondents and all proxies reported ‘no difficulty’ hearing, although what constituted a hearing problem varied, and some misunderstood the question intent.

Understanding the question concept

The majority of respondents and all proxies answered this question on the basis of whether they could or could not hear sounds, even with the use of a hearing aid, and the degree to which they had any difficulty doing so. For example, a respondent with DD, correctly responded to the question assessing his hearing ability with the use of his hearing aids: *“Even with a medical grade hearing aid there is still some difficulty for me to hear.”* Most answered ‘no difficulty,’ and provided examples to substantiate their assessment, such as being able to hear the air conditioning system in the interview room, passing cars, or trees rustling outside the window. Proxy respondents sometimes mentioned the results of hearing tests to support their response: *“Her hearing has been tested and she is fine.”* A few respondents with ID considered their hearing to be particularly good and commented on the sensitivity of their hearing. For example, mentioning that they could hear people whispering or that they needed to wear ear plugs to sleep. One respondent considered that his heightened sense of hearing could be directly related to the fact that he had a disability: *“Sometimes by you having a disability, you can pick up other senses to make up for what you can’t use.”*

Focus on the term ‘hearing aid’

Some respondents focused on the reference to a ‘hearing aid’ in the question stem. They interpreted the question to be about hearing loss severe enough to warrant the use of a hearing aid and responded accordingly, selecting ‘no difficulty’ from the response options provided: *“I don’t use a hearing aid.”* Indeed, all those who interpreted the question in this way answered ‘no difficulty,’ which was not necessarily a reflection of their ability to hear. For example, one respondent with ID answered *“No difficulty. I don’t wear hearing aids,”* but later during the interview told the interviewer that he sometimes needed to ask people to repeat themselves because he couldn’t hear them properly. Interestingly, this phenomenon was also reported by Miller and DeMaio (2006)⁴⁰ and in the 2010 guidelines on cognitive and pilot testing of this question, produced by the Washington Group⁴¹ and ESCAP.⁴² Indeed, confusion with the hearing aid clause meant that some respondents with ID were not able to provide an answer at all. For example, a respondent with ID understood the question to be asking whether he was deaf and answered: *“I’m not deaf.”*

Accounting for other factors

Respondents with ID and those answering on their behalf, did not always factor in other difficulties that impacted on their ability to hear, and in some cases understand, what other people were saying when making an assessment

³⁹ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

⁴⁰ Miller, K., & DeMaio, T. J. (2006). *Report of cognitive research on proposed American Community Survey disability questions*. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention. Access from https://www.cdc.gov/QBank/report/Miller_NCHS_2006ACSDisabilityReport.pdf

⁴¹ <http://www.washingtongroup-disability.com/>

⁴² United Nations Economic and Social Commission for Asia and the Pacific

of their hearing. For example, a few people with ID were described as having an “*auditory processing disorder*” or “*sensory processing disorder*,” which can affect their ability to process sounds. As a result, they may experience difficulty hearing what people are saying when there is a lot of background noise, or they may become overwhelmed by the noises around them. As one proxy respondent tried to explain to the interviewer, “*They can't process what they hear in the same way other kids do. This is because their ears and brain don't fully coordinate.*” Sometimes respondents considered such disorders as a ‘hearing problem’ when considering what the question was asking; proxy respondents did not. For example, one proxy respondent said that the reference person had no difficulty hearing sounds but did have an auditory processing disorder which affected what he heard, “*You might say yellow but he might hear red...but the question was not about auditory processing.*” A respondent with ID, who answered ‘no difficulty,’ explained that she did not have any difficulty hearing “*sounds*” per se, but she did have difficulty “*with loud sounds*” that are “*too over-stimulating,*” such as when people are talking at the same time. However, another respondent with ID, after asking for the question to be repeated, answered “*I have some difficulty,*” explaining that he found it more difficult to hear “*when everybody is talking.*” This respondent also mentioned that he sometimes had difficulty hearing due to a buildup of ear wax. Interestingly, this respondent’s proxy did not consider either of these issues when considering the respondent’s ability to hear and answered ‘no difficulty,’ only mentioning the sensory processing issues during discussion with the interviewer, along with the wax build up: “*Not really. The majority of the time he can hear fine, but he gets ear wax buildup, and they have to irrigate his ears. That does sometimes affect his ability to hear. But he can hear pretty good.*” One respondent with ID commented on the fact that during a seizure, which he experienced almost daily, he could hear, but was not able to make sense of what people said to him. He did not factor this into his assessment of hearing difficulty and responded ‘no difficulty’ to the question. (Interestingly, this same respondent had taken his vision loss during a seizure into consideration when answering ‘some difficulty’ to the previous question about difficulty seeing.) A respondent without IDD explained that because of a stroke he experienced intermittent hearing loss, which would last for about a minute: “*Suddenly with no warning it's gone.*” This respondent answered ‘no difficulty’ because he said he had not had trouble hearing before the stroke. This respondent talked to the interviewer about overcoming the effects of his stroke therefore, speculatively, his response based on his health prior may have been because he only saw his problems as temporary.

Literal interpretation

Some respondents with ID interpreted the question in a more literal way. For example, one respondent who answered ‘no difficulty’ rationalized: “*Because I can hear some things that people can't hear. Somebody's phone can be ringing, and they might be in the bathroom and I'll say, 'your phone's ringing.'*”

Response option selection and age of onset

As mentioned above, the majority of respondents and all proxies answered ‘no difficulty’ in response to this question. However, in some cases, this response may not have been a valid reflection of hearing difficulty due to the interpretative factors described above, such as focusing on the hearing aid clause. Furthermore, people whose hearing difficulties were directly related to their disability did not always indicate a high level of functional difficulty. As such, they would not have been routed to the age of onset question to help determine disability status.

Only three respondents with ID answered ‘a lot of difficulty’ hearing. All three were what might be considered more severe, based on interviewer observations, in relation to their intellectual disability. Although one said that his hearing difficulty was from birth, another, who struggled with reference periods throughout the interview, was not clear when his difficulty began. The interviewer felt that the third respondent may have been negotiating a

recency effect⁴³ when she answered ‘a lot of difficulty’, supported by a response of ‘no difficulty’ provided by a proxy respondent answering on her behalf: “Every time she has a hearing test she passes.” A respondent without IDD answered ‘some difficulty’ due to tinnitus and some hearing loss as a result of exposure to loud noises when he was younger, around the age of 19. This respondent would have been routed to the question about age of onset if it were asked of people with some hearing difficulties (see Question 9 summary). Another respondent without IDD answered ‘don’t know’ to this question because she said:

“It depends on where the sound is coming from. If it’s from my left side, I have no problem hearing. If it is something not in clear eyesight, I mostly hear out of left side, so I will hear something. If it’s coming from my right side, depending on if it is someone talking or a loud noise.”

Equivalency between respondent and proxy reporting

In only two dyad pairs, where responses were provided by both the reference person and their proxy, did those responses differ and were anything other than the answer of ‘no difficulty.’ In both pairs the proxy respondent answered ‘no difficulty’ on behalf of the person with ID. One respondent answered ‘some difficulty’ because he considered his sensory processing disorder that sometimes made it more difficult for him to hear when everyone was talking around him (his proxy did not include his disorder when making an assessment of difficulty level) and when he sometimes had wax in his ear this made it more difficult for him to hear sounds. The other respondent answered ‘a lot of difficulty’ but, with reference to a potential recency effect mentioned above, this respondent may not have understood the question.

Question 3: Mobility

Q3. Do you have difficulty walking or climbing steps? Would you say:

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

7. Don’t know
9. Refused

Source

This question forms part of the WG-SS.⁴⁴ The purpose of this question is to determine whether the respondent has any difficulty or limitation of any kind with getting around on foot, and if so, how much difficulty. That includes any difficulty walking on a flat surface and walking up and down steps that the respondent considers a problem⁴⁵. Difficulties walking could result from not only musculoskeletal challenges but also balance impairments, endurance limitations, or vision loss. The question accounts for functional mobility difficulties without the use of assistive devices like a wheelchair or cane.

Summary

Overall, respondents and proxies considered this question to be asking about their general mobility. They answered according to their ability to move around with their legs, taking into account discomfort, pain, and

⁴³ Respondents focus their thoughts on things that they hear more recently when questions are presented orally.

⁴⁴ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

⁴⁵ [The Washington Group Short Set on Functioning: Question Specifications \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

coordination. This question seemed straightforward and did not cause particular comprehension difficulties. The literal nature of the question topic – walking and climbing steps – was widely understood, and respondents were generally able to provide a response and answer without difficulty. Many, but not all, respondents and proxies evaluated mobility difficulties without the use of assistive devices, noting ‘a lot of difficulty’ or ‘cannot do at all’ if the respondent used a wheelchair, for example. People who assessed their difficulties with the use of assistive devices, such as a rolling walker, an artificial limb, or assistance from an aide, tended to be respondents with ID.

Differences arose in the way in which respondents and proxies assessed their difficulties in order to formulate their response. Some focused on positive elements of what they could do, whereas others more heavily weighted their or their reference person’s mobility limitations. However, respondents with developmental mobility disabilities directly related to their IDD all answered ‘a lot of difficulty’ or ‘cannot do at all.’

Understanding of the question concept

Long-term mobility

Most respondents and proxies thought of this question as asking about general mobility. That is, they felt the question asked if the reference person had a long-term, physical condition that was not expected to change over time. They considered the respondents’ general ability to walk and climb steps while considering the degree of discomfort and pain experienced. For example, one respondent answered ‘some difficulty,’ noting her recurring arthritis pain that sometimes required her to use a cane when walking. While a few people were reminded of specific, salient events in their lives – a broken ankle, for instance – all but two respondents, one with ID and one with DD, answered according to their average, long-term mobility and not according to their difficulty level at a specific moment or caused by a recoverable injury. The cases of these two exceptions were different however, because the respondent with DD was still recovering from a recent ankle surgery, so she accurately reported ‘a lot of difficulty’ as her current condition indicated. Usually, she had no difficulty walking and climbing steps. The respondent with ID, on the other hand, answered ‘some difficulty’ thinking about a particularly memorable bad fall he had in the past that did not currently affect his mobility.

A lack of fitness was not used as a basis for answering this question, even when some respondents and proxies discussed fitness in the interview. For example, one respondent with DD answered ‘no difficulty’ despite mentioning being overweight and becoming “*out of breath if walking up a steep hill.*” One respondent who did not have IDD did consider being out of breath, not due to lack of fitness, but rather, due to long-term lung damage from smoking. She answered ‘some difficulty’ and explained, “*I smoke cigarettes, run out of breath put it that way, especially if it’s a lot of steps, but if its 3 or 4 steps, 10 at the most, I won’t get out of breath.*”

When this question was evaluated previously (using the word ‘stairs’ rather than ‘steps’) by Miller and DeMaio (2006),⁴⁶ respondents similarly considered this question to be asking about long-term conditions that affect mobility rather than short-term conditions that are expected to improve or fitness levels which can change over time.

Limited aspects of mobility

Most respondents considered and selected an answer based on their ability to both walk and climb steps. A few with mobility difficulties, however, considered specific aspects of their mobility abilities. In that, respondents

⁴⁶ Miller, K., & DeMaio, T. J. (2006). *Report of cognitive research on proposed American Community Survey disability questions*. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention. Access from https://wwwn.cdc.gov/QBank/report/Miller_NCHS_2006ACSDisabilityReport.pdf

sometimes focused on the aspects of mobility that they could achieve independently. For example, one respondent considered just her ability going down the stairs when answering. She selected ‘some difficulty’ and said:

“I suffer from osteoporosis knee pain. And because of my knees I don’t have no ligaments...so I don’t go up the steps, it’s hard for me to go up and down the steps. I can go down the steps, but I can’t go up.”

All respondents were aware of their mobility capabilities, including adults with ID who required more day-to-day supportive care. However, there were sometimes limitations in the way some respondents with ID either considered or explained their mobility. For example, one respondent answered ‘no difficulty’ stating that he did not ever take the stairs and only used the elevator. He answered according to his own life experiences since he was restricted from leaving his apartment unless accompanied by an aide or caretaker, but he was not able to provide an explanation of his difficulty.

Response option selection

Many respondents and proxies selected ‘no difficulty’ to this question. As mentioned previously, they considered this question to be asking about mobility and answered ‘no difficulty’ based on their long-term physical abilities. For instance, one respondent said she did not have any “*issues that are consistent.*” A couple of months prior, she had a case of vertigo and almost fell down the stairs, but she did not think this “*counted*” because it was not a consistent mobility difficulty. Similarly, another respondent did not include occasional sports injuries in his answer. He said, “*Right now it should be no difficulties ... I play sports and I know a couple of times I may have had problems with running.*” Others simply stated, “*I walk fine*” or “*No difficulty at all, that’s one thing that I can claim,*” for example.

Consistent or variable limitations

Some respondents with mobility difficulties had consistent, day-to-day limitations, whereas others reported recurring, variable pain from aging-related conditions such as rheumatoid arthritis or chronic back pain triggered by a change in the weather. Respondents with aging-related conditions needed to ‘average’ their difficulties to formulate a response, and some found that challenging. For example, one respondent with ID had difficulties outside her home, where she uses a cane, but not inside her home, where the ground is always level and where she has railings on the stairs. She ultimately selected ‘some difficulty.’

People who selected ‘cannot do at all’ all used assistive devices like wheelchairs or walkers for mobility. Most had IDD that caused severe physical limitations. For example, one respondent said “*Oh I don’t walk at all. I am basically confined to this wheelchair.*”

Positive focus

When formulating a response, some respondents and proxy respondents focused on positive aspects of the reference person’s capabilities. For instance, one respondent who utilized a wheelchair or walker whenever she was out of bed answered ‘a lot of difficulty’ rather than ‘cannot do at all’ because she was able to sit up in bed without assistance. Likewise, one proxy respondent for a person with ID answered ‘no difficulty’ even though, as she explained, “*periodically, he uses the cane outside of the house.*” She answered based on the respondent’s condition the majority of the time, and not based on occasions when he needed his cane. By contrast, the reference person in this case answered ‘some difficulty,’ because he viewed his back pain as being a chronic, recurring problem.

Accommodations

Accommodations, such as assistive devices like wheelchairs or crutches, decreased the perceived difficulty that some experienced. The intent of the question design is for respondents to answer based on their abilities without the use of assistive devices, but not all did so – particularly adults with ID. For example, a respondent who used a wheelchair whenever she was outside the house answered ‘some difficulty’ because, although she had not tried climbing steps in a while, her crutches helped her to walk at home. In this instance, she answered the question including the assistive devices she used for mobility. Likewise, another respondent answered ‘some difficulty’ even though one of his legs was amputated. He utilized an artificial leg to walk and climb stairs but did not account for his artificial leg when answering. In prior evaluation of this question, Miller and DeMaio (2006)⁴⁷ also found that some respondents answered according to the mobility granted to them by assistive devices. By contrast, a respondent without IDD answered ‘cannot do at all,’ although he could take “*baby steps*” with a cane or walker. He went on to explain that he took short walks every day and used the cane to go upstairs. In this case, he did not include his accommodations when forming an answer.

Equivalency between respondent and proxy reporting

The dyad pairs which provided equivalent answers generally were those where the respondent had no mobility difficulties or, in one case, the respondent regularly used a wheelchair, so they each answered ‘cannot do at all.’ In one case, a respondent answered ‘some difficulty’ based on short-term poor mobility he experienced after a bad fall that was memorable and salient to him. His mother, the proxy respondent, answered ‘no difficulty’ in that case, based on his long-term, day-to-day mobility.

In cases where there was not equivalency between the respondent and proxy, there was no pattern whether the respondent or proxy provided a higher difficulty assessment. In a few cases, the respondent had a more positive assessment of their abilities, and they provided an answer with a lower difficulty rating than their paired proxy. In other cases, the respondent answered a higher level of difficulty, though the reasons for a higher difficulty rating were not consistent. In one such case, the respondent felt their aging-related pain was more consistent or chronic than the proxy respondent. In another, the respondent answered with a higher difficulty level based on a salient time he had fallen, whereas his proxy answered based on general mobility.

Age of onset

People who had current mobility difficulties directly related to their IDD all answered either ‘a lot of difficulty’ or ‘cannot do at all’ and would therefore likely be routed to the age of onset question in the NHIS.

In one case, a respondent with DD who had mobility difficulties in childhood due to cerebral palsy answered ‘some difficulty.’ He therefore would not have been routed to the age of onset question in NHIS. He responded this way because his mobility had improved over time, so he no longer used assistive devices and simply had some balance challenges.

⁴⁷ Miller, K., & DeMaio, T. J. (2006). *Report of cognitive research on proposed American Community Survey disability questions*. Hyattsville, MD: National Center for Health Statistics, Centers for Disease Control and Prevention. Access from https://wwwn.cdc.gov/QBank/report/Miller_NCHS_2006ACSDisabilityReport.pdf

Question 4: Cognition

Q4. Do you have difficulty remembering or concentrating? Would you say...

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

Source

This question forms part of the WG-SS.⁴⁸ The purpose of this question is to determine whether the respondent has any difficulty, and if so how much difficulty remembering (recalling incidents or events) or focusing attention on a task that contributes to difficulty in doing their daily activities⁴⁹.

Summary

This question about cognitive functioning captured a range of difficulties which included difficulty focusing on and recalling conversations, remembering the placement of objects, focusing on academics or at work, recalling events from the past, and remembering what to get at the store. Some respondents and proxies selected an answer including the use of assistive devices, whereas others did not. Also, in some cases respondents and proxies noted that remembering and concentrating were different skill sets with different levels of difficulty.

Understanding of the question concept

Generally, respondents and proxies understood this question to be asking about respondents' ability to recall information or focus on something for a period of time. While many respondents and proxies considered both remembering and concentrating in discussion, the respondent's difficulty remembering things was the initial consideration for most. While some viewed remembering and concentrating as different skills, in those cases, most answered according to the more difficult skill. Of interest, no proxy respondent answered 'no difficulty' to this question, and most proxy respondents connected difficulties remembering and concentrating directly to respondents' IDD.

Remembering

As noted by Massey⁵⁰ in her evaluation of a similar question ('Do you have serious difficulty remembering and concentrating') with general population adults, most people initially thought about remembering rather than concentrating, though many also considered concentration secondarily. Common reasons for memory difficulty included the need for repetition, misplacement of objects or forgotten appointments, and general trouble with recall. Similarly, in this study, common aspects of remembering that respondents and proxies considered included remembering everyday tasks, placement of objects (such as keys), appointments, errands, conversations, names of people or places, and events from their past.

⁴⁸ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

⁴⁹ [The Washington Group Short Set on Functioning: Question Specifications \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

⁵⁰ Massey, M. (2016). Analysis of Cognitive Interview Testing of Questions on Cognitive Functioning. National Center for Health Statistics. Hyattsville, MD. <https://www.cdc.gov/QBank/Report.aspx?1162>

Some, particularly adults with ID and their proxies, thought about everyday tasks. These tasks included remembering the daily schedule, such as appointments, medication, and when to arrive at work. For example, one respondent with ID explained his response ‘some difficulty’ by saying, *“I somewhat have a good memory for, like, what time I have to be at a certain place or what time I have to be back home.”* Other examples of everyday tasks included remembering to make the bed, recalling the food they ate, remembering to pay bills, remembering what they were doing or where certain objects were, and recalling what to get at the store.

Another common consideration was remembering what was said in a conversation or when given verbal directions. For example, one respondent with ID explained her answer of ‘some difficulty’ in the following way:

“So remembering things – I have a lot of difficulty remembering a lot of things. If you tell me too much information at once, it won’t register as quick in my brain as you’d think it would ... if you break it down and tell me little by little, then I can repeat it back to you.”

Some respondents with IDD had short-term memory loss that affected their ability to remember what was said or who they talked to. For example, one respondent with DD said that she may repeat herself during a conversation because she has no memory of having said it, although her long-term memory was very good. Likewise, a proxy explained that the reference person with ID had short-term memory loss. She said, *“I kind of equate him to Dory on finding Nemo, you know, you tell him and then you gotta tell him and tell him again, yeh, and maybe again.”* A few respondents thought about remembering events from their own past. While this was typically discussed in terms of difficulty remembering, one proxy, thought of her son’s cognitive delay improving his ability to remember over time. She said he would have difficulty recounting what happened immediately afterwards, but he would remember in detail after a few days.

Concentrating

A few respondents and proxies focused their consideration of this question solely on concentrating, whereas more often, people considered concentrating along with remembering.

Some thought about their difficulties concentrating on academics or on their work. For example, one respondent with DD answered ‘a lot of difficulty’ because she was bored at work and distracted by other stressors in her life. Another respondent with ID, who answered ‘a lot of difficulty,’ said he got distracted easily with background noise. He explained, *“It don’t affect me watching TV, but working it does a little bit.”*

Others thought about difficulties by focusing on conversations they had. One proxy who said ‘a lot of difficulty’ on behalf of a person with ID answered this way because it was hard to know if the reference person was focusing or not. Also, the respondent’s behavior affected the way her mother, the proxy, interacted with her.

“She won’t look at you directly, so you won’t know if she is really paying attention to you. She might hear you. Sometimes it’s difficult to tell if she is actually hearing you and understanding. So, you have to repeat yourself and make her repeat to make sure she understands what her task is.”

Another proxy, answering on behalf of her son with ID, explained her son’s language receptor delay had a cognitive component which made concentration difficult. She said, *“He had the peer counselling, but he also had individual therapy with a psychologist. And, the psychologist kind of taught him how to focus a lot better.”* She answered ‘some difficulty’ rather than ‘a lot of difficulty’ because she had seen “so much” improvement over time.

One consideration which was unique to respondents with ID and their proxies was focusing on leisure activities such as reading for pleasure, listening to the radio, and watching TV. In some cases, the respondents' ability to concentrate on TV or reading was an example of good concentration and focus. One respondent explained that he had no difficulty concentrating when watching Dr. Who or reading comic books. One proxy noted, "*Concentrating - I think he's Okay with that because he fills his whole day with his books, his writing, watching TV.*"

Response option selection

Factors that most often affected response, apart from perceived severity, included whether the response was based on difficulties while using accommodations, considerations of remembering and concentrating as different skills, and difficulties generalizing experiences.

One respondent with ID answered 'cannot do at all,' reflecting the salience of the frustration he felt about issues within his family at the time of the interview. He explained that he could not remember where he put his belongings, and he also said, "*I don't get time to myself because I'm paying attention to everybody else,*"

Accommodations

Several respondents and proxy respondents reported using accommodations, like personal or electronic reminders, notes, and checklists, which helped to decrease their functional difficulty remembering and concentrating. Whether the respondent or proxy based their answer on the reference person's difficulty while using or not using accommodations affected their response. For example, one respondent with DD who answered 'some difficulty' said that she did not respond 'a lot of difficulty' because she is able to record and remember things on her phone with the digital assistant Alexa and on her computer with a calendar. Similarly, a respondent who did not have IDD answered 'some difficulty,' noting that after his stroke, he more often needed to utilize Alexa. Without medications or the help of reminders from Alexa, he would have answered 'a lot of difficulty.' By contrast, others selected an answer based on their difficulty without the use of accommodations. For instance, one respondent with ID said he had 'some difficulty' because he forgets things, such as names or directions sometimes. To accommodate this, he would draw pictures or write notes for himself. Likewise, a proxy respondent answering for her son with ID selected 'a lot of difficulty' because, as she explained, she needs to provide repeated directions to help accommodate his short-term memory loss.

Remembering and Concentrating as Different Skills

In some cases, respondents and proxies noted that remembering and concentrating were different skill sets with different levels of difficulty. Often, the respondent or proxy selected a response that corresponded with the more difficult skill, which was more salient in terms of this question. For example, one proxy respondent for her son with ID said, "*Some difficulty. And it's not the remembering part it's the focusing part.*" Likewise, a respondent with ID explained his answer of 'a lot of difficulty' by saying, "*I get distracted really easy*" – though he said that he only finds remembering things "*a little difficult.*"

More rarely, others attempted to average the two skills to select a general response. For instance, one proxy for a respondent with ID laughed when she heard the question and said, "*Remembering and concentrating are two different questions! He can remember things like a hawk, but he doesn't concentrate well.*" The proxy decided to select 'some difficulty,' but she explained that if she could give two answers, she would answer 'some difficulty'

to remembering and ‘a lot of difficulty’ to concentrating. Massey et al. (2016)⁵¹ previously noted the phenomena of a proxy selecting ‘some difficulty’ as a compromise between two different difficulty levels for ‘remembering’ and ‘concentrating.’

By contrast, for a few respondents and proxies, the skills of remembering and concentrating were explicitly interrelated concepts. For example, a proxy explained that the reference person, her daughter with ID, had difficulty understanding abstract concepts, so it may appear that she has difficulty remembering and concentrating. Also, one respondent without IDD explained that he needed to concentrate in order to remember something he had forgotten.

Nonresponse

A few respondents with ID and one respondent without IDD did not select a response from the list provided. This was because they either could not generalize the relevant life experiences into a single response option or, in the case of one person with ID, the respondent did not understand the word ‘concentrating.’ For example, one respondent could not provide an answer because, he said, *“It depends on what it is. If it’s something that isn’t interesting to me, I’ll probably forget it. You have to explain things to me in a different way. So that I can understand.”* He gave the example of the various technical functions on his wheelchair which, he felt, were too technical to be interesting or memorable. The respondent without IDD likewise felt her distraction levels were *“situational,”* so she did not know how to answer.

One proxy answering on behalf of a person with ID answered ‘don’t know’ to this question. This was because she felt that ‘some difficulty’ exaggerated the problem while ‘no difficulty’ was not accurate either. *“I see a little bit of change there [with the respondent’s memory] but other than that he has a very good memory...I don’t know what to put.”*

Equivalency between respondent and proxy reporting

For those dyad pairs that provided non-equivalent responses – slightly over half of pairs – the proxy always selected a higher difficulty level than the respondent. Indeed, no proxy said ‘no difficulty.’ And, there was a pair in which the respondent with ID said ‘no difficulty,’ and the proxy answered ‘a lot of difficulty.’

Reason given for difficulties. More often, proxy respondents attributed respondents’ difficulties remembering and concentrating directly and specifically to their IDD. Whereas, respondents more often attributed their difficulties, if they reported to have any, to aging, stress, general distractions, lack of interest, or they gave no specific reason. As an example of this difference in considerations, one proxy for her son with ID answered ‘a lot of difficulty, and she explained that his auditory processing disorder affected his ability to remember and concentrate. By contrast, the respondent answered ‘some difficulty’ and said that he was good at remembering, but had some difficulty with concentrating, citing on past schoolwork, specifically.

In a few cases, both members of the dyad felt that respondents’ difficulties remembering and concentrating were due to reasons apart from IDD. For instance, one proxy, who was the girlfriend of the respondent, said that she answered ‘a lot of difficulty’ due to the respondent’s stress and anxiety. The respondent, also thinking of emotional stressors, answered ‘a lot of difficulty’ because he sometimes did not want to remember his past. He said, *“If it’s not what I want to hear – I don’t want to hear that. For what? I want to forget it. But something that is nice, if you’re being nice, then yeah. I’m here for that.”*

⁵¹ Massey, M., Scanlon, P., Lessem, S., Cortes, L., Villarroel, M., Salvaggio, M. (2016). Analysis of Cognitive Testing of Child Disability Questions: Parent-Proxy vs. Teen Self-Report. National Center for Health Statistics. Hyattsville, MD. <https://wwwn.cdc.gov/qbank/report.aspx?1159>

Age of Onset

Four respondents with ID and one with DD selected either ‘a lot of difficulty’ or ‘cannot do at all’ and would therefore be routed to the age of onset question in the NHIS. And, while no proxy selected ‘no difficulty,’ six selected either ‘a lot of difficulty’ or ‘cannot do at all,’ which was almost half of all proxy respondents. Additionally, there were only two cases where both members of the dyad answered at least ‘a lot of difficulty.’

For the purposes of this evaluation, Question 4 routed all proxy respondents who selected an answer to Question 9 (age of onset). That is, all of those who provided a response and did not answer ‘no difficulty’ were routed to Question 9. All but two proxies then responded that the reference person’s difficulties began before age 22. The two exceptions were both non-parents. They were familiar with the respondents as adults only – and not during their development. This highlights the significance of a proxy respondent’s knowledge of the reference person’s development and diagnosis when answering questions intended to capture IDD prevalence.

Those respondents who were aware of the difficulties associated with their IDD, and who attributed their difficulties remembering and concentrating to their IDD when discussing this question, often indicated at Question 9 that their difficulties began before age 22. In those cases, respondents also were routed to Question 9 based on their answers to several questions, not solely this question alone. Two respondents, one respondent with ID and one with DD, were routed to age of onset based on their answers to this question, but despite being aware of their disability and attributing their difficulties to that disability, answered that their difficulties began after age 22.

Question 5: Self-care

Q5. Do you have difficulty with self-care such as washing all over or dressing? Would you say...

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

Source

This question forms part of the WG-SS.⁵² This question aims to identify adults who have difficulty, and if so how much difficulty, taking care of themselves independently. Washing and dressing are used as examples in the question stem because they represent daily self-care tasks. Difficulties with everyday personal care such as washing and dressing may be due to physical difficulties, cognitive functioning, or psychosocial functioning⁵³.

Summary

Similar to findings reported by Miller and DeMaio (2006),⁵⁴ in general, respondents understood this question to be asking whether they had any difficulties with washing all over or dressing because of a physical disability. Most answered ‘no difficulty.’ In contrast to some other questions in this series, respondents did consider any

⁵² [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

⁵³ [The Washington Group Short Set on Functioning: Question Specifications \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

⁵⁴ Miller, K., and DeMaio, T., 2006, Report of Cognitive Research on Proposed American Community Survey Disability Questions, Hyattsville, MD: National Center for Health Statistics. <https://www.nhc.gov/QBank/Report.aspx?1042>

physical assistance they received with these tasks when formulating a response. For people who needed non-physical assistance, they sometimes considered the reminders or other help they received and sometimes they did not.

Understanding the question concept

Irrespective of disability type, the majority of respondents and proxies understood this question to be asking about any difficulty with self-care because of a physical disability. They tended to focus on the examples provided in the question stem, considering any difficulties with washing all over (which included taking a bath or shower), or any difficulties with dressing themselves generally. For example, a respondent without IDD answered ‘some difficulty’ because washing and dressing were “...difficult... but I manage.” A respondent with ID who did not select a response option, explained that a parent would help him get dressed or take a bath. A proxy who answered ‘a lot of difficulty’ on behalf of a person with ID, explained that the reference person “...needs monitoring in the shower” but “...can dress himself for the most part.”

There were aspects of self-care that some respondents had difficulty with but which they did not consider because of focusing on the positive aspects of their abilities as well as the question examples of washing and dressing. One respondent with ID, who answered ‘no difficulty,’ explained that he did not have any difficulty showering, although he did have difficulty with shaving. Likewise, another respondent said that she found getting in and out of the tub difficult, due to her arthritis, but she answered ‘no difficulty’ and explained, “I can wash up when I get in. But, it’s hard for me to get out of the tub.” Another respondent, who had DD, answered ‘no difficulty’ despite not being able to follow her doctor’s diet recommendations or take her prescription medications regularly: “Not washing or dressing but in terms of following up on doctor’s recommendations.”

However, respondents with DD who had more acute physical disabilities, and who were reliant on others for help with all aspects of self-care, considered a broader meaning of the term self-care to include other activities of daily living, such as eating, drinking, and using the restroom.

One respondent without IDD thought about not only physical ability to complete self-care, but she also considered her financial ability when answering ‘no difficulty.’ She explained, “Like if I just have two outfits and I’m living in my car, then yeah I would have difficulties.”

A respondent with ID answered ‘some difficulty’ because he also helps clean up after his roommate who had more severe cognitive difficulties. Although it is unclear why he interpreted the question in the way he did, the respondent noted that he did everything himself.

Response option selection

Thinking about any physical disabilities that affected their ability to wash or to dress, the majority of respondents answered ‘no difficulty’ in response to this question: “No, none.” One proxy respondent, answering ‘no difficulty’ on behalf of someone with ID, explained that she did not need to remind her son to do any “self-care things,” and that he could physically do them on his own. Likewise, another respondent with ID said, “I do it on my own.” Adults answering ‘no difficulty’ were both respondents, with and without IDD, and proxies, answering on behalf of a person with IDD.

A few answered ‘some difficulty.’ This assessment was made by or on behalf of adults with ID or by one respondent without IDD. The assessment was made on the basis that respondents had difficulty with some aspects of self-care. For example, one respondent said he required help getting in and out of the bath, but he was able to wash his hair and dress himself. A proxy noted that her son with ID had a “cleaning calendar” to help remind

him to do occasional tasks like cutting his toenails, and sometimes she had concerns for how well he cleans his teeth. The respondent without IDD had experienced disability later in life and made comparison with what he had been able to do previously. Although he explained that it was not just physical issues that made it more difficult for him to wash and dress himself, but also memory issues, giving the example that sometimes he might forget to shave one part of his head.

An answer of ‘a lot of difficulty’ or ‘cannot do at all’ consistently was due to a higher level of assistance required to do self-care tasks. People who answered ‘a lot of difficulty,’ either respondents with or proxies answering on behalf of a person with ID, explained that the respondent could only perform some tasks independently, or, alternately, they physically could wash and dress themselves, but needed regular reminding and close monitoring. As one proxy said, the reference person needed someone present to help prevent falls in the shower: “...as a safety issue, he cannot be alone in the shower.” Respondents with IDD and proxies answering on behalf of someone with IDD who answered ‘cannot do at all’ described the reference person as being completely dependent on others for help with self-care due to a physical disability: “a total assist.”

Those who were asked the question but were unable to provide a response, were primarily those who had trouble answering questions in the set generally. However, during probing, these respondents were able to describe the type of self-care they could perform and what they needed help with. For example, one respondent explained that he could brush his own teeth, but he needed help with bathing and dressing. Another said he could brush his own teeth and dress himself, but he received help caring for his feet. One proxy who did not provide a response noted a deterioration her son’s condition due to early onset Alzheimer condition associated with his ID.

Accommodations

In contrast to some other questions in this series, when answering this question about self-care, respondents took account of any physical assistance they received from an aide or family member when formulating a response and selected at least ‘some difficulty’ from the options provided. For example, a respondent with ID who answered ‘a lot of difficulty’ said, “my mom helps to wash my hair and body.” Most respondents who used a wheelchair for mobility also noted that they received help from an aide or family member with self-care tasks, and they answered at least ‘a lot of difficulty.’ One respondent, however, answered ‘no difficulty’ because now that he does have his motor chair, he does not need outside help. He explained, “No difficulty unless my back goes out. That’s when I can’t do it by myself at all.” In just one case, a respondent who answered ‘no difficulty’ described needing some physical help from one of his aides when drying himself after a shower.

For those respondents with self-care difficulties that were due to non-physical reasons, assistance they received (in terms of reminders, monitoring, or preparation of their self-care tasks) was sometimes considered and sometimes not when selecting a response. For example, one respondent answered ‘some difficulty’ because, as he explained, “I have to be reminded to get in the shower sometimes because I forget.” Similarly, a proxy selected ‘a lot of difficulty’ because her daughter with ID needed instruction and help knowing how to shower and select clothes for the day. On the other hand, respondents and proxies sometimes did not account for such reminders or assistance. As one proxy said, “Um, it’s really no difficulty. He really just needs verbal reminders sometimes.”

Equivalency between respondent and proxy reporting

Where a response was selected by the respondent, most of the answers provided matched that selected by their proxy. In cases without equivalent answers, the proxy always selected a higher difficulty level. For example, in one case, the respondent answered ‘no difficulty’ while her mother answered ‘some difficulty,’ explaining that her daughter’s intellectual disability made the quality of performed self-care less than ideal. She gave an example of how her daughter would put her shoes on the wrong feet.

In two cases where the respondent with ID was unable to respond to this question, their proxy either reported ‘a lot of difficulty’ or the proxy also did not select a response.

Age of onset

Four respondents, one of which was not part of a dyad, answered ‘a lot of difficulty’ or ‘cannot do at all’ to this question and would have been routed to the age of onset question in the NHIS. In three of those cases, which included people with DD or ID, respondents had physical limitations that prevented them from completing self-care tasks by themselves. They answered according to their need for assistance when bathing and dressing. One respondent with cognitive difficulties answered ‘a lot of difficulty.’

Five proxy respondents answered ‘a lot of difficulty’ or ‘cannot do at all.’ In three of those cases, the reference person had a non-physical difficulty with self-care, either needing to be reminded or helped through the tasks for cognitive reasons. Of those, two paired respondents either did not select a response or answered ‘some difficulty,’ and so they would not be routed to the age of onset question (Question 9) in the NHIS. Therefore, in three cases, both members of the dyad answered at least ‘a lot of difficulty’ – all describing cases of physical disability.

Question 6: Communication

Q6. Using your usual language, do you have difficulty communicating, for example understanding or being understood? Would you say...

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

Source

This question is intended to determine whether a respondent has difficulty, and if so how much difficulty, with communicating with others through language, whether due to difficulties talking, listening, or understanding speech⁵⁵. It forms part of the WG-SS.⁵⁶ The two aspects of communication measured in the question are receptive or expressive language. In-scope reasons a person may have difficulty with communication include mechanical problems such as a hearing or speech impairment, difficulties interpreting sounds, or difficulties composing a sentence or word in the mind.

Summary

Respondents and proxies generally considered this question to be asking about difficulties communicating with other people. They brought four different aspects of communication to bear when answering: cognition (including comprehension, memory, and concentration), interpersonal relationships, ability to hear sounds, and other physical reasons. Cognition and interpersonal reasons were the most commonly cited reasons for communication difficulties. With reference to the examples used in the question stem of understanding and being understood, some respondents considered just understanding, some just being understood, and some considered both together, often noting that ‘understanding’ and ‘being understood’ were different skill sets with different difficulty levels.

⁵⁵ [The Washington Group Short Set on Functioning: Question Specifications \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com)

⁵⁶ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com)

This double-barreled nature of the question was particularly pronounced for one respondent who used an assistive device to communicate. As a result, she found the question unanswerable.

Understanding of the question concept

There were four overarching aspects of ‘communicating’ that respondents and proxies considered when answering this question: i) cognition, ii) interpersonal relationships iii) hearing ability, and iv) other physical reasons. These categories are equivalent to those found by the Washington Group on Disability Statistics (2010⁵⁷) when examining this question previously. This section will examine these four aspects.

Cognition

Common reasons respondents, and particularly proxy respondents, gave for difficulties communicating were related to cognition. Such reasons included difficulty remembering, concentrating on and understanding complex or abstract concepts, slower auditory processing, or speech delays. Several respondents with IDD and their proxies explained that they needed complex concepts ‘broken down’ into smaller tasks or vocabulary to be simplified in order to understand what was being communicated. For example, one respondent with DD explained her answer of ‘some difficulty’ by saying that she struggled to understand what her supervisor was asking her to do at work *“unless it was written down step-by-step.”* Likewise, one proxy respondent who answered ‘some difficulty,’ explained the following about her son with ID: *“You may have to rephrase it a bit for him to get a maximum of the understanding of the question.”* In some overlap with Question 4 (on remembering and concentrating), one respondent with ID provided the same example for both this question and Question 4. He explained his answer, ‘a lot of difficulty,’ by saying, *“Someone will tell me something, and I’ll forget, so I have to go back.”*

Also, some proxies for respondents with ID noted that it was difficult to understand the reference person because they communicated using a specific frame of reference. For example, one proxy, who answered ‘some difficulty,’ said *“In the family we understand him really well, but he’s not really understood by outside people.”* Another proxy similarly said, *“...unless you know all of the background in his mind you will not know who he is talking about. He might bring everything into play...He starts on one topic but then skips to another.”*

Interpersonal Relationships

Several respondents, including two without IDD, considered interpersonal relationships or frustrating social interactions when answering this question. Respondents with ID sometimes considered the unfounded assumptions made by others about their capabilities which resulted in one-sided, ineffective conversations.

Some respondents viewed these difficulties as being problems caused by other people, and they answered ‘no difficulty.’ Others, by contrast, answered based on the difficulty they felt in the circumstance – regardless of perceived blame. For example, one respondent who answered ‘no difficulty’ said, *“But when it comes to communicating, by me having a disability and stuff, a lot of time people don’t listen to you.”* Another respondent, who did not provide a response, said, *“Well I’ve had problems throughout my life when I’ve tried to voice my opinion, people just shut me out. They don’t want to listen to nothing I have to say.”* One respondent explained his answer, ‘a lot of difficulty,’ by saying that he does not understand why people were *“hating on him”* in his personal life. As these quotes demonstrate, some respondents said they felt as if other people do not want to understand them – *“I repeat, but it’s like they don’t want to understand.”* In one case, a respondent who answered ‘some difficulty’ felt that there were occasional misunderstandings between himself and his coworkers about his

⁵⁷ Washington Group / ESCAP Statistics Division. (2010) *Guidelines for cognitive and pilot testing of questions for use in surveys*. Retrieved October 6, 2020, from <https://www.unescap.org/sites/default/files/Disability-question-testing-guidelines.pdf>

intentions and actions, not directly related to his spoken communication. He said, *“I don’t know how to describe it – like sometimes people just don’t understand what I’m doing at the time.”*

In some cases, respondents, particularly adults with ID, noted that communication difficulties were not consistent, and they only emerged in certain scenarios or with certain people, such as at the doctor’s office or when they were in school. For instance, one respondent answered ‘a lot of difficulty,’ thinking about how her speech delay as a child made her afraid to speak with doctors. She said, *“I was scared to explain [my speech delay] at a young age because they were questioning. I didn’t know how to explain it to them. Now, I’m not scared to answer.”* Likewise, another respondent, who answered ‘no difficulty,’ felt that her caretakers treated her like a child at times, though she believed that she had no problem expressing and advocating for herself. Additionally, one respondent without IDD thought about social media interactions when she answered ‘some difficulty.’ She said, *“It’s intense because, if I’m in a conversation and I’m in my regular environment – it just really depends.”*

Ability to hear sounds

A few respondents thought about their difficulties hearing and understanding words when answering this question. This consideration was sometimes thought of in combination with the respondents’ difficulty focusing – particularly in crowded settings or in those with background noise. For example, one respondent without IDD answered ‘some difficulty,’ noting both his ‘lazy tongue’ and intermittent hearing loss caused by a recent stroke. His hearing loss sometimes affected his ability to focus on what people were saying.

However, not all respondents who said they had difficulties hearing sounds when discussing Question 2 (hearing) cited those difficulties as affecting their abilities to communicate when discussing this question. For example, one respondent with significant hearing loss answered ‘no difficulty’ to this question because he had no difficulty expressing himself in any situation.

Other physical reasons

One proxy for a respondent with DD described a physical reason that the reference person had ‘some difficulty’ communicating. She said, *“Because his chest is compressed, he has a tendency to take a deep breath because he is running out of air to speak. He’s got more of a high pitch tone to him.”* Sometimes she needed to have the respondent repeat himself, but this problem was not consistent, so she did not answer ‘a lot of difficulty.’ Additionally, one respondent without IDD explained his answer, ‘some difficulty,’ in part due to his *“lazy tongue”* after his stroke.

Comprehension of the question

Some respondents were not sure what the question aimed to measure. This was, at times, due to the two skills represented (‘understanding’ and ‘being understood’) or the wording of the question itself. For instance, one respondent with ID said, *“What does that mean? Can you give me an example? [pause] Can you word it a different way?”* In this case, the respondent discussed his difficulties with people not listening to his opinions (see the above section ‘Interpersonal Relationships’), and he did not provide an answer. In a few cases, the interviewer needed to repeat the question, and at times break down the question into component parts to elicit a conversation. One respondent seemed to understand an interviewer probe as asking if he was a ‘difficult person’ rather than if he ‘had difficulty,’ adding to the challenge of conducting the cognitive interview for this question.

Response option selection

Several respondents and proxy respondents were not able to select an answer. These cases of nonresponse were due to two overarching reasons: i) ‘understanding’ and ‘being understood’ can be different skill sets for some people, and, relatedly, ii) some respondents were unclear as to the purpose and meaning of the question. Nonresponse occurred with respondents and proxies of adults with ID as well as one respondent with DD who used an assistive device to communicate. Additionally, these two reasons for nonresponse also affected the way in which people who did respond answered the question.

Separate skills

Some respondents with ID and some proxies for adults with ID as well as one respondent with DD who used an assistive device to communicate, had difficulty selecting a response because understanding and being understood can be very different skill sets. Therefore, there may be different difficulty levels for each skill. People who viewed the question as double-barreled selected their answers in different ways. Some were unable to select an answer, some answered based on one skill and not the other, and others aimed to ‘average’ the two skills to form a generalized response. For example, one proxy for a respondent with ID, who did not select an answer, said that the respondent “*understands quite well*” but that you need his frame of reference in order to understand him, otherwise “*you can’t really put it together.*” One respondent with ID who answered ‘no difficulty’ selected his response based on his ability to understand others, even though he said that sometimes people have a hard time understanding him. He explained, “*I would say no difficulties, but my supervisor would say otherwise ... Sometimes, I just have to slow down, just a little bit.*” On the other hand, a proxy who selected ‘some difficulty’ answered based on the more challenging skill for the reference person. She said, “*Mostly he is a really good communicator. He speaks very well. He is not difficult to understand at all.*” However, since he sometimes did not understand complex vocabulary or abstract concepts, she selected ‘some difficulty.’ Rather than selecting one skill or the other, some aimed to average the two skills through their response. For example, one proxy respondent who answered ‘some difficulty’ explained that the reference person understood others very well. He had “*a lot of difficulty being understood*” - particularly for people outside of the family. In that case, ‘some difficulty’ was a compromise between the two skills.

The respondent with DD who was non-oral approached the question with nuance, and she questioned whether the purpose was to measure speech or language abilities. She did not think she had a language disability of any sort, but she could not communicate through speaking, requiring augmentative communication. She would answer differently to the different concepts of ‘understanding’ and ‘being understood: “*Cannot be understood though speech at all versus I have no difficulty understanding.*” As a result, she was unable to select a response, and the question failed to capture her inability to communicate through speech – a key characteristic of her developmental disability.

Equivalency between respondent and proxy reporting

Of the pairs in which both the respondent and proxy provided an answer (14 pairs), most provided equivalent answers; for those with different answers, in all but one pair, the proxy’s answer represented a higher difficulty level than the respondent. In these cases, all the respondents were adults with ID. The proxy respondents connected the reference person’s difficulties to their ID, whereas the respondents often viewed their difficulty as a product of other people’s lack of understanding rather than their own cognitive difficulties related to their ID.

Age of Onset

Four respondents with ID and four proxies, not all of whom were paired, selected ‘a lot of difficulty,’ and would therefore be routed to the age of onset question (Question 9) in the NHIS. Indeed, only one dyad had matched responses that were both ‘a lot of difficulty.’ However, in that case, the respondent did not have a clear understanding of the question. For another respondent with ID, who was not part of a dyad, this was the only question she answered ‘a lot of difficulty.’ This question operated well to capture her difficulty communicating, particularly with doctors, which was an important part of the difficulties she had experienced in her life.

Question 7: Independent living

Q7. Because of a physical, mental, or emotional problem, do you have difficulty doing errands alone such as visiting the doctor’s office or shopping? Would you say...

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

Source

This question has been previously included on the American Community Survey,^{58,59} albeit with dichotomous response options of ‘yes’ or ‘no.’ The question is used in this context with the intention to help inform the extent to which the person with IDD may be able to live independently.

Summary

Most respondents and proxies understood the question intent, that is, to determine whether respondents were able to conduct themselves independently. However, this interpretation did not always align with the level of difficulty as assessed, dependent on respondents’ ability to leave their home unaccompanied, the level of support required to achieve a certain task, whether or not respondents perceived any assistance received as required, and their ability to learn how to do things without help.

Similar to findings from Miller and DeMaio (2006),⁶⁰ four domains of physical limitations, cognitive functioning, emotional restrictions, and access to resources are identified on which respondents based their understanding and response assessment.

- i) **physical limitations**, such as those due to muscle deterioration or because of being in a wheelchair which meant that, for example, respondents had difficulty reaching items from a supermarket shelf or maneuvering a shopping cart: *“I would say some difficulty because if I’m shopping in the grocery store, I won’t be able to reach everything so that is why I said some.”*
- ii) **cognitive functioning**, such as the ability to understand and process information, make good decisions, remember things, or learn new information, including lacking the ability to read or write which meant that, for

⁵⁸ [American Community Survey \(ACS\) \(census.gov\)](https://www.census.gov/acs/)

⁵⁹ [The American Community Survey 2020 Questionnaire \(census.gov\)](https://www.census.gov/2020/questionnaire/)

⁶⁰ Miller, K., and DeMaio, T., 2006, Report of Cognitive Research on Proposed American Community Survey Disability Questions, Hyattsville, MD: National Center for Health Statistics. <https://wwwn.cdc.gov/QBank/Report.aspx?1042>

example, respondents had difficulty handling money, completing paperwork, or navigating their way around an unfamiliar area. As a proxy respondent explained, *“Oh no, he could never do that, he could never travel alone, he would be lost in second.”*

iii) **emotional restrictions** due to past experiences, such as fear of having a seizure in public, fear of men or crowds, mistrust of the medical profession, or generally fearful of how other people might treat them because of their disability: *“Doctors, ‘some difficulty’ because of trust issues.”*

iv) **access to resources**, such as access to public transportation, a motorized wheelchair, or having the financial wherewithal: *“I don’t have no difficulty, but you can say ‘a little’ bit because I do have to have a ride unless I call a cab. That’s the only problem I do need someone driving me.”*

Understanding the question concept

At face value this is a complex question for respondents to answer. They must understand that the question is asking about doing errands, what is meant by doing errands, and whether they have difficulty doing errands by themselves. Respondents must also consider that the question is asking if any difficulty they have doing errands by themselves is related to a physical, mental, or emotional condition or reason. This was compounded by the fact that adults with an intellectual disability were not always aware of their disability (see section 4.1.1.). In addition, respondents had to consider whether they could complete different types of errands alone and whether they could complete all of the errands alone or whether they were able to complete just part of the errand without assistance, and then rate their difficulty level accordingly.

Understanding of the term ‘errands’

The majority thought about ‘doing errands’ as achieving a specific task. However, comprehension of the term ‘errands’ varied. Some considered activities outside of the home; others considered activities inside of the home.

Outside of the home. People with a physical disability only, or mild intellectual disability, or no disability at all, who were generally able to leave their home when they wanted to, understood ‘doing errands’ to correctly involve leaving the home: *“Anywhere you would go that takes you out of the house.”* Many focused only on the errands illustrated by the examples used in the question stem - shopping or visiting a doctor’s office. A few could not think of any other examples of errands that they might undertake. Some also thought about going to the dentist, optometrist, bank, post office, or gas station. A few also included leisure activities in their definition of ‘errands,’ for example, going to a movie theater, a restaurant, bookstore, or the hair salon.

When they thought about going shopping, respondents and proxies generally thought about going to a grocery store. However, their definition of what shopping at the grocery store entailed varied. For example, some respondents were able to select items from the shelf of a grocery store, but they struggled with checkout. One proxy respondent who answered ‘cannot do at all’ said, *“Alone? He can’t do it at all alone. But if I’m in the store, I can send him off to get bananas.”* Another proxy respondent who answered ‘no difficulty’ said that her son was able to go alone to one particular grocery store that he was familiar with, but that she provided him with a shopping list, and he would call her from the store if he had any questions.

Inside of the home. People whose ability to leave the home was restricted and who had difficulty managing daily living activities thought about household chores they could achieve, such as helping to unpack groceries, washing dishes, vacuuming, self-care or cleaning out their pet’s cage. This interpretation was also made by the one respondent without IDD who had a disability.

Doing errands alone

Most respondents required some support in order to carry out certain types of errands, even if they could do some errands alone, or needed support to carry out part of what was involved in achieving an errand.

In general, respondents who could leave the home unaccompanied could manage some, but not necessarily all, aspects of the tasks involved in the examples provided in the question stem. Some respondents went shopping on their own but were accompanied to a doctor's appointment because they needed help with paperwork, remembering what had been said to them, or understanding the technical language used by doctors. As a respondent, who answered 'some difficulty' said, *"I don't read that well and I can't spell so it's easier to have people fill out stuff for me."* A proxy respondent who answered 'some difficulty' said, *"...so the shopping no difficulties, but the doctor's some difficulties with the paperwork."* A few respondents mentioned the difficulties they had understanding "doctor talk" which was the reason why they took someone with them to the doctor's office. Some proxies also mentioned that they had to schedule the doctor's appointment, even if the respondent could attend on their own. On the other hand, some respondents could visit a doctor's office unaccompanied but needed support with shopping. One respondent with ID, who answered 'some difficulty,' explained that he had difficulty counting money and therefore had some difficulty shopping and needed to be accompanied, but in respect of visiting a doctor's office said, *"I can do that by myself, I do that very well."*

Others required help with all types of errands or could not do errands at all. These respondents struggled to follow the processes involved, for example in making and attending a doctor's appointment, or their inability to read made it almost impossible for them to achieve the task. A proxy respondent who answered 'cannot do at all,' on behalf of someone with ID explained, *"She would not know how to get to the doctor's office or understand the process once she did. So she would not know to say she had an appointment or know how to sign herself in even if she were able to get there."* A respondent with ID who answered 'cannot do at all' said, *"I could go to the grocery store but getting the right stuff I couldn't do...I can't read."* It is interesting to note that when answering this question, a few respondents with a physical disability, but not an intellectual disability, stressed that their difficulties doing errands were related to the physical nature of their disability and not the "cognitive process involved" in performing a task, such as when paying for something in a store. One respondent, who had difficulties because of his physical disability, said: *"mentally I'm fine doing things on my own."*

As previously alluded to, visiting a doctor's office required different skills from shopping, while shopping in a grocery store was, for some, a more complex task to achieve alone than shopping in a clothing store. A proxy who answered 'a lot of difficulty' on behalf of a respondent with ID, described how her son *"... could shop on his own, but I don't know if he'd have a pretty good system to know what to buy [in a grocery store]... He goes to the mall all of the time and buys clothes."* Another proxy said that her son could not undertake errands alone in the same way as other people his age because of his processing disorder which meant he found it difficult to shop in a grocery store if there were time constraints, which made him nervous and anxious.

Irrespective of ability, some respondents did not consider that they needed support for any task, or they needed support for only part of a task. When considering doing errands alone they sometimes included being accompanied by their aide, caretaker, or family member in their definition of alone: *"Sometimes I will go by myself with my aide."* Furthermore, when the difficulty was due to a physical disability, respondents did not always take into account any additional assistance received, for example when at the grocery store, such as help reaching something on a shelf, or physically picking out coins from their wallet. One respondent explained that this was because she could do it herself if she had to. One respondent with ID had no understanding as to why she was always accompanied outside of her group home.

It is worth noting that respondents with a developmental disability but not an intellectual disability, and who were more independent, indicated that they managed their lives so as to avoid doing things they needed assistance with. For example, banking online rather than going to the branch, or avoiding crowds in order to avoid *“too much stimulation.”*

Interestingly, support for respondents with ID, to help them do errands alone, sometimes came from the service provider. A proxy who answered ‘some difficulty,’ on behalf of a person with ID, said that the reference person could talk to the doctor alone because *“typically the doctor will follow up with us afterwards.”* Another proxy, who answered ‘a lot of difficulty’ on behalf of a person with ID explained that the reference person had a lot of difficulty visiting the doctor’s office because the staff *“...ask him to complete paperwork or they ask him if his insurance information has changed, that kind of thing. He can’t do that. Either the electronic thing or just paper and pencil filling out a form”* However, he could go to the dentist alone because *“...office staff try to accommodate his disability.”* Staff at the dental practice would telephone the proxy to explain any treatment required. They would also complete the required paperwork rather than asking the respondent to do it: *“So most of the time he is fine. The dentist’s office make the next appointment with him when he is there.”*

Managing money

A key aspect of doing errands alone, such as shopping, mentioned by both respondents and proxies, was the ability of the respondent to manage money. For example, a respondent with ID who answered ‘some difficulty’ in relation to shopping said, *“I don’t count money very well”* explaining that his aide would help with paying for things. A proxy who answered ‘some difficulty’ on behalf of a respondent with ID, described how the respondent could select items in a store but needed supervision at checkout:

She knows how to do some transactions, but she needs somebody looking over her shoulder when she is doing money transactions...If I take her to Target. She is familiar with Target. She can get her own items and get in line and make her purchases. But I still have to look over her shoulder to make sure she didn’t pick up too many things and she has enough money.”

The difficulty, as described by another proxy, was in her daughter’s ability to understand the concept of worth:

“If it’s a small amount, no more than like \$10, she understands. She knows her bills, but then, like when you tell her it’s, you know whatever the price is, and then she just doesn’t understand how much to give the clerk. So she needs assistance with money, she needs assistance with shopping and all that.”

Another proxy explained that her son with ID lived separately from her and was financially independent, earning his own money from his jobs. He was able to pay for small items when shopping at the mall for example, but she managed his finances in relation to things like paying bills. This was because *“...he does not always comprehend printed bank information. ...He knows he has money in the bank but doesn’t really understand the concept of what he can purchase for the amount he has.”* She gave the example of despite having a few hundred dollars in his bank account he had called her to ask if he could afford to purchase two donuts.

Making decisions

A few proxy respondents mentioned that the reason their reference person with ID could not do errands alone was because of their inability to make decisions for themselves. For example, one proxy explained that although her son could go alone to an appointment with his eye doctor, he would need help deciding on new frames: *“He needs help with decision making.”* Another proxy explained that the reference person could not make good decisions regarding her health and therefore someone always had to go with her to a doctor’s appointment: *“She cannot be trusted to make decisions that are right for her own well-being.”*

Forgetfulness

One respondent with ID answered ‘no difficulty’ because he said it was not that he had difficulty or was not able to do things, but because he sometimes “forgets” to do things.

Response option selection

The way in which respondents and proxies interpreted the question did not necessarily correlate with the response option selected. As already discussed, confounding the response process was respondent comprehension of the term ‘errands’ and the term ‘alone’ within the context of their life experiences. Furthermore, the level of support required was not always consistently reflected by the level of difficulty selected.

Rating level of support

When answering the question an initial assessment was made as to respondents’ ability to do anything at all alone or if they always or sometimes had to be accompanied. However, for the population of respondents with IDD, the response process was complicated by the fact that respondents may need help with only part of the task, they may not view being accompanied by their aide, caretaker or family member as requiring assistance, or they may base their response on errands they could do alone if they wanted to.

One proxy respondent, who answered ‘cannot do at all’ on behalf of a person with DD, found it more difficult to select a response option because of the fact that part of the errand could be achieved alone:

“That one was a little confusing because if we are out at the store, he can go aisle to aisle and then he will give me a buzz saying, ‘can you reach this for me or grab this for me.’ So he can go out and about, but he needs someone there with him to help him.”

When rating their level of difficulty, some respondents focused on errands they could do alone. For example, a respondent who answered ‘no difficulty’ did so on the basis that he went to the doctor’s office alone, even though his aide did his shopping for him. Even respondents who were unable to do errands alone focused on other activities they could do. A few considered their ability to go to the movies or the library alone, their job, or focused on chores they did by themselves, such as sweeping the stairs. Others focused on what they could not achieve. For example, one respondent with ID answered ‘some difficulty’ because sometimes he needed help at a doctor’s appointment, even though most of the time he could go alone:

“Most of the time I can go to the doctor but if I go to a new doctor, I have to fill out paperwork and I need help with that or if the doctor asks me certain things and I can’t remember then the aide will help.”

When selecting a response option, respondents did not always account for their aides or family members who accompanied them when doing errands, answering ‘no difficulty.’ For example, one respondent said, “I don’t have any problems shopping at all. I can shop for myself. I just go out and just need someone to help me at the check-out.” Another respondent with ID who answered ‘no difficulty’ told the interviewer that he has someone with him just to make sure he is “...doing the right thing” such as ensuring that he had enough money to pay for things and remembered to get a receipt, which appeared to be reassuring to him as he added, “If I do errands by myself I always like to make sure that I have somebody with me.” Indeed, a few respondents with ID, who answered ‘no difficulty’ appeared to view their support person as an extension of self; there in case additional support was needed, but not a necessity. In fact, a number of respondents with ID who were accompanied by a support person answered ‘no difficulty’ because they said they could do the errands alone but chose not to:

“Maybe sometimes but not all of the time, most of the time I can do it myself. Sometimes I get a little lazy.”
[No difficulty]

“I could do it myself, but sometimes I like to have my husband with me... We like to go together. I like to shop together.” [No difficulty]

However, a respondent with DD who was also non-oral, answered ‘cannot do at all’ explaining that she preferred not to go out alone because of her communication difficulties, it was just easier if someone was with her, as well as feeling safe when someone else was there in case she had a seizure.

One proxy respondent, who was caretaker to a respondent with ID, was unable to select a response, *“She doesn’t go no-where by herself...She has a 24-hour person, so I wouldn’t know how to answer that.”*

Ability to learn

A recurring theme throughout the cognitive interviews, and one which influenced the difficulty rating selected when answering this question, was the focus of some proxy respondents on their child’s ability to learn how to do things, even if it took them a long time to do so and required a great deal of repetition: *“I’m going to say ‘no difficulty’ based on what we have been working on for a long time...repetition, repetition, repetition.”* A few proxies described the travel training their reference person with ID had received from Metro Ready Travel Training⁶¹ which enabled them to travel to certain places alone. It was said to take time and require a lot of repetition but could be achieved: *“It’s a matter of routine.”* One proxy respondent whose son had received this travel training said, *“Absolutely not, no difficulty at all. Just travels by train, knows task, goes and does that exact task. No difficulty.”* A proxy respondent answered ‘a lot of difficulty’ because of her son’s difficulties with decision making, but described his ability to use transportation once he had learned the route or as a result of training he had received from a local charity in how to use Uber or Lyft.

Focus on stressful events

We saw that a few respondents with ID were influenced by memorable stressful events when making their response selection. For example, one respondent, who had described his ability to be independent and go out alone, answered ‘a lot of difficulty’ after recalling a recent incident when he had failed to manage to cash a check. Another answered ‘a lot of difficulty’ thinking about a recent experience where he could not find his mother after going to a department store with her. Interestingly his mother answered ‘no difficulty’ and talked about her son’s ability to be more independent once he had been shown how to do things, citing the metro travel training mentioned above.

Equivalency between respondent and proxy reporting

Cases where the interviewer was unable to achieve a response to this question were from respondents with more severe intellectual disabilities and where their proxy answered ‘cannot do at all.’ Comments such as, *“He needs help with everything”* were made by proxies answering in this way. Where a response was achieved for both parties about half of the proxy responses were the same as those provided by the respondent; about half considered the respondent’s level of difficulty to be greater than that provided by the respondent themselves.

Question sensitivity

The use of the example of visiting a doctor’s office raised some emotional issues for a few respondents who had had bad experiences with the medical profession in the past, or in one case, men in general. For example, a respondent with ID, described the difficulty he had in finding a doctor he could trust and who would treat him in a respectful manner because of his disability. He said, *“Some doctors when you ask them to break it down you get an attitude...Some doctors just tell you to do what they say because you have a disability.”* For another respondent with ID, the question brought up past experiences of doctors whom he had felt were communicating with his

⁶¹<https://www.wmata.com/service/accessibility/MetroReady-Travel-Training-and-System-Orientation.cfm>

caretaker rather than talking to him directly. One respondent with ID was visibly upset during the interview when describing his bad experience during a hospital stay at the start of the COVID-19 pandemic. Because he had not been allowed visitors who could advocate for him, he had felt isolated and alone.

In addition, one respondent with ID understood the use of the term ‘mental’ problem used in the question stem to be implying that he was hyperactive and needed medication to keep him calm, explaining to the interviewer that he was not like that.

Age of onset

Five respondents with IDD, but around half of all proxies answered ‘a lot of difficulty’ or ‘cannot do at all’ to this question and therefore would have been routed to age of onset in the NHIS. One respondent said that he had only needed help with shopping since he had moved out of his parents’ home and lived independently after age 22: *“When I lived with my parents, I never needed to shop alone I guess.”*

Question 8: Learning

Q8. Do you have difficulty learning things most people your age can learn? Would you say...

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

7. Don’t know
9. Refused

Source

This question was adapted from a question developed by the Washington Group on Disability Statistics and UNICEF for administration to an adult proxy respondent with care giving responsibilities for a child.⁶²

‘Compared with children of the same age, does [name] have difficulty learning things?’ The purpose is to assess the respondent’s current ability to learn new things in their day-to-day life.

Summary

Respondents and proxy respondents generally interpreted the question to be asking about respondents’ ability to acquire new knowledge or learn new skills – be they everyday tasks like washing the dishes, specific skills like driving, academic skills like reading and writing, or social skills like reading social cues or understanding nuanced conversations. At times, respondents and proxies considered what they were good at learning rather than assessing difficulties learning directly.

Learning difficulties are integral to some intellectual and developmental disabilities. As such, proxies, who were typically the parent of the reference person with IDD, tended to consider learning difficulties within a disability framework when answering this question. Additionally, for this question, most proxies and many respondents compared the reference person to people of the same age in the general population, and not compared to someone with similar disabilities or from within their own capabilities. When hearing this question, one proxy exclaimed, *“Oh yes!”* She went on to explain her response, ‘a lot of difficulty,’ by noting that learning difficulties were the

⁶² [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

primary difficulty that her son faced due to his ID. Respondents with ID sometimes directly acknowledged their disability when assessing and answering but oftentimes adults with ID did not, noting, for example, that they learn “*slowly*” or they “*ask questions*” as needed.

Understanding of the question concept

This question elicited a variety of considerations. As it asks about what ‘most people your age’ can learn, respondents needed to consider both what they might learn as an adult and also who are ‘most people’ their age.

Due to the complexities of the question, a few respondents and proxies did not provide an answer. This was because they were either unsure what kind of learning they should consider, or they were unsure how to generalize their diverse experiences into a single response, or they were not sure how to measure their learning against ‘most people.’

Interpreting the term ‘learning things’

Respondents and proxies interpreted ‘learning things’ in a variety of ways. Considerations included learning everyday tasks such as self-care routines (brushing teeth and showering), handling money, using new technology, learning specific skills like driving or dancing, learning academic subjects like reading, writing, and math, learning tasks for work, and learning to read social cues.

Some with IDD and most proxies considered every day, practical tasks of daily living, such as brushing teeth, making the bed, cooking, and taking out the trash. Adults with DD and their proxies tended to consider creative and active aspects of cooking, such as coming up with a new recipe whereas respondents with ID and their proxies considered knowledge of how to do daily living tasks. For example, one proxy, who answered ‘a lot of difficulty,’ explained her son’s difficulties in the following way: “*He tries to wash dishes but does not really get them clean. He needs help. Even washing his clothes, he needs help because he would put all of the washing liquid in the washing machine.*” Another proxy selected ‘a lot of difficulty’ thinking of her daughter’s difficulty getting on the bus to her life skills class: “*There have been several instances where she has run across the street not looking both ways, not having the intellect to know that a car can hit me.*”

Handling money and learning to drive were two important life skills that some respondents and proxies focused on and viewed as significant. For instance, one respondent with ID who answered ‘a lot of difficulty’ expressed his desire to have a driver’s license someday. He said, “*I want to. I have a friend who is special needs, and he drives. But he doesn’t go anywhere but work and back home. I want to be like him – just drive and get out there and do stuff.*”

Some respondents and proxies considered academic learning, such as learning to read and write in school. In some cases, having graduated high school or being able to read was evidence for having ‘no difficulty’: “*I’m very qualified. No difficulty at all.*” Also, respondents at times recognized their improvement over time with certain subjects. For example, one respondent explained that she used to not understand math, and now she does. She said, “*Sometimes, I think a long time ago, I had diagnosed with some disability that makes it more difficult.*” For other respondents and proxies, the subjects they learned in school were still challenging and therefore still salient to them. As one respondent, who answered ‘some difficulty’ said, “*Some difficulty is with the writing. I can’t do the writing – someone has to take notes for me. I’m more a visual learning than being able to write it on paper.*” Another respondent said, “*A lot [of difficulty]. Want me to name some? Other people can read, they can spell, just...educational things that they do that I can’t.*”

A few respondents with ID thought about learning social cues and understanding social interactions. For example, one respondent who answered ‘some difficulty’ thought about being too “*trusting*” in people: “*Sometimes I believe what people have told me when I shouldn’t have believed them at all.*” Another respondent who also answered ‘some difficulty’ said he sometimes has difficulty reading social interactions, resulting in miscommunication.

Interpreting the term ‘most people your age’

Adults with IDD and proxies who thought of the question within a disability framework tended to compare the reference person to people without disabilities. Most proxies compared the reference person to the general population without IDD. One notable exception was a proxy who was an aide. She compared the reference person with ID to other people in her care. For many respondents with IDD, it was unclear how they interpreted the term ‘other people your age.’ In some cases, however, the respondent referenced that they were slower than “*the average person*” or were different from “*regular people.*”

Past or present difficulties

Most thought of this question in terms of current learning difficulties, although some respondents and one proxy thought about past learning difficulties – while growing up, prior jobs, or when the respondent was in school. In a few cases, learning in school was particularly cogent or memorable. For example, a respondent with ID explained that his difficulties were caused by other people’s neglect when he was younger. He initially answered “*A lot,*” explaining that when he was in school, no one ever helped him learn.

Positive focus on the respondent’s strengths

Proxies, particularly parents of respondents with ID, did not always just want to concentrate on the difficulties that their children experienced. For example, a few proxies talked about respondents’ ability to learn through observation and repetition. For example, one proxy described her son’s ability to learn specific tasks for his food delivery job at a hospital. Another, who answered ‘a lot of difficulty,’ explained that her son will never drive. But she qualified her answer by also saying, “*He’s a great athlete. He does so much. You would look at him and not know he had disabilities until you spent some time with him.*”

Some respondents also considered things they were good at learning, or they thought of the processes that made them successful at learning something, such as repetition, being shown, or given extra time. In these cases, respondents often selected ‘no difficulty.’ For example, one respondent thought of learning how to cook. He answered ‘no difficulty’ and said, “*If I was showed it once I could pull it up pretty quick.*” Likewise, another respondent said, “*No problems with that it just takes me a little longer to do it.*”

Unclear interpretations

A few respondents had difficulty understanding the question or expressing themselves. In these cases, their considerations of this question were contradictory and non-expansive. For instance, one respondent, who did not provide a response, answered based on typical activities that he did, saying that he enjoyed watching television by himself. Another appeared to be reaching fatigue at this point because he was visibly tired, yawning frequently, and requesting probes to be repeated. Despite answering ‘no difficulty,’ he said that he found learning new things both “*easy*” and “*hard.*”

Response option selection

Respondents with IDD who selected either ‘some difficulty’ or ‘a lot of difficulty,’ almost half, did so because they felt some degree of functional difficulty when learning in their lives – be it in the past or present. This meant that respondents described some barrier or difference (compared to most people) they experienced when learning that affected them personally. For instance, one respondent said he’d like to be able to drive “*like regular people*” so he could be more independent. This respondent (not the same person as the one quoted in ‘Interpreting the term ‘learning things’ above) explained his response, ‘some difficulty,’ stating that learning to drive was difficult for him, because he was nervous that he might get distracted while driving and make a mistake. One exception to this was that a respondent, who did not understand the intent of the question, answered ‘a lot of difficulty’ based on the difficulties that all people have when learning to master a “*hand dance.*”

Why there is or is not a difficulty

When respondents described why they had difficulties learning, most explained that their difficulties were something they always experienced. They mentioned learning more slowly, needing things broken down into tasks, and having difficulty remembering. For example, one respondent with ID explained that it takes him about a month to learn a new task that his boss has given him, but with practice he can learn the task. Similarly, another respondent, who answered ‘some difficulty,’ also spoke of learning tasks for a job and said:

“I was one of the last people there that was getting to know the directions. They gave us a test in order to know that we know how to do the job, and in order to keep the job as long as we wanted. And I was not doing as well.”

A few considered their difficulties as a natural part of the aging process. For example, one respondent with ID, who answered “Some difficulty,” said, “*When you get old it’s hard to learn new stuff.*”

One respondent with DD answered ‘some difficulty’ for specifically tasks that she wanted to learn. She was thinking of learning skills, like cooking, that require “*tedious motor skills.*” She did not report having physical limitations from her DD, though her fine motor skills may have been affected by her nervous system disorder.

Generally, respondents with IDD who selected ‘no difficulty’ did so primarily because they felt a low degree of functional difficulty learning things in their day-to-day life. Some of the specific reasons included that their difficulties were primarily physical, their abilities had improved over time, or, in their view, they had no difficulty because they could always ask questions to ease the learning process. For example, one respondent with ID explained his response, ‘no difficulty,’ by saying “*If people don’t understand, they will ask more questions.*” He further explained that if he was looking at a map and did not know where to go, he would just ask for help.

Two proxy respondents answering on behalf of a person with ID selected ‘no difficulty.’ Both were not the mothers of the reference person – rather, they were familiar with the respondent as an adult only. In one case, the reference person answered ‘a lot of difficulty,’ thinking about his difficulty learning to read.

Nonresponse

Several respondents and a proxy did not provide a response despite being able to explain aspects of their learning or the reference person’s learning. In some cases, respondents asked for examples when they heard the question, unsure what ‘people their age can learn.’ For example, one respondent replied, “*Let me put it to you this way, okay, learn it in what way? When I say reading in what way, like reading, work or what [are] you talking about?*” Likewise, another respondent said, “*Like what?... For my age? I don’t know...that’s hard to explain. I’m always doing things for myself. I’ve never been around people my age.*”

In a few other cases, respondents found it hard to choose a response because they felt they could learn, but they learned differently than others. One respondent expressed his difficulty selecting an answer in the following way: “Depends on what it is. Well, the average person, to pick it up might take seconds. For me, it might take a little longer. It depends on what it is [laughs].” Similarly, another respondent said, “I’ll get it. It may not be on the first round but it may be like the second or third round, but I’ll eventually get it.”

The one proxy who said ‘don’t know’ expressed discomfort comparing her son to ‘other people his age.’ She said, “I don’t know, how would you answer that? ...From a Down’s perspective or a normal adult? That question can’t be answered.”

Equivalency between respondent and proxy reporting

There was a tendency for respondents with ID to select a response option that reflected less difficulty than that which was selected by their proxy. Indeed, there were four dyads in which the proxy selected ‘a lot of difficulty’ and the respondent answered ‘no difficulty.’ This was due to different considerations of the question. For example, one respondent explained her response ‘no difficulty’ by saying the following: “Yeah, like go to church, worshipping god, and I like to do arts and crafts and stuff.” Her paired proxy said, “I’m just thinking most people her age have already graduated from college and know how to write a paper or use the internet and that’s stuff that she doesn’t know how to do or can’t do.” A respondent selected a higher difficulty response than the corresponding proxy in only one case. For that pair, the proxy viewed the respondent as doing well in his job as a handyman, and she answered ‘no difficulty.’ Whereas, the respondent viewed his difficulties through the lens of his disability and answered ‘a lot of difficulty,’ thinking about his inability to read. Dyads in which the respondent had DD gave the same answers.

Age of Onset

No respondents or proxies selected ‘cannot do at all.’ Only a few respondents with ID selected ‘a lot of difficulty,’ so most would not be routed to the age of onset question in the NHIS. However, most proxies answering on behalf of respondents with ID selected ‘a lot of difficulty’ and would have therefore been routed to the age of onset question in the NHIS.

Question 9: Age of Onset

Q9. You said you had difficulty with [Fill from Q3-Q8, if they provided responses other than “No difficulty”], did any of this happen before you turned 22?

1. No, all of this happened after I turned 22
2. Yes, some of this happened before I turned 22

7. Don’t know
9. Refused

Source

This question is from the National Health Interview Survey (NHIS) questionnaire.⁶³ Also, the Washington Group described recommended strategies for the measurement of age of onset prior to its addition on the NHIS⁶⁴. In this study, the question was evaluated alongside the functional difficulty questions to better understand first, whether and how functional difficulty questions routed respondents to this question and secondly, once asked, to

⁶³ [NHIS - 2020 NHIS \(cdc.gov\)](#)

⁶⁴ [When does disability begin? Identifying the age of onset - The Washington Group on Disability Statistics \(washingtongroup-disability.com\)](#)

understand how respondents considered the question and, again what domains of functioning they considered when answering the question.

The purpose of this question in a population survey is to identify respondents with IDD by determining that the age of their disability onset was before 22 aligning with the definition of the developmental period for IDD.^{65,66} Age of disability onset is a critical criterion used for identifying people with IDD and provides a way to differentiate between adults with IDD and adults with other conditions such as Alzheimer’s disease or a stroke.

Summary

For this study, this question was asked of all respondents who reported having any degree of functional difficulties (captured by Questions 3-8) in order to determine when those difficulties happened. The expected response for adults who did not have IDD was ‘No, all of this happened after I turned 22.’ Whereas adults with IDD were expected to respond, ‘Yes, some of this happened before I turned 22.’ In a large population survey like the NHIS a ‘false positive’ case, for purposes of routing to the age of onset question, would occur when a respondent without IDD answers ‘Yes, some of this happened before age 22,’ because they would falsely be counted as having IDD. Alternately, a ‘false negative’ case would occur when a respondent with IDD answers ‘No, all of this happened after I turned 22.’

This question, among those in this question set, presents a unique two-stage challenge to respondents in that it requires a people to i) understand and respond to prior questions in such a way to be routed, and ii) understand and respond to the age of onset question itself. As a result,

some respondents with IDD were not routed to and asked this question or, were routed based on functional difficulties associated with non-IDD conditions, such as arthritis that emerged in adulthood.

Those who were asked the question tended to consider their difficulties along one of two paths: either as lifelong difficulties that have been with them since childhood or as specific, tangible life events. However, a respondent’s consideration of one path or the other did not predict the way a respondent answered. There were also cases of false negatives, nonresponse, and those answering ‘don’t know,’ as well as one case of a false positive among a person without IDD.

Overall, as evaluated, the question under-identified self-reporting respondents with IDD. This happened because the difficulties that many people with IDD experience made it a challenge to be screened into and answer the age of onset question as expected. Characteristics such as having difficulty conceptualizing time, having multiple difficulties that began at different times, or having cognitive delays all contributed to making the question more cognitively burdensome. Figure 1 shows factors that affected response option selection.

⁶⁵ [Criteria \(aaidd.org\)](http://Criteria(aaidd.org))

⁶⁶ Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., ... & Yeager, M. H. (2010). *Intellectual disability: Definition, classification, and systems of supports*. American Association on Intellectual and Developmental Disabilities. 444 North Capitol Street NW Suite 846, Washington, DC 20001.

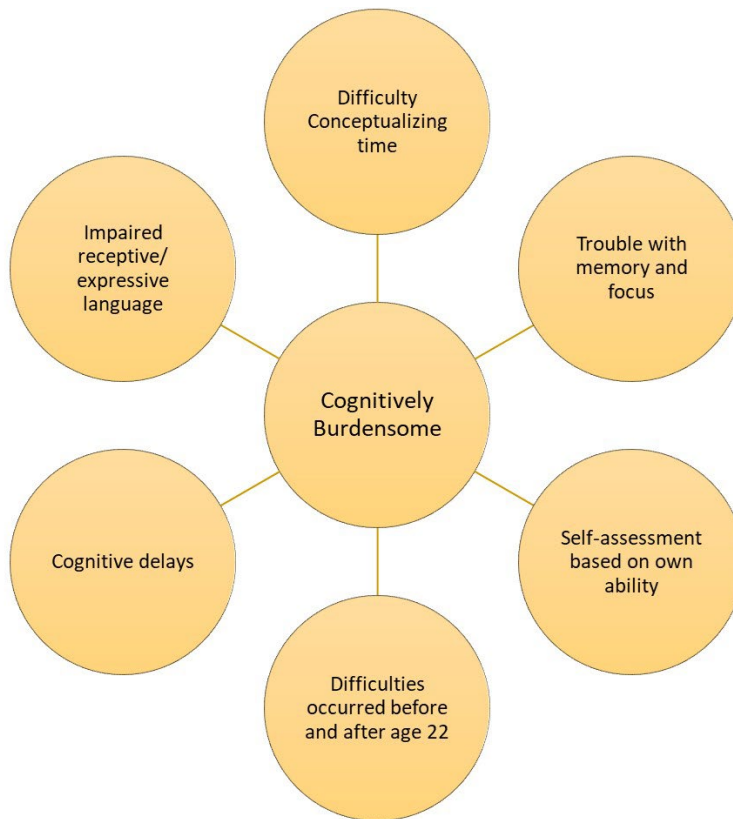


Figure 1: Contributing factors affecting response option selection to age of onset

Question Screening Criteria

Unlike other items in this questionnaire, which were designed to be asked of all respondents, this question was only asked of people who were screened in based on prior responses to Questions 3 through 8. Initially, for Round 1, interviewers only routed respondents to age of onset with answers of at least ‘a lot of difficulty’ to Questions 1-8. This was changed early in Round 1 to any answer other than ‘no difficulty’ to evaluate the age of onset question more fully, as respondents were generally answering with lower levels of difficulty than initially anticipated. In addition, Questions 1 and 2 were dropped from screening to avoid potential false positives from adults without IDD who had childhood vision or hearing loss. Interviewers probed on when difficulties began in order to examine the potential effectiveness of later questions, Questions 10-16, in identifying respondents with IDD. Finally, the question was initially written with the age ‘18’ but was changed to ‘22’ along with the screening questions to better align with the legal definition of IDD⁶⁷.

Understanding the Question Concept

Respondents and proxies approached the question in one of two ways. The first way was to view the question as asking about lifelong difficulties that have been with them since childhood. The second way, which occurred more commonly for respondents with ID, was to view the question more literally - as asking about when their difficulties became noticeable or impactful to their lives. For those who considered the question the second way, some focused on specific, tangible life events to gauge when their difficulties began, whereas others focused only

⁶⁷ Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., ... & Yeager, M. H. (2010). *Intellectual disability: Definition, classification, and systems of supports*. American Association on Intellectual and Developmental Disabilities. 444 North Capitol Street NW Suite 846, Washington, DC 20001.

on their most salient difficulties. Response categories were not mutually exclusive to a specific pattern of interpretation, and therefore, consideration did not predict answer choice.

Most proxies and respondents with DD conceptualized the reference person's difficulties as being with them for their entire lives and associated with a disability. For example, one respondent with DD, connected all his difficulties to a single diagnosis said, *"All began at birth. I was diagnosed with Cerebral Palsy at birth."* Proxies, typically the parents of their paired respondents, often said they noticed difficulties beginning at birth before beginning school. As one proxy respondent explained, *"His babysitter was telling me, 'You need to get him checked out.' ... By the time we got him to evaluation stage he was 2.5 almost 3. And they recommended that he be put around his peers. So, it was suggested that we send him to head start."*

Likewise, some respondents with ID also viewed their difficulties as being lifelong and stemming from their disability. For example, one respondent with ID said, *"No, I've had that problem all throughout my life. It's part of my disability."* Similarly, another respondent with ID spoke about his early childhood illness that led to his disability. He answered 'Yes, some of this happened before age 22' and said,

"I think when I was real, real little there was something wrong with me. I got real, real sick. I guess I was in the hospital for a long time. I just got real sick. I don't know if I had a brain tumor or something, I don't remember what happened. I thought I was just going to turn into a normal guy and then I turned into a special needs guy."

However, others, more often respondents with ID, did not view the question as asking about IDD onset, and rather they focused on salient difficulties or specific, tangible life events when answering. As a result, these respondents and some proxies answered inconsistently, even when they were aware of the childhood onset of IDD-related condition. For example, one respondent with ID who answered 'No, all of this happened after I turned 22' was thinking about his mobility difficulties. He said, *"No. When it comes to climbing stairs no, that happened later. When I was 40 that's when everything started breaking down."* However, when asked about his difficulties learning he went on to say the following about his disability: *"My learning disability I always had that. My intellectual disability I always had that."*

A proxy answering on behalf of a respondent with DD said 'don't know,' although she knew the respondent's condition began at birth. Thinking about his ability to do errands alone (Question 7), she said that she did not know him when he was younger and explained, *"I just know that he could do certain things on his own. He could do more things than he can do now. He had more independence when he was younger."* Another respondent who answered 'Yes, some of this began before age 18'⁶⁸ was thinking about the first time he got glasses. He could remember and pinpoint that event. However, when the interviewer probed about his difficulties remembering and concentrating or learning, the respondent said, he had *"no clue"* when those difficulties began because, as he said, *"I have no memory of when that started."* Yet, when asked if he had the problems when he was in school, he said *"Yes, pretty much when my mom raised me, when I was growing up."*

Response Option Selection

There were some instances of response error, nonresponse, and those saying 'don't know' for this question. When respondents with IDD answered 'No, all of this happened after I turned 22,' said 'don't know,' or they provided no response at all, they would not be identified as having IDD by this question in the NHIS. Sometimes, the respondent focused on a salient difficulty rather than answering based on their earliest emerging difficulty. Other

⁶⁸ This respondent was along the first four, so he received the initial version with the age '18' rather than '22.'

times, the respondent did not know when their difficulties began, or those with multiple difficulties faced a greater cognitive challenge due to the question design. For example, one respondent with ID who spent most of her young life in an institution said, *“I don’t know. I’m sorry,”* with regards to the onset of her difficulty remembering and concentrating (Question 4). Another respondent with ID who had multiple difficulties that began at different times said, *“I haven’t really thought about it...I think I always had a learning disability, I went to a special school, but some of the things I need now came later in life as I got older.”*

There was also one case where a respondent without IDD answered ‘Yes, some of this began before I turned 22,’ resulting in a false positive. She was thinking of her difficulty concentrating and tendency to procrastinate when answering and said, *“Well for that one I’ve been that way my whole life. I’ve always been a procrastinator and I work well under pressure. I don’t just sit down and force myself – for a while now. I think college did not make it better.”*

However, not all cases of respondents with IDD answering ‘No, all of this happened after I turned 22’ were instances of response error. Sometimes adults with ID were screened into age of onset based on their aging-related mobility difficulties or difficulties that they felt specifically began later in life. In those cases, the respondent correctly answered this question by selecting ‘No, all of this happened after I turned 22.’ For instance, one respondent with ID who answered ‘No, all of this happened after I turned 22’ was screened into this question based only upon her answer to Question 3, on mobility, due to her aging-related difficulties. Since these difficulties began at age 50 when she was diagnosed with arthritis, she answered this question without error. Rather, the challenge with capturing this respondent’s IDD in a survey setting would be in her responses to the prior screener questions. As another example, one respondent with ID felt that his difficulties began after graduating high school because he had much more support through his school years. He said that people were kinder to him when he was in school and that *“It was a different world back then.”*

In some cases, it was unclear why a respondent answered the way they did. For example, after one respondent with ID from Round 1 chose the response option ‘No, all of this happened after I turned 22,’ the interviewer asked an open-ended question about when his difficulties began, and he answered *“when I was a little baby.”* The respondent interpreted the rephrased, open-ended question differently than the formal closed question – which had resulted in error. This type of error prompted the interviewers to probe about age of onset by asking about life stages in Round 2, using phrases such as ‘when you were in school’ or ‘while you were growing up,’ for instance.

Proxy Responses

Most proxies were the respondent’s parent, and they viewed the reference person’s difficulties from a broad perspective – as affecting them their entire lives – and they were able to associate the respondent’s difficulties with their disability that emerged during development. They were often aware of specific diagnosis events and sometimes discussed those diagnoses when thinking about the age of disability onset. One proxy noted that her son’s difficulties began, *“As soon as it was evident that he needed to learn things. It was from birth. His disability was from birth.”* Indeed, another proxy remarked that ‘22’ seems like an odd age to ask about, *“because most of the time parents notice things very early on in age.”*

However, the proxies who were not the parent of the reference person were not able to assess whether a difficulty had begun before age 22. In those cases, the proxy based their response on their first-hand knowledge of the respondent as an adult, answering either ‘don’t know’ or ‘No, all of this happened after age 22.’ For example, one proxy respondent who was in a relationship and cohabitating with the respondent explained her answer by saying, *“It began after age 22 because that’s when I met him again. At age 45.”* Despite being aware that the respondent had been diagnosed with a learning disability as a teenager, the proxy did not attribute functional difficulties

displayed in adulthood to any childhood learning difficulties. This speaks to the importance of the relationship that each proxy had with their paired respondent. The closer – and longer – the relationship is, the more complete the proxy’s knowledge of the respondent, especially when assessing the age of onset of functional difficulties and when reporting on medical diagnoses. See also section 4.2.2 on ‘lack of knowledge/difficulties remembering.’

Equivalency between Respondent and Proxy Reporting

There was very little equivalency between the 16 dyads, with just five pairs sharing the same response but one of those pairs both answered ‘No, all of this happened after I turned 22’ because the respondent with ID was screened into this question based upon her aging-related mobility difficulties, and her proxy, who was an aide, did not know details about her development.

There were several instances of one of the pair not selecting a response or instances where the proxy and respondent were answering based on a different set of screener questions or interpreting the question differently, resulting in different answers. Also, in one case, a proxy selected ‘No, all of this happened after I turned 22’ but the reference person, who had ID, selected ‘Yes, some of this happened before age 22.’

Question 10: Learning

Q10. Do you have difficulty understanding and using information like following directions? Would you say...

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

7. Don’t know
9. Refused

Source

A version of this question was tested in a study for the Washington Group Extended Set (WG-ES): ‘Do you have difficulty understanding and using information like following directions to a new place?’ (Washington Group 2010)⁶⁹. The purpose being to assess respondents’ difficulties learning. In-scope interpretations of using information include thinking and logic skills at work, schoolwork, directions for household chores, and following other types of directions.

Summary

Overall, respondents and proxies considered this question to be asking about respondents’ ability to take in and successfully use information for things like completing a complex household task or following an order at work. When answering, respondents and proxies primarily considered the example of ‘following directions’ rather than the phrase ‘understanding and using information.’ This was similar to what was found when a version of this question was evaluated previously (Washington Group, 2010). Some respondents and proxies focused on respondents’ abilities and strengths rather than difficulties, and this positive focus affected response selection. Also, those who did not account for accommodations, like assistive technology, in their answers, tended to select

⁶⁹ Washington Group / ESCAP Statistics Division. (2010) *Guidelines for cognitive and pilot testing of questions for use in surveys*. Retrieved October 6, 2020, from <https://www.unescap.org/sites/default/files/Disability-question-testing-guidelines.pdf>

lower levels of difficulty than those who did, indicating that the use of accommodations was associated with lower day-to-day levels of functional difficulty as compared to the level of functional difficulties without the use of accommodations.

Understanding the question concept

When considering this question, respondents and proxies considered the term ‘following directions’ as either following a series of steps to complete a new task, or, as following a direct order or request from someone. Additionally, most proxies and some respondents with DD considered how information is conveyed to the reference person. Whether oral, written, or broken down into chunks, the mode in which information is given was important to the level of difficulty some respondents experienced.

Following Directions

Respondents and proxy respondents considered ‘following directions’ in one or both of two ways: i) completing a complex new task, like finding a lost item or following directions to a new location, or ii) following a direct request or order from a caregiver or person of authority.

A complex task involving a series of steps. Many respondents and proxies considered ‘following directions’ to indicate completing a new task involving multiple steps. Examples of such tasks included the following: taking transit to a new place, finding a lost item, following a specific diet, using a manual to build something, following a recipe, or taking an exam. Several people with IDD and their proxies said that respondents needed help breaking complex tasks into a series of steps. A respondent with ID, for example, said that if his mother tells him to look for her lost glasses, he tries, but he is unable to figure out how to look unless she gives him step-by-step instructions of where to look and how. Additionally, a proxy for a respondent with ID explained that there are some abstract concepts the respondent is unable to understand, “*such as being told to be ready at a certain time in the future to go somewhere.*” That would require the respondent to create a plan of action and enact it at the correct time – in sequence. Whereas, being told to “*go get ready now*” is a clear direction and was understandable to the respondent.

However, a few respondents with ID thought about directions to do tasks that they had previously learned and that they had mastered, such as work tasks, rather than understanding new information to complete new tasks. One respondent, who answered ‘no difficulty’ said, “*I follow directions pretty good actually.*” He was considering work tasks when responding, but then he further explained that he sometimes has difficulty following directions when there is a busy day at work or when he is trying to follow a cooking recipe: “*Sometimes I ruin it and it tastes a little bit strong sometimes. I should not do that. It’s a little too much.*”

Following orders. Several respondents with ID and a few of their proxies considered ‘following directions’ to mean completing a direct, discrete request: “*follow your order...tell me what to do.*” These orders typically referred to direction to do a known task such as making the bed, brushing their teeth, or putting on deodorant. As one respondent said, “*When someone tells me to do something I do it, but sometimes I don’t.*” She explained that she answered ‘no difficulty’ because she listens to her teachers and friends, but she does not trust strangers. A few respondents thought of ‘following directions’ in terms of following rules and orders about good behavior. Answering based on past behavior, one respondent said he had ‘a lot of difficulty’ because, several years prior, he would not listen to anyone; he would steal money from his mother and go to the store. “*I was terrible,*” he explained. By contrast, he said that following directions to a location was easy, he could just hear the directions once and know where to go.

How Information is Conveyed

Most proxy respondents and a few respondents with DD directly discussed how the mode in which respondents received information affected their ability to understand. One respondent with DD, for example, explained her answer of ‘some difficulty’ in the following way: *“If it’s a task that’s not my strength I need it to be broken down. Write it down or do the task with me.”* Likewise, a proxy answering on behalf of someone with ID, who answered ‘some difficulty,’ said information needed to be given in a way that her daughter can understand. She explained that her daughter recently took confirmation classes at church; they were administered orally, in such a way that made sure the respondent could understand. Similarly, another proxy answering on behalf of someone with DD explained her answer, ‘some difficulty,’ by saying that her daughter would have *“absolutely no problem”* when she uses technology to help with directions, classwork, or when information is typed out as opposed to written by hand. But *“It depends on how the information is given to her.”* Some proxy respondents for adults with ID described giving one small piece of information at a time, or one small step in a process.

Response option selection

The most common response to this question was ‘no difficulty.’ Adults with ID who selected ‘no difficulty’ tended to consider their ability to complete familiar tasks, like work or household tasks or, or their ability to do what they were told. For example, one respondent who answered ‘no difficulty’ thought about his ability to do his familiar job tasks and said, *“Once I learn the job, I’m pretty much good. And people who are familiar with you is good. I go down there and it’s like, ‘oh good to see you again.’”* Another respondent thought about his willingness to follow rules at a summer camp and said that ‘following directions’ *“...means listening to what a person is telling me to do and...obeying the rules.”*

Respondents and proxies who gave an answer other than ‘no difficulty’ said that additional explanation or repetition was required. Strategies to improve the reference person’s ability to follow directions included ‘chunking’ (breaking down longer processes into smaller steps), written reminders, or technological assistance devices to remember and follow directions accurately. For example, one respondent with ID who answered ‘a lot of difficulty’ said that his trouble remembering the task caused him difficulties. He said, *“I think I have a lot of difficulty because sometimes I forget what I’m doing. I forget what I’m supposed to do – a lot of times.”* In a few cases, respondents were thinking about following rules of behavior, and they answered based on their willingness to follow those rules. However, the way respondents and proxies accounted for how information needed to be given for a certain task and also whether accommodations were required affected response option selection – though not consistently.

How information is conveyed

Recognizing that a respondent needed information conveyed in a specific way sometimes did and sometimes did not correspond to a higher difficulty rating. For example, one proxy answering on behalf of a person with DD indicated that the respondent had ‘no difficulty’ understanding directions from her, but upon further reflection, she noted that the respondent would have difficulty following directions from others or from an instruction booklet. She explained, *“Well I would say most of the time he doesn’t have a hard time understanding directions, but if it’s in a pamphlet, he has difficulty understanding it... It’s confusing to him.”* On the other hand, a proxy answering on behalf of her son with ID selected ‘a lot of difficulty’ because he needed directions given *“one piece at a time.”*

Accommodations

Some respondents and proxies considered accommodations when selecting a response option. Accommodations that respondents and proxies mentioned included technological assistance, like directions applications (such as Waze or Google Maps which provide audible directions in real-time) accommodating verbal or written directions

(such as a step-by-step breakdown of a task or multiple repetitions of a request) and simply asking for help. Those who considered such accommodations and included them in the response chose a relatively lower level of difficulty. For example, one respondent with ID answered ‘no difficulty’ because, if he was confused about something, he could ask clarifying questions. By contrast, those who did not include accommodations answered with a relatively higher level of difficulty. A proxy who answered ‘a lot of difficulty’ explained, *“Mostly he would need a lot of repetition to follow directions. But once he’s mastered it, he’s fine.”*

Nonresponse

Nonresponse occurred in instances where the question had not been asked by the interviewer due to time constraints or because, for a few respondents with ID and one proxy answering on behalf of a respondent with ID, they were unable to generalize diverse experiences and select a response option. For example, a respondent with ID commented, *“Sometimes, again, it depends on what the task is...If you told me to go out to a bank that I wasn’t familiar with, I would get lost. Or if you told me to go to a mall that I wasn’t familiar with, I would get lost.”* This respondent was unable to provide responses to several prior questions as well, and he provided the same reasoning: *“It depends.”* Likewise, a proxy said:

“I guess it just depends on the directions. Um, if it is a simple direction such as...put the clothes in the washer and the dryer, she can master that and do that well. If it’s more in-depth and detailed that might be a little more difficult.”

Equivalency between respondent and proxy reporting

Most pairs did not provide equivalent responses, and, in those cases, the proxy respondent tended to answer with a higher level of difficulty than the respondent. In fact, there were a few cases in which the respondent answered ‘no difficulty’ and the proxy said ‘a lot of difficulty’ or even ‘cannot do at all.’ In these instances, the respondents focused on their strengths in doing what they were told whereas the proxies tended to consider the complexity of the directions their reference person was able to recall and complete without additional reminders or assistance. For example, one respondent said, *“Like in football, I play quarterback, and I follow the coach tells me what play to do, and I follow directions about that.”* By contrast, his mother said he needed to be given directions in small steps: *“Definitely, shown and ‘chunking.’ Small steps.”* Likewise, another respondent with ID who answered ‘no difficulty’ thought about his ability to follow orders. He was thinking about doing what he was told when at school. His mother, by contrast, immediately thought about the time he was lost and was found on a street corner not knowing how to ask for help, and she answered ‘cannot do at all.’

Three pairs provided equivalent responses. Initially, both pairs for respondents with DD had matched responses. However, during probing, one of the proxies changed her response from ‘no difficulty’ to ‘some difficulty.’ In this case, as described above in the section on ‘How information is conveyed,’ the respondent had no difficulty following directions from his mother, because she knew how to explain things to him in a way that made sense to him. She changed her response upon considering other modes of directions – in written form, for example. Just one of the respondents with ID and their paired proxy answered in the same way.

There were also three cases in which respondents with ID answered with more difficulty than their paired proxies. In these cases, proxies were thinking about the respondents’ abilities, not just difficulties, with following directions. For example, one proxy explained her response of ‘some difficulty’ in the following way: *“He will tell you to repeat things. He wants you to know that he is different from other people so asks to be shown. If you explain it, it is like there is no problem at all.”*

Age of onset

Few respondents but nearly half of proxies would be routed to age of onset in the NHIS based on their responses to this question. Proxy respondents selected ‘a lot of difficulty’ or, in one case, ‘cannot do at all,’ more often than self-reporting respondents, as just three respondents with ID selected ‘a lot of difficulty.’

Question 11: Learning

Q11. Do you have difficulty analyzing problems and finding solutions? Would you say...

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

7. Don't know
9. Refused

Source

This question was adapted from an item used as part of the World Health Organization Disability Assessment Schedule (WHODAS 2.0).⁷⁰ This assessment tool is used as a diagnostic. The question is used in this context to help determine a respondent’s level of difficulty with problem solving and is intended to capture aspects of learning associated with applying knowledge.

Summary

The way in which those responding to this question interpreted it differed somewhat. Different types of examples were given to illustrate problem-solving capabilities.

Only one respondent with ID answered ‘a lot of difficulty’ to this question,⁷¹ whereas most proxies, answering on their behalf, answered ‘a lot of difficulty’ or ‘cannot do at all.’ Respondents with ID tended to consider more mundane everyday activities or interpersonal relationships when formulating a response, whereas proxies considered more complex problem-solving capabilities.

Some respondents with ID were said, by their proxies, to have difficulty recognizing that something was a problem or difficulty dealing with previously unencountered problems.

Some respondents had difficulty with the term ‘analyzing’ used in the question stem. It was a term that was: i) unfamiliar to them, ii) they were uncertain how to interpret the term within the context of the questioning, or, iii) the term led them to think about solving a math problem.

Understanding the question concept

Understanding the term ‘analyzing’

Respondents with ID did not always understand the term ‘analyzing’ used in the question stem: “*I don’t know what analyzing means.*” They focused on the terms ‘problems’ and ‘finding solutions’ in order to obtain meaning. For example, one respondent said that she did not know what the term ‘analyzing’ meant, but thought the question was asking, if she had a problem, could she find a solution. Another respondent said, “*I don’t think I have*

⁷⁰ [Measuring health and disability : manual for WHO Disability Assessment Schedule \(WHODAS 2.0\)](#)

⁷¹ In this case the interviewer believed that the respondent was dealing with a recency effect.

problems to finding solutions.” In one case, a respondent who had initially been unsure of the question meaning, provided an answer of ‘some difficulty’ after it was explained to her by her husband. Her husband used a concrete example, referencing puzzles that she completed. The respondent was then able to apply that concept more broadly to her everyday activities: *“Oh yeah my puzzles, I guess. I solve my puzzles. Sometimes I stop and I say, ‘oh I’ll stop for a while and come back to it.’ That’s solving my puzzle. And, like my husband [laugh], I’ll say to him, ‘I’ll come back to you later.’”* Respondents with DD and their proxies also sometimes queried the meaning of the term ‘analyzing’ within the context of the questioning. One respondent with DD said, *“Analyzing could be anything.”* A proxy said, *“It depends on what you mean by that. What do you mean by analyze? ... He has a problem with finding the solution, but he will find one.”* The word ‘analyzing’ appeared to lead some, at least initially, to consider difficulties with math. Indeed, two respondents without IDD thought that the question was asking about their ability to solve a math problem. One explained that he had had a lot of difficulty with math from a young age and suspected he had what he termed a ‘math disorder.’ One proxy respondent, answering on behalf of a person with ID, said, *“First thing I thought about was math, but it goes beyond that”* explaining that the difficulties were more conceptual in nature.

Types of problems

Respondents with ID considered how to overcome or find solutions to the kinds of problems they experienced in everyday life. Some considered more practical day-to-day problems that they had to resolve, such as on which day to take out the trash, or how to remove a virus from a computer. One Round 1 respondent with ID explained that she had had a problem getting to the cognitive interview alone, because she had not been *“travel trained.”*⁷² She had been able to overcome that problem by asking a friend to accompany her. One respondent with ID thought about the problem of making new friends at his job, stating, *“I can make friends.... If you want me to I can make new friends.”* Others cited examples of interpersonal problems that they had dealt with or had helped others deal with. One respondent gave the example of how she would calm a friend with autism who sometimes got annoyed and into fights. Other examples included a respondent with ID who explained *“I don’t really have a solutions, it’s just if someone is arguing about a certain thing, I step in and help with the situation.”* Likewise, another described acting as a mediator with *“People who I know.”* Another described helping other people to solve interpersonal issues with staff at their group home.

Proxy respondents answering on behalf of a person with ID, thought about respondents’ ability to cope with more complex problem solving, such as managing or conceptualizing time, or completing tasks involving a number of steps: *“Like change a tire. No way. There’s too many steps involved.”* One proxy explained, *“Analyzing yes, a lot, because that is a lot more thinking and he can’t always put all of that together quickly. He could get it in two months – repetition, repetition, repetition.”* Another said that there were *“...very few situations where he can figure something out.”* Indeed, proxies also mentioned the difficulty respondents with ID had in recognizing that something was a problem: *“I would say a lot, only because sometimes he doesn’t understand what might be a problem.”* A few proxies explained that the difficulty was with the reference person’s ability to reason the problem through: *“...if it is raining and we cannot walk the dog she struggles to accept that the dog cannot be walked and to understand why.”* Proxies also described the difficulty the person with ID had in dealing with new problems that they had not encountered previously: *“It’s the new things that come up that he doesn’t have experience with that he has difficulty figuring out what to do.”* In one case the proxy respondent explained that the reference person did not know how to advocate for herself if she needed help, citing past experiences of neglect by those with caretaker responsibilities and where the respondent was unable to figure out how to get help: *“She doesn’t know to do that.”* One proxy based their response of ‘some difficulty’ on the way in which the

⁷²Respondent was alluding to Metro Ready Travel Training previously mentioned in commentary to Question 7.

person with ID would overreact to problems that he could not solve: *“Well sometimes he doesn’t work through it. He gets very anxious...he will bite himself. He just gets so angry and frustrated that he can’t do it on his own.”*

Respondents with DD considered overcoming problems related to their physical disabilities or described difficulties with critical thinking. For example, one respondent with DD who answered ‘no difficulty’ described having to figure out an alternative route for his wheelchair when part of the sidewalk was being worked on. Another respondent with DD said she had some difficulty with organizing the steps in a process: *“Not what the steps are but the sequential order of the steps.”* Another respondent with DD answered ‘a lot of difficulty’ to this question thinking about difficulties she had navigating the welfare and health systems, as well as her overbearing parents. Both proxies answering on behalf of a person with DD, answered ‘some difficulty.’ One considered the reference person’s inability to make decisions; the other thought about putting together flat packed furniture after the reference person had researched an online demonstration video.

Two of the four respondents interviewed without IDD considered the question to be about their ability to solve math problems, one answered ‘no difficulty’ the other ‘a lot of difficulty.’

A few respondents with ID understood the question as asking whether they make their own decisions. One respondent, who answered ‘no difficulty’ said, *“I do my own decisions and stuff like that.”* Another respondent with ID, who answered ‘some difficulty,’ was concerned about his ability to make decisions about medical matters on behalf of someone else. One respondent with ID understood the question to be asking whether he was able to do things for himself, such as cook for himself: *“If I can do it myself I will.”* Another conflated problem solving with his ability to learn new things. He answered ‘some difficulty’ because *“...if I can’t do it, I ain’t dealing with it no more.”* He gave examples of how people had tried to teach him to use the functions of his power wheelchair without success, and how he had given up learning how to use his sleep apnea machine.

It is worth noting that some respondents with ID found it difficult to explain the reason for their response selection and found it difficult to provide illustrative examples.

Response option selection

In general, respondents and proxy respondents considered how problems were approached or handled in order to help formulate a response to this question, although as mentioned above some proxy respondents said that the reference person may not be able to recognize that a problem exists and some respondents with ID were unable to explain the reason for their answer. The majority of respondents with IDD answered ‘no difficulty’ to this question. Only one respondent with ID answered ‘a lot of difficulty.’ This one respondent was unable to explain his rationale clearly. Two respondents with ID answered ‘don’t know.’ No respondents answered ‘cannot do at all.’ No proxy respondents answered ‘no difficulty’ on behalf of a person with IDD.

Positive focus

Answers from respondents themselves tended to take a more positive focus on problems that the respondent had been able to resolve. Although it should be noted that two proxy respondents also answered with a positive bias. One answering ‘some difficulty’ on behalf of a person with ID, said her son did his best and would try even if he did not succeed: *“It would be ‘some difficulty’ because he is going to try.”* The other answering ‘some difficulty’ on behalf of a person with DD said, *“Just because he will have issues...he has a problem with finding the solutions, but he will find one.”*

Asking for help

Proxy respondents often mentioned that respondents required help with problem solving. A few respondents with IDD said they would ask for help in overcoming a problem but did not always factor in this help when assessing their level of difficulty. For example, one respondent with ID who answered ‘no difficulty,’ said that he would ask other people if they knew how to solve a problem he might have. If he could not come up with a solution, he would ask other people if they could help him with that problem. *“I would need help on that.”* Another respondent with ID who also answered ‘no difficulty,’ explained that if he had a problem he would *“...just pray for that solution then everything will work out.”*

Learning how to manage process

A respondent with DD, who described difficulties organizing steps in a process, answered ‘some difficulty’ as opposed to ‘a lot of difficulty’ because she had found a way to manage this aspect of her disability by first breaking the task into steps and then carrying out those steps over a period of time so that she did not get overwhelmed or confused. She gave the example of buying tickets for an event. She would first see if she could afford the tickets, then if her schedule could accommodate the event. She would then buy the tickets, and finally then she would book the transportation needed to go to the event. She would not tackle all of these steps in the process all at once. Because she had found this way of managing this aspect of her disability she answered ‘some difficulty’ to this question.

Avoiding problems

A few respondents who focused on interpersonal relationships answered ‘no difficulty’ to this question because they said they avoided any conflict or problems by not getting *“...into other people’s business”* or by avoiding *“rude people.”*

Comparison to adults with similar disabilities

One respondent with ID who answered ‘no difficulty’ to this question made comparison to others with similar disabilities: *“...I do have difficulty but it’s no worse than some people that I know have disability that can’t find things or can’t comprehend things.”*

Misunderstanding the category of ‘no difficulty’

As reported elsewhere, one respondent with ID misunderstood the response category of ‘no difficulty’ explaining that it was not easy for him to provide solutions for problems.

Don’t know responses

Two ‘don’t know’ responses to this question were provided by adults with more severe intellectual disabilities who did not understand the question: *“Whatever you just said, I don’t know what it means.”*

Equivalency between respondent and proxy reporting

Proxy respondents tended to select a higher level of difficulty than their reference person. No proxy selected a lower level of difficulty than their reference person. With reference to the respondent-proxy dyads, no respondents with IDD answered ‘a lot of difficulty’ or ‘cannot do at all,’ while no proxy respondents answered ‘no difficulty’ on behalf of a person with IDD. One proxy respondent, answering on behalf of a person with ID, selected ‘cannot do at all.’ This response was based on the fact that the respondent did not know when to ask for help. The proxy recounted situations where the respondent had been neglected: *“I would choose that last one, cannot do at all. I’m just thinking of the situation at day-hab and at her ... school...Why didn’t she tell someone...?”* The respondent selected ‘some difficulty’ stating, *“It’s a bit hard”* but could not explain further or provide examples.

Age of onset

This question would have routed the majority of proxies, answering on behalf of a person with ID, to an age of onset question if included in the NHIS, as they selected the answers ‘a lot of difficulty’ or ‘cannot do at all.’ However, only three respondents reporting for themselves answered this way. One was classified as having ID and struggled to explain his response. The second was classified as having DD and described her struggles dealing with things, for example, dealing with Social Security. The third was classified without IDD and described his math disorder and difficulty he had grasping abstract concepts, which the use of the term ‘analyze’ had made him think about.

Question 12: Learning

Q12. Did you have difficulty learning in school or learning how to read or write? Would you say...

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

Source

This question is intended to capture learning ability in an academic setting. This question was adapted from an item used as part of the Diagnostic Adaptive Behavior Scale® (DABS®).⁷³ DABS was designed for use with children and young people.

Summary

The answers provided to Question 12 were not necessarily a reflection of a respondent’s actual ability to learn in school or to learn how to read or write. This is because interpretation of the question differed and different aspects of the respondent’s ability to learn were taken into account when formulating a response. Some focused on learning in general; others focused on reading or writing. Some made comparison with those in mainstream education; others made comparison with other school children with similar disabilities. In the majority of cases, proxy respondents rated the level of difficulty experienced by the person with IDD higher than the respondents themselves, who were not always aware of their difficulties in this regard. This question also proved sensitive for a few respondents with ID who had had bad experiences in the school system.

Understanding the question concept

Learning in school or learning how to read or write

Most respondents and their proxies understood this question to be asking about past ability to learn in school. As one respondent without IDD said: “*No difficulty at all. I loved school, I loved to learn.*”

People who answered about their general ability to learn in school considered their abilities in different academic subjects, and in a few cases their access to learning support. For example, one respondent with ID, who answered ‘some difficulty,’ talked about how hard it was for him to remember “*all the little details*” during history tests. Another respondent with DD considered her “*significant learning disability in Math*” when answering ‘some

⁷³ [Diagnostic Adaptive Behavior Scale \(DABS\) User's Manual \(aaid.org\)](https://aaid.org/)

difficulty.’ A few others with ID commented on their general inability to concentrate in class: *“It was hard because I was in class with a lot of people I knew, and I just wasn’t paying any attention,”* or their lack of support from teachers and the educational system which made learning hard for them: *“I was put in this teacher’s classroom, and I didn’t do anything. She worked with the other kids but didn’t want to be bothered with me.”* Indeed, the one respondent who used an assistive device to communicate answered ‘don’t know’ to this question because she felt the question was not measuring her ability to learn, but rather her lack of support and assistance in school: *“I didn’t really learn those things in school in a traditional way as the question alludes to. I could have if I had had access to effective communication.”*

Some respondents focused only on their reading and writing ability. For example, one respondent, who answered ‘no difficulty’ in relation to reading and writing, said that he did have difficulty with math: *“Read and write, No....as opposed to learning in school...math was a problem.”* Some respondents had difficulty with both reading and writing skills, while others struggled with one more than the other. For example, a respondent with ID who answered ‘some difficulty’ explained, *“How do I put this. I wasn’t that good of a speller. And I wasn’t much of a writer. And I really couldn’t read that well.”* Others based their response on the skill they were least good at, whether that be reading or writing. For example, a respondent with ID, who answered ‘cannot do at all’ said, *“I can write a little bit but the reading I cannot do at all.”* A proxy respondent who answered ‘some difficulty’ explained, *“He is pretty good at reading. Spelling, he has complications with.”*

It is interesting to note that, during probing, some proxies for respondents with ID mentioned that although the reference person had the ability to read or write, they lacked comprehension skills and struggled to grasp abstract concepts. This aspect was not always recognized by the respondents themselves. One respondent with ID answered ‘cannot do at all’ because he said he could not read, but he said his writing was less of an issue and he was able to take notes in class: *“I listen to the teacher, and I have a notebook. If she wrote it on the board, then I would write it down. I can’t read it, but I can write it down.”*

Generally, respondents thought about ‘reading’ in terms of their ability to read physical books and writing in terms of their ability to write by hand. They did not always consider their ability to use a computer to be a reflection of their reading skills, but they were more likely to consider their ability to write using a computer. For example, a respondent with DD, who answered ‘no difficulty’ mentioned that he had *“fine motor skills deficit”* and *“tight hands”* and since a young age had done all of his writing using a computer: *“Anything that requires dexterity is difficult for me to do.”*

One respondent understood the question as asking what he had learned in school, rather than his difficulty with learning. Another respondent with a more severe ID made a more literal interpretation of the question and answered on the basis that he felt fully supported in his learning at school and therefore had no difficulty: *“I felt very supported...because they always know what was best for me. They were always there when I need them....they helped me with Math and stuff...spelling.”*

Past not present tense

This was the only question in the series which asked about past rather than current level of difficulty. A few Round 1 proxy respondents answered this question based on current difficulty, rather than that experienced in school, although it is unclear if that affected their difficulty rating. It is possible that they did not hear the question correctly and continued to answer about the present because other questions in this series asked about the present. There was also evidence in Round 1 that the change in tense impacted the flow of the interview as different interviewers stumbled over the question administration at one time, initially asking about the

respondent's current difficulty level, which of course may also have impacted respondent comprehension. Neither of these issues were evident in Round 2.

Response option selection

Weighting good versus bad

When formulating their response, respondents and proxies alike tended to consider not just what respondents had difficulty with, but also what school curriculum activities respondents were 'good at.' When selecting a difficulty rating some placed more weight on what they were not good at, while others also factored in what could be achieved. For example, one proxy respondent answering 'some difficulty,' said that her son's hand writing "*...is not good at all and you cannot make out what he is writing*" but he "*...loved history*" and had had no difficulty learning history.

Comparison with others

Many respondents and proxy respondents made comparison with those in mainstream education when answering this question; some others made comparison to those with similar disabilities or made allowances for the respondent's particular disability. As one proxy, who answered 'no difficulty' on behalf of a person with ID, explained:

"Because he was in that special needs classroom, they gave him, he's eight years old and they are giving him work for a five year old. It was his exposure...it was his exposure because he was in that enclosed classroom."

Generally, respondents reporting 'a lot of difficulty' or 'cannot do at all' appeared to be making comparison with those in mainstream education, as opposed to those reporting 'no difficulty' or 'some difficulty.' They said they had not been given the support they needed in mainstream education and appeared to have spent more time in mainstream education than those reporting less difficulty. Older respondents in particular described being left alone at the back of the classroom and given simple tasks to do such as coloring: "*...they gave me crayons and sit me in the corner.*"

Lack of knowledge/difficulty remembering

A few respondents and proxy respondents did not have the knowledge to make a full assessment. For example, a long-term caretaker to a person with ID answered 'don't know' to this question because she had not known the respondent during her school years: "*That one I don't know. Like I said I didn't know her when she was growing up.*" A respondent with ID, who had grown up living in an institution, answered 'a lot of difficulty' because she remembered having a difficult time at school, but did not know or remember much more about it. A few older respondents commented on their ability to remember their school years. As one respondent with ID who answered 'some difficulty' said, "*I've been in school 50 years ago.*"

Focus on one event

A few respondents based their response selection on just one significant event that stood out for them. For example, a respondent with ID answered 'a lot of difficulty' despite telling the interviewer "*I did pretty good on writing and reading in school.*" Instead, he recounted a time when his teacher had told him to stop looking out of the window and to pay attention in class: "*She was pretty angry that day.*"

Accommodations

Accommodations made to help support adults with IDD were not always taken into consideration by respondents when formulating a response to this question. For example, one respondent with DD answered 'no difficulty' but

described being provided with a note taker during middle and high school. Because of his hearing difficulty he could not concentrate on hearing what was being said and take notes at the same time.

Changes over time

A few respondents and proxy respondents described learning ability as changing over time. In these cases respondents appeared to focus on the worst period experienced during their school career. Sometimes their abilities deteriorated because their condition worsened or what they were asked to learn became more difficult as they progressed through the school system. For example, a respondent with ID who answered ‘some difficulty’ said that his difficulties in school were mostly during his senior year in high school when he had been asked to take on more challenging assignments. Sometimes a respondent’s abilities in school improved because of later intervention or the respondent’s behavior or motivation to learn improved. For example, a proxy respondent, who answered ‘a lot of difficulty’ on behalf of a person with ID, explained that the early years were particularly difficult but as the respondent got older, around age 15 or 16, *“He really started grasping all of that. Just reading better and wanting to read. Wanting to learn about something and read about something because he was so interested in trees and airplanes...”* A respondent with ID explained that his ability to learn in school improved over time as he developed his interest in sports, although he did not provide a response to the question. A few other respondents found it difficult to make an assessment across their school career because of changes that had occurred. For example, one respondent was unable to provide a response explaining that he had been in an institution during his early years, where the education *“was very basic”* but that as he went through high school *“in the community”* things had improved for him, and he was able to settle down and focus.

Equivalency between respondent and proxy reporting

In the majority of cases, proxy respondents rated the level of difficulty learning in school or learning how to read or write higher than respondents with IDD rated themselves, even when the rating was made on a similar basis. For example, one respondent with ID said she had ‘no difficulty’ reading or writing. In fact, reading had been her favorite subject in school. However, her mother reported ‘some difficulty’ described her daughters reading ability to be at 6th grade level, and how her daughter had difficulty *“getting her ideas across”* through her writing. One respondent with DD answered ‘no difficulty’ while his proxy reported ‘some difficulty’ because of difficulties with spelling. A proxy answering on behalf of her son with ID, said that he had a lot of difficulty in school with reading, writing and math. Her son, who selected ‘some difficulty,’ also mentioned his difficulty with reading, writing and math in school.

In only two cases did the respondent rate their level of difficulty higher than their proxy. One respondent with ID, who answered ‘some difficulty,’ talked about his difficulty with learning history in school because of the difficulty he had remembering detail, while his proxy compared her son to others with special education needs and answered ‘no difficulty.’ The other respondent was very disappointed in the education he had received, *“For me I had a bad education, my education is real low...”* selected ‘a lot of difficulty.’ This respondent’s partner answered ‘some difficulty’ explaining that the respondent *“...was in special ed. when he was in school because he had a learning problem.”*

Complementarity of Question 12 and Question 8

Respondents and proxy respondents tended to report the same level of difficulty in answer to Question 12 about learning in school, as they had done in answer to Question 8 about learning things other people their age can learn, although the basis of those assessments differed. Respondents and proxies considered academic learning in response to Question 12, whereas Question 8 tended to elicit consideration of more practical skills and competencies, as well as interpersonal skills.

Those respondents providing a higher difficulty rating in answer to Question 12 compared with Question 8, reported feeling that they had received very little help or support when in school. They described feeling segregated or discriminated against because of their disability. One respondent who described himself as illiterate answered ‘cannot do at all’ to Question 12 and ‘no difficulty’ to Question 8, because he focused on the things he could do when shown how, such as cooking a meal or aspects of his paid job. Only one respondent gave a lower difficulty rating to Question 12 compared with Question 8, but he had not grasped the concept of learning intended by Question 8. However, a few proxy respondents did report a lower difficulty rating to Question 12, than to Question 8. For Question 12, these proxy respondents focused on their child’s reading and writing ability, rather than their ability to learn in general, and answered based on current difficulty not past difficulty in school. For Question 8 these proxy respondents based their answer on the fact that the person with ID took longer to process information or learn new things.

Sensitive question

This question brought up uncomfortable memories of school for a few respondents with ID. Older respondents in particular described feeling segregated or ignored by teaching staff because of their disability. Others recounted stressful incidents which had occurred at their school. It was at this point during the interview that one respondent was described as shutting down and disengaging from the interview process. Respondents who showed signs of finding this question sensitive tended to select the response option, ‘a lot of difficulty.’

Age of onset

Around half of adults with IDD and those who answered on their behalf, who provided a response to this question, would likely have been routed to the age of onset in the NHIS because they reported ‘a lot of difficulty’ or ‘cannot do at all’ when answering. All of those without IDD answered ‘no difficulty’ including the person who had previously mentioned his difficulty with math: *“Read and write, No....as opposed to learning in school...math was a problem.”*

Questions 13 to 16: Social participation

Questions 13 to 16 ask about social participation. They ask about the respondent’s difficulty making friends, engaging with people, and controlling their behavior in public. These questions were asked at the end of the cognitive interview which means they were not always administered due to time constraints on the part of the interviewer and fatigue on the part of the respondent. In addition, some of the questions were complex and cognitively burdensome. For example, to answer Question 15, which ask about difficulty getting along with people who they were close to, respondents first had to determine who the people were who were ‘close to them,’ what it means to ‘get along,’ and then determine the extent to which they had any difficulty getting along with the people close to them. At the end of the cognitive interview a few respondents found formulating a response challenging.

When reviewing the findings for this set of questions it is useful to bear in mind that there is variation in the extent and composition of the social networks of people with IDD (van Asselt-Goverts et al., 2015⁷⁴; Smplican et al., 2015⁷⁵). Indeed, people with intellectual disability in particular tend to have smaller social networks than other

⁷⁴ van Asselt-Goverts, A., Embregts, P., Hendriks, A., Wegman, K., & Teunisse, J. (2015). Do Social Networks Differ? Comparison of the Social Networks of People with Intellectual Disabilities, People with Autism Spectrum Disorders and Other People Living in the Community. *Journal of Autism and Developmental Disorders*, 45, 1191-12013.

⁷⁵ Smplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, 38, 18-29.

disability groups (McCausland et al, 2017)⁷⁶ and are vulnerable to more stressful social interactions than other types of negative events in their life (Hartley et al, 2005)⁷⁷.

In addition, based on lessons learned during Round 1 interviewing, at the interviewer's discretion, a method sometimes used in qualitative research, known as photo elicitation (Collier, 1957⁷⁸; Harper, 2002⁷⁹) was used with some Round 2 respondents to help understand their social network, and also to help overcome feelings of fatigue. The method was used as a way to elicit the respondent narrative in an alternative way using a visual, in this case a photo, to complement or support speech for people who may have expressive language difficulties (Renblad, 2000⁸⁰; Nind, 2008⁸¹). The method was applied with 10 respondents with ID, as an alternative or in addition to probing. The findings from the application of this method will form a separate report and do not influence the findings herein.

General findings: Social participation

Sample respondents with an intellectual disability tended to have a limited social network often including only a few family members or sometimes a few people the respondent could call friends. However, the definition of friends varied, occasionally including those tasked with assisting the respondent with daily activities who were not related to the respondent, or those in positions of authority, such a boss or teacher. This was not always the case. There were a few respondents, those with a strong support network, including through organizations such as Special Olympics, who reported a wider social circle.

Regarding their ability or inclination to participate in social interactions with others, respondents could be spilt into two distinct groups. Those who were friendly and trusting and those who were cautious and mistrusting of people outside of their immediate family or caretakers. Indeed, even within their immediate network these traits were evident during day-to-day interactions.

The sample members also reported some stressful interactions, more often, but not restricted to, encounters with people they did not know. In addition, during the administration of this question set, a few reflected on their experiences during the COVID-19 pandemic when they had been unable to see their friends and family in-person.

In terms of being able to route respondents or proxies to age of onset based on a response of 'a lot of difficulty' or 'cannot do at all,' these questions did not perform well as the majority answered 'no difficulty' or 'some difficulty' to all four questions.

⁷⁶ McCausland D., McCallion P., Brennan D., & McCarron M. (2016). The impact of functional limitation on social participation for older people with an intellectual disability in Ireland. *Age and Ageing*, 42, ii1-ii12.

⁷⁷ Hartley, S.L., Maclean, W.E., & Floyd, F. (2005). Perceptions of stress and coping strategies among adults with mild mental retardation: Insight into psychological distress. *Am J Ment Retard* (2005) 110 (4): 285–297. [https://doi.org/10.1352/0895-8017\(2005\)110\[285:POSACS\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2005)110[285:POSACS]2.0.CO;2)

⁷⁸ Collier, J. (1957) Photography in anthropology: a report on two experiments. *American Anthropologist*, New Series, 59 (5), 843–859.

⁷⁹ Harper, Douglas (2002) Talking about pictures: A case for photo elicitation, *Visual Studies*, 17:1, 13-26, DOI: [10.1080/14725860220137345](https://doi.org/10.1080/14725860220137345)

⁸⁰ Renblad K. (2000) Persons with intellectual disability, social interaction and video telephony: An interview study. *Technology and Disability* 13(1):55–65.

⁸¹ Nind M. (2008) Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. Project Report. National Centre for Research Methods. Available from: <http://eprints.ncrm.ac.uk/491/>.

Question 13: Social participation

13. Do you have difficulty making friends?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

7. Don't know
9. Refused

Source

This question was adapted from an item used as part of the WHODAS 2.0.⁸² This assessment tool is used as a diagnostic describing functional limitations. The question is used in this context to help assess a respondent's ability to make new friends.

Summary

Overall, when answering this question, most proxies and respondents thought about the respondent's capability to make new friends. Some respondents thought about making friends in the past, including their capacity to maintain long-lasting, platonic relationships. Others thought about meeting new people and their capacity to be friendly with strangers and acquaintances in casual, social settings. Regardless of how 'friends' itself was interpreted, the capability to make friends was sometimes determined in different ways: by the number of friends, by the ease at which the respondent found good, trustworthy friends, or whether the respondent's friends were only in the disability community. When previously testing this question with parents answering about their child, ages 5-17, Massey et al. (2016)⁸³ similarly found that the parents considered the number of friends their child had and whether any social conflict or tension occurred.

For respondents with IDD, an important factor when selecting a response was whether they viewed themselves as overall outgoing and friendly and trusting or cautious and mistrusting and weary around new people. Whether or not proxy respondents viewed the reference person as being socially capable and able to engage with a variety of people affected response.

Understanding of the question

Making friends

Most respondents and proxies considered this question to be asking about the capability to make new friends. Some interpreted 'making friends' to mean friendly, casual chatting with people. For example, one respondent with DD answered 'no difficulty' and explained, "*I never have difficulty making friends, I'm the nicest guy...I will say hello to you even if I don't know you.*" These respondents and proxies focused on the reference person's ability to engage with a new person and not necessarily form a lasting relationship with that person. Other respondents and proxy respondents interpreted 'making friends' to connote developing a deeper and longer-term connection with an individual. These respondents were considering additional aspects of relationship-building, such as frequency and quality of time spent with the person and if they have shared interests with them. For

⁸² [Measuring health and disability : manual for WHO Disability Assessment Schedule \(WHODAS 2.0\)](#)

⁸³ Massey, M., Scanlon, P., Lessem, S., Cortes, L., Villarroel, M., Salvaggio, M. (2016). Analysis of Cognitive Testing of Child Disability Questions: Parent-Proxy vs. Teen Self-Report. National Center for Health Statistics. Hyattsville, MD. <https://wwwn.cdc.gov/qbank/report.aspx?1159>

example, one proxy for a respondent with ID answered, ‘some difficulty’ because her daughter did not have the opportunity to socialize independently.

Most of the proxies and respondents who interpreted ‘making friends’ to mean forming a long-term connection were thinking of platonic relationships; however, one proxy for a respondent with ID and another respondent with ID thought of both platonic and romantic relationships.

Possible question order effects

Although most proxies and respondents answered based on their current ability to make friends while thinking through this question, a few considered past social experiences in school. This may be a question order effect because the respondent was asked to think about their past experiences in school in Question 12 (Did you have difficulty learning in school or learning how to read or write?). In other words, some respondents may not have only considered their current difficulties due to their past difficulties being primed from the previous question.

Response option selection

Being friendly and trusting versus being cautious and mistrusting

Most respondents and many proxies answered, ‘no difficulty.’ As explanation for their response, many respondents noted that they have friends, and therefore can make friends, or that they are friendly, and therefore anyone could be a friend. For example, one respondent with ID thought about meeting people at work and as a Special Olympics athlete and said, “*No I have no difficulty, I make friends everywhere I go I feel like.*” Likewise, a proxy for a respondent with DD answered, ‘No difficulty’ and said, “*He’s a funny, funny man. He makes friends no matter where he goes. Very friendly. Very funny. Very easy to get along with.*”

A few people who answered ‘no difficulty’ did so with qualifications about being wary of and cautious around new people. For example, one respondent said,

“Making friends? I don’t really have difficulty, if I’ve known them for a long time then I’m pretty good with that. But people I don’t really know – I have difficulty because I don’t know them like that. I get used to them if I know them for a long, long time, I’m fine with them. Hanging out with the right ones, that’s it.”

“No [difficulty]. I stay with myself and do what I need to do.”

In most cases, however, adults with IDD who discussed being wary and cautious of new people, particularly new people without disabilities, answered ‘some difficulty.’ As one respondent with ID who answered ‘some difficulty’ explained, “*People took advantage of me over the years because of my disability, so it’s hard for me to make friends.*” Similarly, another respondent said that she “*does not want to fool*” with people who think they are better than her.

Social boundaries and social cues

While respondents with IDD sometimes described difficulties making friends as being due to being treated poorly or excluded by people outside the disability community, several proxy respondents viewed difficulties making friends as stemming from the respondent’s lack of social skills. For example, one proxy who responded ‘some difficulty,’ was thinking of her son’s difficulty judging the appropriateness of any given friendship, considering factors like age. She explained his difficulty, stemming from his ID, in the following way:

“He has an issue choosing appropriate friends. But he has friends, he has made friends and he has been able to keep them. But there are times for instance where he will want to make friends with a 9-year-old. It might be emotionally appropriate for where he is, but it’s not appropriate, period.”

Friends within the disability community. Some proxies described respondents as only making friends within the community of people with disabilities. Oftentimes proxies who made note of the reference person’s limited community of friends selected ‘some difficulty.’ As one of these proxies explained:

“Some difficulty because, and this is an issue with lots of persons with disabilities, being able to make friends with persons who do not have disabilities is not an easy thing. For one thing, they won’t understand you and you may not have the same interests as them.”

On the other hand, a proxy for a respondent with ID described a similar friend circle (i.e. friends from special education program) and answered, ‘no difficulty.’ This proxy held a positive view of friendships between people with disabilities, because these were *“friends he can call.”*

Nonresponse

Some respondents did not select a response to this question. In a few cases, including for one proxy, that was because the interview had run out of time and the question was not administered. For others, respondents’ considerations were focused on situations where they made friends, and they provided explanations of these situations rather than selecting a specific answer. For example, one respondent with ID said, *“I make friends before when I [went] to camp.”* While he said it was *“easy to make friends,”* he was not able to select a specific answer category. One respondent with DD spoke about the fact that most of her friends were in the disability community, and though she did not select a response, she also described bullying she had experienced in the past due to her physical disability and lack of social skills.

Equivalency between respondent and proxy reporting

For this question, a little over half of the pairs in which both the respondent and proxy provided an answer had equivalent responses. When the members of the dyad answered in different ways, the pairs were evenly split as to who provided an answer with a higher level of difficulty – respondent or proxy.

A lower level of difficulty was reported when a respondent or proxy selected an answer based on the fact that the reference person had a group of friends or were generally friendly. For those pairs in which the respondent answered with a higher level of difficulty than the proxy, respondents were considering their challenges finding and becoming friends with trustworthy people. For example, one respondent said that he didn’t trust *“crazy people”* who pick fights or do drugs. Another respondent said that she had more difficulty making friends as she got older because she was excluded more from social ‘cliques.’ Their paired proxies, by contrast, all answered ‘no difficulty,’ thinking of the fact that the reference person had a group of friends or the fact that the reference person was friendly and outgoing. The opposite was the case for pairs in which the proxy respondent answered with a higher level of difficulty. For example, one proxy respondent answered ‘some difficulty,’ thinking about the fact that, though her daughter with ID had friends at *“day-hab,”* there were no opportunities for outside activities with those friends.

Age of Onset

One proxy respondent answered ‘cannot do at all,’ answering about her daughter with ID who did not initiate conversations with others. Otherwise, all other responses, when a response was selected, were either ‘no

difficulty’ or ‘some difficulty.’ Given that, this question showed limited capacity to route respondents to age of onset in the NHIS.

Question 14: Social participation

Q14. Do you have difficulty dealing with people you do not know well? Would you say...

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

Source

This question was adapted from an item used as part of the WHODAS 2.0.⁸⁴ This assessment tool is used as a diagnostic. The question is used in this context to help assess a respondent’s ability to interact with people they do not know well.

Summary

Most respondents with IDD answered based on their interactions with complete strangers, as opposed to people they knew but did not know well. A few misinterpreted the question entirely. Proxy respondents thought about both strangers and also people respondents knew, but not well.

In regard to this question respondents with IDD could be grouped into two tracts: those who were friendly and trusting of people they did not know well and those who were cautious and mistrusting. However, these respondent characteristics were not consistently considered positive or negative traits and did not predict the level of difficulty assessed. In a few cases, respondents and proxies mentioned that their answer reflected the fact that the difficulty was not with the respondent but with other people who were not empathetic. In addition, some respondents with ID had bad experiences with strangers in the past, and as a result this question proved sensitive in a few cases.

Understanding the question concept

The majority of respondents with IDD understood this question to be asking about their interactions or experiences with complete strangers. A few younger respondents thought about their interactions with acquaintances, such as classmates or fellow college students, whom they did not know. A couple of respondents thought about a difficult relationship with parents or other relatives when formulating their answer.

Respondents with IDD can be divided into two distinct types based on how they described their interactions with people they did not know (or did not know well): those who were friendly and trusting, and those who were cautious and mistrusting.

Respondents with ID tended to describe their cautious nature when interacting with strangers, or they explained that they would actively avoid such encounters. Respondents made comments such as:

⁸⁴ [Measuring health and disability : manual for WHO Disability Assessment Schedule \(WHODAS 2.0\)](#)

“I’d say some because it takes me a while to warm up to people...because people with disabilities ...a regular person takes advantage of them.” [Some difficulty]

“If I don’t really know you, I probably will back away a little bit and shy off. Or, look around. Basically if I am in a house I don’t know or an office, I will look around in my surroundings and make sure I am in a safe place.” [Some difficulty]

“I always give them my first and last name first before I go near them especially when they are strangers because I’m very aware of strangers.” [Non response]

“Remove yourself is the best thing.” [No difficulty]

A few older respondents with less severe ID, along with those reporting DD only (whose disability tended to be more physical in nature), demonstrated more confidence in dealing with people they did not know well or with complete strangers. They described how they would not hesitate to ask for help in the grocery store or how they dealt with people who stared at them in public for example, and they tended to answer ‘no difficulty’ to this question. Nevertheless, during probing adults with DD described finding it difficult to know who to trust and who not to trust.

Proxy respondents, answering on behalf of people with ID, were better able to interpret the nuances of this question, distinguishing between people not known well and people not known at all. They described more positive interactions with people the respondent did not know well but had seen before (such as at church), and in some cases, they described less positive interactions with strangers.

Proxy respondents also appeared better able to discern the overly friendly nature of interactions between respondents with ID and people they did not know well. Proxies were also able to provide a rationale for respondent behavior, taking into consideration their disability and describing their lack of social skills: *“He can be a little in your face with his friendliness and he’s a hugger. And not everyone is a hugger.”* In a few cases, proxies reported that the respondent’s ID meant that they lacked the interpersonal skills to know how to engage with people they did not know well, or that their disability led to them being more withdrawn or even aggressive without their medication. One proxy respondent described how she knew from her son’s body language if he didn’t want to be around someone. Another, who answered ‘a lot of difficulty,’ described how her son would get upset if strangers did not react to him in the way he expected,

“Like if he says hello to somebody and they don’t say hello back and they just walk away, that upsets him. Because he’s always been taught to be nice, say ‘hello’ ...He gets very quiet, and he looks very stern in his face...he gets very hurt...and then he gets frustrated.”

It is useful to note that when the interviewer asked a respondent about her experiences of meeting new people at her on-line reading class this respondent said that she did not consider meeting new people virtually when responding to the question: *“No...because we meet on a computer.”*

Misinterpretation

A few respondents misinterpreted the question. One respondent with ID, understood the question to be asking whether or not he knew people: *“I do know some folks. I don’t know that many people that I know of.”* He went on to explain that he answered ‘some difficulty,’ because he knew some but not all of his cousins. Another respondent with ID understood the question to be asking how much difficulty he had helping his roommate and answered ‘a lot of difficulty’ because, *“I do everything...He don’t know how to do it.”* A respondent with DD, who had difficulty determining who she could trust, thought the question was asking about her ability to make

that judgement and answered ‘some difficulty:’ *“Who I can be friends with and who I can trust.”* Her misinterpretation could be the result of an order effect from the previous question about making friends. A respondent with ID was initially unclear as to the question intent before her husband interjected to provide a more concrete framework. He reminded her of occasions when she had had to meet new people, after which time she answered ‘no difficulty.’

Response option selection

The majority of respondents answered ‘no difficulty’ or ‘some difficulty’ to this question. The two-tract distinction discussed previously for adults with IDD was clear. These respondents tended to describe being cautious and not trusting of people they did not know and actively avoided engaging with such people. Across response categories proxies commented on the friendly and trusting nature of their reference person or said that the respondent’s lack of social skills or awareness of personal boundaries was the basis for their response. The one proxy respondent who answered ‘cannot do at all’ explained that her reference person with ID *“...doesn’t interact with people she doesn’t know, so I’d say very difficulty...She doesn’t initiate friendship.”*

Three respondents with ID selected ‘a lot of difficulty’ because it depended on who they were interacting with, if they misunderstood the question, or could not explain their response.

Two respondents without IDD answered ‘no difficulty’ to this question and two answered ‘some difficulty’ - one because it was not going to be possible to get along with everyone, the other because he had less patience with people as he got older.

Some did not provide a response at all because: i) the interviewer didn’t have enough time to administer the question, ii) the respondent was unable to formulate a response that could be categorized, or iii) the question proved stressful for a few respondents (discussed in more detail below). As one respondent explained, it was difficult for him to provide a response because it depended on the person he was dealing with: *“Some people who you don’t know you can communicate well with them, but other people can be really nasty.”*

Even at this stage of the cognitive interview after hearing the response options read after the administration of each prior question, a respondent with ID misunderstood the response option ‘no difficulty’ selecting it as a ‘no’ response and explaining that he could not deal with people who mocked him in public and that he just didn’t trust strangers.

Difficulty lies with other people

In a few cases respondents and proxies mentioned that their answer reflected the fact that the difficulty was not with the respondent but with other people who were not understanding of their disability: *“Sometimes if they don’t really understand me because of my disability.”* A proxy respondent who answered ‘some difficulty’ on behalf of a person with ID explained, *“It depends on how people talk to her. If people talk down to her, she will not react well to that person.”* However, it is interesting to note that this interpretation sometimes only became apparent during discussion with the interviewer. For example, a proxy respondent who initially answered ‘a lot of difficulty’ changed her response during probing, first to ‘some difficulty’ and then to *“a little difficulty”* as she came to the realization that in actual fact the difficulty her son experienced was in response to the way in which others reacted to his disability. She gave the example of his boss who just *“didn’t get him.”* She said, *“he’s a little tentative until they get to understand him.”*

Equivalency between respondent and proxy reporting

Sometimes the respondent and their proxy provided the same answer to this question; sometimes they did not. Some proxy respondents provided a higher difficulty rating than their reference person. In these cases, the proxy respondent tended to focus on the reference person's inability to understand interpersonal boundaries, describing them as being overly friendly, or the opposite, not knowing how to initiate a conversation with someone they didn't know. A few proxy respondents provided a lower difficulty rating than their reference person, interestingly for the same reasons. In these cases, the proxies answered 'no difficulty' on the basis that the respondent was overly friendly: "*Strangers he will talk to. Because he trusts you.*" One insightful respondent with ID answered 'a lot of difficulty', "*I think it's hard because I want to get to know them. I need to know how to react.*" However, his mother answered 'no difficulty' describing him as "*...everybody's friend.*" In one case, the proxy answered 'no difficulty,' but the respondent answered 'some difficulty' due to misunderstanding the question. In another case, the proxy answered 'some difficulty,' but the respondent answered 'no difficulty' stating that she would simply ignore anyone who was rude to her.

Sensitive question

This question proved to be sensitive for a few respondents with ID and their proxies. This was because of the vulnerable nature of the population being interviewed. Respondents with intellectual disabilities were weary of being taken advantage of, or had experienced bullying, ridicule or even physical abuse from members of the public as a result of their disability. Hence, both respondents and proxies were not always trusting of people they did not know. Respondents related their experiences with others in school or their dealings with members of the public, describing them as "*rude.*" One respondent described how people would laugh at him on the bus and ask him if he was "*crazy.*" Another described his frustration at his inability to schedule disability transportation - because of his speech disorder the dispatcher could not understand him. Younger respondents and people with more severe intellectual disabilities said that they did not talk to strangers at all. They had been told not to by their caretakers or by other people close to them. Visible distress was apparent in a few cases as evidenced through the clenching of fists, sighing, or abrupt verbal response to the question and change in tone of voice. For those showing distress in this way, no response option selection was made by the respondent.

Age of onset

Three respondents with ID said that they had 'a lot of difficulty' dealing with people they did not know. In one case this was the only question asked which would have potentially identified this respondent as having ID for the age of onset question. This is because he associated his other difficulties, walking (Question 3) and concentrating (Question 4), with recent events. Six proxy respondents said that their reference person had a 'lot of difficulty' or selected 'cannot do at all.' No one with DD or anyone without IDD answered in this way.

Question 15: Social participation

Q15. Do you have difficulty getting along with people who are close to you? Would you say...

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

7. Don't know
9. Refused

Source

This question was adapted from an item used as part of the WHODAS 2.0.⁸⁵ This assessment tool is used as a diagnostic. The question is used in this context to help assess a respondent's ability to interact with people they know well, to include family members or close friends.

Summary

Respondents and proxy respondents tended to consider family members or close friends when thinking about people they were close to. Some considered a wider network of people, including people respondents knew at their church, for example.

Most reported 'no difficulty' in answer to this question focusing on the people with whom they had no difficulty getting along with, that is, no conflict. Respondents reporting at least 'some difficulty' tended to make an assessment based on one person with whom they did not get along. In a few cases, the reason for not getting along with a particular person was said to be related directly to their disability, either as a consequence of their disability, or with other people not understanding or accepting the nature of their disability.

Understanding the question concept

Possibly reflecting the fact that there is variation in the extent and composition of the social networks of people with IDD (as discussed in the introduction to this section on social participation), respondents' interpretation of the phrase 'people who are close to you' varied. Most considered family members and close friends when they thought about those they were close to. However, some considered both family members and friends, others thought only of family members, while a few thought about friends only. When considering their family, respondents generally thought about one or both parents and their siblings, but some mentioned their spouse or partner, children, grandchildren, grandparents and cousins. It is worth noting that respondents with ID did not always have or know their family members or have close friends. People who did, tended to describe a small network comprising one of two family members or a "best friend." A few respondents with ID, and a few proxy respondents answering on behalf of a person with ID, considered their aides or caretakers as people they were close to. In addition to family members who he did not see very often, one respondent with ID mentioned a boss with whom he felt close. When asked who she thinks of when she thinks of people close to her, one respondent said she thinks of her immediate family including her pet: "...your parents, siblings, your pets." A proxy respondent answering on behalf of a person with ID mentioned teachers the respondent was close to. A respondent without IDD thought specifically about his intimate relationships when thinking about people who were close to him.

Respondents with IDD who thought primarily of family tended to focus on a difficult relationship with a specific family member. For example, respondents mentioned not getting along with their mother, a difficult relationship with their father, or trouble getting on with a brother or sister. A few proxy respondents also focused on specific relationships, often with them as the mother and main care giver. For example, one mother, who answered 'some difficulty' explained:

Everyone else that's close to him in his family, he has no difficulty with them, it's really just me that he struggles with when I'm quiet or I don't want to have a long conversation...I just want to rest or whatever. So it's really...all his frustration, all his difficulty is really with me...but I've always been the primary person in his life."

⁸⁵ [Measuring health and disability : manual for WHO Disability Assessment Schedule \(WHODAS 2.0\)](#)

Other proxy respondents were more likely to consider a wider range of people or relationships in the respondent's life. For example, a proxy considered the respondent's, *"immediate circle of friends and church friends, school friends, that kind of stuff."*

When considering this question, proxies mentioned behavioral traits and interpersonal skills such as respondents' overly friendly nature, *"she's quite the social butterfly,"* or their bad reaction to certain people or certain situations, *"But with the people close to her she still has very bad behavioral issues with. She has tendencies to react with no triggers."* Respondents with ID did not always recognize such traits. For example, a respondent with a more severe ID, who answered 'no difficulty,' explained to the interviewer that he sends Christmas greetings to the people he is close to. He went on to ask the interviewer for her address so that he could send her a Christmas greeting.

A few respondents with less severe or without an intellectual disability determined that in order for a family member or close friend to be considered 'close,' regular contact was an important determinant. A respondent with DD who answered 'no difficulty' and interacted weekly with the people he considered he was close to, determined that, *"A close friend is someone that you know, um, you socialize with regularly and, um, they are one of a hand full of people three or four people."* A respondent with ID who answered 'no difficulty' described his interactions with his group of friends:

"I go on a [day of the week] I go out with a guys group. We go out to the mall at the food court and go out and get to know that group. And now we do hang out outside of the guys group to movies and things like that."

Contact did not need to be in-person for it to be considered as a mechanism for staying in touch. One respondent mentioned maintaining contact via the telephone. As an aside, a few respondents mentioned that they had not been able to see family or friends as often as they would have liked during the COVID-19 pandemic.

The phrase 'getting along with' was interpreted as meaning if the respondent's relationship with other people was with or without any conflict. A respondent with ID, who answered 'some difficulty,' described conflict that could occur between himself and his mother when he did not do what she had asked of him. A proxy, who answered 'some difficulty' on behalf of a respondent with ID, explained that the respondent considered his sister to be *"too bossy."* On the other hand, a proxy who answered 'no difficulty' on behalf of a respondent with ID described a lack of conflict in the respondent's life due to his friendly nature.

A respondent without IDD answered 'no difficulty' to this question explaining that if she did not get along with someone she would not be friends with them, although she went on to say that just because they were a friend there could still be conflict: *"...if you're my friend, clearly I'm okay with you being around. But it can sometimes be some because, just because I like you doesn't mean you won't irritate me. Like it depends..."*

A small number of respondents with ID considered people more generally when answering, to include strangers. This may have been due to an order effect from the previous question about people they did not know well.

Misinterpretation

A few respondents misinterpreted the question. One respondent with ID thought that the question was asking him if he got along with 'anyone' and answered 'no difficulty' explaining, *"Some of my neighbors I get along with."* One respondent with ID had a more literal interpretation and understood the question to be asking if he was ever

physically close to anyone: *“People who are close to me, come up next close to me. Come up close to me when I sit, you know?...I’m close to them they are close to me.”*

One respondent without IDD thought that the question was too personal for him to be able to quantify it in the way the response options seemed to want him to do, and he answered ‘don’t know:’ *“I honestly don’t know how to answer that.”*

Response option selection

Around half of adults interviewed answered ‘no difficulty’ to this question. These respondents tended to focus on the people they had no difficulty getting along with. As one respondent with ID who answered ‘no difficulty’ said:

“With family I’m fine, and with friends I have difficulty, unless I’m used to them. I only have like one friend, and I’m usually pretty good with him. He’s one of the coworkers I work with, everyone else I’m not really used to.”

Only one respondent answered ‘a lot of difficulty’ to this question and one respondent answered ‘cannot do at all,’ both were people with ID.

Difficulty with a specific family member

Respondents with IDD, reporting at least ‘some difficulty’ often made an assessment based on their perceived level of difficulty with a specific person. For example, considering a difficult relationship with a specific family member (mother, father, sibling). The one respondent who answered ‘cannot do at all,’ said, *“Me and my sister don’t get along. So yeah, I have difficulty. I’ll just leave it at that.”* For some, this difficulty was related to their disability, with one respondent describing *“anger issues”* associated with his disability causing him some difficulty getting along with his mother. However, one proxy explained that their reference person with ID did not get along with his mother, yet he answered ‘no difficulty’ because he gets along with everyone else.

Avoiding difficulty

A few respondents mentioned that they actively avoided people they did not get along with so as to avoid any conflict in their lives. For example, a respondent with ID who answered ‘no difficulty’ said, *“I don’t think I have any difficulty with people who are close to me, because if they put me through a lot of crap I say goodbye.”*

Accounting for the disability

In some cases, proxy respondents made an evaluation of their reference person’s ability to get along with people they were close to within the context of their disabilities. For example, a proxy, answering ‘no difficulty’ on behalf of a person with ID, recounted how the respondent could be *“...loving but also very selfish because emotionally he’s 4 to 9”* and also *“very concerned and giving.”*

Difficulty lies with other people

For a few, the issue was with other people not understanding or never having *“come to terms”* with their disability. One respondent with DD, who answered ‘some difficulty,’ mentioned her difficult relationship with her father who she said never accepted her disability. Another respondent with DD answered, *“A little bit. So like some,”* and talked about the struggle she experiences with not wanting to tell a new friend about her disability for fear of how they might react.

Equivalency between respondent and proxy reporting

Both the respondent and the proxy were administered this question in 11 of the 16 dyads interviewed. In most cases the response provided by each dyad member was the same, with both proxy and respondent reporting ‘no difficulty.’ In three dyads the proxy provided a lower difficulty rating than the respondent. For two of these dyads the proxy reported ‘no difficulty,’ whereas the respondent answered ‘some difficulty.’ Both proxies were considering a specific person, whereas the respondent was considering people generally. In one dyad the proxy reported ‘some difficulty’ mentioning the respondent’s behavioral issues, even with people she was close to, whereas the respondent answered ‘a lot of difficulty,’ again thinking more generally about “*the people outside.*”

Age of onset

All of the proxy respondents who were asked this question by the interviewer answered ‘some’ or ‘no difficulty.’ The proxy respondents would therefore be unlikely to be routed to the age of onset question in the NHIS. The same was true for adults with a developmental disability and adults without IDD. Indeed, only two respondents with ID answered ‘a lot of difficulty’ or ‘cannot do at all’ and therefore, of all of the cognitive interviews completed, this question would have routed only these two respondents to age of onset.

Question 16: Social participation

Q16. Do you [he/she] have difficulty controlling your [his/her] behavior when you [he/she] are together with other people?

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

7. Don’t know
9. Refused

Source

This question was adapted from a question developed by the Washington Group on Disability Statistics and UNICEF for administration to an adult proxy respondent with care-giving responsibilities for a child.⁸⁶ The question is intended to help identify children who may have difficulty socializing, as a potential indicator of an intellectual or developmental disability.

Summary

Many respondents and their proxies, including respondents with and without IDD, considered this question as asking about whether they could act appropriately in social settings or out in public. However, some respondents with ID thought instead of how they behaved in more private, one-on-one settings, such as at home with their caretakers or family members. Additionally, while most respondents thought about their ability to control disruptive, distracting behaviors, a few respondents with ID considered their more moderate, typical expressions of frustration and anger as evidence of having difficulty.

As the final question in the interview, respondents were tired when asked this question, and, in several cases, respondents did not reach it at all because the interview had ended earlier. Additionally, this was the final question

⁸⁶ [The Washington Group Data Collection Tools and their Recommended Use \(washingtongroup-disability.com\)](https://www.washingtongroup-disability.com/)

in a series about social participation – and question order may have affected how respondents considered the question.

Understanding the question concept

Respondents with and without IDD generally interpreted this question in terms of managing their own behavior and acting appropriately in social and public settings. The behavioral traits that most respondents described during discussion included the following: “*acting out*,” “*showing off*,” displaying “*anger*,” or being otherwise overly emotive. A few respondents with ID interpreted the question more broadly to include more moderate behaviors like expressing feelings of frustration or resentment at being asked to do something they did not want to do. Adult self-reporting respondents who interpreted this question as having feelings of frustration or anger in social situations or being too direct with people tended to answer at least ‘some difficulty.’ Proxy respondents sometimes considered things like understanding social cues and processing feelings productively. When this question was tested previously among parents of children ages 5-17, respondents considered their children’s ability to control impulses, emotions, and movements (Massey et al. 2016⁸⁷). While impulses and emotions were considered among this sample, movements were not.

Interpersonal difficulties

The broader interpretations by adults with ID sometimes incorporated the respondent’s willingness to do what they were told by those who were close to them – such as a caregiver. Some respondents focused on the tensions that sometimes arise with caretakers and answered at least ‘some difficulty.’ For example, one respondent explained his answer, ‘some difficulty,’ in the following way: “*Some. If I tell you something is hard and I don’t want to do it and you try and make me do it anyway. I ain’t doing it. That’s some difficulty.*” Likewise, another respondent, who answered ‘some difficulty,’ said of her caretakers: “*they don’t know how to talk to me.*”

Possible question order effects

Several respondents with ID and one respondent without IDD seemed to be thinking about the prior social behavior questions when responding to and discussing this question. This could be because Question 16 comes at the end of a series of questions about social behaviors which were, for some, sensitive and cognitively burdensome. For example, when interpreting the term ‘other people’, a few respondents may have been thinking about those who are ‘close to them.’ For instance, one respondent said, “*When I’m with my friends? ... When I’m with my family I’m fine. With other people? If I’m used to them.*” This could also be because respondents considered a narrow range of people as ‘others.’ One respondent with ID said that he was thinking about the same thing as he thought of in response to Question 15 (Do you have difficulty getting along with people who are close to you?). He talked about his relationship with his mother when he said, “*I have anger issues... I have problems controlling my emotions.*” Another respondent said he had ‘no difficulty,’ but qualified that answer by saying, “*Maybe if I had a relationship with someone, something might change.*”

One respondent, who answered ‘some difficulty’ to all the social behavior questions (Questions 13-16), was thinking about making friends and meeting people who are new. In response to this question she said, “*If you ask me, I’m gonna be truthful.*” If your feelings are easily hurt, she explained, then don’t ask for her opinion. Similarly, a respondent without IDD, who answered ‘no difficulty,’ thought about acting appropriately when around people he does not know well.

⁸⁷ Massey, M., Scanlon, P., Lessem, S., Cortes, L., Villarroel, M., Salvaggio, M. (2016). Analysis of Cognitive Testing of Child Disability Questions: Parent-Proxy vs. Teen Self-Report. National Center for Health Statistics. Hyattsville, MD. <https://wwwn.cdc.gov/qbank/report.aspx?1159>

Response option selection

Interpretation of the question was related to the response option selected, though that association was different for self and proxy respondents. Self-reporting respondents who interpreted the question as asking about ‘showing off’ or ‘acting out’ in public tended to answer ‘no difficulty.’ One respondent, for example, said that he had no problem behaving appropriately. He thought about a former classmate of his who has trouble acting appropriately when he gets angry and would sometimes “*throw a chair.*”

People who interpreted this question as asking if they sometimes become frustrated or angry or are too direct with people generally answered at least ‘some difficulty.’ Some of these respondents thought about more intimate interactions between their caretakers and themselves as opposed to public social settings. For example, one respondent said that he sometimes is frustrated with his girlfriend, and he just needs a little time to reset. He answered ‘some difficulty’ and said, “*I’m trying to teach my girlfriend how to reset right now.*” In this case, the respondent did not have trouble acting appropriately in public social settings, but he was thinking about the private argument he had with his girlfriend.

Proxy responses

Like most of the self-report respondents, proxies tended to view this question in terms of behavioral skills in social settings. Some who selected ‘no difficulty’ noted that the paired respondent was “*mild mannered,*” did not “*have tantrums,*” or was “*cooperative and helpful.*” An answer of ‘no difficulty’ generally indicated that the respondent did not ‘act out’ physically or emotionally when in public. One proxy who answered ‘no difficulty’ did so because her son’s problematic behavior was well controlled by his medication. She said, “*If he was not on the medication then we would have a big problem... He would just go up and hit someone in the street because that person reminded him of his brother, and he was mad at his brother.*” But, on medication he does not display any of that behavior.

The proxies who selected ‘some difficulty,’ or in one case ‘a lot of difficulty,’ generally mentioned different aspects of the respondents’ lack of social awareness – not knowing “*when to stop*” or when it was no longer the respondent’s turn to be “*the center of attention.*” Though, in a few cases, proxies noted that the respondent had difficulty processing emotions or reacted physically without a clear trigger.

Nonresponse

A few respondents, all with ID, did not choose a response option for this question. In those cases, respondents indicated that their answer depended on circumstance, and they were unable to generalize those circumstances to select a single response. For example, one respondent said, “*It all depends. Or let me put it this way: Yesterday something happened, and I was more pissed at something. It all depends what’s happening.*” Another said that one time he was frustrated when his group had to wait to be seated at a restaurant. “*I was getting a little...I wasn’t angry, but frustrated,*” he explained. Regarding having difficulty controlling his behavior, he said, “*Yes and no,*” and did not select a response.

There was a relatively large number of respondents who were not asked the question at all. In these cases, the interview had previously ended due to running out of time or due to respondent fatigue. Deciding to end the interview was typically due to the time elapsed, though in a few cases, it was also due to the respondent’s increasing difficulty to interact in the cognitive interview process.

Equivalency between respondents and proxies

Out of the sixteen respondent-proxy dyads, ten pairs completed this question, meaning that they both were asked this question, and both provided responses.

Slightly over half of the pairs who completed the question provided matched responses, and, while they tended to have similar overarching interpretations, the examples they provided highlighted their unique perspectives. For example, in the case of one of the pairs in which the respondent was living with DD, both the proxy and the respondent, who both answered ‘some difficulty,’ were thinking about the question within the framework of the respondent’s social awkwardness rooted in her developmental difficulties. The proxy thought that the respondent’s difficulties were due to her difficulty processing information quickly enough. She said, “*She may not have the maturity or social behavior skills to know when to stop [teasing].*” The respondent herself said that she would lose interest and “*phase in and out*” when she is in a large group – meaning that she loses focus and is easily distracted. As another example, one respondent with ID and her proxy both considered the contentious relationship that the respondent had with her caretakers. The respondent answered ‘some difficulty’ and noted that she sometimes gets frustrated when her caretakers and staff treat her like a child: “*They provoke me ... they don’t treat me like a human being.*” On the other hand, her paired proxy, one of her caretakers, also answered ‘some difficulty’ and said, “*If there is food there you have to watch her because she cannot have any outside food,*” referring to staff intervening in order to manage the respondent’s medical condition that could lead to overeating.

Those dyads who did not provide equivalent responses tended to consider the question differently, as one may expect. For example, one respondent with ID who answered ‘some difficulty’ was thinking of managing his frustrations with his girlfriend in a healthy, constructive way. He explained, “*Yes, I do [have difficulty]. Because, in the situation when you get upset, you get mad ... It is a learning process, it’s a learning process. It’s hard.*” His proxy respondent, who was his girlfriend, was instead considering the question to be asking about “*acting out*” in public, and she answered ‘no difficulty.’

Age of Onset

Two respondents and one proxy for a respondent with ID selected ‘a lot of difficulty’ and therefore would have been routed to the age of onset question in the NHIS. The proxy respondent said that the reference person, her daughter, did not know how to calm down when she became frustrated in public. She explained, “*She has tendencies to react with no triggers.*” The two respondents who answered ‘a lot of difficulty’ both were thinking of events in the past that caused them to be upset or angry, and their answers did not correspond to current levels of difficulty. In one case, for instance, the respondent thought about the time he had to stay in a hotel because his disability housing did not have room for him.

APPENDICES

Appendix 1: Words and phrases used to describe disability

The purpose of this appendix is to illustrate the diversity of the sample achieved for this study across both rounds of interviewing. The following represents words and phrases that respondents and proxies used when describing their or their reference person’s disabilities or impairments. The descriptions are not necessarily primary or secondary diagnoses, rather, they are self-descriptions.

Attention Deficit Disorder (ADD) Attention-Deficit/ Hyperactivity Disorder (ADHD) Anxiety Arthritis (and rheumatoid arthritis) Auditory delay Auditory processing disorder Autism (and high-functioning autism) Autistic tendencies Back problems Behavioral issues Brain hemorrhage Cerebral Palsy Cognitive delay Cognitive developmental delay Cognitive processing disorder Developmental disability Down syndrome Dysgraphia Dyslexia Epilepsy Febrile seizures Fetal distress Fine and gross motor skill delays Fine motor skills deficit Hearing problems Intellectual and developmental disability Intellectual disability Intellectually impaired Learning delay Learning difficulty Learning disability Limited vocabulary Low muscle tone Math disorder Mental disability Mental retardation (mild)	Monocular vision Multiply handicapped Muscular dystrophy Names of rare genetic disorders Neurapraxia Obsessive compulsive disorder Osteoporosis Problems with adaptive behavior Processing delays Progressive muscle deterioration Profoundly intellectually disabled PTSD (Post-Traumatic Stress Disorder) Quadriplegia Reading difficulties Schizophrenia Seizures Sensory processing disorder Severe receptive language delay Shakes Short-term memory issues Seizures Sensory dysfunction Sensory integration dysfunction Special needs Speech impairment Strabismus Stroke Stutter Traumatic brain injury Tumors (cancerous and non-cancerous) Visually impaired Visual motor skills issues
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Appendix 2: Questionnaire evaluated

Self-Report Questionnaire

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:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
2. Do you have difficulty hearing, even if using a hearing aid? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
3. Do you have difficulty walking or climbing steps? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
4. Do you have difficulty remembering or concentrating? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
5. Do you have difficulty with self-care such as washing all over or dressing? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
6. Using your usual language, do you have difficulty communicating, for example understanding or being understood? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. 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:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
8. Do you have difficulty learning how to do things most people your age can learn? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
➔ Continue to Question 9 if answered “2-4” to any of QUESTIONS 3-8 above. ➔ SKIP to Question 10 if otherwise	
9. You said that you had difficulty with ___ [fill from Q3 – Q8, if answered anything other than “No difficulty”] ___, did [this difficulty/ any of these difficulties] begin before age 22?	1. No, all this happened after I turned 22 2. Yes, some of this happened before I turned 22

<p>10. Do you have difficulty understanding and using information like following directions? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>11. Do you have difficulty analyzing problems and finding solutions? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>12. Did you have difficulty learning in school or learning how to read or write? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>13. Do you have difficulty making friends? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>14. Do you have difficulty dealing with people you do not know well? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>15. Do you have difficulty getting along with people who are close to you?</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>16. Do you have difficulty controlling your behavior when you are together with other people?</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all

Proxy-Report Questionnaire

These questions ask about difficulties [*name*] may have doing certain activities because of a HEALTH PROBLEM.

1. Does he/she have difficulty seeing, even if wearing glasses? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
2. Does he/she have difficulty hearing, even if using a hearing aid? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
3. Does he/she have difficulty walking or climbing steps? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
4. Does he/she have difficulty remembering or concentrating? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
5. Does he/she have difficulty with self-care such as washing all over or dressing? Would you say:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. 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:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. 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:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. 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:	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>➔ Continue to Question 9 if answered "2-4" to any of QUESTIONS 3-8 above. ➔ SKIP to Question 10 if otherwise</p>	
9. You said that he/she had difficulty with ___ [<i>fill from Q3 – Q8, if answered anything other than "No difficulty"</i>] ___ did [this difficulty/ any of these difficulties] begin before age 22?	1. No, all this happened after he/she turned 22 2. Yes, some of this happened before he/she turned 22

<p>10. Does he/she have difficulty understanding and using information like following directions? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>11. Does he/she have difficulty analyzing problems and finding solutions? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>12. Did he/she have difficulty learning in school or learning how to read or write? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>13. Does he/she have difficulty making friends? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>14. Does he/she have difficulty dealing with people he/she does not know well? Would you say:</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>15. Does he/she have difficulty getting along with people who are close to him/her?</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all
<p>16. Does he/she have difficulty controlling his/her behavior when he/she is together with other people?</p>	<ol style="list-style-type: none"> 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all

Acknowledgments. The authors would like to thank all those who contributed to the success of this project, including Dr. Jennifer Johnson, Andrew Morris, Meredith Raymond and Dr. Vicki Gottlich from the Department of Health and Human Services (HHS), Administration for Community Living (ACL). Also, the authors would like to thank Dr. Amanda Reichard at the National Institute on Independent Living and Rehabilitation Research, Professor Gloria Krahn from Oregon State University, Alexandra Bonardi from the Human Services Research Institute, and Dr. Julie Weeks from the Measures Research and Evaluation Branch, National Center for Health Statistics. The authors would like to acknowledge the cognitive interviewers from the Collaborating Center for Questionnaire Design and Evaluation Research, National Center for Health Statistics, including Amanda Wilmot, Dr. Annie MacFadyen, Lauren Creamer, and Dr. Bridget Reynolds. A special thank you goes to Dr. Zachary Smith, Dr. Kristen Cibelli-Hibben, Lauren Creamer and Amanda Titus, who contributed to the writing of an initial summary report on Round 1 of this study (for internal use only). A further thank you to Amanda Titus who also led the CCQDER operations team, and whose diligence and enthusiasm for the study ensured the success of the recruitment effort. The authors also thank the members of the public who gave their time to take part in the cognitive interviews.