

**Cognitive Interviewing Exploration of Inconsistencies in Reports from the
State and Local Area Integrated Telephone Survey program (SLAITS) Questions for the
2011 National Survey of Children with Special Health Care Needs (NS-CSHCN) and the
Survey of Pathways to Diagnosis and Services**

Interviews conducted December 6, 2010 – December 17, 2010 and May 17, 2011- May 31, 2011

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I. Introduction

Inconsistencies in parental reports of their children’s behavioral health conditions were found between the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) and the follow-up 2011 Survey of Pathways to Diagnosis and Services (Pathways) where the same parents were asked the same questions at two time points. The nature and frequency of these inconsistencies indicated potential question design problems. Twenty-four cognitive interviews were conducted. Analysis reveals that the complexity of the experiences parents are asked to report can lead to the potential for shifting answers.

The following report is divided into four sections. The next section, section two, discusses the methods used in this report including the interviewing procedure, sample selection, and sample characteristics. Section three provides an overview of the various paths of question response that could lead to inconsistencies, the main factors parents thought about when answering the questions, and the potential usefulness of follow-up survey questions. Section four provides the question-by-question analysis that shows patterns of interpretation to understand how respondents answered the questions. Appendix A includes the questionnaire that we used in the interviews. Parenthetical numbers denote respondent ID’s.

II. Method

Cognitive interviews are commonly used in the survey research world as a pre-testing method to test survey questions before they go into the field. Cognitive interviews can show how respondents go through the response process when answering survey questions. Specifically, they can show how respondents understand a question and identify potential sources of response error that may suggest changes in the question. With this technique, interviewers administer survey questions, obtain a response, and then probe respondents for other information relevant to the question. Probing can be conducted either concurrently (i.e., immediately after the survey question is administered) or retrospectively (i.e., after the entire survey has been administered).

For this project, researchers employed retrospective probing. Specifically, respondents answered all of the questions before we went back and probed their answers. As a qualitative method, cognitive interviews can also be used in a mixed-method framework to help explain inconsistencies in survey data that cannot be answered with numbers alone. This project was slightly different than our usual evaluation projects because we were not testing the questions per se, but rather we wanted to get the respondent’s narrative to help us understand potential reasons for inconsistent survey reports. To elicit rich narrative we asked open-ended questions at the end to get context for the respondent’s experiences with their children.

Interviewing Procedure

Interviewing was conducted at the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics. Interviews were conducted face-to-face and the average interview length was no longer than one hour. Respondents were recruited in two rounds, December 2010 and May 2011, because of a shift in the research focus of this study. In December 2010 nine interviews were completed and in May 2011 fifteen interviews were completed. In total, we conducted twenty-four interviews, all in English. Only the interviews in May included the open-ended question at the end and in these interviews we followed up on all conditions identified in Question 1 instead of only picking the one with the highest priority to the survey sponsors. As a result, there was more information to work with from the May 2011 interviews so the report is weighted more heavily towards those interviews but information from all the interviews is used when possible.

Sample Selection

Respondents were recruited from newspaper advertisements. The December 2010 newspaper ad targeted parents who had children with Autism or Autism Spectrum Disorders, who were once diagnosed with Autism but no longer have it, or were uninsured. The May 2011 newspaper ad targeted parents with children who have difficulties in any of the following areas: emotions, concentration, behavior, being able to get along with other people. Respondent demographics for the full sample are shown in Table 1. Our sample was mostly female, between the ages of 40-59, Non-Hispanic Black, and had completed some schooling beyond high school. Respondents were selected with a purposive sample in mind, and each participant was given a \$40 remuneration for their participation.

Table 1: Sample Characteristics

	N=24	Total (%)
Gender	Female	18 75%
	Male	6 25%
Age	30-39	1 4%
	40-49	12 50%
	50-59	7 29%
	60-69	3 13%
	70+	1 4%

Hispanic/Non-Hispanic	Hispanic	0	
	Non-Hispanic	24	100%
Race/Ethnicity	Black	20	83%
	White	3	13%
	American Indian	1	4%
Education	Less than HS	1	4%
	HS/GED	5	21%
	Some college	18	75%

III. Summary of Findings

The survey sponsors were puzzled by inconsistencies they found in their data and we conducted twenty-four cognitive interviews to help them better understand the process respondents went through when answering the questions. They fielded the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) and compared the responses to questions about children's current status on a variety of behavioral health conditions to the responses from the same respondents in the follow-up 2011 Survey of Pathways to Diagnosis and Services (Pathways). They found what appeared to be inconsistencies in these reports for a larger number of respondents and thought there might be something else going on other than a real change in these conditions that could explain these inconsistencies. Specifically, they were interested in the inconsistencies that occurred when parents reported that they had been told their child had some behavioral health condition in the past but that they do not currently have the condition in the 2009-2010 NS-CSHCN survey but then reported that they do currently have the condition in the 2011 Pathways follow-up. Inconsistencies in the data can be problematic because they alter national estimates of the proportion of children with these conditions. The goal of the cognitive interviews was to try and understand the process respondents' go through when answering these questions to see if there were response patterns that potentially could lead to inconsistencies in reports of children's current behavioral health status. Although the inconsistencies in the survey data were identified using two time points of data from the same respondents, the respondents from the cognitive interviews were only interviewed once. Therefore, it is not possible to know for sure that the response patterns identified in the cognitive interviews would lead to inconsistencies in reports at different time points. Nonetheless, the analysis of cognitive interviews can identify various interpretive response patterns that have the potential to lead to inconsistent reports.

Overall, the narratives that were captured from parents about their children's behavioral health conditions illustrate how the complexity of understanding and dealing with these conditions renders answering questions about these conditions a difficult task. Parents are often juggling information they hear from doctors or health care providers (hereafter combined with the term 'doctor' unless otherwise specified) with their understanding of the conditions and observations of their children's symptoms/behaviors. The information they hear from doctors can complicate the situation because they often are not given a definitive diagnosis or the diagnosis they are given changes. They also can be told different things about their child's condition from different doctors. Some parents do not believe what the doctors say about their children because it may not fit with what they see their children doing or their understanding of the conditions. The nature of behavioral health conditions may complicate the situation even further because they may be less concrete than other physical conditions like a broken bone where the evidence that it exists and the treatment method are more straightforward. Sometimes the symptoms of these conditions come and go or change over time. Additionally, the majority of parents reported that their children were dealing with more than one behavioral health condition simultaneously. The symptoms of these conditions can be similar or can have compounding reactions that blur the boundaries of the conditions and make it difficult for parents to talk about each condition distinctly. The complexity of the experiences parents are asked to report about can lead to the potential for shifting answers. Exploring the ways in which parents' understandings of their child's condition is shaped, as well as ways in which those understandings can shift, provides insight into why inconsistencies could then be found in survey data.

To investigate the potential for response patterns that could lead to inconsistent reporting of the current status of behavioral health conditions we did an analysis of response patterns to the question "*Does [SC] currently have [CONDITION]?*". Because there was particular interest in the inconsistent pattern where the parent answered this question 'No' in the first survey and then 'Yes' in the second survey, we focus on understanding why parents said 'No' to this question. Eight respondents responded 'No' to this question for at least one of the conditions they had been told their child had; this group is labeled as the '*not currently*' group. Three interpretive themes were identified across these eight respondents. The three patterns of interpretation that explain why parents reported '*not currently*' are: 1) Disagreement between the parent and doctor, 2) Fluid nature of the condition, and 3) Change in diagnosis. Each of these will be described in more detail below.

When looking at the parents who reported '*not currently*' we found that for some parents the story behind this answer was not so straightforward and it was masking an unresolved tension between the doctors' and parents' beliefs about whether or not their child has some condition. Sometimes the parent's perception of their child did not agree with the doctor's assessment of their child and they had to weigh these alternate perspectives when deciding what to report. Some parents reported the doctor's assessment while others reported based on their own perceptions, but ultimately all of these eight parents reported that their child does not currently have the condition. The nature of the differences between the parents' and doctor's perceptions came out in probing. The most common pattern of disagreement occurred where the doctor diagnosed the child with a condition that the parent did not think their child had so the parent answered according to their own belief and reported in the '*not currently*' group. For example, one mother said, "One therapist diagnosed it as ADHD and wanted to slap on some medicine and I

said no” (3258). Parents did not agree with the doctor’s diagnosis of their child for a variety of reasons including their child’s behavior did not match their understanding of the condition, they thought their child’s behavior was normal, they wanted more concrete tests and evidence to show their child has a condition, and their child’s symptoms have improved so they no longer think they have a condition. Although more rare, sometimes it was the doctor who did not think the child had a condition and the parent who thought they did, but ultimately the parent reported along the lines of the doctor’s assessment in the *not currently* group. For instance, one parent’s son tested negative for Autism, but the mom said, “The way RJ does things sometimes I say he do...I think there’s something there but I don’t think it’s complete Autism” (3248). This particular parent had fostered several other children with Autism and so she was familiar with the symptoms of Autism and could see some of them in her son RJ even though she admits she does not think it is complete Autism. Given that there isn’t consensus between the parent and doctor about the state of the child’s condition and the parent has to give a yes or no answer, this creates the possibility for shifting answers. As seen in the interviews, sometimes parents report consistently with their perception of their child and other times parents report consistently with the doctor’s perception. Parents could plausibly shift whose perspective they weigh more heavily in their report at different time points and thus show inconsistencies in their reports. It is also possible that disagreements can change to agreements over time. We had one parent who explicitly talked about how he and his wife used to disagree with the doctor about their child’s diagnosis, but over time came to agree with it as they learned more about the condition (3261).

We also found that the fluidity of these conditions was masked by a straightforward yes or no answer because sometimes the symptoms of these conditions come and go. For example, one parent said her daughter currently has depression but she is “in and out, off and on” (3245). Although these parents ultimately reported ‘*not currently*’, it does seem possible that they could have said yes to this question and would still be accurately reporting about their child’s condition. It is also possible that at another time point the child’s condition could be more active and the parent would then say yes they currently have the condition. The fluidity of the conditions creates a situation where there is the potential for shifting answers when parents are forced to answer in a clear-cut yes or no format that may not fit their experiences. Some conditions, like depression, may be more fluid than other conditions asked about in the survey so the shifting may be more likely to occur for some conditions more than others. In our interviews, this theme only occurred for parents reporting about depression, anxiety, and ADD/ADHD.

Other times, parents reported ‘*not currently*’ because a previous diagnosis had been changed. Sometimes the diagnoses were dropped completely and other times the diagnosis was reclassified as another condition. One mother explained that she had been told by a doctor that her daughter no longer has Autism. She said, “To be honest, she might not have been properly diagnosed, but I’m not a doctor” (2578). In this case the diagnosis was dropped completely. Another mother explained how her child was not getting better under the Autism classification so the educational team reassessed him and said he had an intellectual disability (3129). After this reclassification his symptoms seemed to improve. In situations where a diagnosis has been changed by a doctor before being asked at Time 1, it seems less likely that that diagnosis would change back to where they would say their child has the condition again at some point in the future. In other words, parents who say *not currently* at Time 1 because of a previous change in diagnosis are probably not likely to report their child *currently* has the same condition at Time 2.

However, it is possible that the diagnosis change could occur between Time 1 and Time 2 such that the respondent reports their child *currently* has the condition at Time 1 and then reports *not currently* at Time 2. This would look like an inconsistency in the data that could represent a real change in the diagnosis.

Main Factors behind Parents' Answers

Across all questions, the factors below summarize various ways in which parents based their answers to survey questions. The factor that seemed to have the biggest influence on parental answers had to do with whether they answered questions based on what the doctor told them or their own perceptions about their child's condition. The other factors stemmed from or were related to this main decision making factor. Many of these factors are interrelated and therefore are not mutually exclusive. Several of these factors could be involved simultaneously in parents' answers. The eight main factors are listed below with a brief description.

1. Doctor diagnosis or parents' perceptions
 - a. Parents talked about what doctors (or other health care providers) have told them and also what they believe regarding their children's behavioral health conditions. Sometimes the doctor and parent were in agreement about their child's condition but other times they were not.
2. Basis for parents' perception
 - a. Parents often base their perception about their children's condition(s) on their observations of their child's behavior coupled with their understanding of the condition.
3. Real diagnosis or suggestion
 - a. Parents are not always given a concrete diagnosis, but rather are sometimes told their child could possibly have or has the symptoms of a particular condition. Parents can then make their own interpretations or incorporate other opinions into their belief about what is going on with their child.
4. Basis for diagnosis
 - a. When parents talked about a diagnosis, and this term is used loosely, they considered a variety of people including doctors, therapists, teachers, special education coordinators, etc. Who they thought of or who they considered a "health care provider" may or may not have fit with how the survey sponsors defined this term.
5. Differing diagnoses
 - a. Parents sometimes had received conflicting diagnoses from different doctors or the diagnosis has changed over time and this made answering the questions difficult because they had to decide which diagnosis to report.
6. Whether or not child still exhibits behavior
 - a. Parents often gave examples of their children's behaviors when explaining why they think their child does or does not have a particular condition. Some parents

cited the same behavior in their children but then made opposite judgments about what that meant in terms of whether or not their child has a condition.

7. Influence of medications

- a. Medications were used in parents' justification both for whether their child has a condition and does not have a condition.

8. Definition of the condition

- a. Parents can have different definitions or understandings of these behavioral health conditions compared to each other and also perhaps what the survey sponsors intended.

Some factors seemed to be more predominate for particular conditions most likely because of the nature of the conditions. For example, differing diagnoses were common for Autism Spectrum Disorders because doctors were hesitant to put a clear label on the child, they received conflicting diagnoses from different doctors, or the diagnosis changed to another condition at some point. Behavior or conduct problems seemed to have less clear diagnoses and were often more of a suggestion from a doctor or based on the parent's perception of their child's behavior. Parents talked about how depressive symptoms were not always present but turned on and off at different periods of their child's life based on their observations of their child's behavior. Developmental delay and intellectual disability/mental retardation were the hardest for parents to define but their definition of the condition impacted how they answered the questions. With ADHD/ADD parents were more likely to talk about disagreeing with a doctor diagnosis, reporting their perceptions based on observations of their child, and the influence of medications on their perception of their child's condition. Anxiety seemed to have less clear definitions and diagnoses perhaps because the symptoms are similar to depression and ADHD and other conditions like panic attacks and PTSD.

Follow-up Survey Questions

Based on the eight main factors that go into parents' answers about their child's condition(s) it is possible to think about potential follow-up survey questions that could be used in the questionnaire to generate statistical data that would further explain why parents answered the questions the way that they did. Analyzing the frequencies to these follow-up questions would provide estimates of the prevalence of these different factors. If some factors lead to response patterns that are undesirable from the survey sponsor's standpoint then these respondents could be selected out of particular analyses. It would also give the survey sponsors an estimate of how much influence these undesirable versus desirable response patterns are having on their data. Even if all the response options were found to be within the scope of what the survey sponsor intended to measure, it would still be useful to know if some response patterns are more common than others because then it gives the survey sponsors a better understanding of what their questions are measuring. As examples, a few potential follow-up survey questions are listed below.

- Was this based on your own belief or an actual diagnosis?
- Was there an actual diagnosis given from a doctor or health care provider?
- Was this based on your own observations of your child or something a doctor told you?

- Did medication improve your child’s symptoms?
- Have you been confused about what condition your child has because doctors have told you different things?

IV. Question-by-Question Review

This section of the report presents findings from the question-by-question analysis conducted on all survey questions that were examined. Questions were administered to all 24 respondents and were probed retrospectively. This evaluation includes descriptions of how respondents interpreted question, evaluations of question performance and, where appropriate, researchers also point out areas that may lead to potential response error.

Q1 INTRO: I am going to read you a list of conditions. For each condition, please tell me if a doctor or other health care provider ever told you that [SC] had the condition, even if [he/she] does not have the condition now.

Though Question 1 is broken into seven parts, we nonetheless found issues and concerns that were consistent across these different parts. The first issue relates to whether or not respondents took into account the question’s reference to “a doctor or other health care provider” when asked to answer if their child had ever been diagnosed with each of the different conditions. While most respondents appeared to answer the question as it is posed, specifically, whether or not a doctor or other health care provider had in fact made such a diagnosis, there were nonetheless a significant number of instances where respondents based their answers instead on their own personal sense of whether or not their child had the particular condition. Related to this issue, there were also instances where respondents described how a teacher or someone other than a doctor had diagnosed the child with the particular condition. Although respondents often did not consider these persons to fit the “doctor or other health care provider” description and consequently answered no, this was not always the case. At best it suggests that there may be some confusion or room for divergent interpretations of this question.

The second concern consistent across the seven different subparts of Question 1 pertains to how respondents understood the different conditions. Without knowing how the sponsors themselves define these concepts, we do not attempt to ascertain whether or not respondents’ interpretations were “correct,” but rather, we summarize their descriptions and interpretations of these concepts. We recognize that on some level their understandings of these concepts may be irrelevant to the question since what they really need to assess when answering the question is if, in fact, a doctor or other health care provider diagnosed their child with the condition. However, this may be useful information for sponsors because it may highlight areas where there appears to be some confusion or misunderstanding (or not) among respondents. It can also be important if the respondents are forgoing the doctor’s diagnosis and basing their answers on their own perceptions.

A final concern and one that is related to the one mentioned above, was the extent to which respondents understood the conditions as mutually exclusive. A majority of respondents reported more than one condition present. In fact, 16 of the 19 respondents who reported that their child

had a condition reported more than one condition, and 12 of these 19 reported that their child had 3 or more conditions (*see Table 2*). This suggests that, at best, respondents are being asked to think about multiple conditions in their minds at once, and at worst, respondents may experience difficulty when trying to distinguish between the different conditions they find presented to them. As their in-depth narratives indicate, the diagnosis of these conditions did not typically occur at one discreet moment in time, but rather diagnoses were often added, removed, altered, or supplanted with a different diagnosis. This highlights the extent to which respondents may have trouble keeping overlapping conditions distinct.

1A. Attention Deficit Disorder or Attention-Deficit Hyperactivity Disorder, that is, ADD or ADHD

Yes = 14 No = 10

The majority of respondents who were administered this question responded affirmatively, specifically that yes their child was at some point diagnosed with ADHD or ADD (n=14). Regardless of their answer, there was some indication that their answers were subject to some ambiguity. First, several respondents explained that they answered ‘No’ because the person who diagnosed the condition was not “a doctor or other health care provider.” For instance, one person was thinking of a teacher when answering this question. Secondly, several respondents who answered ‘No’ appeared to have answered incorrectly. In one case, the respondent had forgotten about an interaction between a psychiatrist and her daughter which resulted in a positive diagnosis. In another case, a respondent who answered ‘No’ nevertheless revealed that she recalled being given a prescription for her son’s ADHD. She had refused to fill this prescription, however, which may account for her discrepant answer. In other words, her steadfast disagreement with the official diagnosis may explain why she answered the question incorrectly. Finally, one respondent asked that the question be reread because she wanted to make sure that it was in fact asking whether or not a doctor had told her that her child had ADHD (3263).

There was also indication that there was potential for ambiguity in answers among those who answered ‘Yes’ to this question. For instance, one respondent answered ‘Yes’ but explained that this was not the first diagnosis given to her daughter. She was originally labeled as retarded, which the respondent attributed to a “strong cultural divide” in the rural area where she lived when the diagnosis was made. Though she answered the question accurately, the fact that the ADHD diagnosis came to supplant a previous diagnosis might point to the complexity of the diagnoses and these kinds of behavioral health conditions that respondents have to think about when answering these questions. Another respondent answered ‘Yes’ but explained that she strongly disagreed with the diagnosis, though she admitted that her son’s symptoms were consistent with the symptoms associated with ADHD. However, she was reluctant to label her child as such because of what she perceived as cultural biases that might result. Another respondent who answered ‘Yes’ insisted on offering a caveat – namely, that his son’s ADHD was “controllable.” Further probing, however, revealed that the doctor his son had seen had not told the respondent with certainty that his son did, in fact, have ADHD.

When asked to reflect on their understanding of the term ADHD, respondents, including those who answered ‘Yes’ as well as those who answered ‘no,’ appeared to offer consistent interpretations of this concept. The symptoms they most often described included having problems paying attention and problems focusing and keeping on one task, particularly as it relates to school work. For example, one respondent described how children with ADHD are not able to sit for long periods of time and need “something to keep them busy.” In fact, a noteworthy number of respondents used the exact phrase “can’t sit still” when describing the symptoms that typically accompany ADHD. In the cases where respondents’ children were diagnosed with ADHD, they typically said the problem became most apparent in the context of school, and indeed, most described symptoms related to problems completing school work.

1B. Depression

Yes = 9

No = 15

A majority of respondents answered ‘No’ to this question. In all instances where respondents answered ‘Yes’, they indicated elsewhere in the interview that another condition was also present. In other words, all children who were diagnosed with depression were also diagnosed with another condition or conditions. In some of these cases, the distinction between depression and these other conditions was not always clear for respondents. For instance, one respondent answered ‘Yes’ but when discussing the diagnosis explained that it was very much intertwined with her son’s ADHD and therefore spoke of both conditions simultaneously. Another respondent explained that her son’s Autism leaves him feeling alone and isolated, or in clinical terms “depressed.” Therefore his depression was seen as a direct result of having Autism.

There were several instances where respondents appeared to answer the question incorrectly. In two cases, the respondent answered ‘Yes’ but was basing his or her answer not on a doctor or health care provider’s diagnosis but rather his or her own assessment of the presence of depression. In another case, the respondent answered ‘No’ but upon probing revealed that she had in fact met with a counselor who said her daughter had issues with both depression and anxiety. She said she did not think of this when she first heard the question because she thought the question was referring to having a full-fledged depression disorder rather than just having depressive symptoms, which she thought more accurately characterized her daughter. Another respondent initially hedged a little but finally answered ‘yes.’ She explained that her hesitation was due to her belief that her son could “overcome” the depression. On top of this, further probing revealed that a doctor or other health care provider had never in, in fact, diagnosed her son with depression, and therefore she answered the question incorrectly. Another respondent described how her son exhibited traits consistent with her understanding of depression but nevertheless answered ‘no.’ However; it was unclear if she did so because her son had never actually been diagnosed by a doctor or other health care provider or if this was simply an instance of response error.

Though most respondents were not probed extensively on this issue, we were able to get somewhat of a sense as to how respondents understood “depression.” One respondent defined it as “being isolated and quiet” and exhibiting a “lack of communication.” Another respondent defined it as “someone who is sad all the time” and experiences many “highs and lows.”

Similarly, another respondent who also answered 'No' defined it as "not being active" and experiencing isolation.

1C. Anxiety problems

Yes = 10 No = 14

Analysis of this question revealed several cases where respondents appeared to answer the question incorrectly. Some of these cases were clear instances of response error. For example, one respondent answered 'Yes' but then revealed that her child never had anxiety problems. She explained that she answered incorrectly because she was forced to answer 'Yes' or 'no.' Another respondent who answered 'Yes' said that her daughter "slightly has this." However, probing revealed that she was basing her answer entirely on her own observations and not a doctor or other health care provider's diagnosis.

In other cases it was less clear that respondents had responded incorrectly, but there was some indication that they might have done so. For instance, one respondent answered 'Yes' but explained with the caveat that the diagnosis was "not official." She explained that the category "anxiety" was marked on a form for insurance purposes, but she was not sure if this counted as an official diagnosis or not. Another respondent answered 'No' but revealed that her daughter's counselor did mention that she needed to "find ways to cope with anxiety," which seems to suggest that there was some sort of anxiety diagnosis. However, this same counselor described her daughter's anxiety as "pretty typical for her age" and therefore may not have thought it warranted an official diagnosis. Another respondent initially answered 'No' but upon reflection said that anxiety could be tied to ADHD, a condition that his son has been officially diagnosed as having. He speculated that his son must feel anxiety, and though he was never diagnosed officially as far as he knew, it was possible in his mind that his son did in fact have an anxiety disorder.

Respondents were also probed on their interpretations of the term "anxiety disorder." One respondent thought this referred to being excessively worried. Another described it as being "impatient." Lastly, one respondent who answered 'Yes' to the question said she did so because her son was a perfectionist and would get "very down on himself" when his homework was not perfect. To her these behaviors were characteristic of an anxiety disorder.

1D. Behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder

Yes = 12 No = 11 Refused = 1

Analysis of this question revealed a significant amount of ambiguity in the respondents' answers. In fact, a number of respondents even specifically stated that they wanted to give "in between" answers or wanted to answer "sometimes" rather than 'Yes' or 'no.' One of these respondents finally answered "refused" because neither a 'Yes' nor a 'No' answer accurately portrayed his answer. However, it appeared that he was basing his answer on his own sense of whether or not his son has behavioral or conduct problems and not whether or not his son has been *diagnosed*

with these problems. In fact, in almost all of the cases where there appeared to be some ambiguity, the ambiguity was not over whether or not the child had been diagnosed but whether or not the child did in fact have these conditions, which are clearly two separate issues. In two other cases, the respondents answered 'Yes' but revealed that it was her son's teacher who had diagnosed him with a conduct disorder, which does not align with doctor or other health care provider as specified in the question. Additionally, one respondent based his 'Yes' answer on a diagnosis that was made by his son's school therapist. It is not clear if this individual should be counted as a doctor or other health care provider. For one other respondent, the terms in the question were unfamiliar to her but she thought they did appear to accurately describe her child. She said that she was told that her daughter had conduct problems in elementary school and was put on a behavior plan. This respondent explained that though these disorders sounded like they described her daughter, the school tends not to "emphasize negative parts of a child's behavior" and therefore these terms were never specifically applied to her daughter.

For some respondents, ambiguity in their answers appeared to stem from the fact that their children had overlapping conditions. For instance, one respondent answered 'Yes' but said that this diagnosis occurred at the same time that he was diagnosed with another condition. One respondent who answered 'No' nonetheless provided a description of her son's problems that sounded as though it could be considered a behavioral or conduct problem. Additionally, another respondent answered 'Yes' but revealed that his son was diagnosed with this at the same time that his anxiety and depression was diagnosed and it was not clear how these were different. Finally, one respondent answered 'No' but admitted that his son has behavior problems to the extent that they are associated with having Asperger's disorder. When this respondent first heard the question he explained that he was prepared to answer 'Yes' until the question started referencing more specific problems, like behavioral conduct disorder.

This question in particular seemed to provoke a number of respondents to answer the question based not on whether or not their child had been diagnosed with these conditions but whether or not they observed these kinds of behaviors in their children. For instance, one respondent immediately answered 'Yes' and said, "She wants to do what she wants to do, when she wants to do it." However, probing revealed that she was not sure if her daughter had ever actually been diagnosed with these conditions. It appeared that she was picking up on the word defiant and then answering whether or not this described the child. Another respondent who answered 'No' said she did so because the child "gets along well with other kids and adults." Similarly, another respondent also answered 'No' and said that her child "always respects her elders."

1E. Autism, Asperger's Disorder, pervasive developmental disorder, or other Autism spectrum disorder?

Yes = 8

No = 16

A significant minority of respondents answered 'Yes' to this question (n=8). However, one respondent who answered 'Yes' said that the Autism was "suspected" by a doctor but actually diagnosed by an "educational team," which may or may not fit the criteria specified in the question. Another respondent who answered 'Yes' appeared to be basing her answer on her own sense of her son's situation and not on a doctor's diagnosis. Finally, one respondent answered

yes only after asking the interviewer to reread the question. After probing she revealed that she thought Autism was the same thing as ADHD. It appeared that she really tuned into the term “developmental disorder” and understood this to be the same thing as ADHD. Another respondent who answered ‘Yes’ did so with a caveat – specifically, that she did not know which type of Autism her daughter had been diagnosed with. However, above all the largest problem with this respondent’s answer was that she did not base it on a doctor’s diagnosis but rather on her own assessment of whether or not her child had Autism.

Two respondents who selected ‘Yes’ explained that they wanted to provide more specific answers. One respondent said that she would have preferred to specifically select Autism spectrum disorder. Another respondent explained that though he answered ‘yes,’ in his mind Autism is very different from Asperger’s Disorder, which is the specific condition that his son has. In these cases, the question appeared to lump together too many different conditions. However, in neither case did this prevent the respondent from answering the question correctly.

Though not all respondents were asked to do so, when asked to describe the symptoms or characteristics of Autism, respondents generally appeared to generate similar descriptions, though there were exceptions to this. One respondent described how Autistic children “like order.” Another characterized Autistic children as having “compulsive stacking tendencies.” One respondent who answered ‘No’ to this question described children she knows with Autism and said that they are slow and “delayed” mentally and physically. Another respondent similarly described a symptom of Autism as “being slow in school.”

1F. Any developmental delay

Yes = 7

No = 17

Respondents who answered ‘No’ to this question generated a variety of ways to interpret “any developmental delay.” One respondent thought that it was “something that would develop later on in life.” Another respondent defined it as a child who does not “develop at their full potential for their age.” Some were more specific in their descriptions. For instance, one said that a developmental delay would be “not walking and talking at a certain age” and two other respondents echoed this description but one added “feeding” or eating to this and the other added singing. Three respondents thought it had to do with being slow or somehow mentally impaired. For example, one respondent said that this did not describe her son because he “makes good grades and always has.” One specifically described it simply as “being slow” and another respondent said it meant “half mentally retarded or having Down’s Syndrome.”

It appeared that those who answered ‘Yes’ to this question offered very similar interpretations of the concept, though typically they were able to provide more specific examples in reference to their own children. For instance, one respondent provided a sort of textbook definition of developmental delay, explaining that “normal milestones that occur in a child’s development happen later than expected.” For this respondent, “normal milestones” included talking and drawing, which her child did not begin until later than would be expected. However, this same respondent thought that the reference to ‘any developmental delay’ was rather broad and would have felt more comfortable answering questions about specific areas of developmental delay.

One respondent, however, who answered ‘yes,’ provided a much less precise and more tentative understanding of developmental delay and at first answered “a little” and only answered ‘Yes’ when pushed to select ‘Yes’ or ‘No’.

Finally, among all the respondents who provided an answer to this question, it appeared that several may have answered the question incorrectly. For starters, one respondent who answered ‘Yes’ explained that she did so because her child had been labeled as having a learning disability. It is not clear if sponsors wish for this question to capture those with learning disabilities or if this would more appropriately be defined as an intellectual disability. Another respondent answered ‘No’ but later revealed that her daughter was enrolled in a Head Start program and exhibited signs of having a developmental delay. It was not clear why she answered the question incorrectly.

1G. Intellectual disability or mental retardation

Yes = 6

No = 18

A clear majority of respondents answered ‘No’ to this question. However, those who answered ‘Yes’ tended to describe conditions that overlapped with other conditions. For instance, one respondent even stated that the difference between Autism and intellectual disability for his son was not so clear and that there are “lots of gray areas” between lower end cognitive range of Autism and intellectual disability. Another respondent similarly wanted to answer ‘borderline’ when this question was first administered but finally decided upon a ‘Yes’ answer. For yet another respondent, mental retardation was the first diagnosis given to her child but was later changed to Autism.

Respondents offered rather varied ways of understanding the terms “intellectual disability and mental retardation.” A number of them thought that they have something to do with grades and intelligence levels. This was true for those who answered ‘Yes’ as well as for those who answered ‘no.’ For example, one respondent who answered ‘Yes’ explained that she did so because her daughter’s schoolwork is subpar and she is “slow.” Some understood the concepts more broadly, however. For instance, one respondent understood these to mean having an inability to learn and having “limited cognitive skills.” Another respondent also mentioned that having an intellectual disability meant that one had difficulty with comprehension and “the ability to understand consequences.” One respondent specifically mentioned a learning disability as being an example of an intellectual disability. Another respondent, however, was quite adamant that a learning disability was different from an intellectual disability. Specifically, this respondent said that her son has dysgraphia and dyslexia, but she does not consider these intellectual disabilities; rather, she thinks of them as learning disabilities, which are markedly different from intellectual disabilities. Finally, for one respondent, these concepts appeared very similar to a developmental delay. She defined an intellectual disability as not being on the same level as one’s peers or age group.

Respondents who were probed on this matter tended to see a difference between intellectual disability and mental retardation. For instance, one respondent thought that an intellectual disability referred to “something to do with the mind” and not being able to “think right.’ Mental

retardation to her, however, was more of a ‘disability’ where someone cannot “walk or talk right”. Similarly, another respondent thought that mental retardation meant “needing help 24 hours a day.”

Interestingly, two respondents appeared to define intellectual disability somewhat positively. One thought it had to do with ‘being smart and educated’ and another said that in some sense, his son had an intellectual disability because he was “very advanced in certain areas.” Here he appeared to define disability as anything out of the ordinary, whether positive or negative.

For respondents who answered ‘Yes’ as well as those who answered ‘No’ it appeared that there was some overlap or ambiguity in their child’s diagnoses. One respondent who answered ‘No’ nevertheless described how his son has difficulty writing, and specifically will write his letters backwards. This may or may not be the result of his son’s Autism or an intellectual disability. One child who was originally diagnosed with Autism was later reassessed and diagnosed with an intellectual disability. Finally, another respondent described her son’s case as “borderline” when asked whether or not he was ever diagnosed with an intellectual disability or mental retardation.

Q2: How old was [SC] when you were first told by a doctor or other health care provider that (he/she) had [CONDITION]?

First, it was oftentimes difficult for respondents to recall the age at which their child got diagnosed with any given condition. A total of nine respondents exhibited difficulty recalling their child’s age at the time of diagnosis, evidenced by such things as respondents articulating difficulty and/or forgetfulness (3258; 3261), counting on their fingers (3127), or displaying inconsistency in the narrative (2862; 3129; 3245). The qualitative data suggests that several factors might contribute to respondents’ difficulty in recalling a child’s age at the time of diagnosis. One possibility is that children are often diagnosed with multiple conditions throughout the course of their childhood and adolescence, and it can be difficult for parents and guardians to keep track of their children’s ages at the time of different diagnoses. Of the respondents who reported having a child with at least one condition in Question 1A-G, 16 of the 19 respondents indicated that their child had more than one condition, with 12 respondents reporting that their child had 3 or more conditions (*see Table 2*).

Table 2. Number of Conditions Reported

Subject ID	# of conditions diagnosed in child
2486	0
3130	0
3068	0
3264	0
3262	0
3265	1
3252	1
3257	1
3245	2
3256	2
3261	2

2578	2
3247	3
3263	3
3258	3
3260	3
2862	3
3246	4
3127	5
3125	5
3126	6
3248	6
3128	7
3129	7

In addition to having to cognitively juggle multiple diagnoses in an effort to accurately recall the age of diagnosis, respondents also often described conditions as occurring simultaneously with, as a reaction to, or as a manifestation of other conditions (also discussed in analysis of Question 1A-G). The fluidity among multiple conditions might also account for respondents’ difficulties in recalling age of diagnosis since it can be difficult to delineate clear boundaries between conditions. Respondents might also have difficulty recalling age of diagnosis if conditions are mentioned by providers, even if they aren’t officially diagnosed. For example, one respondent (3246) reported that his son was diagnosed with a learning disability (which he understands to mean “developmental delay”) by the Special Education Coordinator at school at age 9. In this first meeting, the only condition the Special Ed Coordinator diagnosed was the learning disability; however, the coordinator mentioned behavioral problems in this initial meeting. When this respondent was asked, in Question 2, at what age his son was diagnosed with behavior or conduct problems, he replied, “Probably when he was about 9.” (Later in the interview he said this meeting with the Special Ed Coordinator occurred at age 9 or 10.) Here, the respondent appears to use the initial *mention* of behavioral problems as a proxy for recalling the age of diagnosis.

To address the challenges associated with recalling the age of diagnosis, respondents appeared to draw upon several strategies in order to answer the question. Some respondents gave age ranges (3247; 3248; 3258) or estimated the age of diagnosis (3246). Often, respondents would answer the question according to the child’s grade level in school at the time of diagnosis. For example, when trying to recall the age at which his son was diagnosed with ADHD, one respondent answered “around the age of 11 – two school years ago.” During probing the respondent said he should have said that the age of diagnosis was at age 10. Asked if the age was difficult to recall, the respondent said, “It could be. He turned 11 during the school year.” It was at the beginning of the school year that the assessment took place and he turned 11 in January. So technically he really was 10 (3261). Similarly, another respondent remembers the moment of her son’s diagnosis of Asperger’s in terms of his grade level rather than his age. She counts on her fingers beginning with kindergarten in order to recall her answer. Since it was the “summer after” 5th grade, she replies that he would have been 11 years old.

In addition to difficulties recalling age of diagnosis, two additional patterns emerged from the analysis, each which could potentially lead to response error. First, it became clear upon

administration of this question that some respondents who answered ‘Yes’ for the conditions listed in Question 1A-G, did not actually have a doctor or health care provider diagnose the condition. For example, various respondents replied ‘Yes’ to their children having depression in Question 1b (3248), behavior or conduct problems in Question 1d (3265), or Asperger’s Syndrome in Question 1e (3252); however, upon administering Question 2, it became evident that the child was never formally diagnosed. In order to cope with Question 2, which explicitly asks: *How old was [SC] when you were first told by a doctor or other health care provider that (he/she) had [CONDITION]?*, some respondents refused to indicate an age of diagnosis. For example, one respondent (3248) simply said that a doctor never diagnosed her son with depression, but she thinks he is depressed. Similarly, another respondent (3265) said a teacher suspected his son had behavior problems in 1st or 2nd grade, but this respondent never suggested this was an official age of diagnosis. A third respondent (3252), however, provided a definitive answer to Question 2, indicating that his son was 4 years old when he was diagnosed with Asperger’s. During probing, this respondent confirmed that his son has not officially been diagnosed with Asperger’s but rather has been labeled “PDD NOS” (pervasive developmental disorder not otherwise specified). He said his son is too young to receive an official diagnosis of Asperger’s, but he fully suspects this is what his son has. Someone in the health care field has told him that his son is on the Autism spectrum.

A final pattern that emerged from the analysis concerns respondents’ understanding—or misunderstanding—of the terminology and/or meaning associated with specific conditions. The narrative data suggests that it is possible that respondents might not understand what the names of different conditions refer to, but answer the question nonetheless. The respondent mentioned earlier (3246), whose son has a learning disability, confirmed that he understands “developmental delay” to be synonymous with “learning disability.” He also talks about his son’s learning disability in the context of his son’s diagnosis of “slight mental retardation.” The respondent appeared to interchangeably use the terms “learning disability,” “developmental delay” and “mental retardation” to his son’s condition. Yet, he also understood developmental delay to refer to the delay in his son’s development of “growing up” as a mature person; he says his son is “standing still.” This respondent attributes all of his son’s behavioral and conduct problems to this lack of growing up/maturing, thus in addition to understanding a developmental delay to mean a learning disability, he also thinks of developmental delay in the context of social development to mean “growing up”; he does not appear to be thinking about delays in cognitive or physical development (e.g., talking, small motor skills, etc.). In fact, the respondent confirmed that his son began talking, walking and doing things at a “normal” age. This respondent has never heard of the term “intellectual disability” before. Asked what he thinks it means, he returns to his description about “moving forward” and how “something is not being moved; it’s just at a standstill point;” this was the language he used to talk about his son’s behavioral and developmental problems. This respondent’s narrative points to the potential confusion respondents might have around the meaning or definitions associated with particular conditions.

This respondent’s narrative not only points to the ways in which respondents might not have a full understanding of the meanings of each of these conditions, but they might also understand the conditions, once again, to be very fluid and overlapping. Another example of this fluid understanding among conditions involves a mother (3248) who discussed her son’s difficulty in

school as a result of his ADHD, but later attributed this difficulty in school to his learning disability. This mother believes that her son's feelings of frustration and social marginalization in school led to feelings of depression (which has yet to be formally diagnosed). It appears as though respondents are not always certain where the symptoms and meanings associated with one condition ends and another one begins. These fluid understandings, and well as the misunderstandings, of the meaning associated with condition terminology have the potential to lead to response error if respondents think of conditions differently than survey designers intend. Moreover, answering these questions "wrong" early on in the survey has implications for the data collected throughout the remainder of the survey.

Q3: What type of doctor or other health care provider first told you that [SC] had [CONDITION]?

Unlike the difficulties encountered when respondents tried to recall age of diagnosis, respondents appeared to have less difficulty recalling the type(s) of doctor(s) who diagnosed their child. Only one respondent reported not knowing the type of doctor or other health care provider who first told them that their child had a particular condition. All other respondents were able to provide an answer; however, it is difficult to determine whether respondents are accurate in their assessment of the type of doctor who issued the diagnosis.

In general, respondents were much more likely to report having health care providers outside of the school setting diagnose their children; only 3 respondents (3128, 3261, 3246) reported having providers in the school diagnose their kids, with two respondents (3263, 3258) indicating that a school provider diagnosed some conditions, but non-school providers diagnosed other ones. The remaining 11 respondents who reported "knowing" the type of provider who issued the diagnosis, all indicated that it was a non-school provider who diagnosed their child's condition(s).

Yet, as alluded to above, it is difficult to know whether respondents are accurate in their assessment of the type of health care provider who diagnosed their child; however, a couple respondents point to uncertainty and/or ambiguity in their narrative. One respondent (3257) said he thought his son's ADD was diagnosed by a psychiatrist, "but it could have been a psychologist." Another respondent (3261) reported that a "team" at his son's school diagnosed his son with ADHD; included on this team was a psychologist and a school counselor. This respondent considers both of these professionals to be "health care providers," and he was considering both of these people when he answered this question. This respondent's narrative also points to the ways in which respondents are not always certain about the credentials associated with the professionals who diagnose their children, as he believes the school counselor has an MSW, but he's "not sure."

Other respondents named doctors or health care providers that were not included on the survey's list of possible answers. One of these respondents (3252) reported that a "child psychologist," not affiliated with the school system, diagnosed his son's Autism/Asperger's/ASD. It is not clear whether this was the official title of the health care provider, or if perhaps the respondents meant to say child psychologist (which is listed on the survey instrument). Another respondent (3246)

said reported a type of doctor not listed on the instrument; he interchangeably used the terms “school doctors” and “Special Ed Coordinator from the school,” as being the provider(s) who first diagnosed his son with ADD/ADHD, an intellectual disability/mental retardation, behavior/conduct problems, and a developmental delay. This respondent describes the Special Ed Coordinator as “a specialist in the school who works with children with special needs.” He said this person is a “Doctor of Psychiatry.” This respondent’s narrative suggests that respondents might not use the same terminology as survey designers to describe the types of doctors or health care providers who diagnose their children.

Q4: Does [SC] currently have [CONDITION]?

Unlike in Question 1 where the parent is asked to answer based on what a doctor or health care provider told them about their child’s conditions, this question allows parents to answer based on their perception of whether or not their child currently has the condition(s) they reported in Question 1. Parents most often answered this question based on their observations of their child’s symptoms, but sometimes they also talked about the influence of a doctor’s diagnosis or assessment. During probing parents talked about seeing symptoms come and go or improve, how it was difficult to disentangle overlapping symptoms with other conditions, and the influence of medications on their child’s symptoms. Parents made interpretations about whether their child’s condition was current based on these observations. How the parent understood the condition influenced how they interpreted their observations of their child’s symptoms. Parents also answered this question based on what they have heard from a doctor. Some parents agreed with the doctor’s assessment but others disagreed and they talked about this when answering the question. Sometimes parents talked about the same type of behaviors or observations, but they answered the question in opposite ways with some parents saying yes their child currently has the condition and others saying no their child does not have the condition.

When answering this question parents talked about how they saw symptoms come and go or improve. Several parents said ‘Yes’ their child currently has a condition but then qualified it by saying their child’s symptoms have improved or that the symptoms come and go. For example, one parent said her daughter currently has depression but she is “in and out, off and on” (3245). Another parent said her son still has behavioral problems but “it’s not manifesting itself in the same way. He has it more under control.” (3248).

Many parents had children who experienced multiple conditions simultaneously. Some of these parents reported that it was difficult to distinguish the symptoms of the different conditions because they often overlapped or seemed similar. When asked if her son currently has oppositional defiant disorder (ODD) she said, “I want to say yes. It’s hard to distinguish the ADHD from the ODD” (3247).

Several parents talked about medications when explaining their answer to whether or not their child currently has a condition. Some parents used their child’s medicine as proof that they were getting better, while others used it as proof that their child still had the condition. One parent said he doesn’t think his son currently has ADD because the pills he takes are such a low dose and his

son is “functioning” (2862). In contrast, another parent said his son currently has ADD because he can see the “signs” and because the medicine is working (3257).

How parents understand the condition they have been told their child has can impact how they answer this question. One father who disagreed that his son has mental retardation explained that to him mental retardation means a child is so slow he couldn’t function but he does not see characteristics of this in his son (3246). One mother had previously talked about how she believed that once you have ADHD, it never goes away (3248). This could likely influence her ‘Yes’ answer to this question. Another parent said his son does not currently have depression and in probing said his understanding of depression was that it was something you have all the time and that does not characterize his son because his depression is “sporadic” (2862).

Some parents specifically talked about a doctor when explaining their answer to this question. Sometimes they used the doctor’s diagnosis or evaluation as evidence to support why they said their child currently has a condition. For instance, one parent said her son currently has ADHD and still sees a psychiatrist and therapist every week. Other times a doctor’s diagnosis can be less straightforward or could potentially cause some confusion for the parent. One parent responded ‘Yes’ when asked if his son currently has Autism or ASD but clarified by saying his son was diagnosed with pervasive developmental disorder not otherwise specified (PDD NOS) but what he really thinks he has is Asperger’s but the doctors have not wanted to call it that yet because he’s still young (3252). He made a distinction between Asperger’s and Autism because although Asperger’s is part of the Autism spectrum “the wiring in the child...is different” and the professionals are not sure if Asperger’s is really a form of Autism. He said, “I would not call my son Autistic unless I was told” (3252). This respondent’s experience highlights how complex mental health diagnoses can be and that the specific terminology used in the questions could potentially change how respondents answer the question if it does not fit what they have been told.

Some parents do not agree with the doctor’s diagnosis and this influences their answers. For example, one father explained that his son had been diagnosed with slight mental retardation but when asked whether his son currently has the condition he said, “I don’t know about the mental retardation because I haven’t seen it so I’m going to say no. I haven’t seen this” (3246). He also talked about wanting to take his son to get a second opinion. His observations of his son seem to be conflicting with the doctor’s diagnosis and ultimately he answers the question based on his observations. Another parent disagreed with the doctor but this time because the doctor did not diagnose her son with Autism when she thought he had some signs of it. She first answered the question by saying “somewhat” (3248). She is a foster mom who has fostered other children with Autism and she sees some of the same behaviors in her son but she says “I think there’s something there but I don’t think its complete Autism. I see Autism where they zoom out. My girlfriend’s son has Autism and I would say ‘No’.” Her son was tested for Autism but the doctor said he does not have it. She disagrees with the doctor, but if pushed to give a ‘Yes’ or ‘No’ answer she ultimately answers the question ‘No’ based on what the doctor has told her.

Sometimes the same type of observation (e.g. symptoms improving) could lead to different interpretations about the current status of their child’s condition. For example, some parents see evidence that their child is improving and use this as justification for why they say their child

does not currently have the condition whereas other parents use the same evidence to explain why their child still has the condition. One father said his son does not currently have ADHD because “he has improved tremendously” (3261). He has not had a follow up “professional diagnosis” but thought one should be done he just was not sure if he needed to request one. Other parents who similarly believe their child’s symptoms have significantly improved are more hesitant to say their child no longer has a condition without a doctor’s “undiagnosis.” When asked this question about her son’s Asperger’s disorder one mother responded by saying, “he has not been undiagnosed officially” but when pushed to answer she said ‘Yes’ he currently still has Asperger’s but it’s not as pervasive (3127). She says it is tough because a doctor has not said he still has it or does not have it but she has seen his Asperger’s tendencies diminish in the last couple years since his diagnosis.

Q5: To the best of your knowledge, did [SC] ever have [CONDITION]?

To get this question respondents had to say ‘No’ to Question 4 *Does [SC] currently have [CONDITION]*. Nine respondents were administered this question.

Several parents talked about the interplay between what they thought and what they have heard from a doctor. Some of them disagreed with what a doctor has told them while others talked about how the doctor’s diagnosis was difficult to understand either because it was ambiguous or a diagnosis had changed. A couple parents talked about how the symptoms of different conditions can overlap and this can make it difficult to know exactly what a child has. For some conditions it may be possible for there to be real changes that help explain why a child may not have a condition currently but did in the past.

A couple of parents talked about how there was some kind of disagreement between what they thought their child had and what the doctor told them about their child. For example, one mother thinks that her son has some signs of Autism even though the doctors tested him and said he does not have Autism. She answered this question by saying, “No. From the studies the doctors did. Now, I’m going by them” (3248). So she seems to be going by what the doctors have said when answering this question even though she had gone by what she thought when answering previous questions. Another parent talked about disagreeing with the doctors in the past but how he and his wife came to agree their son had ADHD at one point. He answered this question with a ‘No’ and said he was answering based on how was thinking in the past when he disagreed with the doctors. He said if he just answered ‘yes,’ it would not be a complete answer. He explained that his disagreement with the doctor’s assessment of his son was based on some degree of not wanting to believe that his son had ADHD because he said, “You don’t want to label the person just because the label does apply” (3261). When asked what helped him change his mind he said learning more about ADHD. This could be an example of how for some parents it is a process to accept that their child has a behavioral health condition.

A couple of parents talked about ambiguous doctor diagnoses/assessments and this could make it difficult for parents to really know if their child ever had a condition in the past or present. When asked whether his son ever had ADHD, one father answered ‘Yes’ and in probing said, “I think he probably had signs of it. I don’t think he really had it to the fullest” (2862). He went on to

explain that his son might have had it when living with his ex-wife before he moved in with him and received more discipline. When probed about the original doctor's diagnosis he said the doctor explained that she could not really diagnose it yet, even though he continues to see this doctor and take ADHD medication. An ambiguous diagnosis can make it hard for parents to know for sure what conditions their child has now or had in the past.

A change in diagnosis can also make it difficult for parents to know if their child ever had a condition that they were once told they had. Another parent had been told that her daughter no longer has Autism and when asked if she ever had it she said, "I would say yes" (2578) but sounded a little hesitant. When asked about her hesitation she said, "Well, maybe I should say yes and no. I'm kind of confused." A change in diagnosis can be confusing for parents and can make it hard to know whether their child ever did have that condition.

Many of these conditions have related symptoms and these children are often diagnosed with more than one condition which adds to the complexity of understanding each condition distinctly. When asked if her son ever had Autism even though that diagnosis had later been reclassified to an intellectual disability, she answered this question with a "Don't Know" and explained by saying "I think what he had were Autistic like features" (3129). She went on to say that she thought his initial Autism was wrong but that the evidence from his developmental history and cognitive ability tests are not clear cut. This shows that overlapping symptoms from different conditions can lead to changes in a diagnosis. The mother mentioned above who thinks her son has some symptoms of Autism even though there has not been a formal diagnosis acknowledged that her answers about Autism were "evasive" because a doctor said he sees something there but it was not Autism it was more hyperactivity. He has also been diagnosed with ADHD. This also shows how symptoms of conditions can overlap and it can be difficult to differentiate what conditions the child has and this can lead to disagreement between the parent and doctor.

A real change in conditions can also be possible where the condition goes away at some point. One mother said that her son did have depression at one point in his life when he was going through a lot of trauma and transitions. This may be more likely for some conditions, like depression.

Q6: I am going to read a list of reasons why [SC] may no longer have [CONDITION]. For each reason, please tell me if it applies to [SC]. See Q6A-D below.

Five respondents were administered Questions 6A-D because they had previously answered 'No' to Q4: *Does [SC] currently have [CONDITION]?* and 'Yes' to Q5: *To the best of your knowledge, did [SC] ever have [CONDITION]?*. Two of these respondents had response error on previous questions and that is why they were administered these questions but they really should have been skipped because these questions do not apply to their situation. The following analysis is based on the remaining three respondents.

Q6A: I am going to read a list of reasons why [SC] may no longer have [CONDITION]. For each reason, please tell me if it applies to [SC]. Treatment helped the condition go away.

All three respondents answered ‘Yes’ to this question. They talked about medication, therapy, and improved eating habits as the treatments that helped the conditions go away.

Q6B: I am going to read a list of reasons why [SC] may no longer have [CONDITION]. For each reason, please tell me if it applies to [SC]. The condition seemed to go away on its own.

One respondent answered ‘Yes’ and two respondents answered ‘No’ to this question. The respondent who answered ‘Yes’ said, “Wow, that’s a biggie. It comes and goes” (3247). The others did not think the conditions went away on their own, but for another reason such as the treatment worked.

Q6C: I am going to read a list of reasons why [SC] may no longer have [CONDITION]. For each reason, please tell me if it applies to [SC]. The behaviors or symptoms changed.

All three respondents answered ‘Yes’ to this question and talked about how their children’s behavior has changed. Two of them asked for clarification on the time frame of change and what the baseline comparison should be.

Q6D: I am going to read a list of reasons why [SC] may no longer have [CONDITION]. For each reason, please tell me if it applies to [SC]. A doctor or health care provider changed the diagnosis.

All three respondents answered ‘No’ to this question. Two respondents confirmed that a doctor has never told them their child no longer has the condition. One of the respondents has been told that her child no longer has Autism but did not seem to count this as a change in diagnosis, perhaps because the diagnosis was never changed to anything else, it was just dropped.

Q7: Are there any other reasons why you think [SC] may no longer have [CONDITION]?

None of the respondents talked about anything new that they had not already mentioned in the previous questions.

Q8: I am going to read a list of reasons why a doctor, health care provider, or school professional may have told you that [SC] had a condition that (he/she) never had. For each reason, please tell me if it applies to [SC].

Four respondents were administered Questions 8A-C because they had previously answered ‘No’ to Q4: *Does [SC] currently have [CONDITION]?* and ‘No’ to Q5: *To the best of your*

knowledge, did [SC] ever have [CONDITION]?. One of these respondents had response error on previous questions and that is why they were administered these questions but they really should have been skipped because these questions do not apply to their situation. The following analysis is based on the remaining three respondents.

Q8A: I am going to read a list of reasons why a doctor, health care provider, or school professional may have told you that [SC] had a condition that (he/she) never had. For each reason, please tell me if it applies to [SC]. With more information, the diagnosis was changed.

Two respondents answered ‘No’ to this question and one ‘Refused’ to answer. The respondent who refused to answer said that he does not agree with the diagnosis that was given and expects that it will change because he is in the process of getting a second opinion but no change has been made yet. One respondent said the diagnosis had not been changed by the original doctor but that a different doctor had expressed some disagreement with the diagnosis. The other respondent said that a doctor had never diagnosed her son with Autism but her she thinks he has it to some degree. She was not asked any further questions since a doctor had never said her child had the condition she was reporting on in these questions.

Q8B: I am going to read a list of reasons why a doctor, health care provider, or school professional may have told you that [SC] had a condition that (he/she) never had. For each reason, please tell me if it applies to [SC]. The diagnosis was given so that [SC] could receive needed services.

Of the two respondents administered this question, one respondent said ‘Yes’ and the other said ‘No’ to this question. No significant probing was done here.

Q8B: I am going to read a list of reasons why a doctor, health care provider, or school professional may have told you that [SC] had a condition that (he/she) never had. For each reason, please tell me if it applies to [SC]. You disagree with the doctor or other health provider about his or her opinion that [SC] had [CONDITION].

One respondent said ‘Yes’ and the other said ‘No’ to this question even though in probing they both said they disagreed with the doctor. The respondent who said ‘No’ explained, “I do [disagree] but I’m not the professional. So I’m going to say no” (3246).

Q9: Are there any other reasons why a doctor or other health care provider may have told you that [SC] had a condition that (he/she) never had?

None of the respondents talked about anything new that they had not already mentioned in the previous questions.

End of Questions.

Appendix A: Questionnaire

THIS SECTION IS TO BE ASKED ONLY FOR CHILDREN 2 YEARS OF AGE OR OLDER.

Q1 INTRO: I am going to read you a list of conditions. For each condition, please tell me if a doctor or other health care provider ever told you that [SC] had the condition, even if [he/she] does not have the condition now.

1A. Attention Deficit Disorder or Attention-Deficit Hyperactivity Disorder, that is, ADD or ADHD?

YES/NO/DK/RF

1B. Depression?

YES/NO/DK/RF

1C. Anxiety problems?

YES/NO/DK/RF

1D. Behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder?

YES/NO/DK/RF

1E. Autism, Asperger's Disorder, pervasive developmental disorder, or other Autism spectrum disorder?

YES/NO/DK/RF

1F. Any developmental delay?

YES/NO/DK/RF

1G. Intellectual disability or mental retardation?

YES/NO/DK/RF

1H. Any other condition related to emotions, concentration, behavior, or ability to get along with other people?

[IF NO CONDITIONS REPORTED, SKIP TO END]

THE NEXT QUESTIONS SHOULD BE ASKED FOR EACH CONDITION IDENTIFIED BY PARENT. USE THE FOLLOWING TEXT FOR CONDITION FILLS:

[Autism or ASD]

[Developmental delay]
[Intellectual disability]
[ADD or ADHD]
[Depression]
[Anxiety problems]
[Behavioral or conduct problems]

2. How old was [SC] when you were first told by a doctor or other health care provider that (he/she) had [CONDITION]?
3. What type of doctor or other health care provider first told you that [SC] had [CONDITION]? *[Do not read list of options]*
- (1) Pediatrician or other general pediatric health care provider (such as nurse practitioner or physician's assistant in pediatric clinic)
 - (2) Another type of general health care provider (such as family practice doctor or nurse practitioner or physician's assistant in general practice)
 - (3) A specialist pediatrician such as a developmental pediatrician
 - (4) School psychologist / counselor
 - (5) Other psychologist (non-school)
 - (6) Psychiatrist (medical doctor)
 - (7) Neurologist
 - (8) School nurse
 - (9) Physical, occupational, speech, or other therapist
 - (10) A specialist doctor (other than a developmental pediatrician, psychiatrist, or neurologist)
 - (11) Other [RECORD VERBATIM RESPONSE]
 - (12) Wasn't told by a doctor or other health care professional

THE NEXT QUESTIONS SHOULD BE ASKED FOR EACH CONDITION IDENTIFIED BY PARENT. USE THE FOLLOWING TEXT FOR CONDITION FILLS:

[Autism or ASD]
[Developmental delay]
[Intellectual disability]
[ADD or ADHD]
[Depression]
[Anxiety problems]
[Behavioral or conduct problems]

4. A) Does [SC] currently have [CONDITION]?
B) To the best of your knowledge, does [SC] currently have [CONDITION]?
- YES/NO/DK/RF [IF YES, THEN **END**. IF NO, THEN GO TO **Q5**.]
5. To the best of your knowledge, did [SC] ever have [CONDITION]?
- YES/NO/DK/RF [IF YES, THEN GO TO **Q6**. IF NO, SKIP TO **Q8**.]

THE NEXT QUESTIONS SHOULD BE ASKED FOR EACH CONDITION IDENTIFIED BY PARENT. USE THE FOLLOWING TEXT FOR CONDITION FILLS:

[Autism or ASD]
[Developmental delay]
[Intellectual disability]
[ADD or ADHD]
[Depression]
[Anxiety problems]
[Behavioral or conduct problems]

Q6 INTRO: I am going to read a list of reasons why [SC] may no longer have [CONDITION]. For each reason, please tell me if it applies to [SC].

6A. Treatment helped the condition go away

YES/NO/DK/RF

6B. The condition seemed to go away on its own

YES/NO/DK/RF

6C. The behaviors or symptoms changed

YES/NO/DK/RF

THE NEXT QUESTIONS SHOULD BE ASKED FOR EACH CONDITION IDENTIFIED BY PARENT. USE THE FOLLOWING TEXT FOR CONDITION FILLS:

[Autism or ASD]
[Developmental delay]
[Intellectual disability]
[ADD or ADHD]
[Depression]
[Anxiety problems]
[Behavioral or conduct problems]

6D. A doctor or health care provider changed the diagnosis

YES/NO/DK/RF

7. Are there any other reasons why you think [SC] may no longer have [CONDITION]?

THE NEXT QUESTIONS SHOULD BE ASKED FOR EACH CONDITION IDENTIFIED BY PARENT. USE THE FOLLOWING TEXT FOR CONDITION FILLS:

[Autism or ASD]
[Developmental delay]

[Intellectual disability]
[ADD or ADHD]
[Depression]
[Anxiety problems]
[Behavioral or conduct problems]

Q8 INTRO: I am going to read a list of reasons why a doctor, health care provider, or school professional may have told you that [SC] had a condition that (he/she) never had. For each reason, please tell me if it applies to [SC].

8A. With more information, the diagnosis was changed

YES/NO/DK/RF

8B. The diagnosis was given so that [SC] could receive needed services

YES/NO/DK/RF

8C. You disagree with the doctor or other health provider about his or her opinion that [SC] had [CONDITION].

YES/NO/DK/RF

9. Are there any other reasons why a doctor or other health care provider may have told you that [SC] had a condition that (he/she) never had?

10. Let's start from the beginning, can you walk me through your child's experience with this/these conditions (*if they need further encouragement: for example, when did you first notice, what did you notice, how did you respond, etc..*)?