

# **Analysis of Cognitive Interview Testing of Child Disability Questions in Five Countries**

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## **I. Introduction**

This report summarizes the findings from three rounds of testing (seven separate projects) designed to evaluate the questions on child disability for use in surveys for the Washington Group on Disability Statistics (WG) with the participation of the United Nations Children's Fund (UNICEF). The first round of testing was conducted in the United States, India, Oman, Belize and Montenegro between September 2012 and July 2013. The second round of testing was conducted in the United States in March and April 2014, and the third round of testing was conducted in the United States in August of 2014. This report presents findings from the evaluation of the combined data from all three rounds of testing.

This evaluation is based on 258 cognitive interviews that were conducted by research teams in each of the five countries with the guidance of the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS). Cognitive interviewing is a qualitative question evaluation method used to evaluate the validity of survey questions (Willis 2005; Miller 2011). Utilizing this method, the main goals of the project were to: 1) assess respondents' interpretation of the survey questions and 2) identify potential response problems that could impact data quality.

The following report is organized into four sections. Following this initial introduction, section two discusses the methods used in this question evaluation study, including the sample selection, sample characteristics, and interviewing procedure. Section two also summarizes the cognitive interviewing methodology and describes how data analysis was conducted. Section three provides a summary overview of the findings. Section four presents a detailed question-by-question review of the findings. The final instrument is presented in appendix A.

## **II. Methodology**

We evaluated questions using cognitive interviewing. This is a qualitative question evaluation method used to uncover potential response errors that can occur during the question response process, errors that may not be immediately obvious. These include problems with comprehension, recall, constructing responses, and the mapping of responses onto the survey question (Willis 2005; Tourangeau, Rips, and Rasinski 2000).

### *Sample*

A team of researchers in each country conducted interviews with a total of 258 individuals. In the first round, 70 interviews were conducted in India, 45 each were conducted in Montenegro and Belize, 32 were conducted in Oman and 22 were conducted in the United States. In the second round, 34 interviews were conducted in the United States, and in round three 10 interviews were conducted in the United States. In each country, the research team recruited a purposive sample of parents or guardians of children ages 2 to 17 who may or may not have difficulties in the following areas: seeing, hearing, walking, learning, and/or behavior.

Respondent demographics for the full sample are shown in Table 1. The sample was a little over half female, and most of the interviews were conducted in English.

**Table 1: Demographic Profile**

		<b>N=258</b>	<b>Total (%)</b>
<b>Gender</b>	Female	148	57%
	Male	110	43%
<b>Country</b>	Belize	45	17%
	India	70	27%
	Montenegro	45	17%
	Oman	32	12%
	United States	66	25%
<b>Language of interview</b>	English	122	47%
	Arabic	33	12%
	Hindi	58	22%
	Montenegrin	45	17%
<b>Age of child</b>	2-4	44	17%
	5-8	95	37%
	9-11	41	16%
	12-14	40	15%
	15-17	38	15%

### *Interviewing Procedures*

The questions were written in English and then translated into Hindi, Montenegrin and Arabic. Interviews were conducted by native speakers of each language. During the interviews, retrospective, intensive verbal probing was used to collect response process data. First, respondents were administered all questions, and then interviewers returned to each question and probed retrospectively. Probes included such things as: Why did you answer the way that you did? How did you arrive at your response? Can you tell me more about that? Can you clarify what you mean? Video and audio recordings and written notes of interview summaries were used to conduct data analysis. All interviews were conducted face-to-face. Interviews typically lasted 60 minutes and respondents were remunerated for their time.

### *Data Analysis*

Data were analyzed using the constant comparative method of analysis, in which analysts continually compared data findings to original data (Lincoln and Guba 1985; Strauss and Corbin 1990; Creswell 1998). This involved a process of data synthesis and reduction (Strauss and Corbin 1990; Suter 2012). Synthesis and reduction were carried out in five incremental yet iterative steps: analysts conducted interviews, produced summaries, compared across respondents, compared across groups, and reached conclusions (Miller, Willson, Chepp, and Padilla, 2014)). Specifically, once interviews were conducted, interview data were summarized, detailing how and why each respondent interpreted the question and formulated their answers. Next, the summaries were compared across respondents, to identify common themes. Once themes were identified, themes were compared across subgroups, to identify ways in which different groups of respondents processed questions differently depending on their differing experiences and cultural backgrounds. Finally, conclusions about question performance and interpretation were made. With each analytic step in this process, data were reduced and systematically extracted in order to produce a theoretical summary detailing a question's performance. As such, these different analytic steps represent both data reduction and a movement toward larger conceptual themes. Analysts used Q-Notes, an analysis software tool developed by NCHS, to facilitate data organization and analysis.

### III. Overall Findings

**Parent respondents:** In health related surveys, parents often act as proxies for their children particularly in situations where age and disability preclude child self-reports. While there may be some concern that using parent respondents impacts the validity of findings since the child's subjective experience and perceptions are not recorded (Eiser and Morse 2001; Davis *et al.* 2007), using parents as proxies has been shown to facilitate assessments of children over a wide age range. Additionally, due to children's immature cognitive development, their limited social experience and dependency on parental support, parents may provide more consistent and accurate assessments of some domains. In fact, parent reports are generally more accurate for externalized problems (such as behavior and physical functioning) than for internalized problems (such as pain or emotional disturbance) (Varmi, Limbers and Burwinkle 2007).

It is important to understand how parent respondents formulate answers to questions about their children's difficulties since the differences in the way these strategies are employed impact data. In this survey, respondents relied on four main strategies:

- 1) **Based on their own assessment.** Parents often relied on their own observations and assessments. This was, by far, the most frequent method employed by parents across all five countries. Parents evaluate their children's difficulties based on their own observations, drawing upon their expectations for their child and children in general in order to formulate their answers. Parents have differing expectations for their children. These expectations are based on the particular context of each child and can be influenced by disability status, age, cultural norms and other factors. Additionally, parents often answer based on the amount of time and effort they have to devote to "dealing with" a particular difficulty. In formulating their answers, respondents almost

always relied on their own assessments first, moving on to other strategies only when this strategy did not provide a ready answer.

- 2) **Based on child's self assessment.** Parents also relied on information from their children to assess their children's difficulties. For example, a respondent in India indicated that his son has "no difficulty" walking even though he has a problem with his foot because the child "doesn't complain even he hurting when walking." This respondent trusted that if his son did not complain, there must not be a problem. Similar trust is evidenced by the respondent in Belize who answered "some difficulty" because her daughter "complains about her sight especially with work on blackboard and sitting behind in class or far distance she have problem." While this strategy was not commonly employed by parents in the United States, respondents in the other four countries relied on it quite frequently.
- 3) **Comparisons with others.** The introductory phrase for most of the questions ("Compared to children of the same age...") prompts respondents to formulate an answer based on a comparison. However, the majority of respondent narratives do not mention explicit comparisons indicating that this was not a commonly used strategy. It is possible that respondents who did not mention comparisons in their narratives made comparisons implicitly. In some cases, respondents compared their children to people, such as older or younger siblings, who were not the same age as their children.

In most cases, respondents who gave answers on the extreme ends of the 4-point response scale (i.e., "no difficulty" or "cannot do at all") did not actively draw on comparisons to come up with their responses. Most respondents seemed to feel that having "no difficulty" in an area was not a relative condition. Similarly, respondents generally felt that it was not necessary to use a comparison to answer "cannot do at all." For example, one respondent whose daughter can't walk said that she was not making a comparison when she answered the question because "she can't walk at all. It's an absolute." Therefore, a comparison was unnecessary. This pattern of avoiding comparisons held true for other respondents whose children had severe difficulties. In contrast, respondents who answered using the two middle points of the response scale (i.e., "some difficulty" and "a lot of difficulty") were more likely to support their answers with comparisons.

**Normal difficulties:** One difficulty that respondents experienced when formulating their answer was not being sure if their child's difficulty was 'normal' or something that should be reported. Even when explicitly comparing their children to other children, they were not always sure if the difficulty should be reported. In many of these cases, respondents chose "some difficulty" to indicate their uncertainty. In some cases where respondents did not consider the comparison clause, they chose "some difficulty" even if they believed the child's difficulty was normal. For example, a respondent in the United States indicated that her daughter had "some difficulty" with remembering. She said, "Just like everyone. I have to remind her sometimes."

- 4) **Based on professional assessment.** Some respondents formulated their answers based on what they have been told by professionals. Professionals included doctors, physical therapists, speech therapists, teachers, teaching aids, and counselors. For example, many parents referred to diagnoses from eye doctors when assessing their children's difficulties seeing.

## Summary

In the first round of testing, some issues emerged as a result of respondents' use of the different strategies described above. Certain issues are characteristic of all survey questions that ask respondents to report behaviors or characteristics of their children and not indicative of problems with the questions themselves. Some of these patterns may be more prevalent in certain types of questions. For example, for questions about learning, respondents were very likely to compare their children to others (as is customary in a school learning context) for questions about routine and emotions, respondents were less likely to make explicit comparisons to other children. In subsequent rounds of testing, questions were revised using design strategies aimed at limiting the variations in response strategies employed by respondents. The remainder of this report will describe each question individually. The strategies employed and experiences considered by respondents when answering each question will be described in detail. Question revisions and the results of the second and third rounds of testing will also be discussed.

## IV. Question-by-Question Review

Unless otherwise noted, the response categories for all questions are:

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

## SEEING

**Initial testing-** All respondents in the United State, India and Montenegro were asked:

*Does [he/she] wear glasses?*

1) *Yes* 2) *No*

All respondents were able to confidently answer this question without need for clarification and most were able to readily provide narrative support for their answers.

Essentially all respondents understood the question to refer to glasses used to correct vision. One Indian respondent, however, answered "yes" because her child wears "toy glasses and sunglasses."

Inconsistency occurred in a few cases depending on whether respondents focused on the act of wearing glasses or on whether the child had been prescribed glasses. Three respondents answered "no" because their children did not wear the glasses they had been prescribed while two respondents answered "yes" because their children had been prescribed glasses (although they did not wear them.)

Respondents in Belize and Oman were asked:

*Does [he/she] wear glasses or contact lenses?*

1) *Yes*            2) *No*

Again, all respondents were able to confidently answer this question without need for clarification, and most were able to readily provide narrative support for their answers.

**Rounds two and three-** Respondents were asked:

*Does [he/she] wear glasses?*

This unrevised question, asked to 45 respondents, performed similarly to how it performed in round one.

**Final recommendation:** No further revisions are suggested for this question.

A follow-up vision question was asked to respondents in all five countries:

*Does [he/she] have difficulty seeing [when wearing his/her glasses]? Would you say...*

**Initial testing-** Nearly all of the respondents were able to answer this question without hesitation. Respondents relied on a combination of indicators in evaluating their children's difficulties with vision. While some respondents relied on professional diagnosis or complaints from their children, most respondents relied on their own assessment of their children's vision difficulties. Respondents had various understandings of what constitutes a seeing problem. In these cases, respondents deduced a problem from their own observations (e.g. sitting close to the TV or squinting). In a few cases, respondents may have observed signs of vision problems, but did not interpret those problems as difficulties. For example, one respondent whose daughter has an unnamed genetic disorder indicated that her child has "no difficulty" seeing but clarified during probing that her child has no peripheral vision. She went on to explain that due to her child's other limitations (with mobility and learning), she only needs to see close up. Since the child's lack of peripheral vision does not affect the things she is able to do, the respondent did not believe her daughter's difficulties with vision are not a problem. Therefore, she answered "no difficulty."

**Rounds two and three-** In an attempt to resolve confusion over the "with glasses" clause, the question was rewritten with the clause at the beginning of the question:

*[When wearing glasses his/her glasses,] does he/she have difficulty seeing?*

The revised question was administered to 44 respondents. None of the respondents asked for clarification of the "glasses" clause. All of the respondents whose children wear glasses answered based on their children's vision with glasses. Therefore, putting the "glasses" clause at

the beginning of the question seemed to resolve this difficulty with the previous version of the question.

**Final recommendation:** No further revisions are suggested for this question.

## HEARING

**Initial testing-** Respondents in all five countries were asked:

*Does [he/she] use a hearing aid?*

1) *Yes*            2) *No*

Most respondents were able to answer this question without difficulty. There was some confusion over the term ‘hearing aid.’ Four respondents, asked for clarification regarding the term ‘hearing aid.’ One of the four asked, “Is that the thing deaf people put in the ear to hear better?” Another respondent from India believed ‘hearing aid’ meant headphones to listen to music and answered ‘yes’ to the question. Similar to the “wearing glasses” question, this question also resulted in some inconsistent responses from respondents whose children had been prescribed hearing aids but who did not use them. For some children, the hearing aids cause discomfort and tend to amplify unwanted sounds. Therefore, these children do not want to use the hearing aids. In these cases, some respondents were not sure whether to answer “yes” because their children have been prescribed the aids or “no” because they don’t use them.

**Rounds two and three-** In revising the question, it is possible to add a definitional clause to explain ‘hearing aid.’ However, lack of understanding the term ‘hearing aid’ was seen as a minor issue; the vast majority of respondents from each country did understand the concept. It was determined that adding such a definitional clause would primarily complicate the question, making it more confusing to all respondents. Therefore, no revisions were made to this question. It would, however, be important that the concept of ‘hearing aid’ and the translation is considered for each country that this set is fielded.

The unrevised question was asked to 45 respondents in rounds two and three. While one respondent whose daughter has a cochlear implant answered “yes,” in general this question performed similarly to how it performed in round one.

**Final recommendation:** No further revisions are suggested for this question.

A follow-up hearing question was asked to respondents in all five countries:

**Initial testing-** Respondents were asked:

*Does [he/she] have difficulty hearing, [when using his/her hearing aid(s)]? Would you say...*

All respondents were able to answer this question without hesitation.

**Listening vs. hearing-** Respondents interpreted this question to be about either auditory hearing or about listening, relying on one or both of these two interpretations to come up with their answers. While respondents in all countries considered aspects of hearing and listening, respondents in the U.S. were more likely to primarily consider listening than respondents in other countries. Most respondents in other countries answered based on their children's auditory hearing even when noting that their children had trouble listening.

While some respondents answered based on professional diagnosis or based on child reports of difficulty, most respondents relied on their own observations to assess their children's hearing. Respondents determined that their children had "no difficulty" hearing because their children displayed behaviors such as responding appropriately, replying when called and listening to music. Likewise, respondents indicated that their children had "some difficulty" hearing if they did not respond when called or reply appropriately. There was some inconsistency when respondents relied on their own assessments, especially for those who interpreted the question as a question about listening. For example, some respondents believed that it is normal for children to ignore their parents. These respondents chose "no difficulty." Other respondents thought that the same type of ignoring behavior indicated a problem and responded "some difficulty" or "a lot of difficulty."

Several respondents with children who wear hearing aids based on their child's hearing without the hearing aid. These respondents reported that their children do not like to wear their hearing aids and, therefore, do not wear them very often.

**Round two-** In an attempt to clarify the "with hearing aid" clause, the question was rewritten with the clause at the beginning of the question:

*[When wearing glasses his/her hearing aid,] does he/she have difficulty hearing?*

The revised question was administered to 34 respondents. None of the respondents asked for clarification of the "hearing aid" clause. However, several respondents noted that their children hear better without the hearing aid. These respondents tended to base their answers on their children's hearing without the hearing aid since this is how their children hear best.

Respondents in this round of testing continued to distinguish between hearing and listening. Respondents who answered "no difficulty" tended to answer based on hearing although many of them noted that their answer would be different if the question asked about listening. For example, one respondent who answered "no difficulty" because she is sure her child does not have an actual hearing problem, said, "If the question was listening, that would be different...She's a kid, so they all have selective hearing." Like this respondent, other respondents who noted that their children have difficulty listening felt that this was a normal difficulty.

Respondents who were not sure whether their child's difficulty was due to hearing or listening generally answered "some difficulty." One of these respondents said, "I don't know if he's ignoring me or if he really can't hear."



A third category of respondents also answered “some difficulty.” These respondents have children who have difficulty processing sounds. One of these respondents described her son’s difficulty by saying, “I know his hearing is fine because they did auditory testing. However, his response time to questions is delayed or he won’t respond at all.” Respondents in this category describe behavior that may appear to be indicative of a hearing difficulty but attribute the behavior to difficulties with attention, processing or focus rather than physical hearing.

**Round three-** While this question is intended to focus on auditory hearing, many respondents focused on listening. In order to resolve this conceptual ambiguity, the revised question explicitly asks about “difficulty hearing noises.” The “hearing aid” clause performed well at the beginning of the question, so it is kept there.

*[When using his/her hearing aid(s),] does (name) have difficulty hearing noises like peoples’ voices or music?*

This revised question was asked to 10 respondents. All respondents answered either “no difficulty” or “some difficulty” although one respondent changed her answer to “a lot of difficulty.” This particular respondent first answered “some difficulty” because her son has “some hearing.” She later reinterpreted the question to mean “how much difficulty” rather than “how much hearing.”

Almost all respondents interpreted this as a question about auditory hearing. Respondents who answered “no difficulty” often explained their answers by describing how their children respond appropriately when spoken to. However, other respondents who answered “no difficulty” distinguished between the functions of processing, listening and hearing. These respondents described how their children often do not respond appropriately when spoken to. However, despite their children’s unresponsiveness, these respondents answered “no difficulty” because auditory hearing tests had shown that their children can physically hear.

Two of the respondents who answered “some difficulty” were also thinking about physical hearing. These respondents both relied on professional, auditory tests for confirmation that their children can hear. In these cases, the children who have multiple, severe issues and who are non-verbal, do not respond consistently or reliably to voices or other sounds. For these children, the level of hearing difficulty is difficult to assess within the context of other severe disabilities. One of these respondents explained her answer of “some difficulty” saying:

*It’s relative because of the mental delay that goes with the hearing loss. You can’t test her like you would a normal child. It’s hard to judge because she can’t tell me.*

A single respondent whose child has severe ADHD answered based on her child’s ability to process sounds rather than on his physical ability to hear. In the case of the hearing question she answered “some difficulty” even though he can physically hear. She explained her answer saying:

*Sometimes he has a lot of difficulty. Physically he can hear, but he's failed hearing tests as well- not because he can't hear. It can't be no difficulty. His day to day life shows that he has problems with hearing.*

### **Final recommendation:**

Overall, the revised question on hearing is an improvement over previous versions. Hearing is an extremely complex function that is related to auditory hearing, cognition, attention and attitude. Respondents' narratives demonstrate how difficult it can be to distinguish difficulties with auditory hearing from other issues. This revised question more effectively steers respondents away from interpretations related to listening and attention than previous versions. A final suggestion is to use "sounds" instead of "noises" in the question in order to avoid any negative connotations. Therefore, the final question reads:

*[When using his/her hearing aid(s),] does (name) have difficulty hearing sounds like peoples' voices or music?*

### **WALKING**

The questions about walking are divided into two age groups (2-4 and 5-17). Two additional walking questions were developed for use in India. Analysis of these questions is included for comparative purposes at the end of this section although the questions were not considered for inclusion in the final module.

**Initial testing-** Parents of 2-4 year olds in all five countries were asked:

*Compared with children of the same age, does [he/she] have difficulty walking? Would you say...*

Respondents interpreted this question in two ways:

- **Physical act of walking:** Almost all respondents understood this question to refer to the physical act of walking. To these respondents, difficulty walking included problems with balance, frequent falls and limping. Respondents who answered "cannot do at all" gave reasons for their children's inability to walk, often attributing the difficulty to an overall condition such as cerebral palsy or paralysis. These parents often mentioned alternative forms of mobility such as crawling or using a wheelchair.
- **Willingness to walk:** Several respondents mentioned their children's willingness—rather than physical ability—to walk. For example, one respondent, who indicated that his child has "some difficulty" walking, described how his 2-year-old son "uses a stroller all the time" and frequently "asks to be picked up."

**Assisted or unassisted?:** Four of the 34 respondents were unsure of their answers because the question does not specify whether to include an assistive device (such as a walker or crutches) when assessing walking ability. One respondent's daughter can walk several yards with a gait trainer, which is a kind of walker with a seat and straps, but without the gait trainer, she is not

mobile at all. Ultimately this respondent decided that the question was referring to whether her child could walk unassisted, so she answered “cannot do at all.”

Respondents in Belize, Montenegro, Oman and the United States with children between the ages of 5 and 17 were asked a series of two walking questions.

*Compared with children of the same age, does [he/she] have difficulty walking 500 yards on level ground? (That would be about.... [Insert country specific example]) Would you say...(children 5-17)*

*Compared with children of the same age, does [he/she] have difficulty walking 100 yards on level ground? (That would be about.... [Insert country specific example]) Would you say...*

In answering these questions, respondents considered several factors:

**Mobility:** Most respondents interpreted these questions to be about general mobility. Narrative support included examples of a variety of activities that require physical mobility (such as walking, running and playing). Most of the supporting narratives, particularly for those respondents whose children have “no difficulty” walking, describe respondents’ children as active people who enjoy playing sports. Respondents also gave examples of the places their children walk regularly, such as to school or to the store.

Respondents who answered “some difficulty” referred to their children’s frequent falls, complaints of pain, weakness, tiredness and speed. Those who answered “cannot do at all” generally described their children’s overall condition. Some gave examples of alternative methods of mobility such as use of a wheelchair while others described how their children are completely immobile.

**Navigation:** Two respondents with children who are blind responded “a lot of difficulty” or “cannot do at all” because their children can’t navigate without assistance due to their vision.

**Stamina:** Some respondents considered stamina to be a dimension of this question while others did not. A few respondents answered “some difficulty” or “a lot of difficulty” because their children get tired when walking long distances. However, other respondents answered “no difficulty” because even though their children may become tired, they are able to walk a long distance. For some respondents, generally those whose children had functional limitations, stamina was seen as result of those functional limitations. Their children had a hard time walking long distances because illness or disability made them tired. For respondents whose children did not have functional limitations, stamina was an extension of the “willingness to walk” pattern seen in younger children. These respondents noted that their children were physically able to walk but that they did not enjoy walking or grew tired easily because they didn’t exercise enough.

**External conditions:** Some respondents said their answer would depend on the road conditions or the weather. For example, one respondent in Belize answered “no difficulty” but said her child would have “some difficulty” walking on a road with hills. Other respondents referred to level ground and pot holes. Some respondents, particularly those in Oman, mentioned that heat or rain can influence how well their children are able to walk.

**Question order:** Previous testing of similar questions on adults had indicated that it was preferable to ask about the shorter distance first and then follow up with a question about walking a longer distance. However, in the initial rounds of testing of the children’s questions, the walking questions were not asked in the preferred order. Respondents were first asked about the longer distance (500 yards/meters) and those who answered “no difficulty” were not asked about the shorter distance (100 yards/meters). For this reason, it is difficult to evaluate how respondents evaluated their children’s walking based on the two different distances.

Respondents who answered that their children had some level of difficulty walking the longer distance (500 yards/meters) were then asked about the shorter distance (100 yards/meters). Almost all respondents gave the same answer to both of these questions. For example, if a respondent answered that his/her child had “some difficulty” walking 500 yards, he/she would also answer that this/her child had “some difficulty” walking 100 yards and cite similar reasons for the two answers. There were six cases where respondents gave different answers to the two questions. Three of these cases were instances where the differences in the children’s ability to walk a long distance versus a short distance were due to a physical limitation. For example, one respondent indicated that her daughter could walk 100 meters with “no difficulty” but that it would cause her “some difficulty” to walk 500 meters because her illness causes her to tire more easily than other children. In the other three cases where respondents gave different answers to the two distance questions, they indicated that their children were physically able to walk the longer distance. For example, a respondent in Belize said that her daughter would have “some difficulty walking 500 meters “not because she can’t do it but because she doesn’t like to.”

There were a few other aspects of these questions that caused some difficulty for respondents:

**Assisted or unassisted?:** Some respondents were unsure how to answer because these questions do not specify whether to consider walking ability with an assistive device or without. The previous questions (vision and hearing) specified inclusion of an assistive device (hearing aid and glasses), but this one did not. One of these respondents had a hard time choosing between “cannot do at all” and “a lot of difficulty” because her daughter, who has cerebral palsy, “can walk with orthotics and crutches or a walker.” Ultimately, this respondent chose “cannot do at all” because she decided that the question was asking about walking ability without supports. Other respondents chose to answer based on their children’s mobility with devices such as walkers, braces and prosthetic legs.

**500 yards/100 yards:** Although some respondents seemed to have an accurate idea of these distances, most did not. Most respondents interpreted 500 yards/meters as “a long

distance.” For example, one respondent said, “I don’t know how far 500 yards is, but I know he can walk long distances.”

**Compared with children of the same age:** Most respondents did not make an explicit comparison. Those who did compared their children to other children in the neighborhood, classmates and siblings. A few respondents were not sure whether to compare their child to other disabled children or to “normal” children. Respondents whose children are disabled said they are not able to compare their children to others because of their differing ability levels.

**Round two-** In round two, a few changes were made to the walking questions. In order to clarify whether respondents should consider their children’s ability to walk “assisted or unassisted,” a preliminary question was added to the walking section. Like the questions about glasses and hearing aids, this question is intended to frame the questions that follow.

All respondents were asked:

*Does (name) use any equipment or receive assistance for walking?*

Respondents who answered “yes” gave examples of equipment their children use such as gait trainers, orthotics, leg braces, physical therapy tape and walking sticks. Two respondents also included use of wheelchairs. Respondents explained that their children need assistance for reasons such as visual impairment, difficulty understanding traffic laws and low muscle tone that requires physical support.

For all of the walking questions in both age groups, an additional clause was added at the beginning to clarify that respondents should focus on their children’s walking ability *without* equipment or assistance.

Parents of 2-4 year olds were asked:

*[Without the use of any equipment or assistance,] does (name) have difficulty walking?*

All four respondents with 2-4 year olds answered based on their children’s physical ability to walk. Two of these respondents have children who use equipment, and while one of them was thinking of her child’s walking using equipment (orthotics) she ultimately answered “some” because “he’s not a very coordinated kid.”

A similar ‘equipment or assistance’ clause was added to the questions focusing on 5-17 year olds. Additionally, a country specific example was inserted to illustrate the distance. Football fields were used because they are a common cultural reference in the United States. The “comparison” clause was removed because most respondents did not attend to it and it did not seem to be useful in clarifying the intent of the question.

Finally, the order of the two walking questions was switched. In the second round, respondents were first asked about their children’s ability to walk 100 yards. Unless they responded “cannot

do at all,” they were then asked about the longer distance. This preferred question order was determined from previous testing of similar walking questions on adults.

Respondents with children ages 5-17 were asked:

*[Without the use of equipment or assistance], does (name) have difficulty walking 100 yards/meters on level ground? That would be about the length of one football field.*

*[Without the use of equipment or assistance], does (name) have difficulty walking 500 yards/meters on level ground? That would be about the length of five football fields.*

Similar to respondents in the initial round of testing, respondents in this round answered based on their children’s mobility, stamina and ability to navigate. Stamina was particularly prominent in the question about walking a longer distance. A lot of respondents noted that their children would complain or refuse to walk 500 yards even though they are physically capable of walking this distance. Some respondents answered “some difficulty” because their children complain while others answered “no difficulty” because their children are physically capable of walking that distance despite complaints.

**Assisted or unassisted?** The addition of the ‘equipment or assistance’ clause seemed to clear up any confusion in this area. Respondents whose children walk with equipment or assistance answered the question considering their children’s ability to walk without these aids.

**100/500 yards:** Referring to a these lengths in terms of ‘football fields’ clarified the distances for all but one respondent. This respondent noted that she “is not into sports,” so this reference was not useful to her.

**Round three-** The walking questions were revised to ask about walking both *without* assistance and walking *with* assistance. The vision and hearing questions ask about seeing and hearing *with* glasses and *with* hearing aids. The rationale for this is because the questions are intended to capture children’s functional performance. Applying this rationale to the walking questions, it is necessary to ask about walking *with* the use of equipment.

The questions for parents of 5-17 year olds were further simplified by eliminating any reference to distance. This was done because inclusion of the distances caused some respondents to focus enjoyment of walking and willingness to walk rather than physical ability to walk.

In round three, respondents who answered “yes” to the question about using equipment or assistance for walking were asked a series of two questions:

*When using his/her equipment or assistance, does (name) have difficulty walking?*

This question was only asked of one respondent who answered “yes” to the previous question, so there was not enough data to draw definitive conclusions. It should be noted, however, that this single respondent changed his answer. He first answered “cannot do at all” because without

equipment his daughter cannot walk at all. The respondent changed his answer to “some difficulty” when he realized that the question was asking about walking when using equipment. Response error may result if respondents don’t attend to the introductory phrases of the questions.

Next respondents in this category were asked:

*Without the use of equipment or assistance, does (name) have difficulty walking?*

Again, this question was asked only to the single respondent. Having changed his answer to the first question in this series, this respondent was attuned to the introductory phrase of this question and had no difficulty answering based on his daughter’s ability to walk *without* using equipment.

Respondents who answered “no” to the question about using equipment or assistance for walking were asked a single question:

*Compared with children of the same age, does (name) have difficulty walking?*

Nine respondents were asked this question. Eight of these responded based on their children’s physical ability to walk. Similar to the previous walking questions, this walking question prompted respondents who answered “no difficulty” to describe their active or athletic children. One respondent answered “cannot do at all” based on her child’s physical ability to walk. This child, who has a genetic disorder, may never walk and is just learning to stand.

A single respondent answered based on something other than physical walking ability. This respondent’s child is hard to control and frequently runs away from adults. When the child was younger, she kept him on a child-leash, but even though he has outgrown the leash, he still runs away. In this case, the respondent answered “some difficulty” because it is difficult to control his behavior when walking with him.

Respondents with children 2-4 years old, were asked the follow-up probe:

*How much concern do you have about this? 1) no concern at all 2) a little concern 3) a lot of concern 4) somewhere between a little and a lot*

Only one respondent was asked this follow-up probe. This respondent, whose two year-old has not learned to walk yet, answered “somewhere between.” He chose this answer because:

*I know there are things that can help her even if she can’t walk, but I want her to be as normal as possible and I think walking is needed for that.*

**Final recommendation:** For older children (5-17), it is recommended to ask about walking both short (100 meters/yards) and long distances (500 meters/yards). While the testing of questions using these distances was inconclusive in this series of testing, these questions have been tested

in adults. It is important to capture children who have difficulty walking longer distances (for example, to school) and these children might not be screened in based on a single walking question.

There is some risk of response error in the series of two questions intended for respondents whose children use equipment or assistance. For these questions, it is important that respondents attend to the introductory phrases directing them to answer based on walking *with* or *without* assistance.

In field testing, it is recommended to use the follow-up probe for the younger age set to help distinguish children who have significant, physical difficulties walking and those who display developmentally normal reluctance or coordination difficulties.

## **SELF-CARE**

**Initial testing-** To assess children's difficulties with self-care, parents of 5-17 year olds in all five countries were asked:

*Compared with children of the same age, does [he/she] have difficulty with self-care such as feeding or dressing him/herself? Would you say...*

Almost all of the respondents focused on the two specific examples given in the question (feeding and dressing), while a few focused on a broader understanding of the concept of "self-care." Several respondents had trouble choosing an answer because their children could feed themselves with no problem but were not able to dress themselves. These respondents either didn't answer the question or they averaged their children's abilities in the two areas by answering "some difficulty."

Respondents based their responses on a variety of factors:

**Dressing (putting on clothes/choosing clothes):** Respondents described a wide variety of problems dressing. A lot of children had trouble fastening buttons, tying shoes or putting their clothes on right-side out. For some respondents who answered "no difficulty" these problems constituted normal difficulties, but other respondents answered "some" or "a lot" of difficulty based on these problems. Similarly, inconsistent answers also occurred with respondents who described their children's difficulty with matching colors or choosing appropriate styles. Seventeen respondents focused exclusively on dressing when formulating their responses.

**Feeding:** Respondents interpreted feeding as the physical act of eating (child can't hold a spoon), the ability to eat without making a mess (child spills soup) or the ability/willingness of the child to choose appropriate foods (child doesn't like vegetables). There was inconsistency in respondents' interpretation of what constitutes a difficulty. For example, some respondents thought it was normal for young children to be messy eaters ("no difficulty") while others found this to be a problem ("some difficulty.") Seven respondents focused exclusively on feeding.



**Laziness/speed:** Some respondents indicated a difficulty if they believed their children were “lazy” or “slow.” Respondents who described their children in this way did not answer consistently. One said, “He can do it but he doesn’t want to.” This respondent answered “no difficulty” because his child is physically able to dress himself. Other respondents interpreted laziness or lack of willingness as a problem and answered “some difficulty.”

**Rounds two and three-** While the self-care question was not revised, a probe question was added to help clarify which aspects of self-care respondents considered in their responses and to help determine which responses are beyond the scope of the question. This probe question was asked to all respondents who answered that their child has some level of difficulty with self-care (respondents who did not answer “no difficulty”):

*What type of difficulty does your child have with self-care? (choose all that apply):*

- *Willingness to eat*
- *Choice of clothing*
- *Needs repeated reminders*
- *physical ability to eat*
- *physical ability to dress*

*Something else (please specify)*

As in the first round, respondents primarily focused on aspects of feeding and dressing when formulating their responses. Again, a few respondents had difficulty answering due to their children’s differing ability levels in these two areas.

Respondents answering “some difficulty” frequently focused on aspects of self-care (such as choice of clothes or willingness to eat) that are beyond the scope of the question. The probe question accurately revealed these distinctions. Overall, respondents focused on aspects of their children’s self-care that require the most parental attention. For example, when children need frequent reminders to get dressed in the morning or fuss a lot about choice of food, parents interpret this as a difficulty. This is in contrast to aspects of self-care that may be problematic but which are managed with a consistent routine. For example, one respondent has a child who is fed through a G-tube because he has short-bowel syndrome and cannot eat regular food. This respondent answered “some difficulty” not because her child can’t eat but because she has to remind him over and over again to get dressed. She said, “The G-tube is not an issue. We’ve managed that. It’s the dressing that I have to deal with every day.”

**Final recommendation:** No further revisions are suggested for this question, but it is recommended to use the probe question in field testing to help determine an appropriate cut off point for inclusion.

## **COMMUNICATION/COMPREHENSION**

Each age group (2-4 and 5-17) was asked one comprehension question and one communication question.

**Initial testing-** To assess comprehension, parents of 2-4 year olds in all five countries were asked:

*Does [he/she] have difficulty understanding you? Would you say...*

This question was administered to 34 parents or guardians who had children between ages 2 and 4. All respondents were able to answer this question without clarification.

Respondents interpreted the question in three ways:

**Comprehension of meaning:** Most respondents understood the question to be about the comprehension of meaning. Respondents confirmed comprehension through their children's appropriate responses to what had been said to them. Several respondents answered based on their children's understanding of vocabulary. Bi-lingual children, in particular, had difficulty with words. For two respondents, the communication of meaning could be non-verbal. For example, one respondent's daughter could understand "tone" but not words. Another respondent's child understood sign language. These respondents answered "some difficulty" or "a lot of difficulty."

**Hearing:** For five respondents, this question overlapped with the hearing question. These respondents noted that their children have difficulty understanding *because* they can't hear.

**Compliance/following directions:** Ten respondents answered based on their children's level of obedience. For example, one respondent from Belize answered "some difficulty" because when he tells his child to do something, it takes a long time for the child to obey even when he clearly understands the instruction.

**Rounds two and three-** Similar to respondents in the initial round of testing, respondents in these rounds answered based on their children's (verbal or non-verbal) comprehension and ability to follow directions.

**Final recommendation:** No further revisions are suggested for this question.

**Initial testing-** One of two versions of the question testing communication was asked to respondents with children ages 2-4:

*Do you have difficulty understanding what your child wants? Would you say...*

*Do you have difficulty understanding your child? Would you say...*

Twenty-five respondents were administered version 1 and four respondents were administered version 2. There were no obvious differences in the way that respondents interpreted the two versions of the question.

All respondents understood the question to be about verbal or non-verbal expression of meaning:

**Verbal communication:** In general, respondents understood both versions to pertain to their children's ability to communicate meaning. Most respondents who focused on their child's verbal ability focused on their children's speech, listing difficulties such as pronunciation, speed and articulation. One respondent, however, indicated that she has "some difficulty" understanding her 3 year-old daughter because "she speaks in broken sentences." This child's words are clear but, at 3, she is not able to express ideas in a way her mother understands.

**Non-verbal expression:** Four respondents mentioned their children's non-verbal communication strategies. For example, one respondent whose daughter is non-verbal due to an unnamed genetic disorder described how her daughter claps to indicate she is happy. This respondent answered "a lot of difficulty" rather than "cannot do at all" because her daughter is able to convey some meaning non-verbally.

Other factors that influenced the way respondents answered these questions were context and parental expectations:

**Context:** Inconsistent responses were seen from respondents whose children could be understood by family but not by strangers. Some respondents answered based on their own ability to understand their children while others answered based on how well their children can communicate with other people.

**Rounds two and three-** Since there were no substantive differences in respondents' interpretations of the two questions, the simpler version was chosen for round two. Respondents with 2-4 year olds were asked:

*Do you have difficulty understanding [name]?*

Like the respondents in the first round of testing, the respondents in round two answered this question based on their children's verbal and non-verbal expression of ideas. Several respondents noted that they, as parents, could understand their children even though others could not. This led to some inconsistency in how parents responded. One respondent, whose daughter only communicates by crying, answered "some difficulty," saying, "I'm her mom and so I feel like moms just know their kids even though she is non-verbal." Similarly, another respondent who answered "some difficulty" said, "As a mom, I understand her language." However, in contrast to the previous respondent, this respondent's child is *able* to speak and communicate. This respondent answered "some difficulty" because her child does not speak in public.

**Final recommendation:** No further revisions are suggested for this question.

The next set of questions was used to assess the comprehension and communication of older children.

**Initial testing-** Parents and guardians with children ages 5-17 were asked:

*Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty understanding other people? Would you say...*

Respondents based their answers on the following factors:

**Responsiveness:** About half of the respondents (n=118) based their answers on their children's ability to respond appropriately when spoken to. Respondents who answered "no difficulty" provided a wide range of examples of appropriate responses. Some children could hold a conversation while others could follow directions or provide requested information. Respondents who indicated that their children had some level of difficulty understanding others described the ways in which their children were not able to respond appropriately. For example, one respondent from Montenegro who responded "a lot of difficulty" said, "I ask her to bring me one thing and she does... but complicated orders, she can't understand."

**Language context:** In areas where more than one language is commonly spoken, some respondents (n=15) answered based on their children's ability to understand multiple languages. For example, a respondent from Belize explained her answer of "some difficulty" saying, "If others speak in English, he finds it difficult to understand but in Marathi, there is no difficulty in understanding other people." Even if these respondents attended to the phrase "usual language," within multilingual contexts, it was difficult to identify a child's "usual language."

**Relating to others:** Sixteen respondents answered based on their children's ability to relate to others. For example, a respondent from Montenegro answered "no difficulty" because her daughter "has a lot of empathy and feeling for others." Respondents in this category emphasized their children's ability to understand other's emotions and points-of-view rather than their comprehension.

**Hearing/non-verbal:** Parents of children with hearing difficulties were not consistent in how they interpreted this question. Ten respondents whose children have hearing difficulty, or who are non-verbal, based their answers on their children's ability to understand words while 18 answered on their children's ability to understand gestures. For example, a respondent from India said that she has to talk to her grandson "in actions and gestures all the time since he cannot hear and talk." However, she went on to say, "He understands all those gestures and actions and does what is told to him with ease if he wants to do it." This respondent answered "a lot of difficulty" because while her grandchild can't hear, he can understand some communication.

**Attention:** Six respondents answered based on how well their children pay attention. Most of these respondents answered "some difficulty." For example, a respondent from Montenegro explained her answer of "some difficulty," saying, "If she is interested in the subject of the story, she will listen and respond. Otherwise, she will ignore you. Yet, she understands everything, and I know so because later on, she can retell what someone said, even when she was not involved in the conversation." Another respondent made the distinction between understanding and attention and answered "no difficulty." This

respondent, also from Montenegro, said, “He understands other people perfectly, but usually he is preoccupied with his games. He just acts as if he didn't understand.”

**Vocabulary:** Five respondents answered based on their children’s understanding of vocabulary. Several respondents mentioned that their children don’t know as many words as other children while one answered “some difficulty” because her son doesn’t know some words like “condom.”

Fifteen respondents asked for clarification or to have the question repeated because they did not understand the phrase “usual language.” Twelve respondents answered based on their children’s ability to *be understood* by others rather than on their ability to *understand* others. The household context also influenced respondents’ answers:

**Context:** Some respondents noted that their children can understand close relatives but have trouble understanding outsiders. This was most often the case with children who rely on gestures to communicate or those who have some cognitive disability. For example, one respondent from India said, “He has no difficulty to understand what the family members want to say but finds it difficult to understand outsiders.” These respondents often answered “some difficulty” to indicate that their child has difficulty understanding in certain contexts.

**Round two-** The phrase “usual language” was removed since it did not help to clarify the intent of the question and in some cases caused additional confusion. In the second round of testing, parents of 5-17 year olds were asked:

*Compared to children of the same age does (name) have difficulty understanding other people?*

Respondents in round two continued to exhibit a wide range of interpretations of this question. They based their answers on their children’s hearing ability, empathy, ability to follow a conversation and their functioning within specific contexts. One respondent asked, “What does understanding mean? Language? Facial expressions? Verbal or non-verbal?” Several respondents with disabled children noted that they felt that it did not make sense to compare them to children without disabilities.

**Round three-** This question was not asked in round three. Because the question was not understood consistently by respondents, it is recommended that this question be eliminated. The basic elements of ‘understanding’ are captured elsewhere in the module in the questions related to hearing and cognition.

**Final recommendation:** Do not include this question in the survey.

**Initial testing-** Respondents with children ages 5-17 in all five countries (n=170) were asked:

*Compared with children of the same age and using [his/her] usual language, does [he/she] have difficulty being understood by other people? Would you say...*

Respondents interpreted the question in two ways:

- **Expression meaning:** Most respondents (n=79) interpreted this question to be about the verbal or non-verbal expression of ideas or meaning. Respondents who answered “no difficulty” reported that their children could converse in social situations, express their needs, describe events and succeed in school. Respondents whose children are verbal described their children’s difficulties expressing themselves, processing ideas or using grammar and vocabulary. Respondents whose children are non-verbal answered inconsistently. Some answered based on their children’s ability to communicate meaning with gestures and some answered based on their children’s inability to use spoken language.
- **Clarity of Speech:** Forty-four respondents answered based on the clarity of their children’s speech. Problems with clear speech included, pronunciation, stuttering, and speaking to quickly.

Twenty-five respondents asked for clarification or to have the question repeated because they did not understand the question. One of these respondents asked, “How should I know about others?” Eleven respondents were not able to answer the question at all because they felt that it did not apply to their children (generally because their children were non-verbal). Fifteen respondents asked for clarification of the phrase “usual language.” Respondents had difficulty with this phrase particularly in areas where multiple languages are spoken. Respondents’ answers were also influenced by the context of their children’s disabilities:

**Context:** Some respondents noted that their children can be understood by members of their immediate household but have trouble being understood by outsiders. This was most often the case with children who are non-verbal and communicate through gestures and those children who have severe speech difficulties. These respondents often answered “some difficulty” to indicate that their children have difficulty being understood in certain contexts.

**Round two-** The phrase “usual language” was removed since it did not help to clarify the intent of the question and in some cases caused additional confusion. In the second round of testing, 30 parents of 5-17 year olds were asked:

*Compared to children of the same age, does (name) have difficulty being understood by other people?*

Like the respondents in the first round of testing, respondents in round two answered based on their children’s ability to communicate both verbally and non-verbally. Respondents continued to struggle with the issue of context. Several respondents noted that they would give different answers depending on the context. For example, some children can be understood by family

members but not strangers while other children can be understood very well by people who use sign language but well at all by people in general. Like several respondents in the first round, two respondents could not distinguish a difference between this question about *being understood* and the previous question about *understanding*. To these respondents, the two questions were the same.

**Round three-** In order to clarify the context, the communication question was split into two questions, one asking about communication within the context of the household and the other asking about communication outside of the household. The scope of the question was limited by adding the clause, “when (name speaks...)”

In round three eight respondents were asked:

*When (name) speaks, does he/she have difficulty being understood by people inside of this household?*

**Formation of words:** Most respondents (n=5) interpreted this question to be about how clear their children’s spoken words are (clarity of speech). For example, one respondent whose son is deaf, said, “He speaks well. You wouldn’t think he was deaf.” This respondent answered “no difficulty” because members of the household can understand what words he’s saying when he speaks. Another respondent answered “cannot do at all” because his child can’t say any words. This respondent can understand his daughter’s “basic human emotions” through the variations in her cries, but that is the limit of her ability to communicate.

**Expression of ideas:** Two respondents interpreted the question to be about expression of ideas. For example, one respondent answered “some difficulty” because her child exaggerates a lot. Similarly, the other respondent in this category answered “a lot of difficulty” because her son has difficulty responding coherently.

A final respondent was unsure how to respond because she was not sure which interpretation to base her answer on. Ultimately, she chose to answer based on clarity of speech because even though her son has difficulty holding a conversation, she and her husband are usually able to figure out what he’s talking about.

**Composition of household:** One respondent noted that she understands her son much more than her husband does. This highlights the possibility that the answer to this question may differ across a range of household members. In this case, the respondent chose the most extreme answer category. If she had been answering for herself, she would have answered “some difficulty” but since her husband has a much harder time understanding her son, she answered “a lot of difficulty.”

**Final recommendation:** No further revisions are suggested for this question. However, in order to account for children who use sign language, rather than spoken language, it may be beneficial to include a series of questions about communicating with sign language.

The next communication question was asked to the same eight respondents:

*When (name) speaks does he/she have difficulty being understood by people outside of this household?*

**Formation of words:** Four respondents interpreted the question to be about how well their children form words. For example, one respondent answered “some difficulty” because her son does not pronounce vowels clearly and mispronounces a lot of words. The respondent whose daughter is non-verbal answered “cannot do at all” because the child is not able to form words.

**Expression of ideas:** Four respondents answered based on their children’s ability to communicate ideas to others. Two of these respondents described their children’s difficulties speaking due to anxiety. For example, one of these children speaks clearly and can be understood at home, but doesn’t speak at all in public. The respondent answered “a lot of difficulty” since the child has so much trouble speaking. Two other respondents answered based on their children’s inappropriate responses. One of these often answers in non-sequiturs that don’t make sense to the child, while the other one frequently makes aggressive or violent comments. This respondent said, “They would understand the words she is saying but they don’t understand why she would say it.”

In summary, the revised communication questions perform better than the original questions. The scope of interpretation of these questions is much narrower than for previous versions. Additionally, the series of two questions helps respondents distinguish between understanding within-household and out-of-household. While it was noted that there may be a range of understanding within the household, this is likely to be easier for respondents to resolve than the differences in understandings between family (in-household) and strangers (out-of-household).

**Final recommendation:** No further revisions are suggested for this question. However, in order to account for children who use sign language, rather than spoken language, it may be beneficial to include a series of questions about communicating with sign language.

## **LEARNING**

Respondents with children 2-3 years old were asked a single question to assess their child’s learning.

**Initial testing-** Respondents in all five countries with children ages 2-3 (n=27) were asked:

*Compared with children of the same age, does [he/she] have difficulty learning the names of common objects? Would you say...*

Two respondents asked for the question to be repeated before they were able to answer because they were initially unsure of what was meant by the phrase “common objects.” After hearing the question again, both respondents were able to answer.

Respondents interpreted the question in two ways:



- **Ability to speak:** Most respondents answered based on their children's ability to say the names of common objects. The children of these respondents were verbal. Difficulties included problems with pronunciation and the need for a repetition.
- **Recognition of objects:** Some respondents answered based on their children's ability to recognize and point to objects. These children were non-verbal and could not say the names of the object even though they could identify them through gestures. Some respondents whose children are non-verbal answered "some difficulty" to indicate that their children can't speak while others answered "no difficulty" since their children can recognize many objects.

**Rounds two and three-** No changes were made to this question for the second and third rounds of testing. The question performed similarly to how it performed in the first round of testing.

**Final recommendation:** No further revisions are suggested for this question.

Older children's learning was assessed with a series of two questions about learning and memory.

**Initial testing-** Respondents in all five countries with children ages 3-17 (n=183) were asked:

*Compared with children of the same age, does [he/she] have difficulty learning to do new things? Would you say...*

Respondents interpreted this question in three ways:

- **Ability to learn in context:** Most respondents considered the question to be about how easily their children are able to learn to do new things or acquire new knowledge. Almost all respondents focused on either school related or physical (sports and games) activities.

For respondents who interpreted the question in this way, difficulties included problems that impeded learning such as the child's need for extra time or repetition to master the new information or ability. Some respondents noted that their children's ability to learn depended on the type of activity. Since some things are easy to learn and others hard, these respondents answered "some difficulty."

Respondents whose children had differing levels of ability in physical and mental domains tended to prioritize mental ability." For example, a respondent in Montenegro said, "The boy is mentally fit. There he has no problems, but when it comes to doing something which requires physical activity, he cannot do it." This respondent answered "some difficulty." In contrast, a respondent in India described her son's ability to learn complicated dance routines after seeing them only one time. This respondent answered "a lot of difficulty" because her son has trouble with his studies and prefers to learn things "when they are taught like a song."

- **Interest/Willingness:** Twenty-five respondents answered based on their children's interest in learning but there was inconsistency in how they formulated their answers. A respondent in India who answered "some difficulty" said her son can learn new things "but only if they interest him." Another respondent answered "a lot of difficulty" because her son "doesn't like to learn." These respondents answered based on their children's desire to learn rather than on their ability to learn. In contrast, a respondent, from Montenegro, indicated that his son has "no difficulty" learning. He said, "What interest him, he immediately learns. For example, video games."
- **Anxiety about new things:** A small number of respondents (n=12) focused on their children's reaction to "new things." These respondents focused on their children's reactions to unfamiliar things rather than their ability to learn.

Twelve respondents asked for clarification of the question. Specifically, several respondents weren't sure about what was meant by "new things."

**Round two-** This question is intended to focus on the child's ability to learn, so the question was simplified by removing the phrase "to do." Parents of children 5-17 were asked:

*Compared with children of the same age, does [he/she] have difficulty learning new things? Would you say...*

Respondents answered this question considering their children's ability to learn in school and at home. "Some difficulty" was often chosen to indicate that the child has difficulty learning in a particular context but not in another. Several respondents focused on the qualifier "new," answering based on their children's anxiety about new situations.

**Round three-** The qualifier "new" led some respondents to focus on their children's anxiety in new situations rather than on their ability to learn. Therefore, the question was simplified by eliminating the word "new." Respondents were asked:

*Compared to children of the same age, does (name) have difficulty learning things?*

Almost all respondents interpreted this as a question about leaning in the context of school. In fact, one respondent, whose child was about to start school, answered most of the questions, including this one, in light of her anxiety about her child's ability to be successful in a school context. This respondent answered "some difficulty" for this question because she was concerned about her son's ability to sit still in a classroom even though she noted that he is a quick learner and academically ready for kindergarten. The two respondents with profoundly disabled children did not consider a school context because their children are not in school. Therefore the context of their answers was different from the other responses. These respondents both answered "a lot of difficulty" noting that they did not want to say "cannot do at all."

Several respondents expressed uncertainty about the clause, "compared to children of the same age." These respondents were not sure how to make a meaningful comparison between their children and other children. For some this was because they were not familiar with other

children's learning. Those with disabled children were not sure whether to compare them to other disabled children or to typical children. One such respondent resolved her uncertainty by deciding to make the comparison with other disabled children (answering "some difficulty" rather than "a lot of difficulty") because she felt this comparison was more relevant.

**Final recommendation:** No further revisions are suggested for this question.

A second learning question, focusing on memory, was administered to parents of children ages 5-17.

**Initial testing-** Respondents in all five countries (n=170) were asked:

*Compared with children of the same age, does [he/she] have difficulty remembering things that they have learned? Would you say...*

Most respondents interpreted this to be a question about retention of knowledge or ideas. These respondents focused on their children's ability to memorize stories and lists, memories of earlier events and their children's general forgetfulness. Twenty-three answered based on their children's ability to learn. In this way, their narratives were similar to the narratives they provided for the previous question on learning.

Nine respondents did not answer the question at all. Of these, four respondents didn't provide an answer because they felt that the question was the same as the previous question on learning. The other five non-answering respondents could not formulate an answer because, due to various conditions, their children do not learn and are, therefore, not able to remember things they've learned.

**Rounds two and three-** This question is intended to focus remembering rather than learning, so the question was simplified by removing the clause "things they have learned." Parents of children 5-17 were asked:

*Compared to children of the same age, does (name) have difficulty remembering things?*

Like the respondents in the initial round of testing, those in rounds two and three answered based on their children's ability to remember facts, people, things, events and to-do items. Several parents of severely disabled children commented that they could not be sure of how much their children remember. These respondents answered "a lot of difficulty," assuming that their children remember *something*. Several other respondents were not sure what a normal level of forgetfulness would be and were therefore unsure whether to answer "no difficulty" or "some difficulty."

**Final recommendation:** No revisions are recommended for this question. However, since it is not clear what level of forgetfulness respondents consider "normal," a probe question should be used in field testing to determine a cut-off point for inclusion.

## **EMOTIONS**

**Initial testing-** Respondents in all five countries with children between the ages of 5 and 17 (n=170) were asked:

*Compared with children of the same age, how much does (he /she) worry or feel sad?  
Would you say... (5-17)*

Respondents answered this question either based on their children's temperament or on their children's reactions to particular situations:

- **Temperament:** About half of respondents answered on the basis of their children's general emotional state. Most respondents focused on either worry or sadness while others considered fear or anxiety.
- **Situational:** About half of respondents focused on specific situations or emotional triggers. For example, a respondent from Belize answered "more." When asked why, she said, "[My son worries about me. If I get sick he worries." When the narrator asked the respondent about her son's emotional state at other times (when she's not sick), the respondent changed her answer to "the same or less." Respondents such as this one answered based on particular situations or conditions that did not necessarily represent their children's general emotional state.

Ten respondents were not able to answer the question at all. Five of these could not answer because they did not understand the question while the other five were not able to answer because they felt that the question did not apply to their children. These respondents reported that their children did not feel or express emotions at all, so they could not answer the question. Ten respondents answered the question with difficulty because they were not sure how to assess their children's emotions. For example, a respondent from India said, "How can I know how worried or sad another person is?" These respondents did not feel confident in assessing an internal emotional state based on outward cues. In India, in particular, several respondents noted that they did not recognize worry and sadness in children. These respondents felt that young children have nothing to be worried or sad about.

**Round two-** For the next round of testing, the question was not revised but the response categories were clarified. Four response categories were used: "not at all," "a little," "a lot" and "somewhere between a little and a lot."

Respondents in the second round of testing answered similarly to those in round one. Generally, respondents answered based on worry, sadness or some other emotion such as fear or anger. Quite a few respondents were not sure which answer category to choose for children with a "normal" amount of sadness at worry. Most of these chose "a little," feeling that it is normal for people to have a little bit of sadness, but others chose "not at all" to indicate that their children's sadness was not a problem.

**Round three-** This item was separated into two conceptually distinct questions: one on worry and one on sadness. Further, rather than asking about intensity (for which respondents had no consistent standard), the response options were changed to ask about frequency.

Eight respondents with children ages 5-17 were first asked:

*How often does (name) seem anxious, nervous or worried? (Would you say: daily, weekly, monthly, a few times a year or never?)*

All respondents interpreted the question in the same way. Respondents answered based on how frequently their children were emotionally unsettled or distressed. The respondents that chose “daily” said that their children felt anxious or worried multiple times a day and that their children’s level of worry and anxiety was not normal compared to other children of the same age. Those that chose “daily” also mentioned that anxiety management was a part of their daily role as parents. For example, one respondent who chose “daily” explained, “I have a lot of picture reminders at home. Like a daily schedule and trying to stick to like a routine.”

There was still some overlap in response categories for respondents who felt that their children’s level of anxiety was “normal.” For example, one respondent that chose “monthly” mentioned sporadic emotional outbursts that are “normal” for children of the same age. Two other respondents who chose “never” felt that their children’s anxiety was also at a “normal” level. These children may have some nervousness or worry, but it is never on a level that would be cause for concern. For example, one respondent who chose “never” elaborated:

*It depends on the situation... I wouldn't be concerned of her nervousness or anxiousness. Cause it might be like a roller coaster ride that she is scared to get on or something like that. It's not like she is scared to enter a building or a room...*

As in previous versions of the question, respondents with severely disabled children may answer within the context of their children’s disabilities. This can be seen in the respondent that chose “never” because her child (who is severely disabled) is incapable of worry or anxiety as an emotion.

The same set of respondents was next asked:

*How often does (name) seem sad or depressed? (Would you say: daily, weekly, monthly, a few times a year or never?)*

All eight respondents interpreted the question in the same way. Respondents based their answer on how frequently their children seem outwardly sad or depressed. Respondents filtered out the emotion of anger and only selected their answer based on sadness, but many noted that there was a connection between their children’s anger and their children’s sadness. The respondents that chose “daily” and the respondents that chose “weekly” were concerned about their children’s sadness and described how their children isolated themselves and stayed in their own room. For example, one respondent who chose “weekly” described her daughter in this way:

*She'll just want to go and sit in her room. Not do anything, just sit. Not go to sleep. Just sit in her room and she'll separate herself from her siblings.*

Respondents who chose “monthly,” “a few times a year” or “never” were generally not concerned about their children’s level of sadness. Respondents in this group described their children as “happy” or “full of joy.” These respondents said their children were only sad in situations where being sad is appropriate, for example when the child is sick.

**Final recommendation:** It is recommended to use the two emotions question from round three rather than the single question that was used in round one. Separating the original “emotion” question into two distinct questions increased the consistency in how respondents formulated their answers. When respondents were asked, “Compared with children of the same age, how much does (he/she) worry or feel sad.”, respondents were thinking of either worry, sadness, fear, anger or any combination those emotions when answering. With the questions separated, respondents were able to focus on the relevant constructs when answering each question.

## **BEHAVIOUR**

There were separate behavior questions for younger children and older children.

**Initial testing-** Respondents with children ages 2-4 in all five countries (n=40) were asked:

*Compared with children of the same age, how much does (he/she) kick, bite or hit other children or adults? Would you say...*

*1) The same or less*

*2) More*

*3) A lot more*

All respondents interpreted the question in the same way, answering based on how much or how often their children hit, kick or bite. However, there was little consistency in respondent’s answers. Some respondents whose children hit, kick or bite frequently, answered “the same or less” because they considered this normal behavior for 2-4 year olds. Other respondents described similar behavior but answered “more.” Respondents had different understandings of how much hitting, kicking and biting is normal in this age group which led them to choose different answers despite similar behavior from their children.

Seven respondents were not able to answer the question because their children do not kick, bite or kick at all. These respondents wanted to answer “none” or “not at all” instead of the available option (“the same or less”).

**Rounds two and three-** The response options were clarified by adding the category “none.” In general, the question performed similarly to how it performed in the initial round of testing. Two respondents chose “none.” One chose this because her child “is not aggressive at all” and therefore, does not kick and bite at all while the other described how her disabled daughter kicks and bites reflexively, but not to be mean.

**Final recommendation:** No revisions are recommended for this question.

Older children's behavior was assessed with a slightly different question.

**Initial testing-** Respondents with children 5-17 the United States and Montenegro were asked:

*Compared with children of the same age, how much difficulty does (he/she) have controlling his/her behavior? Would you say...*

1) *The same or less*                      2) *More*                                      3) *A lot more*

While respondents with children ages 5-17 in Oman, Belize and India were asked the same question with a different set of response categories:

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

The question performed similarly in all countries despite the different answer categories. However, the first set of response categories elicited more comparisons with children of the same age.

The question was interpreted in two ways:

**Control over actions/emotions:** Most respondents (n=122) answered based on their children's ability to control their reactions to emotions such as anger, fear and anxiety. Many respondents described how their children get angry easily, react violently to minor situations and take a long time to calm down. For example, one respondent explained her answer of "some difficulty" by explaining that her son "can't control his anger. Once he threw a stone at his uncle because he was angry." Another respondent explained his answer of "no difficulty" by saying, "He thinks before he acts. He does not say harsh words. Often, respondents noted that their children could not hold still. This was particularly true for children who had been diagnosed with ADHD or "Hyperactivity."

**Obedience/parental control:** Forty-five respondents answered based on their children's level of obedience. One respondent answered "more." He said, "[My son] shows a lot of stubbornness and refuses to follow my orders." In contrast, another respondent answered "the same or less." He said, "[My son] agrees to whatever is being told to him by [us] even if he does not want to do it he still do it." About half of the respondents in this category took this interpretation to its extreme and answered based on their ability to control their children. These parents described their strategies for controlling their children's behavior.

Fifteen respondents asked for clarification because they did not understand the question. Specifically, some respondents were not sure what was meant by the term "behavior." Eight respondents did not answer the question because they did not understand the question or because they felt that it did not apply to their children because their children do not have "behavior" due to their profound disabilities.

**Rounds two and three-** In the second round of testing, the question was asked using the comparative response categories plus “none.” Respondents with children ages 5-17 were asked:

*Compared with children of the same age, how much difficulty does (he/she) have controlling his/her behavior? Would you say...*

- 1) *None*                      2) *The same or less*                      3) *More*                      4) *A lot more*

In general, respondents answered based on their children’s ability to control impulses, emotions and movements. Nine respondents asked for repetition and four had difficulty answering. One respondent could not choose an answer because he felt his child had no control at all. This respondent said, “Her environment is always controlled around her.” Another of these respondents could not answer because she could not make the comparison with other children and two of these respondents initially understood the question to ask “How much does he/she control her behavior?” rather than “How much difficulty..”

Final recommendation: No revisions are recommended for this question. However, since it is not clear what level of difficulty controlling behavior respondents consider “normal,” a probe question should be used in field testing to determine a cut-off point for inclusion.

#### **ATTENTION 5-17**

**Initial testing-** Respondents in all five countries with children ages 5-17 (n=180) were asked:

*Compared with children of the same age, does (he/she) have difficulty completing a task? Would you say... (5-17)*

Respondents who answered “no difficulty” gave examples of tasks their children typically complete. These tasks included school work, household chores and games. Respondents who answered “some difficult,” “a lot of difficulty” and “cannot do at all” had various explanations for their children’s difficulties in this area:

- **Physical ability:** Thirty-six respondents answered based on their children’s physical difficulties completing tasks. Most of these respondents answered “a lot of difficulty” or “cannot do at all” due to their children’s muscle weakness, inability to walk or vision difficulties.
- **Attention/cognitive ability:** Thirty-four respondents answered based on their children’s cognitive difficulties completing tasks. These children were physically able to complete tasks but had difficulty staying focused or understanding how to follow instructions.
- **Motivation/obedience:** Thirty-three respondents answered based on their children’s motivation or obedience. These children are physically and cognitively able to complete tasks but are often unwilling to complete them. For example, one respondent answered



“some difficulty” “If I make a promise to her that we will go for a walk if she cleans her room, she will do it. When she knows there is a reward, she's willing to obey. If that is not the case, she is very stubborn.”

Seventeen respondents asked for clarification because they did not understand the question. Specifically, some respondents were not sure what was meant by the term “task.” Eight respondents did not answer the question because they did not understand the question or because they felt that it did not apply to their children because their children do not do “tasks” due to their profound disabilities. There were other factors that influenced respondents’ answers:

- **Depends:** Twenty-four respondents noted that their children’s ability to complete tasks depends on factors such as the difficulty of the task or incentives provided for completion. A respondent in Belize said of her son, “It depends on the task. If it is age appropriate and of his interest, he has no problem.” This respondent, like most of the respondents in this category, answered “some difficulty.” There was no consistency in how these respondents answered, however, as some answered based on the things their children can do while others answered based on the things their children can’t do.
- **With assistance or without:** Some respondents answered based on their children’s ability to complete tasks with assistance while others did not. For example, several respondents noted that their children need a lot of reminding or repeated instruction or that their children need physical support to do tasks; many of these answered based on their children’s ability to complete their homework and chores with reminders or with physical support. Without these reminders, their children would not be able to complete the tasks. Other respondents answered based on their children’s ability without reminders or support. For this reason, respondent’s answers varied.

**Rounds two and three-** This question was revised in an attempt to resolve two areas of difficulty. The phrase “completing a task” was replaced with “focusing on an activity.” Also, the clause “that he/she enjoys doing” was added. Respondent with children ages 5-17 were asked:

*Does (name) have difficulty focusing on an activity that he/she enjoys doing?*

Although most respondents in rounds two and three answered based on activities their children enjoy, such as games, television and hobbies, a few respondents still thought their child’s ability to focus would “depend on the activity.” Respondents with severely disabled children continued to have difficulty answering this question either because their children don’t enjoy activities or are not able to do any activities. Several of these respondents compared their disabled children to other disabled children rather than to children of the same age in general.

**Final recommendation:** No revisions are recommended for this question.

## **COPING WITH CHANGE**

**Initial testing-** Respondents with children ages 5-17 were asked:

*Compared with children of the same age, does (he/she) have difficulty accepting change to plans or routine? Would you say...*

The question was interpreted in several ways:

**Daily routine:** Thirty-six respondents answered based on their children's reaction to changes in their daily routine. Twenty respondents answered "no difficulty" because their children are not upset by deviations in their daily routines. About half of these respondents indicated that the reason their children have "no difficulty" is because the children do not have a routine or their routine has never been changed. Sixteen respondents indicated that their children had some level of difficulty dealing with changes to their typical daily routine.

**Looking forward to plans:** Thirty-five respondents answered based on their children's tendency to react to changes in plans they were looking forward to. For example, a respondent in the U.S. answered "some difficulty" and said, "You know, kids... if you changed the plans —especially if he had his mind set on something and you changed it—of course [my son's] going to be upset a little bit." Those who answered "no difficulty" indicated that their children could accept changes to plans as long as they were given a reasonable explanation.

**Temperament:** Thirty-three respondents answered based on their child's temperament or general ability to deal with changes. Those who answered "no difficulty" described their children as "adaptable" or "flexible" and those who answered "some difficulty" or "a lot of difficulty" described their children as "rigid" or "stubborn."

**Travel:** Eight respondents in Montenegro provided information about their children's enjoyment of travel. A typical respondent gave this explanation, "[My son] likes to change the environment and likes to travel a lot. He loves the sea, loves to swim." Because all of these respondents were in the same country, this interpretation may have been the result of how the question was translated or how the question was asked.

**Change in life circumstance:** Five respondents gave examples of their children's difficulties adjusting to changes in life circumstances. For example, a respondent in the U.S. described her daughter's difficulty accepting the fact that she can't visit her ill grandmother. Another respondent in India described how her son did not like getting sick. These respondents were thinking about their children's reaction to extraordinary circumstances rather than their ability to accept changes to their typical routine.

Seven respondents were not able to answer the question because their children had severe disabilities. These respondents felt that the question did not apply to their children because either their children do not express emotions or because their routine consists entirely of a caregiving routine imposed by the caregivers. Thirty-six respondents asked for clarification because they did not understand the question or needed an example.

**Rounds two and three** - This question was revised with the goal of tightening its focus on identifying children who are rigidly attached to routines and schedules. In order to steer respondents away from a focus on children's disappointment with cancelled plans, that language was removed from the question. The comparison clause was also removed because it did not seem to help respondents frame the question as many were not familiar with the routines of other children.

In rounds two and three, respondents with children ages 5-17 were asked:

*Does (name) have difficulty accepting changes in his/her routine?*

Respondents in these rounds were more focused on daily routines than those in round one. Two respondents could not answer the question because they felt that their children did not have set routines. Additionally, there were a few respondents who did not understand the question as intended. Three of these answered based on their children's need for a routine. For example, the mother of a profoundly disabled child explained that her child needs to be fed at regular intervals. Two respondents answered based on their children's reaction to unusual circumstances like moving to a new house. Finally, one respondent answered "some difficulty" because his daughter resists going to bed at night. This respondent was thinking about his child's difficulty following her routine rather than her difficulty with changes to the routine.

**Final recommendation:** No revisions are recommended for this question.

## **RELATIONSHIPS**

**Initial testing-** In the initial round of testing, there was one relationships question and three separate playing questions. Beginning with the relationships question, respondents in all five countries with children 5-17 were asked:

*Does [he/she] have difficulty getting along with children of his/her age? Would you say...*

The majority of respondents answered "no difficulty" to this question, but there were a variety of interpretations of this question:

**Friends:** The majority of respondents (n=74) considered the question to be about their children's friends. Most respondents noted that their children have plenty of friends and answered "no difficulty." Respondents answered "some difficulty," "a lot of difficulty" or "cannot do at all" to indicate varying degrees of difficulty their children have in making friends and keeping friends or if they children only have friends of the "wrong" age or gender. For example, a respondent in India answered some difficulty because her daughter, "... likes to have male friends more and her friends call her Tom boy." Even though her daughter has friends, the respondent felt that a girl preferring male friends is a difficulty.

**Child's disposition:** Sixty-three respondents answered based on their children's disposition. Some children were described as "social" or "outgoing" while others were

described as “introverted,” “shy” or “loner.” These respondents were thinking about how much their children like to engage with others rather than in the number of friends they have.

**Conflict:** Seventeen respondents answered based on the level of conflict their children are involved in. For example, a respondent in India indicated that her son has “no difficulty” getting along because “...he does not fight unless provoked, but he would not fight with someone for no apparent reason.” Another respondent answered “a lot of difficulty” because her son “...fights and argues a lot. He wants everything for himself.”

**Others:** Ten respondents answered based on the qualities of others. For example, some children can’t mix with the children in their neighborhood because the neighborhood is not safe. Parents of disabled children noted that their children enjoy the company of other children but that the other children don’t understand them. Therefore, they answered “a lot of difficulty” or “cannot do at all.”

Six respondents asked for clarification because they weren’t sure what was meant by “getting along.”

**Rounds two and three-** Conceptually, this question showed a great deal of overlap with two of the playing questions. Therefore, in order to simplify the module, these questions were combined into one conceptually unified question.

Respondents with children 5-17 were asked:

*Does [name] have difficulty making friends?*

Most respondents were able to answer this question without difficulty. Respondents assessed their children’s difficulties making friends by considering the number of friends they have and how much conflict they have with their friends. Some respondents wondered about the definition of “friend.” One respondent considered a friend to be someone her child could confide in while another respondent thought about classmates that her child is fond of but with whom he does not interact.

**Final recommendation:** No revisions are recommended for this question.

## **PLAYING**

Initially, there were three separate playing questions.

**Initial testing-** Respondents with children ages 2-4 (n=41) were asked:

*Compared with children of the same age, does [he/she] have difficulty playing with toys or household objects?*

This question was generally interpreted in two ways:

**Playing with toys:** Almost all of the respondents interpreted this as a question about playing with toys (n=37). Respondents described the types of toys their children enjoy playing with such as trucks, dolls, games and puzzles. A few respondents indicated that their children have physical difficulties playing. For example, three children do not have the muscle control to hold toys. Other respondents indicated that their children get bored easily, only like specific kinds of toys or do not take proper care of their toys.

**Interacting with other children:** Three respondents answered based on their children's ability to interact with other children. One respondent answered "a lot of difficulty" because she was concerned about her son's tendency to "fight with other children." The two other respondents answered "no difficulty" because their children "play with everyone."

**Household objects:** Few respondents mentioned household objects. Those that did mentioned things like keys or kitchen utensils that their children might play with. One respondent was confused by the term "household object" because he said it made him think of things that children shouldn't play with such as cleaning products and household chemicals.

**Rounds two and three-** This question was simplified by removing reference to toys or household objects. In this round, respondents with children 2-4 were asked:

*Does (name) have difficulty playing?*

Respondents in these two rounds answered based on their children's ability to play in general. Respondents noted their children's mental and physical barriers to play. One respondent had difficulty answering because she was not sure if she should compare her child to typical children. This respondent ultimately answered "some difficulty" even though her child is profoundly disabled and communicates only through cries. This respondent said, "I don't think she has any difficulty playing how she wants to although she couldn't play with kids her own age."

**Final recommendation:** No revisions are recommended for this question.

The next playing question expanded the age range and focused on playing with other people.

**Initial testing-** Respondents in all five countries with children 2-12 were asked:

*Compared with children of the same age, does [he/she] have difficulty playing with other children?*

Almost all respondents answered this as a question about their children's social interactions. Indeed, most respondents reiterated the narratives they had given for the previous question on relationships. Respondents who indicated that their children have "no difficulty" in this area answered in this way because their children have friends and are generally social or they enjoy playing sports and games with other children. For those that have difficulties, problems include

not being interested in other children, preferring computer games to friends and having friends of the wrong age.

Three respondents did not answer the question because they felt that it did not apply to their profoundly disabled children.

A different question was administered to parents of older children.

**Initial testing-** Respondents with children age 10-17 were asked:

*Compared with children of the same age, does [he/she] have difficulty doing things with other children? (Include things that children usually do together.) Would you say... (10-17)*

All respondents answered this question based on their children's social interactions. Many respondents felt that they had already answered this question as they interpreted it similarly to the question on relationships. Additionally, parents with children ages 10-12 had also answered the previous playing question. These respondents repeated the narratives they had provided in support of their previous answers and some of them said, "As I said before..." Respondents who answered "no difficulty" described their children's friendships and social activities which included shopping, sports, playing games and talking.

Three respondents did not answer at all because they felt that the question did not apply to their children due to their severe disabilities that limit their movement and cognition.

**Rounds two and three-** Since these two *playing* questions show considerable conceptual overlap with the *relationship* question, these three questions were replaced with a single item:

*Does [name] have difficulty making friends?*

See above for results of the rounds two and three.

**Final recommendation:** No revisions are recommended for this question.

## **WALKING (INDIA)**

**Initial testing-** First, parents or guardians who had children between ages 5 and 17 in India were asked:

*Compared with children of the same age, does [he/she] have difficulty walking a longer distance, for example, to a store? Would you say...*

Respondents were not sure whether to answer based on their children's ability to walk assisted or unassisted. Three respondents answered based on their children's mobility in a wheelchair rather than on their children's ability to walk. Some respondents evaluated their children's ability to walk using supports such as braces, sticks and parents' hands. Other respondents based their answers on how well their children can walk without support.

Respondents interpreted this question in three ways:

**Mobility:** Most respondents interpreted this as a general mobility question. Respondents offered narrative support for their answers by describing their children's general activities such as walking to and from school and playing sports.

**Need for supervision:** Four respondents answered based on their children's cognitive ability to walk to the store alone. These respondents answered "some difficulty" or "cannot do at all" because their children need supervision in traffic or are unable to understand how to get to the store.

**Pain and tiredness:** Respondents who answered "some difficulty" provided evidence of a variety of physical symptoms that make it difficult for their children to walk. The most frequent were their children's complaints of pain and tiredness. Other physical indicators of difficulty walking were limping and falling.

**Recommendation-** This question was developed specific to the Indian context and will not be used in the final module.

**Initial testing-** Next, parents or guardians who had children between ages 5 and 17 in India were asked:

*Compared with children of the same age, does [he/she] have difficulty walking a short distance for example, across a room?*

This question was administered to respondents in India whose answer to the previous walking question (2b) was anything other than "no difficulty." The question asks about "walking across a room" but respondents uniformly interpreted this as "moving about the home."

**Different answer:** Some of those who answered "some difficulty" or "a lot of difficulty" to the previous question had different answers for this question. For some, moving about the home is easier than walking outside because the distance is shorter and because there is furniture to pull up on. Many of these respondents changed their answers from "some difficulty" to "no difficulty." For other respondents, moving about the home is harder than walking outside because the furniture gets in the way and there is no one to support the child's walking.

**Same answer:** Some respondents gave the same answer to this question as to the previous question. The children of these respondents had the same problems moving about the house that they did walking outside. Problems walking included feeling pain, using an assistive device and having stiff muscles. Most of the respondents who answered "cannot do at all" to the previous question answered the same way to this question. Their children were not able to walk at all due to various conditions, and therefore, the distance or location did not matter.

**Recommendation-** This question was developed specific to the Indian context and will not be used in the final survey.





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## Appendix A

CHILD FUNCTIONING AND DISABILITY (AGE 5-17)		CFD
<p><b>CFD1.</b> I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE IN DOING CERTAIN ACTIVITIES.</p> <p>DOES (<i>name</i>) WEAR GLASSES OR CONTACT LENSES?</p>	<p>Yes ..... 1 No..... 2</p>	2⇒CFD3
<p><b>CFD2.</b> WHEN WEARING HIS/HER GLASSES, DOES (<i>name</i>) HAVE DIFFICULTY SEEING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty..... 1 Some difficulty..... 2 A lot of difficulty ..... 3 Cannot do at all ..... 4</p>	<p>1⇒CFD4 2⇒CFD4 3⇒CFD4 4⇒CFD4</p>
<p><b>CFD3.</b> DOES (<i>name</i>) HAVE DIFFICULTY SEEING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty..... 1 Some difficulty..... 2 A lot of difficulty ..... 3 Cannot do at all ..... 4</p>	
<p><b>CFD4.</b> DOES (<i>name</i>) USE A HEARING AID?</p>	<p>Yes ..... 1 No..... 2</p>	2⇒CFD6
<p><b>*CFD5.</b> WHEN USING HIS/HER HEARING AID(S), DOES (<i>name</i>) HAVE DIFFICULTY HEARING NOISES LIKE PEOPLES' VOICES OR MUSIC?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty..... 1 Some difficulty..... 2 A lot of difficulty ..... 3 Cannot do at all ..... 4</p>	<p>1⇒CFD7 2⇒CFD7 3⇒CFD7 4⇒CFD7</p>
<p><b>*CFD6.</b> DOES (<i>name</i>) HAVE DIFFICULTY HEARING NOISES LIKE PEOPLES' VOICES OR MUSIC?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty..... 1 Some difficulty..... 2 A lot of difficulty ..... 3 Cannot do at all ..... 4</p>	
<p><b>CFD7.</b> DOES (<i>name</i>) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?</p>	<p>Yes ..... 1 No..... 2</p>	2⇒CFD10

<p><b>*CFD8.</b> WHEN USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (<i>name</i>) HAVE DIFFICULTY WALKING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty..... 1  Some difficulty..... 2  A lot of difficulty..... 3  Cannot do at all..... 4</p>	
<p><b>*CFD9.</b> WITHOUT USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (<i>name</i>) HAVE DIFFICULTY WALKING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>Some difficulty..... 1  A lot of difficulty..... 2  Cannot do at all..... 3</p>	<p>1⇒CFD11  2⇒CFD11  3⇒CFD11</p>
<p><b>*CFD10.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (<i>name</i>) HAVE DIFFICULTY WALKING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty..... 1  Some difficulty..... 2  A lot of difficulty..... 3  Cannot do at all..... 4</p>	
<p><b>*CFD11.</b> DOES (<i>name</i>) HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING HIM/HERSELF?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty..... 1  Some difficulty..... 2  A lot of difficulty..... 3  Cannot do at all..... 4</p>	<p>1⇒CFD12  4⇒CFD12</p>
<p><b>*CFD11A.</b> WHAT TYPE OF DIFFICULTY DOES (<i>name</i>) HAVE WITH SELF-CARE (CHOOSE ALL THAT APPLY)?</p>	<p>Willingness to eat..... 1  Choice of clothing..... 2  Needs repeated reminders..... 3  Physical ability to eat..... 4  Physical ability to dress..... 5  Other..... 6</p>	
<p><b>*CFD11B.</b> HOW MUCH CONCERN DO YOU HAVE ABOUT THIS DIFFICULTY?</p>	<p>No concern at all..... 1  A little concern..... 2  A lot of concern..... 3  Somewhere between a little and a lot..... 4</p>	
<p><b>*CFD12.</b> WHEN (<i>name</i>) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF YOUR HOUSEHOLD?</p>	<p>No difficulty..... 1  Some difficulty..... 2  A lot of difficulty..... 3</p>	

<p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>Cannot do at all ..... 4</p>	
<p><b>*CFD13.</b> WHEN (<i>name</i>) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE OUTSIDE OF YOUR HOUSEHOLD?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	

<p><b>CFD14.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (<i>name</i>) HAVE DIFFICULTY LEARNING THINGS?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	
<p><b>CFD15.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (<i>name</i>) HAVE DIFFICULTY REMEMBERING THINGS?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	<p>1⇒CFD16  4⇒CFD16</p>
<p><b>*CFD15A.</b> HOW MUCH CONCERN DO YOU HAVE ABOUT THIS DIFFICULTY?</p>	<p>No concern at all ..... 1  A little concern ..... 2  A lot of concern ..... 3  Somewhere between a little and a lot ..... 4</p>	
<p><b>*CFD16.</b> HOW OFTEN DOES (<i>name</i>) SEEM ANXIOUS, NERVOUS OR WORRIED?</p> <p>WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?</p>	<p>Daily ..... 1  Weekly ..... 2  Monthly ..... 3  A few times a year ..... 4  Never ..... 5</p>	
<p><b>*CFD17.</b> HOW OFTEN DOES (<i>name</i>) SEEM SAD OR DEPRESSED?</p> <p>WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?</p>	<p>Daily ..... 1  Weekly ..... 2  Monthly ..... 3  A few times a year ..... 4</p>	

	Never.....5													
<p><b>CFD18.</b> COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DIFFICULTY DOES <i>(name)</i> HAVE CONTROLLING HIS/HER BEHAVIOUR?</p> <p>WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?</p>	<p>None.....1</p> <p>The same or less.....2</p> <p>More .....3</p> <p>A lot more.....4</p>	<p>1⇒CFD19</p> <p>2⇒CFD19</p>												
<p><b>*CFD18B.</b> DO YOU THINK THAT:</p> <p>HIS/HER DIFFICULTY CONTROLLING HIS/HER BEHAVIOUR IS NORMAL FOR CHILDREN OF THIS AGE?</p> <p>HE/SHE NEEDS HELP TO OVERCOME THIS DIFFICULTY?</p> <p>IF NOT ADDRESSED, THIS DIFFICULTY WILL CAUSE PROBLEMS IN THE LONG TERM?</p>	<table border="0"> <thead> <tr> <th></th> <th>Yes</th> <th>No</th> </tr> </thead> <tbody> <tr> <td>Normal.....</td> <td>1</td> <td>2</td> </tr> <tr> <td>Needs help.....</td> <td>1</td> <td>2</td> </tr> <tr> <td>Problems in the long term .....</td> <td>1</td> <td>2</td> </tr> </tbody> </table>		Yes	No	Normal.....	1	2	Needs help.....	1	2	Problems in the long term .....	1	2	
	Yes	No												
Normal.....	1	2												
Needs help.....	1	2												
Problems in the long term .....	1	2												
<p><b>CFD19.</b> DOES <i>(name)</i> HAVE DIFFICULTY FOCUSING ON AN ACTIVITY THAT HE/SHE ENJOYS DOING?</p> <p>WOULD YOU SAY <i>(name)</i> HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty.....1</p> <p>Some difficulty.....2</p> <p>A lot of difficulty.....3</p> <p>Cannot do at all.....4</p>													
<p><b>CFD20.</b> DOES <i>(name)</i> HAVE DIFFICULTY ACCEPTING CHANGES IN HIS/HER ROUTINE?</p> <p>WOULD YOU SAY <i>(name)</i> HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty.....1</p> <p>Some difficulty.....2</p> <p>A lot of difficulty.....3</p> <p>Cannot do at all.....4</p>	<p>1⇒CFD21</p> <p>4⇒CFD21</p>												
<p><b>*CFD20A.</b> HOW MUCH CONCERN DO YOU HAVE ABOUT THIS DIFFICULTY?</p>	<p>No concern at all.....1</p> <p>A little concern.....2</p> <p>A lot of concern.....3</p> <p>Somewhere between a little and a lot.....4</p>													
<p><b>CFD21.</b> DOES <i>(name)</i> HAVE DIFFICULTY MAKING FRIENDS?</p> <p>WOULD YOU SAY <i>(name)</i> HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty.....1</p> <p>Some difficulty.....2</p> <p>A lot of difficulty.....3</p> <p>Cannot do at all.....4</p>													



CHILD FUNCTIONING AND DISABILITY (AGE 2-4)		CFD
<p><b>CFD1.</b> I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE IN DOING CERTAIN ACTIVITIES.</p> <p>DOES (<i>name</i>) WEAR GLASSES OR CONTACT LENSES?</p>	<p>Yes..... 1</p> <p>No ..... 2</p>	2⇒CFD3
<p><b>CFD2.</b> WHEN WEARING HIS/HER GLASSES, DOES (<i>name</i>) HAVE DIFFICULTY SEEING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1</p> <p>Some difficulty ..... 2</p> <p>A lot of difficulty ..... 3</p> <p>Cannot do at all ..... 4</p>	<p>1⇒CFD4</p> <p>2⇒CFD4</p> <p>3⇒CFD4</p> <p>4⇒CFD4</p>
<p><b>CFD3.</b> DOES (<i>name</i>) HAVE DIFFICULTY SEEING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1</p> <p>Some difficulty ..... 2</p> <p>A lot of difficulty ..... 3</p> <p>Cannot do at all ..... 4</p>	
<p><b>CFD4.</b> DOES (<i>name</i>) USE A HEARING AID?</p>	<p>Yes..... 1</p> <p>No ..... 2</p>	2⇒CFD6
<p><b>*CFD5.</b> WHEN USING HIS/HER HEARING AID(S), DOES (<i>name</i>) HAVE DIFFICULTY HEARING NOISES LIKE PEOPLES' VOICES OR MUSIC?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT AT ALL?</p>	<p>No difficulty ..... 1</p> <p>Some difficulty ..... 2</p> <p>A lot of difficulty ..... 3</p> <p>Cannot do at all ..... 4</p>	<p>1⇒CFD7</p> <p>2⇒CFD7</p> <p>3⇒CFD7</p> <p>4⇒CFD7</p>
<p><b>*CFD6.</b> DOES (<i>name</i>) HAVE DIFFICULTY HEARING NOISES LIKE PEOPLES' VOICES OR MUSIC?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1</p> <p>Some difficulty ..... 2</p> <p>A lot of difficulty ..... 3</p> <p>Cannot do at all ..... 4</p>	
<p><b>CFD7.</b> DOES (<i>name</i>) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?</p>	<p>Yes..... 1</p> <p>No ..... 2</p>	2⇒CFD10
<p><b>*CFD8.</b> WHEN USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (<i>name</i>) HAVE DIFFICULTY WALKING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1</p> <p>Some difficulty ..... 2</p> <p>A lot of difficulty ..... 3</p> <p>Cannot do at all ..... 4</p>	

<p><b>*CFD9.</b> WITHOUT USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (<i>name</i>) HAVE DIFFICULTY WALKING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>Some difficulty ..... 1  A lot of difficulty ..... 2  Cannot do at all ..... 3</p>	<p>1⇒CFD10A  2⇒CFD10A  3⇒CFD11</p>
<p><b>*CFD10.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (<i>name</i>) HAVE DIFFICULTY WALKING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	<p>1⇒CFD11  4⇒CFD11</p>
<p><b>*CFD10A.</b> HOW MUCH CONCERN DO YOU HAVE ABOUT THIS DIFFICULTY?</p>	<p>No concern at all..... 1  A little concern ..... 2  A lot of concern..... 3  Somewhere between a little and a lot ..... 4</p>	
<p><b>CFD11.</b> DOES (<i>name</i>) HAVE DIFFICULTY UNDERSTANDING YOU?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	
<p><b>CFD12.</b> DO YOU HAVE DIFFICULTY UNDERSTANDING (<i>name</i>)?</p> <p>WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	
<p><b>*CFD13.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (<i>name</i>) HAVE DIFFICULTY LEARNING THINGS?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	
<p><b>*CFD14.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (<i>name</i>) HAVE DIFFICULTY LEARNING THE NAMES OF COMMON OBJECTS?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	



<p><b>CFD15.</b> COMPARED WITH CHILDREN OF THE SAME AGE, DOES (<i>name</i>) HAVE DIFFICULTY PLAYING?</p> <p>WOULD YOU SAY (<i>name</i>) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?</p>	<p>No difficulty ..... 1  Some difficulty ..... 2  A lot of difficulty ..... 3  Cannot do at all ..... 4</p>	
<p><b>CFD 16:</b> COMPARED WITH CHILDREN OF THE SAME AGE HOW MUCH DOES ( NAME) KICK, BIT OR HIT? WOULD YOU SAY NOT AT ALL, THE SAME OR LESS, MORE, A LOT MORE?</p>	<p>Not at all..... 1  The same or less ..... 2  More..... 3  A lot more ..... 4</p>	