## Analysis of Cognitive Testing of Child Disability Questions: Parent-Proxy vs. Teen Self-Report

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### I. Introduction

This report summarizes the findings of a study testing child disability questions asked to pairs of parents and their teenage children, or parent-teen dyads. These questions were developed by the Washington Group on Disability Statistics (WG) with the participation of the United Nations Children's Fund and are intended for use in country-wide surveys. The purpose of this study was to evaluate the differences in the ways these questions are answered by parent-proxies versus how they are answered by teens themselves. These questions had previously been tested in a cross-national evaluation of parent-proxy respondents (Massey, Chepp, Zablotsky, & Creamer, 2014).

This evaluation is based on 80 cognitive interviews that were conducted by a team of researchers from the Center for Questionnaire Design and Evaluation Research (CQDER) at the National Center for Health Statistics in April 2015. Cognitive interviewing is a qualitative question evaluation method used to evaluate the validity of survey questions (Willis, 2005; Miller, 2011). The main goals of the project were to: 1) assess whether teens and parents interpret and respond to these questions in the same way and 2) determine whether these interpretations and responses align with the intended scope of the questions.

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 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.

### **Methods**

Cognitive Interviewing: The aim of a cognitive interviewing study is to investigate how well survey questions perform when asked of respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers based on that intent. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves a survey's scientific goals. Findings of a cognitive interviewing project typically lead to recommendations for improving a survey question. Alternatively, results can be used in post-survey analysis to assist in data interpretation.

Traditionally, cognitive interviewing studies are performed by conducting in-depth, semi-structured

interviews with a small sample of approximately twenty to forty respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking and their rationale for that specific response. Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to provide both textual verification and the process by which they formulated their answer, elusive errors are revealed.

As a qualitative method, the sample selection for a cognitive interviewing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of questions being examined. When studying questions designed to identify persons with chronic conditions, for example, the sample would likely consist of respondents with previously identified chronic conditions in order to discover potential causes of false negative responses, as well as some respondents with no known chronic condition in order to examine potential sources of false positive reporting. Because of the small sample size, not all social and demographic groups are represented.

As is normally the case for analyses of qualitative data, the general process for analyzing cognitive interview data involves synthesis and reduction—beginning with a large amount of textual data and ending with conclusions that are meaningful and serve the ultimate purpose of the study. With each incremental step, a data reduction product is created (Miller, Willson, Chepp, & Padilla, 2014). The steps consist of: 1) Conducting interviews to produce interview text; 2) Synthesizing interview text into summaries to produce detailed summaries; 3) Comparing summaries across respondents; 4) Comparing identified themes across subgroups; and 5) Making conclusions. Although these steps are described separately and in a linear fashion, in practice they are iterative; varying levels of analysis typically occur throughout the qualitative research process. As each step is completed, data are reduced such that meaningful content is systematically extracted to produce a summary that details a question's performance. In detailing a question's performance, it is possible to understand the ways in which a question is interpreted by various groups of respondents, the processes that respondents utilize to formulate a response as well as any difficulties that respondents might experience when attempting to answer the question. It is the ultimate goal of a cognitive interviewing study to produce this conceptual understanding, and it is through data reduction that this type of understanding is possible.

Sample: A team of researchers from the CQDER interviewed 40 parent-teen dyads for a total of 80 respondents. The research team recruited a purposive sample of teens aged 12-17 and their parents. Teens both with and without (parent or self-identified) difficulties with seeing, hearing, walking, learning, and/or behavior were recruited through newspaper advertisements, email list contacts and flyers. A screening process was employed over the telephone to determine eligibility for participation. Three-quarters of the adult respondents were female while 60% of the teen respondents were male. Half of the parent respondents were 50 or over, and 68% of the teen respondents were 15-17 years old. Full parent and teen respondent demographics for the full sample are shown in Table 1.

Table 1. Demographic profile of respondents					
	Parent (n=40)		Teen (n=40)		
Age (parent)		Age (teen)			
30-49	20	12-14	13		
50 - 64	20	15-17	27		

Gender (parent)		Gender (teen)	
Female	30	Female	16
Male	10	Male	24
Race (parent)		Race (teen)	
Black	17	Black	20
White	16	White	16
Asian	1	Asian	0
Multiple	2	Multiple	4
<b>Education (parent)</b>			
No HS diploma	2		
HS diploma /GED	4		
Some college	7		
College Degree	10		
<b>Graduate Degree</b>	17		

### Interviewing Procedures

Interviewing Procedures: During the interviews, retrospective, intensive verbal probing was used to collect response process data. First, respondents were administered all of the survey 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/or audio recordings and written notes of interview summaries were used to conduct data analysis. All interviews were conducted face-to-face in the Questionnaire Design Research Laboratory within the CQDER. Interviews typically lasted 60 minutes and respondents were given \$40 once the interview was complete.

Data Analysis: Analysis of interviews was performed in the manner described in the above description of cognitive interviewing methodology. After each interview was conducted, summary notes were written for each question. Summary notes included the way in which a respondent interpreted and processed individual questions, what experiences or perceptions the respondent included as they formulated their answer, and any response difficulties experienced by the respondent. After all interviews and summaries were completed, interviews were compared to identify common patterns of interpretation and response difficulties for each question.

A data entry and analysis software application (Q-Notes) was used to conduct analysis. Q-Notes, developed by CQDER, ensures systematic and transparent analysis across all cognitive interviews as well as provides an audit trail depicting the way in which findings are generated from the raw interview data.

## **III. Overall Findings**

One of the underlying questions in conducting survey research using proxy responses is the validity of those responses as compared to self-report data. Given that the teen disability question set was originally designed as a proxy instrument—wherein a parent would respond about their teenage child—this cognitive interviewing project was designed to investigate whether or not parents and their teenagers respond to this questionnaire's items similarly. There are two ways of approaching this: by looking at question answers across each dyad—the parent-child pair—or by comparing and contrasting the

response patterns of each member of a dyad. While more detailed results of this dyad analysis will be presented alongside the question-by-question analysis below, this section will provide a brief overview of the findings from these two analytic approaches.

The simplest way to compare the responses of the individuals in the dyad are to look at the answers they provided to the survey questions. The first step in such an analysis is to determine the percentages of parents and teens who answered questions using the same response category. Chart 1, below, shows the level of agreement between the parent/teenager dyads in the cognitive interviewing sample (n=39 dyads) by question domain:

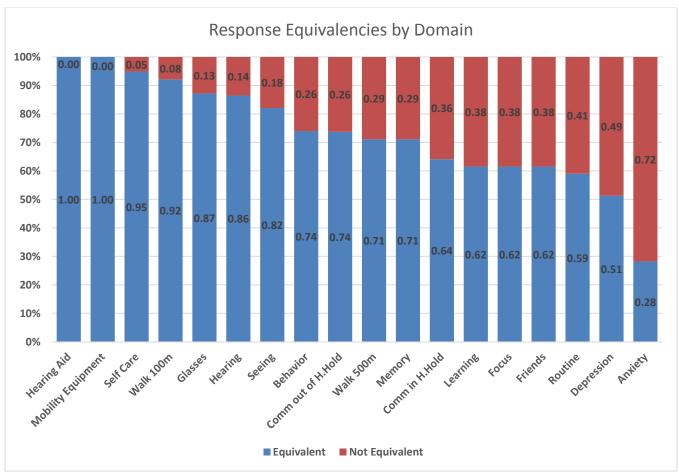


Chart 1: Response Equivalencies by Domain, n=39 dyads

Agreement within the dyads was relatively high, with only one domain, anxiety, exhibiting more disagreement than agreement within the parent/teen pairs. Besides the questions about the teen's use of hearing and mobility aids, the highest amount of agreement is found in two domains that the parent can easily observe—self-care and the teen's ability to walk 100 yards on level ground. On the other hand, the domains where the parents and their teens agreed the least—anxiety, depression, ability to cope with changes in routine, friendship formation, ability to focus and ease of learning—are areas of the teens' lives to which parents potentially have little access.

Another way to look at this trend is to consider the "direction" of the dyad's disagreement—whether the teen rated him or herself to have more or less difficulty (or experienced something less frequently) than the parent rated the teen. Chart 2 adds in the direction of the disagreement, and is ordered with the domains where teens rated themselves lower on the difficulty scale than their parents on the left:

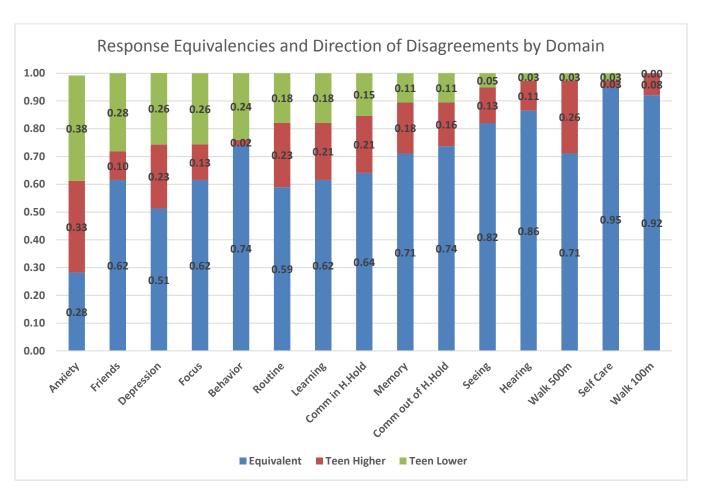


Chart 2: Response Equivalencies and Direction of Disagreements by Domain, n=39 dyads

Overall, teens tended to rate themselves as having more difficulty (or experiencing an emotion more frequently) than their parents. Only three domains—ability to control behavior, friendship formation and ability to focus—showed the opposite pattern, with the teens expressing less difficulty than their parents' proxy responses.

Turning to the qualitative data captured during the cognitive interviews can help explain this trend. The general pattern of the quantitative findings indicates a relationship to the "observability" of the domain—there were high levels of agreement between the parents and teen in those domain where the parents could largely observe what the question was asking about, but low agreement where they could not. This same trend is present in the qualitative data, where the members of the dyads used similar patterns of interpretation in the observable domains, and more divergent patterns of interpretation in the les observable domains. Start by considering those domains where the teens and their parents had high levels of agreement—such as walking 100 yards and self-care. In both of these domains, parent and teen respondents not only *answered* the questions nearly identically (as seen above in Chart 1), but also applied similar patterns of interpretation. For example, when thinking about teens' difficulties walking 100 yards, both the teens and their parents tended to concentrate on signs of physical ability (such as specific examples of times the teen has or has not been able to walk that far, or indicators of the teen's

general fitness), signs of a teen's stamina or lack thereof, or about signs the teen was in pain (see Figure 9 in the Question-by-Question Analysis section below). While the teens were able to consider a wide range of, and more detailed explanations of, experiences related to their difficulty walking 100 yards, they approached the question in nearly the exact way their parents did. Likewise, the parents and teens both answered and patterned their response to the self-care question in very similar ways. While the two types of respondents' response schemas were not identical (see Figures 11 and 12 below for the parents' and the teens' schemas, respectively), their general approach of each group was the same: they thought about examples of general self-care (such as indicators of independence), examples of ability to eat, and examples of ability to dress. As can be seen in Figure 12, the teens did think about two specific (and potentially out of scope) constructs that the parents did not—relating to appetite and the propensity to stress over wearing fashionable clothes.

This similarity in the response patterns of these two domains across the parents and the teens is due to the fact that nearly everything both groups considered when answering the questions were observable by both the parent and the teen. On the other hand, there was much more divergence in the answers in the domains where only the parents considered observable phenomena, and the teens mostly considered non-observable perceptions—such as anxiety and friendship formation. Figures 20 and 21 (below, in the Question-by-Question Analysis section) show how the parents' and teens' response processes to the anxiety question differ: The parents had a much narrower interpretation of the question, and focused on their observations of how the teens responded to the stressors of everyday life (such as applying for college or starting new schools) or on whether or not the teen had ever been diagnosed with anxiety. The teens, on the other hand, considered a much wider range of constructs that not only included those that their parents had thought of, but also about personal feelings of safety, empathy, extreme emotions, and their general concept of self. The patterns of interpretation were likewise divergent across the dyad pairs in the friendship formation question: Parents considered that which they could see, and thought about the number of friends they believed their teen had, and the intensity or quality of those friendships based on observable factors such as the amount of time they interacted with their friends and in what social contexts. In contrast, the teens had a very narrow (and perhaps more in scope) interpretation of this question—focusing on their perceived ability to make friends and keep friends, and did not consider observable factors such as the number of friends they had or the amount of time they spent with them. The differences between these two approaches to this question can be seen in the Question-by-Question section below in Figures 26 and 27.

The general pattern across both the quantitative and qualitative analysis of the dyads was that in domains where parents could rely on their observation- in addition to other inputs such as reports from the teens and professional diagnosis- there was high levels of agreement between the parents and teens across both survey response and question interpretation, while there was markedly less agreement and more divergent patterns of interpretation in the less observable areas. Overall, the combined quantitative and qualitative analysis of the dyad pairs in this cognitive testing project largely confirm what the survey methodology literature says about proxy response (see for example Moore 1988; Theunissen et al 1998; and Cobb and Krosnick 2009): that asking proxy respondents about empirical phenomena is more likely to produce comparable results to self-responds than will asking about less empirical phenomena.

**Preferred Respondents:** These questions were originally designed to be asked of parents in order to capture their children's general functional difficulties that may require intervention or services. For younger children, parent-proxies are able to provide this information, but this may not be the case for teens. Therefore, a primary goal of this project was to determine whether it would be better to ask these questions to parent-proxies or teen self-responders.

Despite a high degree of agreement, there are differences in the results seen between the two groups. As described above and in the question by question review below, teens and parents do not always interpret these questions in the same ways. Further, even when they understand the questions similarly, their responses do not always align. These differences vary from one domain to the next. For some questions results are similar regardless of who is asked while for other questions, either teens or parents may provide a more accurate portrayal of the teens' difficulties. In general, teens respond based on a more granular examination of their difficulties while parents have a more general perspective. For example, in the domain of seeing, parents usually answered based on their teens' ability to see *in general* while teens tended to indicate that they had some level of difficulty if they had a harder time seeing *under certain conditions* (e.g. seeing from far away or with an outdated prescription). These different perspectives were more pronounced in domains that were less observable to parents.

It is also important to consider what would be missed by asking one group over the other. Asking parents about their teens' difficulties may miss cases where the teen has a difficulty unseen by the parent. For example, a teen with extreme anxiety might be able to function such that the anxiety is undetected by the parent. Similarly, a parent may be unaware of teens' difficulties making friends or of pain experienced while walking. Asking teens about their own difficulties may miss cases where the teen is unconcerned about a difficulty that has been observed by the parent. For example, a teen may have serious behavioral issues that may seem normal to the teen in comparison to his/her peer group.

Therefore, while teens often do have greater insight into the specifics of their difficulties, parents are able to provide fairly accurate information about how their teens' difficulties impact their functioning. Since the focus on functioning aligns with the original intent of the questions, it is appropriate to use parent-proxies to assess teen difficulties.

## IV. Question-by-Question Review

This section provides in-depth analysis of the performance of each question including respondents' patterns of interpretation, response difficulties or points of confusion. The section is organized by question domain. Within each domain-section, the parent question is treated first, followed by the teen question and finally a section addressing the interpretations within the parent-teen dyads for each question. Figures accompany the narrative analysis when needed for clarity. Within figures, patterns of interpretation present for one set of respondents are seen in color while patterns only present for the other set of respondents are seen in gray. In each dyad analysis section, a table is included showing dyad agreement. The totals in these agreement tables differ slightly from the overall totals because they only include dyads that have data for both the parent and the teen. Therefore, because there was some missing data due to skip patterns or missed questions, some dyads were excluded from these tables.

## Seeing

CFD1. DOES (NAME) WEAR GLASSES?

Yes	20
No	20

This initial vision question was asked of all parent respondents.

**Interpretation:** Parent respondents interpreted the question in two ways.

Wearing corrective lenses: Almost all respondents answered based on whether their teen wears corrective lenses (glasses or contacts). Respondents who answered "yes" have teens who wear glasses or contacts all the time or for specific activities such as reading.

*Prescription for corrective lenses:* While several respondents reported that their teens have been prescribed corrective lenses which they do not wear, only one respondent answered based on the prescription only. This respondent described how her teen had lost several different pairs of glasses. The respondent answered "yes" based on the prescription even though teen's last pair of lost glasses had not been replaced.

#### T1. DO YOU WEAR GLASSES?

Yes	19
No	21

This initial vision question was asked of all teen respondents.

**Interpretation:** Teens interpreted the question in three ways.

Wearing corrective lenses: Almost all respondents answered based on whether they wear corrective lenses (glasses or contacts). Respondents who answered "yes" wear glasses or contacts all the time or for specific activities such as reading.

*Glasses only:* A single respondent answered based on the fact that she does not wear glasses. She wears contact lenses but answered "no" because she does not wear glasses.

*Prescription for corrective lenses:* While several teens reported that they have been prescribed corrective lenses which they do not wear, only one respondent answered based on the prescription only. This teen has had multiple, ongoing vision issues. At the time of the interview, she had recently received a prescription but had not gotten the glasses yet. She answered "yes" based on having the prescription.

### Dyad Analysis for CFD1 and T1

Table 3. Agreement between parents and teens on wearing glasses (CFD1 and T1)

		Parents		
		No	Yes	Total
Teens	No	18	3	21
	Yes	2	17	19
	Total	20	20	40

As seen in Table 3, this question performed similarly for parents and teens. Except for the single teen respondent who answered "no" based on wearing contact lenses (and not glasses), parents and teens interpreted the question similarly. Other cases of discordance resulted when one person in the dyad answered based on the teen's having a prescription while the other answered based on the teen's actually wearing glasses.

The intention of this question was to identify teens who use corrective lenses for vision difficulties. Therefore, interpretations that omit contact lenses or that are based on having a prescription but not wearing glasses are out of the intended scope. Though there were relatively few out of scope responses, these were seen in both parents and teens. Therefore, there is no clear benefit to asking this question to either teens or parents.

CFD2: [WHEN WEARING GLASSES] DOES (NAME) HAVE DIFFICULTY SEEING?

No difficulty	32
Some difficulty	5
A lot of difficulty	2
Cannot do at all	1

Parent respondents who answered "yes" to the question on glasses (CFD1) were asked this follow-up question with the introductory phrase ("When wearing glasses...") and those who answered "no" were asked only the stem.

**Interpretation:** All respondents understood this as a question about how well their teens see. Most respondents who answered "no difficulty" noted that their teens exhibited no symptoms of vision trouble (squinting, bumping into things) and that the teens could do things that require vision (reading, watching television, playing sports). A few respondents answered based on the fact that their teens had not complained of vision difficulties. Still other respondents cited eye doctor's reports and eye exams as evidence that their teens have no difficulty seeing. Some respondents made a distinction between vision and other difficulties such as color blindness and attentional issues, but all answered based on vision.

Respondents who answered that their teens have some level of difficulty thought about the prescriptions their children have. Two respondents who answered "some difficulty" chose this answer because their teens may have difficulty seeing when their prescriptions are outdated. Another respondent's teen doesn't wear his glasses, which led the respondent to assume he must have "some difficulty" seeing. This respondent had answered "no" to the question on glasses because his teen does not *wear* his glasses. Therefore, it is unclear how the respondent would have answered if the question had been asked with the introductory phrase, "When wearing his glasses..."

Uncertainty: It should be noted that several respondents readily provided an answer to this question but later in probing stated that they were uncertain. For example, one respondent who answered "no difficulty" said, "I think that's true. I'm not 100% sure." Another respondent answered "a lot of difficulty" due to her daughter's macular degeneration which causes dots of blindness at the center of her daughter's vision. This respondent said, "It's hard for me to tell, because I can't see though her eyes and she's a very quiet person, so she won't always say. Sometimes she'll just wait for an answer or try and figure it out instead of saying 'I can't see it.'"

**Response error:** Response error was seen in the respondent who answered "cannot do at all." This respondent described her son's difficulty seeing the ball when playing sports. However, it was clear from her description that her son could see well enough to function in most situations. Even on further probing, the respondent did not change her answer, but it was not clear why.

T2: [WHEN WEARING YOUR GLASSES] DO YOU HAVE DIFFICULTY SEEING?

No difficulty	27
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Some difficulty	10
A lot of difficulty	2
Cannot do at all	1

Teen respondents who answered "yes" to the question on glasses (T1) were asked this follow-up question with the introductory phrase ("When wearing your glasses...") and those who answered "no" were asked only the stem.

**Interpretation:** All respondents understood this as a question about how well they see. Most respondents who answered "no difficulty" described their ability to do things that require vision such as reading and playing video games. Many of the teens provided this answer based on a comparison to how they well they see without glasses or how they used to see with an old prescription. Several respondents answered "no difficulty" even though they experience fatigue or headaches from reading because despite these symptoms, they can still see.

However, headaches and fatigue were also cited by several respondents who answered "some difficulty." Other respondents who answered "some difficulty" described vision difficulties such as blurriness and squinting. Several respondents answered "some difficulty" because they can see well up close but have difficulty seeing clearly when things are far away. Thus, these respondents chose this response as an average of their ability to see across distances. Two respondents provided this response because "sometimes" they have difficulty seeing- in particular when their eyeglass prescriptions are out of date.

**Response error:** Response error was seen in one respondent with high functioning Down syndrome. This respondent, who could clearly see quite well, answered "cannot do at all," but it is likely that she did not understand the response categories or that she thought this category indicated that she had "no difficulty at all."

Dyad Analysis for CFD2 and T2

Table 4. Agreement between parents and teens on seeing (CFD2 and T2)

		Parents	Parents				
		No			Cannot Do at		
		difficulty	Some Difficulty	A lot of Difficulty	All	Total	
Teens	No Difficulty	26	0	0	1	27	
	Some Difficulty	4	5	1	0	10	
	A lot of Difficulty	1	0	1	0	2	
	Cannot Do at All	1	0	0	0	1	
	Total	32	5	2	1	40	

As seen in Table 4, there was some discordance in parents' and teens' answers to the question on teens' ability to see. As described above, this discordance was almost always a result of the differences in the ways parents and teens are able to observe teens' difficulty seeing rather than on differing interpretations of the question. Some parent respondents noted this difference in their expressions of uncertainty (see above). This pattern was exemplified by a respondent who answered "no difficulty" and then was asked, "How do you know she can see clearly?"

She responded, "I don't know. She [the teen] doesn't complain about it... It seems like she can see."

Thus, having access to more detail about their experience of seeing, teens were able to provide more specific information about their ability to see well in a variety of situations. Parents, relying on overtly observable phenomena, provided responses that addressed their teens' general ability to see and function.

Asking this question to parents identified cases of teens with observable difficulties functioning due to vision impairment but did not miss any severe cases. Similarly, asking this question of teens identified cases of significant impairment to functioning in addition to minor difficulties seeing in specific situations.

## **Hearing**

CFD3: DOES (NAME) WEAR A HEARING AID?

Yes	0
No	40

All parent respondents were asked this initial question on hearing aids.

**Interpretation:** Most respondents understood this as a question about their teens' use of hearing aids. Respondents demonstrated their understanding of the question by explaining what hearing aids are. For example, one respondent defined a hearing aid as, "...some kind of device to put in the ear to enhance hearing...for someone whose hearing is below normal; it would make them hear better."

T3: DO YOU WEAR A HEARING AID?

Yes	0
No	40

All teen respondents were asked this initial question on hearing aids.

**Interpretation:** Most respondents understood this as a question about hearing aids. However, a few respondents stated that they were thinking of their ability to hear when answering the question. For example, one respondent said that when she heard the question it made her think, "Am I able to hear?" However, she answered "no" because she does not wear a hearing aid. Another respondent said he answered "no" because he doesn't "have any hearing trouble." Thus, essentially, these respondents jumped ahead to the next question, but this did not appear to lead to any response error.

### Dyad Analysis for CFD3 and T3

Teens and parents were similar in their approaches to this question. However, teens were more likely to jump ahead, answering based on their hearing ability (although this did not lead to any response error).

**CFD4:** [When using his/her hearing aid(s),] does (*NAME*) have difficulty hearing sounds like peoples' voices or music?

Since all parent respondents answered "no" to the question on hearing aids (CFD3) they were all asked this follow-up question without the introductory phrase. There is missing data on two respondents.

No difficulty	36
Some difficulty	2
A lot of difficulty	-
Cannot do at all	-

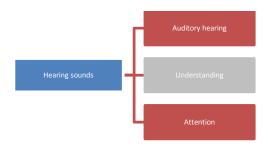


Figure 7. Schema of Parent Responses to the Question on Teens' Ability to Hear Sounds (CFD4)\*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** As depicted in the red boxes in Figure 7, parent respondents answered based on auditory hearing and attention.

Auditory hearing: Almost all parent respondents understood this as a question about auditory hearing and processing of sound. While nearly all parent respondents were thinking about their teens' auditory hearing, they considered various sources of evidence. Some respondents relied on observation. For example, one respondent, who answered "no difficulty," noted "She knows the lyrics to all the songs and she never says, 'huh?' when I talk to her." In contrast, a respondent who answered "some difficulty" described how she has to repeat things several times even when her daughter is looking at her and trying to understand what she's saying. Several respondents cited recent hearing tests as evidence that their teens had "no difficulty" with auditory hearing. Finally, several respondents said that their teens have never complained of hearing trouble. Therefore, these respondents answered "no difficulty."

While many parent respondents made a distinction between auditory hearing and listening skills, only one (described below) answered based on her teen's ability to listen. For example, one respondent, who answered "no difficulty," said that her teen "hears fine unless he doesn't want to hear what I have to say." This demonstrates what many of these respondents call "selective hearing" where the teen ignores or does not pay attention to sounds- usually commands or inquiries from their parents. This was considered by most parent respondents to be "normal teen behavior" and not indicative of a hearing difficulty. Therefore, even respondents who noted that their teens did not "listen" answered "no difficulty" to the hearing question.

Attention: In contrast to the respondents described above, a single respondent answered on the basis of her teen's ability to listen and pay attention. She said, "It's not like he's deaf or anything. [Child's Name] is wrapped up in his own little world and isn't listening." Because her son is often "spacey" at home and at school, this respondent answered "some difficulty."

**T4:** [WHEN USING YOUR HEARING AID(S),] DO YOU HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC?

Since all teen respondents answered "no" to the question on hearing aids (CFD3) they were all asked this follow-up question without the introductory phrase.

No difficulty	35
Some difficulty	5
A lot of difficulty	-
Cannot do at all	-

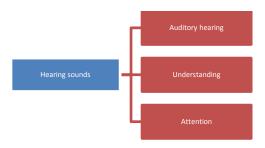


Figure 8. Schema of Teen Responses to the Question on Their Ability to Hear Sounds (T4)

**Interpretation:** As depicted in Figure 8, teens understood this question in three different ways.

Auditory hearing: Almost all teen respondents understood this as a question about auditory hearing. Narrative support from the teens included examples of things they can hear such as voices and music (which were the examples given in the question). Teens also described their ability to hear in different environments (loud or quiet) and their ability to hear at different distances (near and far). One respondent explained her answer of "no difficulty" saying, "I can hear what people are saying in the classroom no matter where I sit." Most teens felt that it was normal to have more difficulty hearing in loud environments or at far distances and answered "no difficulty" even as they described trouble hearing under these conditions. In contrast, another respondent answered "some difficulty" because she can hear just fine up close, but has trouble hearing people who are far away.

*Understanding:* Two teens interpreted the question to be about difficulties they have understanding people. One teen said, "I was thinking about whether I misunderstand—not whether I hear a sound or not—but whether I misunderstand something." This respondent answered "no difficulty" because he does not regularly have trouble understanding people. A different respondent answered "some difficulty" because she has trouble understanding the accents of the other students at her school.

Attention: Several teens distinguished between auditory hearing and attention, describing times that they "tune out" or stop paying attention to people who are talking. However, only one teen respondent based his answer on this interpretation. This respondent said that he can hear fine but described how sometimes he gets "tired or spaced out" and doesn't listen to people. Based on this interpretation, he answered "some difficulty."

### Dyad Analysis of CFD4 and T4

Table 5. Agreement between parents and teens on hearing (CFD4 and T4)

		Parents				
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	32	1	0	0	33
	Some Difficulty	4	1	0	0	5
	A lot of Difficulty	0	0	0	0	0
	Cannot Do at All	0	0	0	0	0
	Total	36	2	0	0	38

Table 5 demonstrates general agreement between parents and teens in their responses to questions on hearing. As seen by comparing Figures 7 and 8, there was slight variation in how teens and parents interpreted this question. Teens considered understanding in addition to auditory hearing and attention while parents only considered the latter two when answering this question.

In almost all cases of disagreement between parents and teens, both respondents in the dyad answered within scope, considering auditory hearing (rather than attention or understanding). In these cases, the member of the dyad who answered "some difficulty" (usually the teen) focused on a specific aspect of auditory hearing such as the ability to hear low voices or sounds that are both near and far while the member of the dyad who answered "no difficulty" answered based on a more general notion of auditory hearing. In a single case of disagreement, the teen the teen's response was out of scope, focused on her ability to understand, while the parent's response was in scope, focused on auditory hearing.

Therefore, asking parents this question identified all significant cases of teens' difficulty hearing. Asking teens this question identified all cases of general difficulty hearing as well as some minor instances where the teens had difficulty hearing in very particular circumstances.

## Walking

CFD5: DOES (NAME) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?

This question was asked of all 40 parent respondents.

Yes	1	
No	39	

**Interpretation:** All parent respondents understood this question as asking about things like wheelchairs, canes, crutches, braces, walkers, and people to assist with their teens' walking. Respondents noted that they primarily thought about equipment that would be used for a permanent condition. Along this interpretation, only one parent said "yes" referring to a wheelchair that her son uses for mobility.

Another parent mentioned she purchased special sandals that have arch supports to help her teen walk because she had flat arches. This respondent answered "no" because she did not consider the arch supports to be special equipment. She explained "They serve her walking" but she did not consider this to be at the "level of special equipment."

T5: DO YOU USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?

This question was asked of all 40 teen respondents.

Yes	2
No	38

**Interpretation:** Almost all respondents understood this as a question about whether they use equipment to move around.

Most respondents thought of tools such as crutches and wheelchairs, but one respondent also included physical therapy. This respondent initially answered "no" but then changed her answer to "yes." At first, she was thinking about physical equipment, "like crutches and leg braces." She then decided that the physical therapy she receives for a recent leg injury is a form of assistance, saying, "I guess physical therapy is assistance."

One respondent, who answered "yes" based on his use of a wheelchair, interpreted this as a question about mobility in general. He explained that in this question he considered a wheelchair to be "assistance for walking." However, even with a wheelchair, he said he could not walk at all. He explained "I wasn't sure if I should include the fact that I can't walk at all...I did say "yes" because I do use the wheelchair to help me move in general."

## Dyad Analysis of CFD5 and T5

This question performed similarly for parents and teens

**CFD6:** WITHOUT USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (NAME) HAVE DIFFICULTY WALKING 100 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF ONE FOOTBALL FIELD.

Respondents who said that their children did not use special equipment were not asked this question (CFD5), so it was only asked to one parent respondent.

No difficulty	ı
Some difficulty	-
A lot of difficulty	-
Cannot do at all	1

**Interpretation:** The single respondent explained that walking without equipment was something her son "cannot do at all." She explained that while her son could move from place to place without a wheelchair she did not consider this to be walking. "He can get down from his chair and he can scoot along the floor, he can go up and down the stairs, on his butt, so when you say "walking" he does not walk, but he can move."

**T6:** WITHOUT USING YOUR EQUIPMENT OR ASSISTANCE, DO YOU HAVE DIFFICULTY WALKING 100 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF ONE FOOTBALL FIELD.

This question was only asked of one respondent who said he needed equipment or assistance to walk (T5). The second respondent who answered "yes" to this question initially answered "no" and was asked the follow-up questions that followed.

No difficulty	ı
Some difficulty	-
A lot of difficulty	-
Cannot do at all	1

**Interpretation:** This respondent answered "yes" to the question on assistance for walking based on his use of a wheelchair for mobility. However, he answered this question based on his ability to walk.

**CFD7:** WITHOUT USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (NAME) HAVE DIFFICULTY WALKING 500 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF FIVE FOOTBALL FIELDS.

All respondents skipped out of this question

T7: WITHOUT USING YOUR EQUIPMENT OR ASSISTANCE, DO YOU HAVE DIFFICULTY WALKING 500 YARDS ON LEVEL

All respondents skipped out of this question.

**CFD8:** WHEN USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (NAME) HAVE DIFFICULTY WALKING 100 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF ONE FOOTBALL FIELD.

This question was asked to the respondent who answered "yes" to the question on equipment (CFD5).

No difficulty	ı
Some difficulty	-
A lot of difficulty	ı
Cannot do at all	1

**Interpretation:** This respondent explained her answer of "cannot do at all" by saying, "He cannot walk, at all, even with braces." Therefore, while she answered "yes" to the equipment question based on her son's use of the wheelchair for mobility, she answered this question based on his ability to walk.

**T8:** When using your equipment or assistance, do you have difficulty walking 100 yards on level ground? That would be about the length of one football field.

This question was only asked of the one respondent who selected said "yes" to the question on equipment or assistance (T5).

No difficulty	ı
Some difficulty	-
A lot of difficulty	-
Cannot do at all	1

**Interpretation:** The respondent answered "cannot do at all" because he can't walk. He answered "yes" to the previous question based on using the wheelchair for mobility and "cannot do at all" to this question based on his ability to actually walk.

**CFD9:** When using his/her equipment or assistance, does (name) have difficulty walking 500 yards on level ground? That would be about the length of five football fields.

All respondents skipped out of this question.

**T9:** When using your equipment or assistance, do you have difficulty walking 500 yards on level ground? That would be about the length of five football fields.

All respondents skipped out of this question

**CFD10:** COMPARED TO CHILDREN OF THE SAME AGE, DOES (NAME) HAVE DIFFICULTY WALKING 100 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF ONE FOOTBALL FIELD.

The thirty-nine parent respondents who answered "no" to the question on equipment or assistance (CFD5) were asked this question.

No difficulty	38
Some difficulty	1
A lot of difficulty	-
Cannot do at all	-

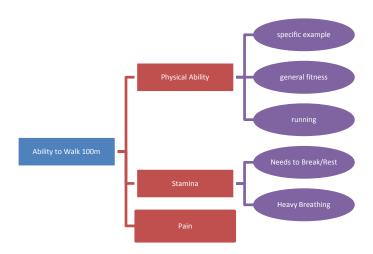


Figure 9. Schema of Both Parent and Teen Responses to Question on Walking 100 yards (CFD10 and T10).

**Interpretation:** As depicted in Figure 9, respondents considered their teens' physical abilities, stamina or pain when walking.

Physical abilities: Most respondents answered based on their teen's physical ability to walk or run. One respondent (who answered "no difficulty") said, "I assumed you meant physically capable of walking." while another answered "no difficulty" because her teen "does not have physical problems to prevent her from walking." Some respondents offered specific examples of their teen walking or running 100 yards (or more). For example, one respondent who answered "no difficulty" said of his teen, "He's a boy

scout, so he hike...5-6 miles." Other respondents noted their teens' general fitness. For example, one respondents said, "She's very strong." Yet another respondent described her teen saying, "She's quite an active child." Both of these respondents said their teens had "no difficulty" walking 100 yards.

*Stamina*: Several respondents thought about their teen's stamina. For example, one respondent who answered "no difficulty" noted that his daughter would not be out of breath if she walked 100 yards. Another respondent compared his teen to her brother who "gets wobbly, tired and takes a lot of breaks."

*Pain*: A few respondents thought of pain their teens might experience when walking. One respondent indicated that her teen has "some difficulty" walking because her daughter has flat arches which causes painful blisters on her feet. Another respondent answered "no difficulty" saying of his daughter, "She and her friends walk a whole lot... she's never complained of her legs hurting."

100 yards: When asked how they visualized the distance in this question, about half of respondents stated they explicitly thought of a football field. Others thought of something else that was at least 100 yards that their child had walked, for example a mall or the distance to school or someone's house. A few gave estimates of distances that were much longer than 100 yards. For example, one respondent said it was about one and a half miles. Several respondents said they did not explicitly consider the distance, rather they took the question to mean, "How much difficulty does your child have walking?" and answered based on that. For example one respondent said "no difficulty" and explained "I guess, I didn't even measure the distance in my mind, because I was already assuming, he's not in the category of someone who would need a walker."

**Compared with children of the same age:** Most parents did not appear to take note of the preface to this question ("Compared with children of the same age...") rather they answered based on their child ability to walk. This is indicated in that even parents who noted that their children were less fit than other children, answered that they have "no difficulty" walking.

**T10:** DO YOU HAVE DIFFICULTY WALKING 100 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF ONE FOOTBALL FIELD.

No difficulty	35
Some difficulty	3
A lot of difficulty	-
Cannot do at all	1

The thirty-nine parent respondents who answered "no" to the question on equipment or assistance (T5) were asked this question.

**Interpretation:** As depicted in Figure 9, respondents considered their own physical abilities, stamina or pain when walking.

*Physical abilities:* Most respondents thought of their physical ability to walk/run or their general fitness. Many described playing a sport or engaging in some other structured physical activity like dance or marching band. Some provided specific examples of walking 100 yards or more, while others simply described themselves as "in shape." Quite a few respondents thought about their ability to run rather

than their ability to walk. For example one respondent said "no difficulty" explaining "I know that I can run a football field, so I know I can walk it with ease."

Stamina: Several respondents considered their stamina when walking 100 yards. For example, one respondent said she could walk 100 yards, "...without breathing heavily...I could do it again and again." Another respondent said she could "walk around a football field more than once without getting tired or needing a break." Both of these respondents answered "no difficulty."

*Pain*: Three respondents thought about pain from walking 100 yards. One teen said, "I never feel pain when I walk." This respondent answered "no difficulty." Another teen said she feels pain in her knee when she walks, so she answered "some difficulty." A third respondent also answered "some difficulty" saying, "If I walk for a long time, it hurts."

**Response error:** A single respondent answered "cannot do at all" This respondent, who has Down Syndrome, seemed not to understand the question or answer categories, as she later described how she took walks with her mom and her dog.

100 yards: Most respondents answered based on walking the length of a football field, which was the example given in the question. The respondents who pictured a specific field seemed to have an accurate gauge of the distance, for example, one girl knew she had "no difficulty" because "at my old school, last year, we used to have a football field, and I used to walk back and forth all the time." Other respondents thought of a generic or NFL football field and appeared to have a less accurate sense. This is illustrated by a teenage who said "when you said a football field, I pictured the stadium and then thought just of the field itself." However, when she was asked how long this was she greatly overestimated it, guessing it was about "the distance from here to the metro station"—a distance of about 900 yards.

Other respondents did not think about distance in terms of a football field but conceived of 100 yards as a "moderate" distance. For example, one respondent pictured walking to a friend's house or going up a hill. Others knew they could walk or run miles, and therefore were confident they could walk a shorter distance without directly considering the length of this shorter distance. One boy said "no difficulty" and noted he walks a mile to and from school every day and knows a mile is more than a football field.

### Dyad Analysis for CFD10 and T10:

Table 6. Agreement between parents and teens on walking 100 yards (CFD10 and T10)

		Parents				
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	35	0	0	0	35
	Some Difficulty	3	0	0	0	3
	A lot of Difficulty	0	0	0	0	0
	Cannot Do at All	0	1	0	0	1
	Total	38	1	0	0	39

As seen in Table 6, there was a high level of agreement between teens and parents on the question on walking 100 yards. Additionally, there was little variation in how parents and teens interpreted this question. In the three cases of disagreement (discounting the single case of response error), the parents

responded "no difficulty" based on their teens' general physical ability to walk while the teens answered "some difficulty" based on their level of stamina or the presence of pain when walking.

There was no clear advantage to asking either the parents or the teens about teens' difficulty walking 100 yards.

**CFD11:** COMPARED TO CHILDREN OF THE SAME AGE, DOES (NAME) HAVE DIFFICULTY WALKING 500 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF FIVE FOOTBALL FIELD.

No difficulty	34
Some difficulty	4
A lot of difficulty	-
Cannot do at all	1

This question was asked of 39 parent respondents.

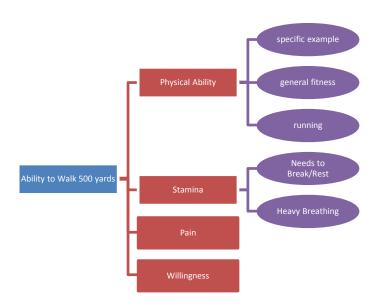


Figure 10. Schema of Both Parent and Teen Responses to Question on Walking 500 yards (CFD11 and T11).

**Interpretation:** The interpretive schema for this question is presented in Figure 10. While most parent respondents reported thinking of a physical ability to walk, some parents mentioned thinking about their children's stamina, pain or their willingness to walk 500 yards.

Physical ability: The majority of parent respondents primarily considered their teens' physical ability to walk. A large set of this group said "no difficulty" because their children were active and enjoyed walking, running or playing sports. For example, one respondent said her daughter "likes to walk; she's very active." Another respondent thought about his daughter going on hikes while they were on vacation. He answered "no difficulty" because "She has no physical difficulty doing it even though she doesn't want to do it." Finally a different respondent, also thinking about physical ability, said "cannot do at all" because her son had a recent knee injury and "At this time, it would be a bit too much on his knee."

*Stamina:* Some respondents thought about their teens' stamina when answering this question. For example, one respondent answered "some difficulty" saying, "She's out of shape. I think she could make it... but she'd be panting." Another respondent answered "no difficulty" because his son does not have to stop and take breaks when walking.

*Pain:* Several respondents thought about pain their teen might have when walking 500 yards. One respondent answered "some difficulty" because her daughter gets painful blisters when she walks. Another respondent answered "no difficulty" because his daughter can walk "long distance" and "her legs don't hurt."

Willingness: A few respondents considered their teens' willingness to walk. For example one father who said his daughter would have "some difficulty" explained, "I walked ... roughly four miles, and I took her with me, and we had to take a few breaks...She just didn't want to do it." In contrast, several respondents noted that their children would not want to walk that distance just to walk, but would have no difficulty walking a similar distance to get to a place they wished to go. One woman said "no difficulty" noting "it depends, if it's a concert she wants to go to, then no difficulty."

**500** yards: Most respondents understood this distance in terms of football fields, picturing either five fields in a row or their child walking or running back and forth over a single football field multiple times. However, many respondents thought of distances that were much longer than five football fields. One respondent estimated it was about a mile and a half saying she though it was: "from here [one local town] to [another local town]: 500 seem like a lot of walking." Additionally, one respondent considered the distance around a football rather than the length field, saying "five times around a football, is about a mile" making the distance in her mind larger than 500 yards.

As with the question on walking 100 yards, many respondents did not explicitly consider the distance, but just knew their child could walk "long distances."

Compared with children the same age: Most parents did not explicitly compare their teens to others of the same age. For example, one of the parents who said his daughter would have "some difficulty" walking 500 yards noted that he was not initially comparing her to other children and that this level of difficulty is normal for children her age; he added that if he were to compare her with other children her age, he would say "no difficulty." Conversely, another parent who answered "some difficulty" did make the comparison, saying that her child had recently gone on a hike with other students and had more difficulty and walked slower than other children.

**Table 3.** Walking 100 yards versus walking 500 yards (parents)

	500 yards							
		No difficulty	Some	A lot of	Cannot do	Total		
S			difficulty	difficulty	at all			
ırd	No difficulty	34	3	-	1	38		
100 yards	Some difficulty		1	-	-	1		
	A lot of	-	-	-	-	-		
	difficulty							
	Cannot do at all	-	-	-	-	-		
	Total	34	4	-	1	39		

As seen in Table 3, responses to the question about walking 100 yards were almost always concordant with responses to walking 500 yards. Of the 39 parents asked this question, 35 reported their child had the same level of difficulty walking 100 yards as 500 yards; 34 reported their child had no difficulty walking either 100 yards or 500 yards and one parents said "some difficulty" for both 100 yards and 500 yards. Three parents said their child had "no difficulty" walking 100 yards but "some difficulty" walking 500 and one parent said their child had "no difficulty" walking 100 yard but walking 500 yards was something their child "could not do at all."

Same level of difficulty walking 100 and 500 yards: Respondents who said their children have the same level of difficulty walking 100 yards as 500 yards gave similar reasons for both answers. For example, all respondents who said that their teen played sports or other structured physical activities said their teen would not have difficulty walking either 100 or 500 yards. Several parents noted that for their teen, there was no meaningful difference in the ability to walk 100 or 500 yards such as a mother who said "...for a growing, healthy, teenage, 15 year old boy, it's the same."

More difficulty walking 500 yards: Two of the three respondents who said that their child had "some difficulty" walking 500 yards but no difficulty walking 100 yards, gave examples of distances much longer than 500 yards. One respondent thought of a 4 mile walk he had taken with his daughter while another respondent said she thought it was "about a mile." Likewise, the respondent who said her son had "no difficulty" walking 100 yards but "cannot do at all" when asked about his difficulty walking 500 yards, said that her son regularly walked 30 minutes to school and that this distance was about 5 miles. It is not clear if these respondents would have answered differently if they had a more accurate idea of the distance of 500 yards.

**T11:** COMPARED TO CHILDREN OF THE SAME AGE, DO YOU HAVE DIFFICULTY WALKING 500 YARDS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF FIVE FOOTBALL FIELD.

Thirty-nine teens were asked this question.

No difficulty	26
Some difficulty	10
A lot of difficulty	3
Cannot do at all	1

**Interpretation:** As depicted in Figure 10, teen respondents answered this question based on the same set of interpretations as parent respondents.

Physical ability: Most respondents answered based on their ability to walk or in many cases run 500 yards. A few teens provided specific examples of walking that distance (or longer). For example, one teen said he had walked his uncle home the distance of 1 or 2 miles with "no difficulty." Quite a few teens, like the one who answered "no difficulty" and said, "I'm a walker. I like long walks," thought about their ability to walk a long way in general. However, a lot of teens had experience running, rather than walking, longer distances and thought about this instead. Most of these teens drew on examples from their sporting activities such as soccer, track or football practice. One respondent who said "no difficulty" and explained "every time you said 'walking a football field,' I was thinking about running it." Another respondent said "I think about football fields and having to run the whole length of a football field five times in soccer practice." These teens answered on the basis of their experience running, assuming that if they could run it, they could also walk it with no difficulty.

Stamina: Some teens thought of their ability to walk this distance without becoming tired or out of breath. One respondent answered "no difficulty" saying, "I'm pretty athletic. I wouldn't get tired walking 5 football fields." A different respondent answered "some difficulty" because he would get tired and have to sit down while walking that distance. A third respondent answered "a lot of difficulty" saying, "That's more work! I could do it but I would be tired and panting."

*Pain:* A few teens answered based on pain caused by walking. One was thinking about knee pain. When he walks short distances, his knee cramps up, but with longer distances, the knee stretches out and does not hurt. This teen answered "no difficulty" because walking a long distance would not cause his knee to hurt. Another teens answered "some difficulty" because his "muscles would be sore" after walking this distance. Still another answered "a lot of difficulty" saying, "I was imagining how much pain I would be feeling in my legs."

Willingness: A few teens balked at the idea of walking 500 yards. One teen said, "That's crazy! Football fields are huge and then walking 5 of those!!! (Sighs). That's, no, I don't think I would even voluntarily do that." This teen answered "a lot of difficulty" to express her reluctance to walk that distance.

**500 yards:** Most teens reported thinking of the distance in terms of five football fields in a row. Others said they knew they had walked or run longer distances in the past and so were confident they could walk the shorter distance. One respondent, said he had run a half-marathon and hiked about 12 miles, while others talked of regularly practicing sports on large fields. Several, particularly those who thought they would have difficulty walking 500 yards, said they guessed it would be a distance much longer than 500 yards is in actuality. For example, one teen estimated it was about two miles, another thought that walking around the tidal basin, an actual distance of about two miles was only 300 yards, another teen thought it was three or four miles. While some teens conceived of a large difference between 100 and 500 yards, several teens did not see a meaningful distinction the distances. One teen said, "What's the difference? To me, that's both just walking."

**Table 4.** Walking 100 yards versus walking 500 yards (teens)

	500 yards							
		No difficulty	Some	A lot of	Cannot do	Total		
100 yards			difficulty	difficulty	at all			
	No difficulty	25	8	2	-	35		
	Some difficulty		2	1	-	3		
	A lot of	-	-	-	-	-		
	difficulty							
	Cannot do at all	1	-	-	-	1		
	Total	26	10	3	-	39		

Table 4 compares teens' responses to the two walking questions. The majority of respondents answered "no difficulty" walking either 100 yards or 500 yards; eight respondents said they would have "no difficulty walking 100 yards, but "some difficulty" walking 500 yard; and two said they had "no difficulty" walking 100 yards and "a lot of difficulty" walking 500 yards. Two of the three respondents who said they would have "some difficulty" walking 100 yards also thought they would have "some difficulty" walking 500 yards and one respondent thought he would have "a lot of difficulty" walking 500 yards.

**Response error:** Response error was seen with the respondent who said "cannot do at all." This respondent has Down syndrome and did not answer consistently within the response categories.

Same level of difficulty walking 100 and 500 yards: Most teens who thought they would have "no difficulty" walking either 100 or 500 yards said there was no meaningful difference between the distances for them as both would be very easy for them. This was particularly true for respondents who played sports and those who walked or ran regularly. The two respondents who said they would have "some difficulty" walking either 100 or 500 yards noted that they had some pain in walking. One had ACL surgery less than 1 year ago and felt pain when she walked. The other said her legs were not "in the best shape" and might get sore walking.

More difficulty walking 500 yards: The respondents who said they had more difficulty walking 500 yards than 100 yards tended to overestimate the length of 500 yards. These respondents considered it to be a very long walk and said that distance would tired them out. Likewise, the respondent who said she would have "a lot of difficulty" walking 500 yards but no difficulty walking 100 yard, seemed to overestimate the larger distance.

### Dyad Analysis for CFD11 and T11:

<b>Table 7.</b> Agreement between parents and teens on walking 5	)0 vards (CFD11 and T11)
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	- 0	Parents	0			
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	25	1	0	0	26
	Some Difficulty	8	2	0	0	10
	A lot of Difficulty	1	1	0	1	3
	Cannot Do at All	0	0	0	0	0
	Total	34	4	0	1	39

As seen in Table 7, there was some disagreement in teens' and parents' responses to the question on walking 500 yards. Almost all of this disagreement was due to teens overestimating the distance of 500 yards. Additionally, when parents answered based on their teens physical ability to walk 500 yards, but teens answered based on their willingness to walk 500 yards, the teens' answers indicated a greater level of difficulty.

Therefore, parents' responses to this question provided a more accurate (in scope) indicator of their teens' difficulty walking 500 yards.

#### Self-Care

CFD12: DOES (NAME) HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING HIM/HERSELF?

This question was asked of all parent respondents.

I	No difficulty	39
	Some difficulty	1

A lot of difficulty	-
Cannot do at all	-

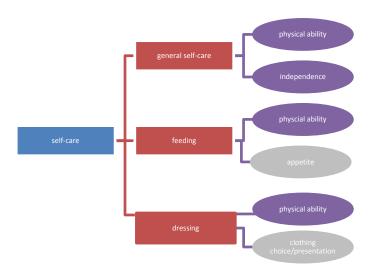


Figure 11. Schema of Parent Responses to Question on Teens' Self-care (CFD12).\*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** Almost all respondents answered "no difficulty" and described their children as physically and mentally able to perform self-care tasks. Several respondents also noted that the ability to do self-care activities can be impacted by access to self-care tools such as food, soap and water. While all respondents understood this as a question relating to self-care, respondents focused on different aspects of self-care when formulating their responses, as seen in Figure 11. Most respondents focused on a general notion of self-care or on feeding and/or dressing which were the examples given in the question.

General self-care: Many respondents answered based on a general concept of self-care that included hygiene and other aspects of self-care in addition to feeding and dressing. One respondent described her notion of self-care as "Brushing teeth, combing hair, getting dressed, showering, managing his clothes and attending to personal hygiene..." This respondent answered "no difficulty" because her son can do all of those things by himself.

In fact, many respondents described their children as "independent" and often based their responses on their teens' ability to perform self-care activities without help or reminders. For example, one respondent described her son's troubles getting ready in the morning due to motor-planning issues. She related that it is difficult and time-consuming for him to get dressed and do other self-care activities. However, she answered "no difficulty" because her son does not need her help. "It takes him a while to get dressed in the morning. He has a tougher time than the average kid, but he never needs me to help him so...no difficulty." Similarly, a different respondent answered "no difficulty" because her teen "does everything independent....This means that she never makes a mess, cooks food on her own, and dresses and bathes herself."

A few respondents thought soley of their teens' physical ability to perform general self-care activities. One such respondent said, "I thought about him physically feeding himself, but I also thought about him

preparing something and eating it and getting himself physically dressed." This respondent answered "no difficulty."

*Feeding:* A few parent respondents focused on feeding, describing their teens' physical ability to eat. One respondent who answered "no difficulty" described how her son eats too much due to Prater Wiley Syndrome which makes it impossible for him to stop eating on his own. Despite her teen's issues with appetite, this respondent was focused on the physical aspects of feeding, and therefore, answered "no difficulty."

*Dressing:* A few parents thought about dressing when answering the self-care question. One respondent whose son is in a wheelchair due to Spina Bifida said, "He gets dressed by himself. He sits on the edge of the bed and puts his clothes on." This respondent answered "no difficulty." Although several respondents mentioned that their children have difficulty choosing clean, stylish or matching clothing, all respondents based their responses on their teens' physical abilities. For example, one respondent said, "He don't have a problem putting on clothes and shoes and stuff like that. Only problem he may have is able to coordinate clothes." This respondent answered "no difficulty" despite her teens' difficulties coordinating clothes because he is physically able to get dressed.

T12: DO YOU HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING YOURSELF?

This question was asked of all teen respondents.

No difficulty	38
Some difficulty	1
A lot of difficulty	-
Cannot do at all	1

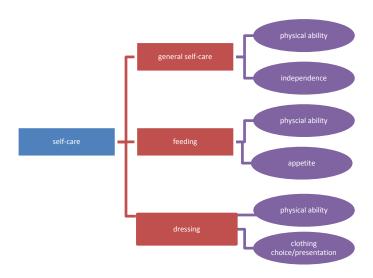


Figure 12. Schema of Teen Responses to Question on Self-care (T12).

**Interpretation:** Almost all respondents answered "no difficulty" and described themselves as physically and mentally able to perform self-care tasks. Several respondents also noted that the ability to do self-

care activities can be impacted by access to food and clothing. For example, one respondent said, that a person who "did not have any food in their house" would have "some difficulty" with feeding. Most respondents focused on a general notion of self-care as well as on feeding and/or dressing which were the examples given in the question. Overall patterns of interpretation for this question are presented in Figure 12.

General self-care: Most teen respondents answered based on a general concept of self-care that included hygiene and other aspects of self-care in addition to feeding and dressing. One respondent described her notion of self-care as "taking care of yourself, brushing your teeth, using the bathroom by yourself, putting on your clothes, being able to walk by yourself, being able to shower by yourself, being able to cook for yourself, being able to clean for yourself and talking to people." Based on this very broad definition of self-care, this respondent answered "no difficulty" because he can do all of those things independently.

Some respondents answered in terms of their physical ability to perform self-care tasks. For example, one respondent answered "no difficulty" based on her physical ability to perform self-care tasks. She said, "I can literally pick food up and put it in my mouth. I can literally take clothes off and on." Other respondents emphasized their self-concept as "independent" and "able to do things on my own."

*Feeding:* A few teen respondents focused on feeding, thinking about both physical ability to eat as well as appetite. One respondent answered "some difficulty" based on his lack of appetite. He said, "I was thinking about feeding. Sometimes my medication prevents me from having an appetite, and I forget to eat." Meanwhile, a different respondent answered "no difficulty" because he has a healthy appetite. He said, "For breakfast, lunch and dinner, I'm right on time!"

*Dressing:* Only two teen respondents thought exclusively about dressing when answering the self-care question. One considered the physical ability to dress while the other thought about the ability to select clothing. The latter said she was thinking about how "some people take how they look too seriously" and "get really frustrated and pull out all of their clothes trying to find something perfect to impress people at school. But they run out of time and end up coming to school all mismatched." This respondent answered "no difficulty" because she does not have this problem.

**Response error:** A response error was seen in a single respondent who answered "cannot do at all." This respondent Down syndrome, and though she is high functioning, she did not always understand the answer categories. It seems that she understood "cannot do at all" to mean "no difficulty at all" since she went on to describe how she is able to feed and dress herself every day without assistance.

### Dyad Analysis of CFD12 and T12

Table 8. Agreement between parents and teens on self-care (CFD12 and T12)

		Parents				
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	37	1	0	0	38
	Some Difficulty	1	0	0	0	1
	A lot of Difficulty	0	0	0	0	0
	Cannot Do at All	1	0	0	0	1

Total	39	1	0	0	40
IOtai	33		0	U	70

Table 8 shows that there was little disagreement between teens and parents in their responses to the question on self-care. As depicted in Figures 11 and 12, patterns of interpretation were also similar between teens and parents. Most respondents, both teens and parents, focused on general self-care skills or physical skills related to either feeding or dressing. Teens introduced new patterns of interpretation not seen in parent respondents that focused on their personal experience of feeding or dressing (appetite and choice of clothing).

In each of the two cases of discordance, one member of the dyad focused on physical ability to perform self-care activities while the other focused on the need to manage their own or their teen's self-care activities. For example, in one case, the parent answered "some difficulty" because her teen needs repeated reminders to get dressed and attend to hygiene while the teen answered "no difficulty" because he is physically able to get dressed and ready for the day.

In general, it seems that parents' interpretations may veer out of scope when they focus on the need to manage their teens' self-care activities (need for reminders) while teens' out of scope answers focused on less physical aspects of self-care activities. However, in this sample, none of these out of scope interpretations resulted in response error. Because of this and because there was a lot of overlap in parents' and teens' responses to this question regardless of differences in interpretation, it is difficult to determine whether there is an advantage to asking one group over the other.

### Communication

**CFD13:** WHEN (*name*) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF THIS HOUSEHOLD?

No difficulty	30
Some difficulty	10
A lot of difficulty	1
Cannot do at all	-

This question was asked of all parent respondents.

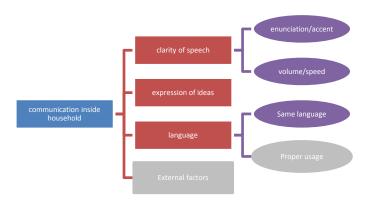


Figure 13. Schema of Parent Responses to Question on Communication inside Household (CFD13). \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** Respondents generally understood this as a question about communication. However, as shown in Figure 13, three separate patterns of interpretation were used by parent respondents to define what they meant by communication: clarity of speech, expression of ideas and language.

Clarity of speech. Some parent respondents answered based on their teens' ability to enunciate, or the physical ability to speak, form words, and pronounce words properly. One parent respondent answered "no difficulty" and described how her teen has "no speech impediment." Another parent respondent answered "no difficulty" and explained that she was able to "literally understand what he is saying: the speech, if it's clear." Volume was also a factor in clear speech. One parent respondent said that her teen speaks at "normal volume." This respondent answered "no difficulty." Similarly, another respondent who also answered "no difficulty" said, "We can hear her loud and clear!"

Expression of ideas. Some parent respondents interpreted "being understood" as getting one's point across. For example, one parent respondent said that her teen has no difficulty in her "ability to articulate...her thoughts. They're not cluttered, they're well thought-out expressions." This respondent answered "no difficulty." Another parent respondent answered "some difficulty" because her teen's father does not always understand the points that their teen tries to make since he does not keep up with teen culture.

*Language*. Two parent respondents interpreted "being understood" as the ability to speak the same language. One respondent mentioned that there is no language barrier to make it difficult to understand his teen. This respondent answered "no difficulty" because they speak the same language. Similarly, another parent respondent noted that everyone in the household speaks English.

**Response Error:** One instance of response error was seen when a respondent answered based on whether her teen understands people inside the household rather than on whether her teen is understood.

**Inside this household:** Respondents understood the phrase "inside this household" in two ways. Most parent respondents interpreted "people inside of this household" as the people who actually live in the house. Other parent respondents interpreted this phrase to refer to immediate family members but not always family members who actually live with the teen. For example, one parent respondent mentioned that her parents, brother, and son's father do not live in the same house as she and the teen, but they are around a lot. Similarly, another parent respondent included family members who visit the home as people inside of this household while another parent respondent included extended family members as well.

T13: WHEN YOU SPEAK, DO YOU HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF THIS HOUSEHOLD?

No difficulty	28
Some difficulty	11
A lot of difficulty	1
Cannot do at all	-

This question was asked of all teen respondents.

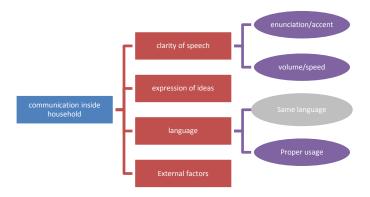


Figure 14. Schema of Teen Responses to Question on Communication inside of Household (T13). \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** Four patterns of interpretation emerged for this question: clarity of speech, expression of ideas, proper usage and external factors. These patterns are shown in Figure 14.

Clarity of speech. Several teens interpreted "being understood" as the ability to enunciate, or the ability to speak clearly and pronounce phonemes correctly (without mumbling, slurring, or stuttering). For example, one teen answered "some difficulty" due to his accent. He explained that not everyone in his family can understand his New York accent, so he has to speak slower so that they can understand him. Other teens also considered the speed of their speech. One teen respondent explained: "Nine out of ten times they understand, but sometimes I talk too fast, or too slow." This teen answered "no difficulty" since she is usually understood. Other teen respondents also explained that even if they talk fast, their parents are used to it and can understand them. A few other teens thought about volume mentioning that people can hear them just fine because, as one teen respondent explained, "Most of the time I talk loud enough."

Expression of ideas. Some teen respondents interpreted "being understood" as the ability to make a point or express oneself according to their life experiences or knowledge-base that is understood by both the teen and parent. These teen respondents meant that making a point involves the cooperation of both the teen and their parent to understand something. One teen respondent explained that communication is more than understanding the words, it also about understanding each other. Another teen respondent mentioned that it is about "having your message heard," while another teen respondent felt that she is understood when she can compromise with her parents, or come to a mutual agreement about something.

*Proper usage*. Some teen respondents interpreted "being understood" as the ability to use words and language correctly. For example, one teen respondent talked about his ability to use appropriate vocabulary when talking, while another teen respondent explained that most of the time his grammar is fine. These teens both answered "no difficulty."

External Factors. A few teen respondents noted that external factors such as noise or distractions can influence others' ability to understand them. One teen respondent mentioned that sometimes it is loud in the house because of the TV or music being on, so it is hard for his mom to understand him when he speaks. This teen answered "some difficulty." In other cases, parents may be distracted. One teen respondent explained that when his mom is on a conference call for work, it is hard for her to understand him because she is not giving him full attention. He also answered "some difficulty."

**Inside of this Household:** The majority of teen respondents interpreted "people inside this household" as the actual house they live in with people. However, a few teen respondents interpreted "people inside of this household" as their peers, specifically when they are at their house. For example, one teen respondent was thinking about when his friend comes over to the house as a guest, while another teen respondent included his neighbors as people inside of this household. Interestingly, one teen respondent explained that besides his family, he was including his friends with whom he talks (over the internet) while playing on his PlayStation, even though they are not physically in the household.

### Dyad Analysis for CFD13 and T13:

**Table 9.** Agreement between parents and teens on communication in the household (CFD13 and T13)

		Parents				
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	21	7	0	0	28
	Some Difficulty	7	4	0	0	11
	A lot of Difficulty	1	0	0	0	0
	Cannot Do at All	0	0	0	0	0
	Total	29	11	0	0	40

As depicted in Figures 13 and 14, teens and parents were similar overall in their patterns of interpretation for this question. Most respondents, both teens and parents, focused on clarity of speech or expression of ideas. However, as seen in Table 9, parents and teens did not always arrive at the same response. There were several reasons for this discordance:

- 1) Sometimes parents and teens had similar interpretations of the question (focusing on either clarity of speech or expression of meaning) but disagreed on their response. For example, either the parent or the teen might feel that the teen mumbles or speaks too fast while the other disagreed with that assessment. This occurred in several cases where the parent noted that the teen had gone to speech therapy (and therefore had some difficulty with speech) but the teen felt that his/her speech was clear.
- 2) At other times, the teens and parents interpreted the question in different ways. In these cases, parents generally focused on expression of ideas while their teens focused on clarity of speech. For example, one teen who answered "a lot of difficulty" described his severe stutter that required speech therapy while is mother answered "no difficulty" because his stutter does not interfere with her understanding of what he's trying to say. In another instance, a father answered "some difficulty" because his teen is often sarcastic and doesn't say what she means while the teen answered "no difficulty" because she speaks clearly.
- 3) Finally, there were instances where the teen answered based on external factors such as noise level or their parents' attention. In these cases, the teens answered "some difficulty" while the parents answered "no difficulty" based on their teens' clear speech.

Asking teens this question missed some cases where the teen required or had required speech therapy. Asking teens also resulted in some "false positives" based on external factors. Asking this question to parents missed some cases when parents answered based on expression of meaning rather than clarity of speech. However, the advantage of asking parents is that cases that required speech services were identified while minimizing false positives.

**CFD14:** WHEN (name) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE OUTSIDE OF THIS HOUSEHOLD?

No difficulty	30
Some difficulty	9
A lot of difficulty	-
Cannot do at all	-

The question was asked of all parent respondents. One parent respondent did not provide an answer simply responding, "Don't know."

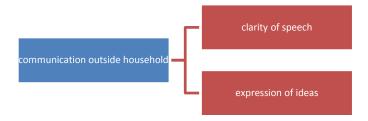


Figure 15. Schema of Parent and Teen Responses to Question on Communication Outside of Household (CFD14).

**Interpretation:** In comparison to the previous question about communication inside the household, the schema that the parent respondents applied to this question is much more limited, with only two interpretation patterns: Clarity of speech and expression of ideas.

Clarity of speech. Some parent respondents interpreted "being understood" as the ability to enunciate, or the physical ability to speak, form words, and pronounce words properly. For example, one parent respondent, who answered "no difficulty," said that his teen does not slur words. Another parent respondent was thinking about a time when she went to a restaurant and her teen had to repeat herself when ordering because she was not speaking clearly. Since this was an unusual situation, the respondent answered "no difficulty." Another answered "no difficulty" and spoke about how her son used to have speech problems, that is, difficulty pronouncing words, but no longer has a speech problems.

Expression of ideas. A couple of parent respondents interpreted "being understood" as getting one's point across, or the ability to express oneself and have other's relate to what is expressed. One parent respondent explained how it is specifically easier for her teen to get her point across to her friends because they have similar interests. However, another parent respondent mentioned that while his daughter can speak clearly, has no issues with volume of speech, and can articulate, she sometimes has a problem getting her point across to people. He said: "Yes, people can understand her, but she could also be misunderstood. She is an interesting child; her thought process is interesting." Therefore, the respondent answered "some difficulty" because people understand the teen's words but not her ideas.

**Outside of this household:** Most parent respondents interpreted "people outside of this household" as any people that they don't live with. For example, one parent respondent stated: "Anyone who doesn't live in the household." Another parent respondent said, "People who don't live with us." Examples included friends, acquaintances, people at schools, such as teachers, community and neighborhood members, church members, doctors, and parents' coworkers. However, some parent respondents also thought of strangers, such as people the teen encounters at stores, restaurants, or on the street.

**Certainty:** In addition to the respondent who answered simply, "Don't know" several parent respondents expressed uncertainly about their knowledge of this question. Some assumed that there was no problem because they have "never heard anyone say anything about that." Several parent respondents felt that if people outside the household did have difficulty, then these people would either tell them or their teen. For example, one parent respondent explained that if her teen's teacher had a problem understanding her, then the teacher would let the parent know. Another parent respondent stated, "Somebody would tell me if there was a problem."

T14: WHEN YOU SPEAK, DO YOU HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE OUTSIDE OF THIS HOUSEHOLD?

No difficulty	30
Some difficulty	10
A lot of difficulty	-
Cannot do at all	-

The question was asked of all teen respondents.

**Interpretation:** As seen in parent respondents, teen respondents understood this as a question about communication, but there were two distinct patterns of interpretation (Figure 15).

Clarity of speech. Similar to their responses to the previous question, most teens interpreted "being understood" as the physical ability to speak clearly. Several teens mentioned that they can pronounce words and do not stutter or mumble. One teen respondent, who answered "some difficulty," said that sometimes during class presentations, the teacher will ask her to repeat herself because she of the fact that she mumbles. Some teen respondents talked about physical problems of speaking that they had when they were young—such as mumbling or stuttering—but no longer have. For example, one teen respondent talked about how she used to have a lisp when she was young due to losing her teeth. She no longer has this speaking issue, and therefore answered "no difficulty." For a few teens, volume was also a factor. These teens answered "some difficulty" because their teachers sometimes ask them to speak louder.

Expression of ideas. Some teen respondents interpreted "being understood" as the ability to get their point across or express themselves. One teen mentioned that it is easier to express meaning among peers at school since they are "mostly of the same age" and "grew up around the same time" so they can relate to each other when speaking. Another teen was first thinking about the physical ability to speak, but then explained how he can also get his point across. He said: "When I'm talking to a teacher, they know what I'm saying and I can get my point across to them." Therefore, this teen answered "no difficulty."

**Outside of this household:** Teen respondents interpreted "people outside of your household" as those people living outside the home. They thought of their friends, community members, people at school,

and people at church. A few teens also thought about strangers such as people at stores and people commuting to work.

## Dyad Analysis for CFD 14 and T14

**Table 10.** Agreement between parents and teens on communication outside the household (CFD14 and T14)

		Parents				
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	24	6	0	0	30
	Some Difficulty	6	4	0	0	10
	A lot of Difficulty	0	0	0	0	0
	Cannot Do at All	0	0	0	0	0
	Total	30	10	0	0	40

Parents and teens interpreted this question in similar ways and there was a high level of overall agreement for the question on communicating outside the household (Figure 14 and Table 10). In cases where parents and teens disagreed in their responses, the one indicating greater difficulty tended to focus on a specific incident or area of communication while the other answered in general. For example, one parent respondent answered "some difficulty" because a teacher reported that her child speaks too fast when giving class presentations while the teen answered "no difficulty" based on his ability to communicate in general. Additionally, several teens answered "some difficulty" due to vocabulary differences between groups (slang or regional colloquialisms) while their parents answered based on their ability to communicate in general.

Because out of scope interpretations were seen equally for both parents and teens, here was no clear advantage to asking this question to either teens or parents.

# Learning

**CFD15:** DOES (*NAME*) HAVE DIFFICULTY LEARNING THINGS?

No difficulty	23
Some difficulty	17
A lot of difficulty	-
Cannot do at all	-

This question was asked of all parent respondents.

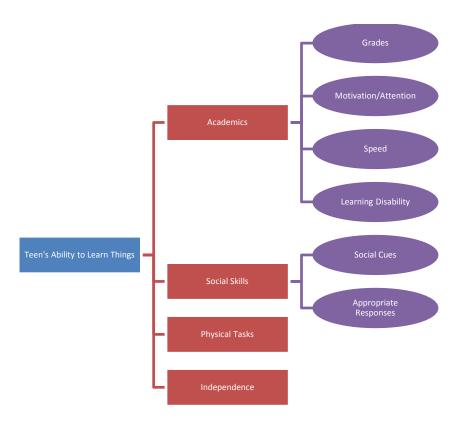


Figure 16. Schema of Parent Responses to Question on Learning (CFD15).

**Interpretation:** Figure 16 depicts the patterns of interpretation seen in parents' responses to the question on learning. While most respondents focused on learning in an academic context, some respondents thought about their teens' ability to learn physical skills, social skills, or to be independent.

Academics: Most respondents answered based on their teens' learning in the context of school. Many respondents answered "no difficulty" based on their teens' "good grades." These respondents felt that the grades were an accurate reflection of their teens' ability to learn. However, a few respondents answered "no difficulty" despite their teens' poor or inconsistent grades. For example, one respondent described how her son is in danger of failing English. She answered "no difficulty" because he can quickly and easily learn things that he wants to know about.

Motivation, attention, and speed were factors for other respondents as well. One parent answered "some difficulty" based on her daughter's attention to school work, explaining that, "She loses focus very easily. If it doesn't come to her right away, she doesn't want to give it the thought necessary to complete the task." Quite a few parent respondents considered the speed at which their teens learn. For example, one parent answered "no difficulty" because her teen is "actually a really quick learner" while another respondent answered "some difficulty" because her son is a "slow learner." She went on to say, "He is able to grasp concepts; he can arrive at an understanding ultimately… It just takes longer."

Diagnoses of learning disabilities or AD(H)D were mentioned by several respondents. Some parents used these diagnoses to explain their answers of "some difficulty." For example, one respondent said of her son:

He was diagnosed with a language-based learning difficulty and so sometimes, he has a hard time with concepts with reading comprehension and abstract concepts that aren't concrete. They can be hard to wrap his head around.

In contrast, other respondents answered "no difficulty" despite their teens' diagnoses. For example, one respondent described his son with Attention Deficit/Hyperactivity Disorder (ADHD) saying, "He gets anxious and he's hyper, but he doesn't have any problem learning things. He's in the same class and learns the same things as the other kids."

Social Skills: A few respondents answered on the basis of their teens' social skills. These respondents focused on either social skills or appropriate responses to others. One respondent answered "some difficulty" because her son does not respond to social cues. She said, "He doesn't quite get what normal people understand." Another parent described how her daughter forgets that she is not supposed to hit her brother. "She actually forgets," said the respondent. Based on this and similar behavior, the respondent answered "some difficulty" despite the fact that the teen "does fine academically."

*Physical Tasks:* A single parent respondent thought about her son's ability to perform specific tasks such as peeling an orange, sweeping the floor or using a knife and fork properly. Because her son is slow at learning these tasks, the respondent answered "some difficulty" even though he his academic performance is stellar.

*Independence:* A single parent answered based on her son's ability to learn life skills. This respondent framed the concept of learning things as "learning to do things for one's self." Based on this definition of learning things, she answered "some difficulty" because her son doesn't keep his room clean or come home "at a decent hour."

**Comparisons:** Unlike some of the other questions in this set, this question did not ask respondents to answer based on a comparison to "children of the same age." However, many respondents did make comparisons to their teens' peers, their siblings or even themselves as teens. One parent said, "Well, as far as learning goes, it's a bell curve." She answered "no difficulty" because she believes her son is at the higher achieving end of the bell curve compared to his classmates. The single respondent whose daughter had Down syndrome was not sure whether to compare her daughter to typical teens or to others with similar conditions. She ultimately selected her answer of "some difficulty" based on a comparison to typical teens.

T15: DO YOU HAVE DIFFICULTY LEARNING THINGS?

No difficulty	23
Some difficulty	16
A lot of difficulty	1
Cannot do at all	-

This question was asked of all teen respondents.

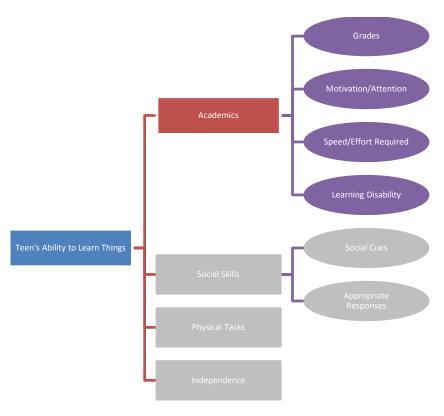


Figure 17. Schema of Teen responses to Responses to Question on Learning (T15). \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** All teen respondents thought about learning in the context of school, although a few mentioned learning sports or job skills as well as academics.

Academics: Most respondents focused exclusively on learning in a school context. When asked what they were thinking about when they selected their responses, the teens said things like, "learning new concepts at school-like math or science," "school and learning daily lessons," and "a new concept in class." However, rather than focus on grades, most of the teens thought about the speed and difficulty of mastering the material they were taught in class. For example, one teen said she has to "take notes and do homework." She also added, "I have a tutor and a study buddy." This teen was comparing herself to other students for whom the material "just clicks automatically." She felt that she had to work harder to understand the material, so she answered "some difficulty." Similarly, another respondent answered "no difficulty" because he can "pick it [new material at school] up really quickly."

Teens differentiated learning based on the subjects they learn at school. For example, one teen said, "I'm great at algebra, but anything that involves reading is hard for me." Most teens provided an average of their ability to learn across all subjects. For example, one respondent answered "some difficulty" saying, "I just, kind of, factored in all the subjects." However, several teens based their answers on their performance in a single school subject rather than on their overall ability to learn. For example, one respondent answered "some difficulty" because she's "having a hard time in science." Likewise, another respondent answered "no difficulty" because he does well in social studies and reading (and despite the fact that he doesn't do well in algebra). Several teens answered "some difficulty" because they have difficulty in "some subjects."

A few respondents answered based on whether they have learning disabilities or not. One teen said, "This question is asking whether I have a learning disability? I don't have one." This respondent answered "no difficulty" based on the fact that she doesn't have a learning disability. Teens who *had* been diagnosed with learning disabilities often answered on that basis as well. For example, one teen said, "I answered "some difficulty" because I have ADHD." This respondent went on to describe how the symptoms of his condition affect his ability to learn, "I have trouble focusing and I'm really jittery in my seat."

Comparison to others: While this question did not specifically ask for a comparison, teen respondents frequently based their responses on their ability to learn relative to their peers. For example, one respondent answered "no difficulty" saying "I never feel like I'm behind other students." Another respondent answered "no difficulty" because "In relation to people my age, I'm above average in test scores and other things." Another said, "I'm better than some and worse than others." This respondent chose "some difficulty" to represent an "average learner." Some respondents took the comparison to an extreme. For example, one teen answered "some difficulty" explaining that an answer of "no difficulty" would mean that "I would probably be in all honors classes."

Dyad Analysis for CFD15 and T15

Table 11. Agreement between parents and teens on learning (CFD15 and T15)

	Parents							
		No			Cannot Do at			
		difficulty	Some Difficulty	A lot of Difficulty	All	Total		
Teens	No Difficulty	16	7	0	0	23		
	Some Difficulty	7	9	0	0	16		
	A lot of Difficulty	0	1	0	0	1		
	Cannot Do at All	0	0	0	0	0		
	Total	23	17	0	0	40		

A little more than half (n=25) of the dyads were in agreement, with both members of the dyad answering "no difficulty" or "some difficulty" (Table 11). As depicted in Figures 16 and 17, different patterns of interpretation were seen for parents versus teens when answering this question. Teens tended to focus exclusively on academics which makes sense given the amount of time teens typically spend focused on academics. Parents, on the other hand, had a broader interpretation of "learning." While most parents, like their teens, focused on academics, others focused on areas, such as social skills, that were not necessarily within the intended scope of the question.

Cases of disagreement resulted from either the parent or the teen focusing on a single academic subject while the other focused more generally. For example, in one dyad, the parent answered "no difficulty" saying, "He [the teen] gets pretty good grades," while the teen answered "some difficulty" because he had to try extra hard in Algebra.

Teens' responses identified cases that were very narrowly focused on academics with some false positives seen when teens focused on their need to study or compared themselves to above average peers. Meanwhile parents' broader interpretation of the question may not necessarily be out of scope. Therefore, there may be some benefit to asking this question of parents.

CFD16: COMPARED WITH CHILDREN OF THE SAME AGE, DOES (NAME) HAVE DIFFICULTY REMEMBERING THINGS?

No difficulty	19
Some difficulty	20
A lot of difficulty	1
Cannot do at all	-

This question was asked of all parent respondents.

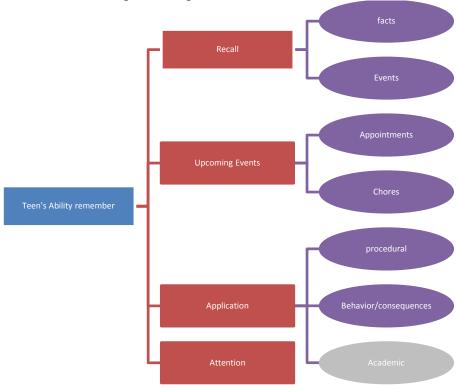


Figure 18. Schema of Parent Responses to Question on Teen Memory (CFD16) \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** As seen in Figure 18, there were several patterns of interpretation. However, the majority of parents based their response on the overlapping components of their teen's ability to produce retrospective information and their ability to keep up with upcoming events.

*Recall:* The majority of parents based their response on the teen's ability to recall information when needed. Parents cited their teens' ability to recall conversations, events that occurred in earlier years, details about a TV show, concepts and/or facts. For example, one mother who answered "no difficulty" said of her son:

...he is good in history and if he watches a program he can then go into quite amount of detail about what he learned from the program...this is how I knows he remembers well.

*Upcoming events:* The teens' ability to remember to do impending tasks, such as homework, home chores and keep appointments, was also the basis of some respondents' answers. Some parents who answered "no difficulty" described how their teens keep up with homework or house chores on their own, while parents who answered "some difficulty" described how their teens forget to do these tasks. For example, one parent, speaking of her teenage daughter, said: "She has trouble remembering instructions from her parents. She can repeat what people said but forgets to clean up her room." This

respondent answered "some difficulty" despite the fact that the teen "remembers what was learned in school... remembers gossip well." Another parent who answered "a lot of difficulty" said that her son "...forgets appointments even if he is told he must put it on his phone to remember."

Application of prior knowledge: Some parents also considered the teen's ability to build on existing knowledge or skill. For example, a parent who answered "no difficulty" noted that her teen is able to easily implement what he learned in a cooking show to the kitchen at home. A few of the parents who answered "some difficulty" mentioned the inability to create associations between disagreeable behavior and its consequences in order to modify it. These parents noted for example that the teen "has a hard time remembering how to behave appropriately...he'll engage in same problematic behavior again and again."

Attention: Some parents—all of whom answered "some difficulty"—based their answer in part on the teen's attentiveness. These parents thought of their teens as absent minded, focusing on other priorities, or having "selective hearing." For example, one parent explained, "It is not really a memory issue as much as attention – probably. Only a subgroup of parents who based their answer on the teen's ability to concentrate mentioned that memory difficulty was due to a mental condition. One parent who answered "some difficulty" mentioned that her teen is able to focus when taking medicine for ADHD.

**T16:** DO YOU HAVE DIFFICULTY REMEMBERING THINGS? WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?

No difficulty	16
Some difficulty	23
A lot of difficulty	1
Cannot do at all	-

This question was asked of all teen respondents.

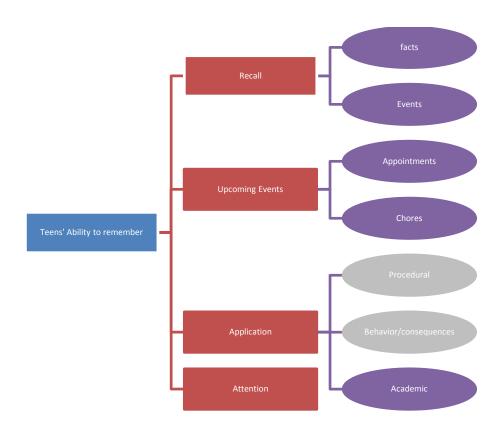


Figure 19. Schema of Teen Responses to Question on Memory (T16). \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** Teens' understanding of this question was similar to their parents' understanding (Figure 19). However, most teens answered based on their ability to recall information and to apply prior knowledge, and a smaller proportion of them focused on remembering upcoming events, as compared to their parents.

*Recall:* The majority of respondents based their responses on their ability to recall information, such as facts or past events, when needed. Teens described their ability to remember details of general or social life events such as remembering what they ate the day before, the age tonsils were removed, dates or phone numbers, and conversations. Also of importance was the ability to remember specific information learned in school that might be needed on an exam. Many of the respondents who answered "no difficulty" based their answer on their ability to recall retrospective information without difficulty. In contrast, some respondents who answered "some difficulty" focused on their inability to remember events from the past, personal information about acquaintances, or their struggles to remember information about an academic subject for an exam.

Application of prior knowledge: Another pattern demonstrated by respondents was the ability to apply previous knowledge. Unlike their parents, however, teens focused application of knowledge almost exclusively on academics. Teens provided examples such as the ability to use math equations or to assimilate complex material.

*Upcoming events:* Some respondents answered on the basis of their ability to recall when home chores or homework were due, or being conscious of upcoming appointments or deadlines. While respondents who reported "no difficulty" said they could remember these tasks, those who reported "some difficulty" described forgetting appointments, homework or home chores.

Attention: A few respondents answered based on their ability to focus on new information. One participant who had ADHD, answered "some difficulty" because he doesn't "...remember important details that people just said...for example, when you asked the question about how do these all apply, I had to say I'm sorry, what?" Other respondents based their answer on not paying attention to where they put things (e.g. keys). One participant said, "I loose things a lot, I'll put something down and have no idea where it is...it doesn't happen every day but a fair amount to get annoyed."

#### Dyad Analysis for CFD16 and T16

**Table 12.** Agreement between parents and teens on memory (CFD16 and T16)

		Parents				
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	12	4	0	0	16
	Some Difficulty	7	15	1	0	23
	A lot of Difficulty	0	1	0	0	1
	Cannot Do at All	0	0	0	0	0
	Total	19	20	1	0	40

As depicted in Figures 18 and 19, there was some overlap in how teens and parents understood this question. Both teens and parents thought about aspects of memory such as recall, remembering upcoming events and aspects of memory that relate to attention. The two groups differed in their focus: with parents focusing on behavior, and teens focusing on academics. Where there was discordance, as depicted in Table 12, the two members of the dyad tended to focus on different aspects of memory. In cases where the parent indicated that the teen had more difficulty with memory, the parent focused on the need to remind the teen to do chores, remember appointments or manage things (backpacks, books, homework sheets). Similarly, when the parent indicated that the teen had less difficulty with memory, the parent focused on the teen's ability to do all those things without reminders. Meanwhile, these teens focused on their feelings of mental distraction and their difficulty recalling past events. Therefore, parents focused on aspects of their teens' memory that they have to manage through reminders and teens focused on aspects of their memory that they deal with internally such as memorizing and recalling.

#### **Emotions**

CFD 17: HOW OFTEN DOES (NAME) SEEM ANXIOUS, NERVOUS OR WORRIED?

Daily	11
Weekly	10
Monthly	7
A few times a year	9
Never	3

A total of forty respondents answered this question.

A few respondents had difficulty selecting from the given response categories. For example, one respondent wanted to choose "a few times a week" because she felt that the answer options did not reflect the frequency of her teen's anxiety. This respondent, considered choosing "daily" at first. However, she explained that her teen did not feel anxious every day but rather "somewhere between daily and weekly," and ultimately selected "weekly." Similarly, another respondent said: "I wish there was an answer between daily and weekly." This respondent chose "daily" even though she didn't feel that it accurately represented the frequency of her teens "worrying about the future."

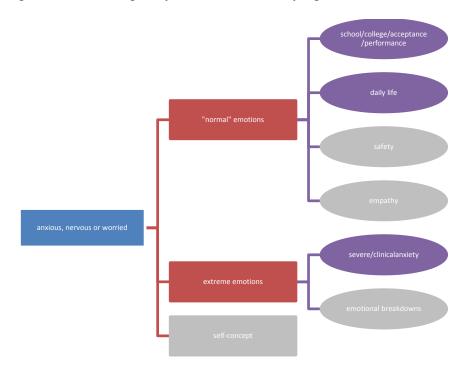


Figure 20. Schema of Parent Responses to Question on Anxiety (CFD17) \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** Respondents answered this question based on their conceptualization of their teens' feeling anxious, nervous, or worried. Parents' response patterns are depicted in Figure 20.

Normal emotions: The majority of respondents answered based on the premise that some degree of anxiety was "normal" and not necessarily problematic. Most respondents stated that their teens felt anxious, nervous, or worried related to school. More specifically, these feelings were related to grades, extracurricular activities, and college applications. Some respondents viewed this type of anxiety as beneficial. One respondent, speaking about her daughter, said, "Children her age should be anxious."

Other respondents described how their teens feel anxious as a result of situations of daily life such as conflicts with family members, money worries, health concerns, and minor inconveniences. One respondent who answered "weekly" described how her teen is worried about making enough money to support his girlfriend while another, who also answered "weekly," described her son's stress regarding peers and social media posts. These respondents also indicated that these feelings of anxiety, while not always pleasant or welcome, were "just part of life."

Extreme emotions: Some respondents described their teens' struggles with general anxiety—or specific clinical disorders that caused severe, persistent anxiety—as opposed to anxiety that is a "normal" reaction to external phenomena. Some of these parents described their teens as "easily stressed," "wound up," or "moody." For example, one parent described her daughter as "a worrier." Several parents said their teens take medication or receive treatment for anxiety or other disorders such as anorexia, ADHD, or trichotillomania.

**Uncertainty:** Respondents learned about their teens' anxiety through direct communication with their teens and by observation of behavior. Some respondents said that their teens were very vocal about their anxiety. For example, one respondent who answered "daily" said, "I know because she can't stop talking about it." Others could tell when their teens were nervous because they acted differently. One respondent who answered "a few times a year" said her son "gets nauseous and rocks back and forth" before football games.

However, many respondents expressed uncertainty about their teens' anxiety. One parent who answered "daily" said, "I wish we had a better handle on it." Other respondents said that their teens didn't talk about their feelings. One respondent who answered "weekly" said, "She isn't very communicative, so it's hard to tell if she's anxious." Another described his daughter as "shy and quiet." He answered "a few times a year," but said, "Whether or not she's anxious more than that, that's what she shows."

T17: TEENS: HOW OFTEN DO YOU FEEL ANXIOUS, NERVOUS OR WORRIED?

Daily	8
Weekly	10
Monthly	8
A few times a year	11
Never	3

A total of forty respondents were asked this question.

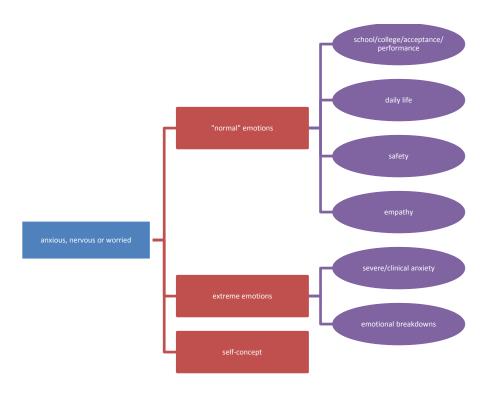


Figure 21. Schema of Teen Responses to Question on Teen Anxiety (CFD17)

**Interpretation:** Respondents answered this question based on their feelings of anxiety, nervousness and worry. However, as seen in Figure 21, these feelings come from different sources.

Normal emotions: The majority of respondents reported feeling anxiety as "normal" reactions to external stimuli, which were almost always related to school (including homework, tests, peer relationships, extracurricular activities and college acceptances). Asked to describe the anxiety that she feels "weekly," one respondent said, "Like there's a test that you'll have to study for but you're worried that you'll fail. Just the usual." Other respondents thought about anxiety related to the activities of daily life. Respondents in this category felt stress related things such as family relationships, getting to appointments on time, planning events, potential emergencies or sometimes overlapping stimuli. For instance, one teen explained her "weekly" response by saying:

I just have a lot on my plate and sometimes, it just feels like everything is hitting you all at once. I just have a lot of people asking for a lot of things as once. I have to juggle home, school, my acting at school, my academics and my acting outside of school and it's just a lot.

Two respondents thought about the safety of their general surroundings. One answered "a few times a year" because he lives in a "bad" neighborhood and sometimes he has to look over his shoulder when walking down the street. Similarly, another respondent moved to a better neighborhood that is safe in contrast to his old neighborhood. He answered "never" because he doesn't have to worry about safety any more.

Two respondents answered on the basis of their feelings of concern for others. One respondent answered "monthly" because she worries about her brother, who is a "daredevil," and the health of her family members.

Extreme emotions: A few respondents answered this question based on the presence of an extreme condition of anxiety. These respondents tended to cite a specific diagnosis such as "clinical anxiety" or "anorexia" that caused these feelings. A few other respondents thought about their ability to handle stress and the condition of having an "emotional breakdown." Regardless of the frequency of their anxiety, respondents in this category felt that their feelings were more extreme than normal stress.

*Self-concept:* A few respondents answered based their understandings of their own personalities. One respondent said, "I'm just not a worrier" while another said, "I'm not an anxious person." Despite admitting to having feelings of anxiety or worry in certain situations, these respondents answered "never" based on their general self-concept.

Answer categories: While the answer categories relate to *frequency* of anxiety, respondents also considered *intensity*. Some respondents answered "never" because they never have anxiety to a degree that they "can't handle it." These respondents dismissed "low level" expressions of these emotions. They did not consider them to be "serious enough." For example, one teen answered "monthly," and mentioned that despite feeling minor anxiety or worry often, she only considered "serious worry" for this question because "it would last longer." This respondent indicated that she experiences "serious worry" whenever something major occurs, such as a visit to the hospital. Others answered "weekly" or "daily" to represent the constancy of their generalized worry. One respondent said, "I am usually worried or constantly thinking about one thing or another."

## Dyad Analysis for CFD17 and T17

**Table 13:** Agreement between parents and teens on anxiety (CFD17 and T17)

		Parents	Parents						
		Daily	Weekly	Monthly	A few times a year	Never	Total		
Teens	Daily	3	2	2	1	0	8		
	Weekly	5	3	2	0	0	10		
	Monthly	1	2	1	4	0	8		
	A few times								
	a year	1	3	2	3	2	11		
	Never	1	0	0	1	1	3		
	Total	11	10	8	9	3	40		

As seen in Table 13, only 11 of the 40 dyads were in exact agreement. Some of the disagreement within dyads was due to confusion over the category "weekly." Respondents often wavered between "weekly" and "daily," and they were especially unsure which to choose to indicate anxiety that occurred less frequently than daily but more frequently than once a week. Several expressed a desire for "a few times a week." Often, one member of a dyad chose "daily" while the other chose "weekly" even though they were both thinking "a few times a week." Therefore, it may make sense to conflate the response categories "daily" and "weekly" especially since they represent a similar timeframe. Collapsing these two categories nearly doubles the level of overall agreement to almost one half. (18/40).

After combining these two response categories, roughly half of the dyads were in disagreement with an equal number of teens and parents rating the teens' anxiety as higher (11/40 each). Some of this

disagreement was a result of differing interpretations as seen in Figures 20 and 21 which show that teens had a broader range of interpretations than parents did. However, even when both members of a dyad interpreted the question in the same way (for example both thinking of anxiety about tests and homework), their responses were not necessarily in agreement.

This was largely because teens responded based on their feelings (an internal process) while their parents answered based on external manifestations of these feelings. Teens made direct reports of their feelings while parents referred to their teens' nervous behavior such as nail biting, vomiting before a big sports event or general moodiness as well as reports from the teens themselves. Therefore, parents were not always aware of the how much anxiety their teens were experiencing. As one parent said, "I'm not exactly sure what she's feeling. She doesn't talk about it, but I try to pay attention." Similarly, one of the teens said, "My mom may answer differently. These are my feelings. She may not know."

Some dyads' responses were particularly far apart. For instance, one member may have answered "daily" while the other answered "a few times a year." In some of these cases, the teens were not emotionally expressive or the parents were not particularly attuned to their teens' emotions. More common, however, was for one member of the dyad to think about severe (e.g. "freaking out") anxiety while the other thought about mundane worries such as "Will I be able to connect to the wi-fi?"

In general, asking this question to parents missed some cases of teens with serious emotions that parents aren't aware of. Asking this question to teens missed at least one case where the parent had serious concerns about the teen's behavior.

CFD 18: HOW OFTEN DOES (NAME) SEEM SAD OR DEPRESSED?

Daily	2
Weekly	12
Monthly	5
A few times a	11
year	
Never	10

All 40 parent respondents were asked this question.

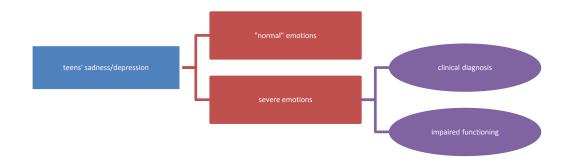


Figure 22. Schema of Both Parent and Teen Responses to Question on Teen Sadness (CFD18 and T18)

**Interpretation:** As depicted in Figure 22, all respondents understood this as a question about their teen's expression of emotions.

Normal emotions: Most respondents distinguished between depression, a more serious emotion, and sadness, a less serious emotion and answered based on their teens' expression of "normal" feelings of sadness. Respondents felt that expressing feelings within this range was "normal" and that these feelings would be experienced by everyone at some point. One respondent who answered "a few times a year" said, "Depressed to me is more of like a health issue, like something is not stable. Something's throwing you off a bit. Like a cold....something everybody gets sometimes."

Severe Depression: Several respondents answered based on severe depression only. These respondents thought about clinical depression specifically, and answered "never" based on the fact that their children did not have clinically-diagnosed depression. As one of these respondents explained, "I was thinking if he has a depressed disorder or manic."

Another respondent answered this question by thinking about whether her child experienced impairment as a consequence to feeling sad or depressed. The respondent said, "I was picturing that [sadness] being more like harboring really strong feelings about a situation where a child wouldn't be able to function, or takes a while to get back to functioning." Given that her teen did not display any deficits in daily functioning, the respondent answered "never."

**Response options:** Some respondents had difficulty choosing a satisfactory answer category. In particular, a few respondents had a hard time distinguishing between "weekly" and "monthly." For example, one respondent said her child felt sad or depressed, "once every week or two" but not every week. She was not sure whether to choose "weekly" or "monthly" but ultimately picked "monthly" because her child's depressed/sad feelings did not occur every week. Another respondent commented:

This [question] is challenging because it doesn't say what the duration of the distress is, so he usually is depressed for anywhere from 6-10 days at a time, and that might happen once a month, but it's many days when it happens, so it's probably 50% of the time, but... It's cyclical. There are weeks were he's fine. It's not daily because he can have 2 weeks without it, and it's not monthly because it happens more often than that.

This respondent selected "weekly," as an average of his teens' depression. Other respondents didn't average over time but rather answered based on the most recent few weeks. For example, one respondent thought about how her daughter had been crying for no reason over the previous few weeks. Even though this was an unusual pattern, the respondent answered "weekly" based on this recent behavior.

T18: How often do you seem sad or depressed?

Daily	2
Weekly	8
Monthly	12
A few times a	10
year	
Never	8

All 40 teen respondents were asked this question.

**Interpretation:** Respondents answered this question based on their understanding of depression and sadness (**Figure 22**).

*Normal emotions:* Most respondents answered based on what they consider to be the normal expression of feelings of sadness. The majority of respondents considered it "normal" to experience both sadness (and its more extreme form of depression) at one point or another. As one respondent said, "Everybody has that feeling sometimes." This respondent answered "monthly." Another respondent who also answered "monthly" said, "Everyone gets sad about something. No one is 100% happy all the time."

Depression only: Eight respondents answered based on whether or not they currently have severe depression. These respondents stated that even though they experienced sadness due to distressful situations—such as school, friends, or the loss of a loved one—they do not experience depression. One respondent answered "never" because he did not consider himself as someone who suffers from depression. He said, "I think [the question] kind of threw me off with 'depressed' because I don't consider myself suffering from depression…I do feel sad…"

Sadness and Depression: A few respondents who made clear distinctions between sadness and depression had difficulty selecting an answer because the frequency of their feelings varied. One respondent said, "I tend to get sad more than depressed [which is] extended sadness." This respondent eventually selected "monthly" because he had to average the times he felt sad and the times when he felt depressed. He stated, "I probably get sad weekly, and I would say that depression is less frequent than monthly, so I averaged them out." In this case, this respondent viewed the question as double barreled.

**Response options:** Respondents also reported having difficulty answering this question because they were uncertain about the frequency of their feelings. Also, the reference period of the question itself was not specified. For example, one respondent disclosed that after the passing of a family member, he felt sad every week, but since then he's been "handling it well." Taking this into account, he did not know whether the question was asking about his emotional feelings in general or at the present moment. If he had been asked right after the passing, he would have said "weekly," but he ultimately selected "a few times a year" as an average of his feelings over time.

# Dyad Analysis for CFD18 and T18

Table 14. Agreement between parents and teens on teens' depression (CFD18 and T18)

		Parents					
					A few		
					times a		
		Daily	Weekly	Monthly	year	Never	Total
Teens	Daily	0	2	0	0	0	8
	Weekly	1	5	0	2	0	10
	Monthly	1	5	3	3	0	12
	A few times						
	a year	0	0	2	5	3	8
	Never	0	0	0	1	7	2
	Total	10	11	5	12	2	40

There was little variation in how teens and parents interpreted this question overall. However, differences in interpretation within individual dyads resulted in discordant answers in half of the pairs (Table 14). For example, when one member of the dyad answered based on whether or not the teen had clinical depression and the other member of that dyad answered based on "normal" sadness, their responses could be quite different with those who answered based on "normal" emotions giving higher ratings of frequency and those who answered based on severe depression giving lower ratings. As seen with the previous question on anxiety, teens answered based on their feelings while parents answered based on external manifestations of those feelings. However, unlike with the anxiety question, teens' outward manifestations of sadness as interpreted by their parents generally matched their reported feelings. Therefore, there was no clear benefit to asking this question of either the teens or their parents.

## **Behavior**

**CFD19:** COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DIFFICULTY DOES (*name*) HAVE CONTROLLING HIS/HER BEHAVIOR?

None	14
The same or less	13
More	11
A lot more	2

This question was asked of all parent respondents.

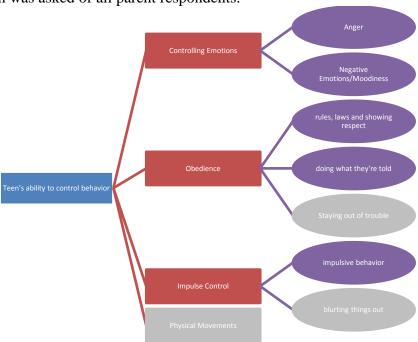


Figure 23. Schema of Parent Responses to Question on Teen Behavior (CFD19) \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** As depicted in Figure 23, parent respondents focused on three aspects of controlling behavior: controlling emotions, obedience and impulse control.

Controlling emotions: More than half of parent respondents answered based on their teens' abilities to control their anger or other emotions. For example, one respondent answered "the same or less" because her teen "knows how to step back and count when someone makes him mad." Another respondent answered "more" because her teen "has trouble controlling his emotions" which manifests through crying at home and school.

Obedience: Several respondents answered this question based on their teens' abilities to follow rules or do what they're told. Some respondents described their teens who follow rules as "angels" or "wellbehaved." In contrast, other respondents described how their teens talk back, show disrespect, get in trouble in school, or break the law. One respondent said, "He talks back; he's disobedient; he doesn't do his chores when he's supposed to." Although the teen does his chores sometimes, the respondent felt that he didn't do them as frequently as other teens, so she answered "more."

Impulse control: A few respondents thought about their teens' impulse control when answering this question. As an example, one respondent talked about her adoptive son who has multiple diagnosed disorders including Attention Deficit Hyperactivity Disorder (ADHD), Impulse Control Disorder, and a mood disorder. This respondent answered "a lot more" based on her teen's inability to control his impulses. This teen has trouble not acting on his desires even though he "knows right from wrong." She said, "He has impulses and drives and he feels compelled to act on them." Her son's inability to control his impulses has caused him to get in trouble at school and to be arrested. Similarly, another respondent answered "more" saying of her teen, "When she gets mad, she doesn't control her behavior well. She uses profane language, slams the door or throws something."

**Comparison:** This question which begins, "Compared with children of the same age..." explicitly asks respondents to make a comparison, and, in fact, the response categories (*none*, *the same or less*, *more and a lot more*) push respondents to make a comparison. Indeed, in formulating their responses, many respondents, such as the one mentioned above, did make a comparison. However, some respondents were not sure how to compare their teen to others or where the concept of "normal" factored into their response.

Some respondents indicated that it was difficult to compare their teens to others. One respondent indicated that his daughter has "more" difficulty controlling her behavior because sometimes she acts out in anger at home. This respondent said, "I'm not seeing other children of the same age but at school events. There they are nice but of course I can't see other children at home." Thus, it was difficult for him to know whether his daughter's behavior was really indicative of "more" difficulty. Meanwhile, another respondent indicated that her son has "more" difficulty controlling his behavior. She said that he's "not really different than other kids" but she answered "more" because the fact that he doesn't do his chores is "not normal."

**None/the same or less:** Respondents at times did not differentiate between these two response categories. Some respondents answered "none" to indicate that their teens behaved similarly to other teens. For example one respondent answered "none" because his son is "a normal behaved kid." In contrast, other respondents answered "the same or less" to indicate that their children were "normal." One respondent said, "No one has 'none.' We are all imperfect."

**T19:** COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DIFFICULTY DO YOU HAVE CONTROLLING YOUR BEHAVIOR? WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?

None	19
The same or less	15
More	5
A lot more	1

This question was asked of all teen respondents.

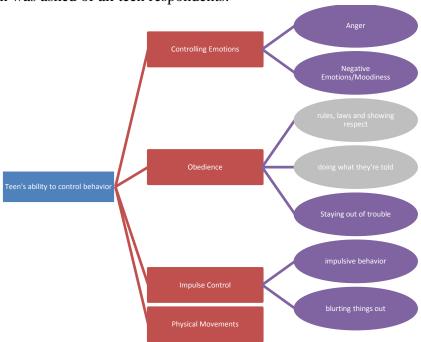


Figure 24. Schema of Teen Responses to Question on Teen Behavior (T19) \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** As seen in Figure 24, teens considered several aspects of controlling behavior when answering this question.

*Obedience*: Most teens thought about "behavior" as being "well-behaved" which meant that they thought about how much they get into trouble at school and at home. One teen said that behavior is about "not doing something that will get you into trouble. Not saying things you're not supposed to say." Another teen said, "I try to control myself in class so I don't get in trouble." These teens both answered "the same or less" because they are able to stay out of trouble.

*Impulse control:* Some respondents answered the question based on their ability to control their impulses. One respondent described controlling his behavior as the ability to "stay focused when the time demands and not act on sudden impulses." Several respondents specifically mentioned controlling their impulse to "blurt things out." One teen said, "Compared to other kids in my class, I blurt things out all the time." This respondent answered "more." Similarly, a different respondent answered "the same or less" saying, "I know when to keep my mouth shut."

Controlling emotions: A few respondents thought about their ability to control their emotions and stay calm. Respondents mentioned that it can be difficult to stay calm when faced with the stress typical of a

modern teen. One respondent answered "the same or less" because he can remain calm when confronted by aggressive people. Another respondent answered "the same or less" because he's is able to "stay calm generally." A third respondent who answered "a lot more" said, "I have tons of bad moods." This respondent was thinking of her ability to control her emotions in general.

*Physical movements:* A single respondent answered based on his ability to control his physical impulses. He gave the example that when he has an itch he will scratch it. Unlike the other respondents, this respondent was not thinking about social behavior but only his response to physical impulses.

**Comparison:** This question which begins, "Compared with children of the same age..." explicitly asks respondents to make a comparison, and, in fact, the response categories (*none*, the same or less, more and a lot more) push respondents to make a comparison. In fact, the majority of respondents answered did make a comparison. For example, a respondent who answered "the same or less" explained his response, saying "I can control myself in class pretty much like the other kids. I do talk too much in class, but that's normal." Another respondent answered "the same or less" and said, "Kids nowadays are just out of control and I have more control over myself than other kids."

None/the same or less: Unlike the parent respondents, teen respondents demonstrated a more clear differentiation of these response categories. Teens who selected "none" generally did so to indicate that they have "no difficulty controlling their behavior." Some respondents who chose "none" while making a comparison to their peers. For example, one teen said, "I don't go with them [peers who get in trouble] because I can make the decision for myself." Other teens chose "none" in the absence of a comparison such as the teen who said, "I chose 'none' because I don't have any difficulty with my behavior." Teens who chose "the same or less" made specific comparisons to their peers, generally indicating that they were "like the other kids in my class."

## Dyad Analysis for CFD 19 and T19

Table 15. Agreement between parents and teens on teens' behavior (CFD19 and T19)

Tuble 10 ingredient between parents and teems on teems behavior (CIDI) and II)						
		Parents				
		None	The same or less	more	A lot more	Total
Teens	None	10	6	2	1	19
	The same or less	5	4	5	1	15
	more	0	1	4	0	5
	A lot more	0	1	0	0	1
	Total	15	12	11	2	40

As seen in Figures 23 and 24, parents and teens had overlapping, but divergent, interpretations of this question. Teens thought about staying out of trouble while parents had the slightly different focus of following rules or respecting authority. Teens also thought about particular situations where they are called on to control their behavior such as stopping themselves from "blurting things out."

Table 15 shows the overall agreement for this question, Counting "none" and "the same or less" as the same [since both indicate no difficulty], twenty-nine out of the forty dyads were in agreement. In 9 dyads, the parent indicated that the teen had more difficulty controlling behavior than the teen did. In several of these cases, the teen thought the question referred to severe behavioral difficulties or disabilities such as diagnosed ADHD or autism.

In other cases where the parent rated the teen's behavior as worse, the teens compared themselves to their immediate peer groups while the parents compared the teens to teens in general or did not make an explicit comparison. Some parents acknowledged the difficulty in assessing the child compared to other children. One parent said, "I'm not seeing other children of same age, but at school events, they are nice, but of course I can't see other children at home."

However, most parents were able to make this comparison based on a comparison to children in general or to an ideal child of the same age as their teen. For example, one child discussed difficulty controlling his impulse to break rules at school but answered "the same or less" because his behavior is similar to his friends' behavior. His mother, on the other hand, answered "more" because her son's impulsive behavior "may be normal for a 5 year old but not normal for a 13 year old."

In an extreme case, a parent answered "a lot" and described his son's severe behavioral difficulties:

Impulse control is a big factor for him. Even if he knows he shouldn't do something he still does it, he has some impulses and drives that I think are not typical and feels compelled to act on them in a way that I think most of his peers would not. He seems incredibly fixated on electronics and more specifically, he had some trouble with sexually oriented material on the internet and just couldn't tolerate barriers to that and would constantly break through those barriers, and eventually got arrested last year.

However, the teen in this dyad answered "the same or less" because he goes to a special school where the children have similar behavioral issues.

The two teens who indicated that they had a greater degree of difficulty controlling their behavior than their parents did both had idiosyncratic understandings of the question: one was the respondent with Down syndrome while the other thought exclusively of controlling physical movements.

Therefore, it appears that posing this question to parents picked up some cases of legitimate concern that were not captured by asking teens while asking this question of teens did not yield any additional information.

## **Attention**

CFD20: DOES (NAME) HAVE DIFFICULTY FOCUSING ON AN ACTIVITY THAT HE/SHE ENJOYS DOING?

No difficulty	30
Some difficulty	8
A lot of difficulty	2
Cannot do at all	-

This question was asked to all parent respondents.

**Interpretation:** Parent respondents uniformly understood this as a question about their teens' ability to mentally focus on an activity. Respondents talked about focus, attention, and distractibility when doing activities. One respondent who answered "no difficulty" said of her teen, "Whatever she wants to do, her attention is there." In contrast, another respondent answered "some difficulty" saying, "Even if she really enjoys doing something she likes, she gets distracted."

*Enjoyable activities*: Most respondents focused on activities their teens enjoy doing. Respondents reported that their teens like doing activities such as sports, drawing, computer games, and playing musical instruments. One respondent answered "some difficulty" based on his teens' ability to focus on an activity he does NOT enjoy (doing chores), but later noted that he has no difficulty focusing on things he enjoys.

**Response error:** Response error was likely seen in two respondents who answered "a lot of difficulty," but who focused on barriers that prevent their teens from doing enjoyable activities instead of their teens' ability to focus on the activities themselves. One of these respondents described how it's difficult to get her daughter to play basketball because the teen has so much anxiety about changing at school. When the teen plays basketball, she enjoys it and is focused. The other respondent answered based on the fact that her son isn't allowed to play football anymore. He used to enjoy it but he hasn't been able to play due to a brain injury.

T20: DO YOU HAVE DIFFICULTY FOCUSING ON AN ACTIVITY THAT YOU ENJOY DOING?

This question was asked of all teen respondents.

No difficulty	34
Some difficulty	6
A lot of difficulty	
Cannot do at all	-

**Interpretation:** Teen respondents uniformly understood this as a question about their ability to mentally focus on an activity. Respondents talked about focus, attention, and distractibility when doing activities. Respondents were readily able to offer examples of activities they enjoy doing such as art, computer games, talking with friends, and playing sports. One respondent who answered "no difficulty" said that when she enjoys an activity she "gives it her undivided attention." In contrast, another respondent answered "some difficulty" saying, "I sort of have a short attention span." Respondents distinguished between internal distractions such as boredom or a desire to do something else and external distractions such as loud music or a buzzing phone. However, respondents considered their ability to focus despite both types of distraction.

Dyad Analysis for CFD 20 and T20

Table 16. Agreement between parents and teens on teens' attention (CFD20 and T20)\*\*\*\*

		Parents		•		
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	24	8	2	0	34
	Some Difficulty	5	0	0	0	5
	A lot of Difficulty	0	0	0	0	0
	Cannot Do at All	0	0	0	0	0
	Total	29	8	2	0	39

There was little variation in how teens and parents interpreted this question, and over half the dyads were in agreement (Table 16). In 10 cases, parents' ratings of the teens' difficulty with focus were higher than the teens' ratings. A few of these parents were thinking about diagnoses of ADHD or

depression that interfere with their teens' focus while the rest of these cases can be attributed to response error. This error was seen when respondents either changed their responses to "no difficulty" or were thinking of their teens' difficulty focusing on boring or difficult tasks. In the two most extreme cases where the parents answered "a lot of difficulty" while the teen answered "no difficulty," the parent was thinking of barriers to their teens' participation in enjoyable activities while the teen was thinking of doing enjoyable activities.

The teens who rated their difficulty focusing higher than their parents did were thinking of their difficulty focusing despite intrusive distractions (such as loud music) or a particularly difficulty task (such as difficult choreography).

Therefore, asking this question to parents captured several cases of ADHD that were missed by asking teens. Meanwhile, both parents and teens yielded "false positive" cases primarily due to response error.

### **Routine**

CFD21: DOES (NAME) HAVE DIFFICULTY ACCEPTING CHANGES IN HIS/HER ROUTINE?

No difficulty 16 Some difficulty 21 A lot of difficulty 3 Cannot do at all

This question was asked to all parent respondents.

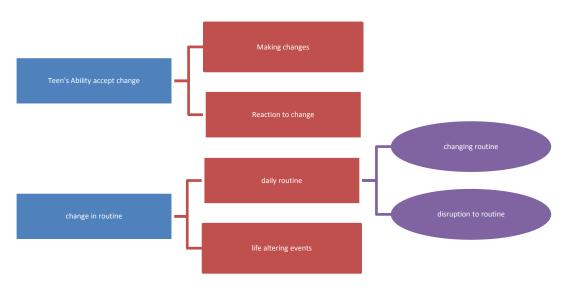


Figure 25. Schema of Parent and Teen Responses to Question on Accepting Change (CFD21 and T21).

**Interpretation:** The response schema for parents' responses can be seen in Figure 25. Parent respondents uniformly interpreted this as a question about their teens' ability to adjust to a changes in

routine. However, there were subtle differences in the aspects of routine that respondents focused on when formulating their responses.

# **Changes in routine:**

Daily routine: Most respondents focused on their teens' ability to adapt to a general change in routine such as leaving the house earlier every morning or changing dinner time. For example, one respondent answered "some difficulty" and said:

[teen]is a bit more change averse than most kids. He gets up at 4:30 every morning; he's a planner and likes to do things at a set time.

However, some respondents thought of specific deviations from the usual routine such as going to bed later than usual or having an unexpected doctor's appointment. One respondent thought of a recent Saturday morning when she had to wake her teen up early to go to an appointment. He was not happy to have his sleep disrupted and complained about it loudly, for a long time. Based on this incident, the respondent answered "a lot of difficulty."

Life changes: Other respondents thought about their teens' ability to adapt to bigger life changes that would bring about a change in routine. For example, several respondents talked about their teens' reaction to moving to a new house or school environment. One respondent answered "some difficulty" because his son experienced "culture shock" when he started being homeschooled.

# **Accepting changes:**

Making changes: Some respondents described their teens' ability to make changes to their routine. Respondents who answered "no difficulty" tended to characterize their teens as "adaptable" or "easy going." Other respondents described their teens' difficulties making changes. One respondent who used this pattern of interpretation explained: "He just wants things to be the same all the time." Another described how her son eats the same thing for lunch every day and refuses to eat anything different. Both of these respondents answered "a lot of difficulty."

*Reaction to change*: Other respondents thought about their child's reaction to changes or routines. For example, one respondent answered "a lot of difficulty" because while her son is able to make changes to his routine, he complains about it a lot. Another respondent answered "some difficulty" because her teen likes routine. She said, "It throws her a little bit when there's no routine."

T21: Do you have difficulty accepting changes in your routine?

No difficulty	13
Some difficulty	24
A lot of difficulty	3
Cannot do at all	-

This question was asked of all teen respondents.

**Interpretation:** In this question, both "change in routine" and "accept" were interpreted in various ways by the teen respondents. The response schema for teens can be seen in **Figure 25**.

Routine: Teens had two major interpretations of the phrase "change in routine."

Daily routine: Some respondents thought about their daily routine. Several respondents listed their daily schedule of waking, eating, going to school, doing activities and homework, and then going to bed. One respondent said, "I'm used to waking up at a certain time and if my schedule changes it would be hard." This respondent answered "some difficulty" saying, "It's hard for me to change because I'm so used to it." Another respondent described how her mother had to start waking her up 45 minutes earlier." This respondent answered "no difficulty" because she considers herself to be "pretty flexible." Quite a few respondents also thought specifically about their class schedule at school.

A few respondents thought about specific disruptions to their normal routine such as doctors' appointments or unexpected things that interfere with their ability to go about their daily schedule. For example, one respondent answered "some difficulty" because he doesn't like it when his schedule is disrupted by his brother taking too long in the shower. He notes that things like doctors' appointments that disrupt the schedule are harder to deal with than actual changes to his overall schedule. Another respondent noted that it's easier her for her deal with these types of disruptions if the disruption is something she wants to do.

Life changes: Some respondents thought about the changes in their routine brought about by major life events such as going to college, moving to a new house, or the divorce of their parents. One respondent thought about changes such as his brother going to college. He answered "no difficulty" because he has always been able to adapt to changes such as this. Another respondent thought about the changes he's had to make in his life and routine since he was arrested. He answered "no difficulty" because he was able to make those changes.

## **Accepting changes:**

Making changes: Some respondents thought about how difficult it is for them to get used to changes or incorporate changes into their regular routine. For example, one respondent answered "some difficulty" because she hasn't "gotten used to" her dad moving several states away. Another respondent also answered "some difficulty" reporting that it took a few months to incorporate wearing new contact lenses into his regular routine.

Reaction to change: Other respondents thought about how much they like having a routine in general. Respondents who answered "no difficulty" often described themselves as "flexible" or "adaptable" while those who answered "some difficulty" or "a lot of difficulty" described themselves as "inflexible" or "rigid." One respondent said, "I'm kinda a routine addict. It's hard to accept changes." These respondents were not thinking about whether it would be difficult to do the changes, but rather how they would feel about changes to their routine.

Dyad Analysis for CFD21 and T21

**Table 17.** Agreement between parents and teens on difficulty with change to routine (CFD21 and T21)

CCH	ратень анс	i icens on a	ijjicuity wiii	i change to	Tourne (CI I	721 ana 121)
	aronts			•	•	

		No difficulty	Some Difficulty	A lot of Difficulty	Cannot Do at All	Total
Teens	No Difficulty	7	5	0	0	12
	Some Difficulty	7	15	2	0	24
	A lot of Difficulty	1	1	1	0	3
	Cannot Do at All	0	0	0	0	0
	Total	15	21	3	0	39

As seen in Figure 25, parents and teens interpreted this question in similar ways. Just over half of the dyads were in agreement. In cases where the teens rated their difficulty with change as more severe than their parents did, the teen invariably thought about their (often extreme) dislike for change while their parents thought about the teens' outward ability to deal with or enact changes. For example, one teen answered "some difficulty" because he really likes to have a set routine while his mother answered "no difficulty" because her son was recently able to adapt to a new wake up time even though he didn't like it.

In cases where the parents rated the teens' difficulty adapting to change as more severe than the teens did, the parents often thought about their teens' love of planning and routine coupled with their frequent complaints when faced with change while the teens considered their ability to change despite disliking it. For example, one teen who answered "no difficulty" while his parent answered "some difficulty" said, "I get cranky about it, but I can adapt."

In two cases, the teens and the parents based their responses on different time frames. The parents thought about their teens' ongoing difficulty with change throughout their childhood while the teens described how their ability to deal with change had improved as they had age and answered based on their recent behavior.

There is no clear advantage either to asking teens or to asking parents this question. Asking parents missed cases where teens have a strong aversion to change while asking teens missed cases where parents were influenced by teens' complaints about change.

# Relationships

CFD22. PARENTS: DOES (NAME) HAVE DIFFICULTY MAKING FRIENDS?

No difficulty	20
Some difficulty	13
A lot of difficulty	7
Cannot do at all	-

All parent respondents were asked this question.

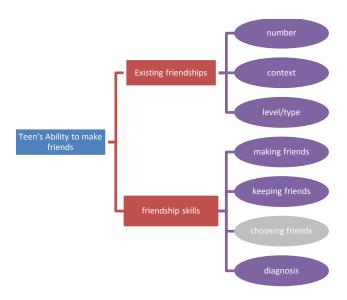


Figure 26. Schema of Parent Responses to Question on Making Friends (CFD22) \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** Respondents interpreted this question to be asking about their child's existing friendships, their child's skills in creating and maintaining friendships, or their child's temperament. Many respondents mentioned thinking about more than one of these patterns of interpretation when answering this question. Most parents recognized that different people, including teenagers, desire different numbers and types of friendships and answered the question as it related to how their teen's ability to make friends allowed them to have the types and numbers of friends that the teen desired.

Existing friendships: Most parents understood the question first and foremost as asking if their child currently had friends. Several respondents who answered "no difficulty" making friends explained that their child had lots of friends. For example, one father said of his daughter, "She's little Miss Popularity."

The context of their children's friendships was also a factor for some parent respondents. These parents noted that their children had friends in some contexts but not others (for example, friends from a past school but no friends in current school). These respondents tended to answer "some difficulty" because while their children have friends, they do not interact with them during their regular school day. For example, one mother who answered "some difficulty" said:

He's very active in boy scouts, very gregarious in boy scouts, has no difficulty making friends at all, but he's very selective about where he makes friends, and so has not developed one solid friendship at his high school. [where he has been for] 2 years.

Likewise, several parents whose children did not invite their school friends to their houses, also answered "some difficulty." One parent explained "he has friends, but I don't think he communicates a lot,...I'll tell him invite your friends to paintball, and he'll choose not to tell them."

Level and type of social contact influenced respondents' answers as well. Respondents frequently considered their perceptions of the closeness their teens' friends. Some parents noted that their children did not have "real friends" meaning close friends. One of the respondents who said her son had "a lot of difficulty" making friends explained that it took her son months to find a group of friends to sit with at

lunch and that he still did not have any "real" friends. On the other hand, another mother answered "no difficulty" and explained that her daughter is an introvert and that "she doesn't have a big group of friends, but she doesn't want a big group of friends, I don't understand it...[my daughter thinks] 'a couple of people that I really like, that's good enough to for me' and she's very close with the friends she has."

Friendship skills: Some respondents also thought about their children's social skills in making and keeping friends when answering this question. Respondents who thought their child had good social skills and had "no difficulty" making friends said things like "he makes friends real easy, when we go on vacation, he always makes a friend." Other parents also answered "no difficulty" describing how their shy teens had the ability to make friends when needed. One such mother explained, "It's not like she makes good friends quickly, but she's never had problems."

This interpretation extended to children's ability to keep friends. Several parents who reported their child had "some difficulty" making friends, made comments about their child's ability to keep friends. One mother said, "It's easy for her to make friends, but keeping them is kind of a challenge." Or another who explained "I don't think she had difficulty making friends per se, but I think she might have difficulty keeping friends sometimes."

A minority of parents attributed their child's lack of friendship skills to either anxiety or autism. Parents of children whom they described as socially anxious or awkward said this could interfere with making new friends. One mother stated "his social skills are not that great...he's a talker and can become annoying."

**Uncertainty:** Some respondents expressed uncertainty about how best to respond to this question. Parents were not always aware of their teens' friendships since their teens did not bring friends over or go out with their friends often. For example, one mother stated that her teen:

... could have a full social life on his phone; we don't know. The nature of friendship has changed in a generation, for me it was you spent all your time on the phone or hanging out, and now they're hanging out virtually, so I could be totally clueless. We don't know.

T22. TEENS: DO YOU HAVE DIFFICULTY MAKING FRIENDS?

No difficulty 23 Some difficulty 17 A lot of difficulty -Cannot do at all -

This question was asked of all teen respondents.

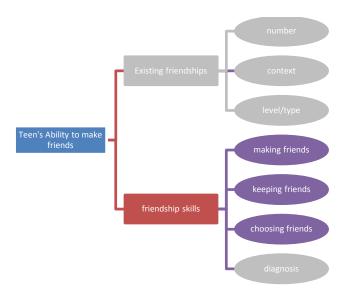


Figure 27. Schema of Teen Responses to Question on Making Friends (T22) \*

\*Gray indicates patterns not seen in this set of respondents

**Interpretation:** Teens focused on their friendship skills when answering this question.

Friendship skills: Most respondents answered based on their ability to make friends when put in an unfamiliar situation. One teen, who answered "no difficulty" said:

A lot of people tell me I make friends very easily and I'm friendly and that's how I know so many people, because if I go to the rec center or something and I don't know anybody there, I'm still going to find a way to know somebody so I that can play with them, play basketball with them.

Another teen, who also answered "no difficulty" explained, "I've never had trouble making friends. I meet someone – boom you're my friend."

Respondents who said they had "some difficulty" making friends in new situations generally attributed this to shyness or anxiety. For example, one respondent explained "I'm not the most outgoing person, I'm not going to just go to somebody and start talking to them, and that's what I meant by making friends." Likewise, another said "If I'm in a strange environment, then I'll be really shy and not outgoing." Many in this group did have close friendships, but they were established friendships, and they thought primarily about the time and easy of making new friends when answering the question.

Some teens thought about their ability to keep friends when answering this question. For example, one teen who answered "some difficulty" said this was because friends had "dropped her" in the past. She described the experience of losing one particular friend:

all the sudden she stopped talking to me and started talking to other people....when she gets around certain people, and they don't like me and they don't even know me. She's like "oh, you don't like her, I don't like her either."

A few respondents thought about their ability to choose people to be friends with. Some answered that they had "no difficulty" making friends because they could identify people who would make good

friends, while others answered "some difficulty" because some of their friends were not true friends. For example one teenager who answered "no difficulty" talked about part of making friends as being able to avoid "fake people" and pick "real friends." She explained, "There's a lot of people that try to be your friend, and it's not right, there's a lot of fake people out there and there's a lot of real friends ..." Similarly several respondents said they had "some difficulty" because they were "selective" in their choosing friends and did not find people in their school they wanted to pick as friends. For example one boy who said he had "some difficulty" making friends explained, "It's not that I don't have friends, it's that just I'm sorta cautious about making new friends...not just overly rushing into friendships."

## Dyad Analysis for CFD22 and T22

Table 18. Agreement between parents and teens on teens' relationships (CFD22 and T22)

		Parents				
		No			Cannot Do at	
		difficulty	Some Difficulty	A lot of Difficulty	All	Total
Teens	No Difficulty	16	4	3	0	23
	Some Difficulty	4	8	4	0	16
	A lot of Difficulty	0	0	0	0	0
	Cannot Do at All	0	0	0	0	0
	Total	20	12	7	0	39

Interestingly, parents and teens were focused on different areas when answering this question. The question asks about *making* friends, and, in fact, teens focused exclusively on the skills of friendship. Parents, on the other hand, focused on their teens existing friendships. This may be related to parents' uncertainty about how to answer this question. It is possible that description of existing friendships is a form of indirect observation of teens' friend-making skills, but parents' assessment of these friendships had more to do with parental expectations of the number and type of friendships their children should have than with their children's friendship skills. Thus the parents' answers tended to be slightly out of scope.

This question may be better answered by teens than by their parents. When the parents were asked, there were more "false positives" due in part to interpretations of the question that tended to be out of scope. Teens, on the other hand, provided lower difficulty ratings with in scope interpretations. However, regardless of who was asked, no severe cases were missed.

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CHILD FUNCTIONING AND DISABILITY (AC	GE 5-17)	CFD
CFD1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE.		
DOES (name) WEAR GLASSES?	Yes	
CFD2. [WHEN WEARING HIS/HER GLASSES], DOES (name) HAVE DIFFICULTY SEEING?		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
CFD3. DOES (name) USE A HEARING AID?	Yes	
CFD4. [WHEN USING HIS/HER HEARING AID(S),] DOES (name) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC?		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
<b>CFD5</b> . DOES ( <i>name</i> ) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes	2⇔CFD10
CFD6. WITHOUT USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].		
WOULD YOU SAY ( <i>name</i> ) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty	4⇔CFD8
CFD7. WITHOUT USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].		
WOULD YOU SAY ( <i>name</i> ) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty	
CFD8. WHEN USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].		

WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	4⇔CFD9
CFD9. WHEN USING HIS/HER EQUIPMENT OR ASSISTANCE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇔CFD12
CFD10. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	4⇒CFD12
CFD11. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇔CFD12
<b>CFD12</b> . DOES ( <i>name</i> ) HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING HIM/HERSELF?		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇔CFD13
CFD13. WHEN (name) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF THIS HOUSEHOLD?		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	

CFD14. WHEN (name) SPEAKS, DOES HE/SHE			
DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  CFD15. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY LEARNING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  CFD16. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY REMEMBERING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY REMEMBERING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY REMEMBERING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY REMEMBERING THINGS?  WOULD YOU SAY (name) BEEM ANXIOUS, NERVOUS OR WORRIED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  MONTHLY A TEMEMBER A YEAR OR NEVER.  THE SAME AGE, DOES (name) HAVE DIFFICULTY TOES	HAVE DIFFICULTY BEING UNDERSTOOD BY		
SAME AGE, DOES (name) HAVE DIFFICULTY LEARNING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  CFD16. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY REMEMBERING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, A LOT OF DIFFICULTY, OR CANNOT DO AT ALL?  CFD17. HOW OFTEN DOES (name) SEEM ANXIOUS, NERVOUS OR WORRIED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  CFD18. HOW OFTEN DOES (name) SEEM SAD OR DEPRESSED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  Weekly 2  Monthly. 3  A few times a year. 4  Never. 5  CFD19. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DIFFICULTY DOES (name) HAVE CONTROLLING HIS/HER BEHAVIOR?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  The same or less 22  More 3  A lot more 4  CFD20. DOES (name) HAVE DIFFICULTY FOCUSING ON AN ACTIVITY THAT HE/SHE	DIFFICULTY, SOME DIFFICULTY, A LOT OF	Some difficulty2 A lot of difficulty3	
DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  CFD16. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (name) HAVE DIFFICULTY REMEMBERING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  CFD17. HOW OFTEN DOES (name) SEEM ANXIOUS, NERVOUS OR WORRIED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WEEKLY 2  Monthly. 3  A few times a year. 4  Never. 5  CFD19. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DIFFICULTY DOES (name) HAVE CONTROLLING HIS/HER BEHAVIOR?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  None. 11  1⇒CFD20  The same or less 2  A lot more. 4  CFD20. DOES (name) HAVE DIFFICULTY FOCUSING ON AN ACTIVITY THAT HE/SHE	SAME AGE, DOES (name) HAVE DIFFICULTY		
SAME AGE, DOES (name) HAVE DIFFICULTY REMEMBERING THINGS?  WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  CFD17. HOW OFTEN DOES (name) SEEM ANXIOUS, NERVOUS OR WORRIED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WEEKLY 1  Daily 1  Weekly 2  Monthly 3  A few times a year 4  Never 5  CFD18. HOW OFTEN DOES (name) SEEM SAD OR DEPRESSED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  Monthly 3  A few times a year 4  Never 5  CFD19. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DIFFICULTY DOES (name) HAVE CONTROLLING HIS/HER BEHAVIOR?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  A lot more 3  CFD20. DOES (name) HAVE DIFFICULTY FOCUSING ON AN ACTIVITY THAT HE/SHE	DIFFICULTY, SOME DIFFICULTY, A LOT OF	Some difficulty2 A lot of difficulty3	
DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  CFD17. HOW OFTEN DOES (name) SEEM ANXIOUS, NERVOUS OR WORRIED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  Daily	SAME AGE, DOES (name) HAVE DIFFICULTY		
ANXIOUS, NERVOUS OR WORRIED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  Weekly	DIFFICULTY, SOME DIFFICULTY, A LOT OF	Some difficulty2 A lot of difficulty3	1⇔CFD17
MONTHLY, A FEW TIMES A YEAR OR NEVER?   Weekly			
OR DEPRESSED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?  Weekly		Weekly2Monthly3A few times a year4	
MONTHLY, A FEW TIMES A YEAR OR NEVER?       Weekly			
SAME AGE, HOW MUCH DIFFICULTY DOES (name) HAVE CONTROLLING HIS/HER BEHAVIOR?  None		Weekly2Monthly3A few times a year4	
WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?  The same or less	SAME AGE, HOW MUCH DIFFICULTY DOES (name) HAVE CONTROLLING HIS/HER		
FOCUSING ON AN ACTIVITY THAT HE/SHE		The same or less2 More	
	FOCUSING ON AN ACTIVITY THAT HE/SHE		
No difficulty		No difficulty1 Some difficulty2	

WOULD YOU SAY (name) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	A lot of difficulty	
CFD21. DOES (name) HAVE DIFFICULTY ACCEPTING CHANGES IN HIS/HER ROUTINE?		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	1⇔CFD22
<b>CFD22</b> . DOES ( <i>name</i> ) HAVE DIFFICULTY MAKING FRIENDS?		
WOULD YOU SAY ( <i>name</i> ) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	

# **Teen Instrument 12-17**

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T1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOU MAY HAVE IN DOING CERTAIN ACTIVITIES.		
Do you wear glasses?		
	Yes	
T2. [WHEN WEARING YOUR GLASSES], DO YOU HAVE DIFFICULTY SEEING?		
WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
T3. DO YOU USE A HEARING AID?	Yes1	
	No2	
T4. [WHEN USING YOUR HEARING AID(S)], DO YOU HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY,	No difficulty	
SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Cannot do at all4	
T5. DO YOU USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes	2⇔T10
T6. WITHOUT USING YOUR EQUIPMENT OR ASSISTANCE, DO YOU HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL	Some difficulty1 A lot of difficulty2	

	T	
GROUND? THAT WOULD BE ABOUT THE LENGTH OF $1$ FOOTBALL FIELD.	Cannot do at all3	3⇒T8
WOULD YOU SAY YOU HAVE: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?		
T7. WITHOUT USING YOUR EQUIPMENT OR ASSISTANCE, DO YOU HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS?  WOULD YOU SAY YOU HAVE: SOME DIFFICULTY, A LOT OF DIFFICULTY OR	Some difficulty	
CANNOT DO AT ALL?		
T8. WHEN USING YOUR EQUIPMENT OR ASSISTANCE, DO YOU HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	4 <b>⇒</b> T12
T9. WHEN USING YOUR EQUIPMENT OR ASSISTANCE, DO YOU HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELD. WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
T10. Do you have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field.	No difficulty	
WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?		
T11. DO YOU HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS.	No difficulty	
WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?		

T12. DO YOU HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING YOURSELF?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty
T13. WHEN YOU SPEAK, DO YOU HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF YOUR HOUSEHOLD?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty
T14. WHEN YOU SPEAK, DO YOU HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE OUTSIDE OF YOUR HOUSEHOLD?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?  T15. DO YOU HAVE DIFFICULTY LEARNING THINGS?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR	No difficulty
T16. Do you have difficulty remembering things?	A lot of difficulty
WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty
T17. HOW OFTEN DO YOU FEEL ANXIOUS, NERVOUS OR WORRIED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?	Daily       1         Weekly       2         Monthly       3         A few times a year       4         Never       5
T18. HOW OFTEN DO YOU FEEL SAD OR DEPRESSED?  WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?	Daily       1         Weekly       2         Monthly       3         A few times a year       4         Never       5

T19.COMPARED TO CHILDREN OF THE SAME AGE, HOW MUCH DIFFICULTY DO YOU HAVE CONTROLLING YOUR BEHAVIOR?  WOULD YOU SAY: NONE, THE SAME OR LESS, MORE OR A LOT MORE?	None       1         The same or less       2         More       3         A lot more       4	
T20. DO YOU HAVE DIFFICULTY FOCUSING ON AN ACTIVITY THAT YOU ENJOY DOING?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
T21. DO YOU HAVE DIFFICULTY ACCEPTING CHANGES IN YOUR ROUTINE?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	
T22. DO YOU HAVE DIFFICULTY MAKING FRIENDS?  WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty	