

Glenn Fujiura, Ph.D. is a faculty member of the Department of Disability and Human Development at the University of Illinois at Chicago, where he serves as the Director of Graduate Studies for the MS program, and as Associate Dean for Academic Affairs for the College of Applied Health Sciences. His research includes studies of fiscal structure and demography of the disability service system; family policy; long-term care; poverty, disability, ethnic and racial issues in disability, and on the statistical surveillance of disability. He has served as Chair of the U.S. Administration on Developmental Disabilities Commissioner's Multicultural Advisory Committee, was a 1999 recipient of the National Rehabilitation Association's Switzer Scholar award, and was a member of the President's Committee on Mental Retardation during the Clinton administration. Dr. Fujiura is a member of the National Academy of Sciences Committee on the External Evaluation of the National Institute on Disability and Rehabilitation Research and was recently appointed editor-in-chief of the journal, *Intellectual and Developmental Disabilities*.

Health Status Measurement of Persons with Intellectual Disabilities: Development and Testing of Self Report Health Related Quality of Life

Glenn T Fujiura, Ph.D. and Carrie Behrens
University of Illinois at Chicago

Background

The project seeks to adapt and psychometrically evaluate self- and proxy-report versions of a widely used health outcomes measure, the SF-12, for use with persons with intellectual disabilities (ID). While specific physiologic indices are the “gold standard” for assessing health outcomes, such specific measures are often difficult to implement in the field setting (Patrick, 2000). More generalized self report health measures such as health related quality of life (HRQL) are commonly used in the context of community based services. HRQL is the perception of physical and mental health. HRQL has emerged as an especially important outcome in health-related disability evaluations since physiological indicators often poorly covary with participatory outcomes (Guyatt, Feeny, & Patrick, 1993). Despite the priority given to health outcomes for persons with ID, very little empirical attention has been devoted to the assessment of health related quality of life (HRQL) and persons with ID, and among these studies virtually all employ proxy respondents (Sabaz, Cairns, Lawson, Bleasel, & Bye, 2001).

While there have been debates over the relative importance of subjective versus objective indicators of HRQL, the vast majority of HRQL conceptualizations emphasize the centrality of self-report. The debate is somewhat more polarized among researchers working with cognitively impaired populations such as those adults with Alzheimer's dementia (Smith et al., 2005). Despite the obvious methodological challenges in reliably and validly measurement subjective states, subjectivity remains central to the construct and thus, its measurement. One's appraisal of functioning and satisfaction is recognized as a key outcome, regardless of how well self report maps onto objective assessments of physical, cognitive, and other health indices (Majani, Giardini, & Scotti, 2005). The issue is especially significant for ID given the effort in recent years to establish self-determination as a core value in the field's operating principles. If

subjectivity is at the core of the outcome construct, then the incorporation of a reliable and valid self report would seem particularly important for the evaluation of program outcomes in the field.

Research Objectives

The goal of the larger project is to adapt and psychometrically evaluate a self-report version of the widely used health outcomes measure, the SF-12. Research activities encompass three distinct phases: (1) SF-12 adaptation and preliminary field testing, (2) psychometric evaluation of preliminary field test data, and (3) final field testing, psychometric evaluation and validation.

Described here are the outcomes of the Phase I effort in which cognitive testing of interview items were tested via a “think out loud” interview request. The cognitive testing was used to evaluate subject understanding of item wording and concepts. In the original proposal, the cognitive testing phase was expected to result in minor modifications of items and lead to an instrument revision that would be field tested in Phase II and psychometrically evaluated in a large sample Phase III. As discussed below, the results of the cognitive testing suggests more fundamental adaptations are required in self report protocols.

Methods

Interview Questions

Interview questions were adaptation of the SF-12, the short version of the SF 36, the most widely used instrument for HRQL measurement. Use of the SF-12 (or the SF-36) in ID research is very limited and has primarily been used for assessments of parents’ health (Allik, Larsson, & Smedje, 2006; Chen, Ryan-Henry, Heller, & Chen, 2001; Llewellyn, Gething, Kendig, & Cant, 2003) and less frequently as a measure for the person with ID via proxy (Caldwell, 2006). Only two small studies to directly assess persons with cognitive impairments using adaptations of the SF-36 have been reported (Jones, Dagnan, & Ruddick, 1997; Ruddick & Oliver, 2005). This is not surprising given the well documented difficulties in eliciting reliable and valid self report with people with intellectual disabilities. The SF instruments however, have been used for persons with other cognitive impairments such as early to mid-stage dementia (Arlt et al., 2008).

Wording and response formats were simplified. Phase I involves adaptation of the items and response sets in the SF-12 for use as a self-report instrument or persons with intellectual disabilities. Wording and response formats of the SF 12 were modified to attenuate or eliminate the bias against physical limitations. An example of the interview question and cognitive testing format is shown in **Box 1** below (the full protocol appears in **Appendix A**).

Subjects

Ten adult subjects (six female, four male) were recruited through area non-profit community developmental disability agencies. All were verbally skilled with mild to moderate degrees of intellectual impairment and had basic conversational skills. Our original plan was to employ the Peabody Picture Vocabulary Test to screen out any individual who scored below the age equivalent of 3 years but the screening was judged unnecessary for this initial pool of interviewees.

BOX 1. Cognitive Testing Protocol Example: Health Question and Probes

. In general, would you say your health is:

___ Very good

___ Okay

___ Bad

[General Interpretation probe]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation probe]

In this question, what does the word “health” mean to you?

[Response Interpretation probe]

What does [selected response] mean to you?

[Interpretation Difficulty probe]

In answering this question about “health”, did you think about?

[Definition Boundaries probe]

What kinds of things did you think about when we said “health”?

Consent forms had been signed in the weeks preceding the interview and assents were granted just prior to the interview.

Procedure

The adapted SF-12 questions were presented in a 1:1 interview format. Interviews were conducted at various agency sites at the convenience of the participant: day program meeting rooms and residences. Our focus was on maintaining a conversational ambiance rather than standardization of procedure.

Interviews began with introductions and a brief summary the project in which the task was described as “trying to improve a questionnaire about health” and needing their help and insights. After requesting a final assent to participate, rapport was developed via conversation and simple questions about where they lived, what they were doing before we arrived and similar mundane topics.

Each person was asked to “think out loud” as they try to answer the health questions, a procedure that few of the subjects appeared comfortable doing. Thus, the follow-up probe questions were the main source of cognitive testing information. Probes focused on whether interviewees understood questions as intended. The interviewer was instructed to compliment responses, and then request the additional elaboration.

Interviews were audio recorded.

Findings and Progress to Date

Ten adults, verbally skilled with mild to moderate degrees of impairments, were interviewed with limited success. Despite efforts to make the interview setting as informal and non-evaluative as possible, the cognitive testing was being treated as something other than “thinking

out loud” by the participants. Although all participants had been described as “talkative” by staff, much of the responding was in the form of simple one-word answers, looking to the interviewer for response cues, or avoiding direct answers altogether. It was clear that many of the interviewees believed, despite our best efforts, that the interview was evaluative in intent. Our conventional cognitive testing approach using “think out loud” and follow up probes was not effective. In the original research plan, information gleaned from cognitive testing would help clarify item construction; our focus turned to better understanding the dynamics of the interview in order to modify the cognitive testing protocol.

A Reanalysis via Conversational Analysis

Conversation analysis (CA) is a qualitative methodology (ethnomethodology) employed in the study of face-to-face verbal exchanges. Epistemologically, CA focuses on understanding how a person’s view of the social setting influences interactions, specifically in the form of conversation. Since conversation is the principle form of social interaction, a CA could provide insights into the expectations and understandings of participants. Emerging from an emphasis on cognition in sociology, the approach was developed to study social organization from a phenomenological perspective (Goodwin & Heritage, 1990). A major methodological theme in CA is a focus on the use of words, sounds, emphases to accomplish particular a particular outcome.

The purpose of conversational analysis is to better understand, through the deep analysis of the elements of a conversation how interactions are understood in specific contexts. The focus on “context” emerges from the historical foundations of CA which has roots in sociology and emphasis on social behavior. Conversations are thus data for studying mutual understandings and shared communicative meanings. Our use of CA was focused on the more concrete matter of identifying points of miscommunication and better understanding any consistent difficulties in the question content.

Rationale

The central organizing principles of cotemporary approaches to supporting persons with ID are self-determination and choice (Parmenter, 2001; Stancliffe, 2001). Core objectives are to enable individuals “to act volitionally and to become causal agents in their lives” (Wehmeyer, 2005). As Antaki and Rapley (1996ba) noted in their CA of persons with ID, “What the client says is inseparable from what he or she is asked” (p. 435).

There are few examples of CA applied to persons with ID. Antaki and Rapley (1996ab) employed conversational analysis to critically examine the potentially distorting role of interview dynamics in interviews assessing quality of life for persons with ID. Their rationale emerged from a concern over the use of standardized interview protocols overlook or obscure the subtleties of the interview interaction. The investigators found the use of paraphrasing in communicating complex concepts, pre-questions (or, question “prepping”), and affecting responses through verbal and non-verbal cues. Antaki and Rapley argue for greater caution in and sensitivity to the process of gathering self reported data. Holmes (2003) employed CA to explore the use of “small talk” at work for persons with ID. Her focus was on the manner in which employees with ID negotiate the daily interpersonal demands of the workplace such as friendly teasing. Holmes found that workers with ID often failed to recognize social norms that

are provided in conversational cues. Even minor transgressions can have long-range impacts; an example was a subject who did not recognize a supervisor attempting to transition a casual conversation to business matters and maintained the social exchange.

Methodology

The methodology was straightforward but detail oriented. Transcripts were generated from the audio recordings. Each verbal interaction was carefully coded in order to describe the ebb and flow of a conversation and variations in word use, vocalizations, points of emphases among other analytic items are highlighted. The analyst focuses on the strategies and other processes that the participants deploy in the course of the conversation. Identifying the strategies and processes is to the purpose of the CA.

The key concept is this notion of a sequence of interactions where a verbal statement such as a greeting or a question requires a reciprocal response. In the CA framework, these sequences operate within norms such that the form of response (or lack of response) can be treated as indirect evidence beliefs, perceptions or implicit rules that direct behavior (Goodwin & Heritage, 1990). Box 2 below is an illustration of one of the coded verbal sequences.

BOX 2. Example Transcript Conversational Analysis

Interviewer: What does feeling nervous feel like?

JB: Nervous is like, (3.9) □nervous is like umm□ (3.6), nervous is □let's see nervous is □ (2.4) that's a tough question.

CB: [Yeah]

JB: [Let's see], nervous is like, when you, ah (2.2) well you do something but you don't, you don't like people rushing you to do it, then you get all nervous.

codes:

(0.0)

Numbers inside parentheses indicate the duration of pause of speech

□word□

Boxes surrounding a word indicates soft speech compared to the surrounding talk

[Inaudible]

Single brackets around the word "inaudible" indicates that a word or sentence is inaudible in the recording

Other codes used in the CA identified, but not shown in this sample passage were: (1) audible laughter (double parentheses), (2) laughing while talking (double parentheses around the word), (3) overlap in speech between speakers (double brackets around the word), (4) the beginning point of an overlap of speech, (5) the end of an overlap of speech, and (6) loud speech (uppercase word).

We approached the analysis with no a priori hypotheses, but rather with an opened ended question regarding how each of the subjects were reacting to the items and to the question and answer process.

CA Results

Each of the 12 questions have been modified based on the CA and 11 new probe questions added. The following issues were identified:

1. Elimination of multiple choice; interviewees were seeking cues from the interviewer.
2. Additional language simplification; the more successful items in the original cognitive testing were the simplest in terms of terminology. Employed more probes to get at concepts of “calm” “nervous” “energy” “interfere”.
3. Elimination of “hard” and “easy” discriminations which added a layer of interpretation and appeared to confuse interviewees.
4. Eliminated negative phrased questions (“ . . . get less done . . .” “ . . . not do things you usually do . . .”); subjects appeared reluctant to respond to negative phrasing.
5. Separated the concepts “sad” and “nervous” that had been combined in a single question; nervous was a difficult concept for most subjects.

Box 3 below illustrates the modification of the question used in the cognitive testing as a result of the CA.

BOX 3. Question Modification Based on Conversational Analysis

Original Question #1:

In general would you say your health is:

__ *Very good*
__ *Okay*
__ *Bad.*

changed to

“Do you feel healthy?”

With the follow up probes:

What does it feel like to be healthy?
What does it feel like to be not healthy?

Listing the options of “very good, okay and bad” resulted in participants mirroring the interviewer; this was a leading question. In many interviews participants answered questions by repeating the interviewer’s last option. The probes were suggested by the tendency of interviewees to answer questions by referencing other people instead of themselves. The intent of this follow question is keep the dialogue focused on the participant.

Modified Questions Set and Probes

Appendix B summarizes the second round of modifications and probe questions. These are being field tested in late spring of 2011.

Discussion and Implications

Our preliminary work suggests that only the “outer shell” of self-report has been addressed in the very large methodological literature on interviewing persons with ID: reducing response errors via alternative task demands or screening out those persons who may be unreliable or unproductive respondents. Cognitively oriented studies suggest a great deal is yet unknown about the parameters of self-report for persons with ID. Realistically speaking, cognitive models will not dramatically change our capacity to gather interview data but we most certainly need to better understand how to improve the sensitivity, scope, and validity of self-report by identifying strategies for facilitating response and response accuracy.

The present effort adds to the limited research on the feasibility of conducting meaningful cognitive testing of persons with ID (Antaki & Rapley, 1996; Kravetz et al., 2003). Development and evaluation of cognitive testing protocols represents an important task for future research.

The dialogue over self-report is largely focused on the capacity of the person to fit the measurement task. Perhaps a shift in perspective is necessary. Can the measurement tasks be re-evaluated and adapted to the capabilities of the interviewee by better understanding how responses are formulated? Can more flexible designs and interview formats and compensatory cognitive strategies enhance accuracy and expand the pool of potential self-respondents?

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APPENDIX A

Modified SF 12 for Cognitive Interview

- 1. In general, would you say your health is:**
___ Very good *
___ Okay
___ Bad

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “health” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Interpretation Difficulty]

In answering this question about “health”, did you think about?

[Definition Boundaries]

What kinds of things did you think about when we said “health”?

The following questions are about everyday activities you usually do. Does your health stop you from doing these activities? If so, how much?

- 2. Easy activities, such as moving a table, pushing a vacuum cleaner, bowling, or cleaning up your room?**
___ not at all
___ a little
___ a lot

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

- 3. Hard activities, like walking up lots of stairs**
___ not at all
___ a little
___ a lot

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “hard activities” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

During the past 4 weeks . . .

4. . . . how often did your health cause you to get less done than you usually do?

___most of the time

___a little of the time

___none of the time

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

5. . . . how often did you not do some things you wanted to?

___most of the time

___a little of the time

___none of the time

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

6. . . . how often did you get less done than you usually do because bad feelings such as feeling sad or nervous?

___most of the time

___a little of the time

___none of the time

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

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[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

<p>7. . . . did you do things <u>less carefully</u> than usual because of bad feelings such as feeling sad or nervous?</p> <p>___ most of the time</p> <p>___ a little of the time</p> <p>___ none of the time</p>

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

<p>8 . . . did pain make it hard for you to do your normal activities?</p> <p>___ most of the time</p> <p>___ a little of the time</p> <p>___ none of the time</p>

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

<p>These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.</p> <p>How much of the time during the past 4 weeks...</p> <p>9. Have you felt calm and peaceful?</p> <p>___ most of the time</p> <p>___ a little of the time</p> <p>___ none of the time</p>
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[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

10. Did you have a lot of energy?

- | |
|---|
| <p><input type="checkbox"/> most of the time</p> <p><input type="checkbox"/> a little of the time</p> <p><input type="checkbox"/> none of the time</p> |
|---|

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

11. Have you felt sad and depressed?

- | |
|---|
| <p><input type="checkbox"/> most of the time</p> <p><input type="checkbox"/> a little of the time</p> <p><input type="checkbox"/> none of the time</p> |
|---|

12. During the past 4 weeks, how much of the time has your health or your feelings interfered with visiting friends or family or doing fun things with other people?

- | |
|---|
| <p><input type="checkbox"/> most of the time</p> <p><input type="checkbox"/> a little of the time</p> <p><input type="checkbox"/> none of the time</p> |
|---|

[General Interpretation]

Now, could you please tell me, in your own words, what you think this question is asking?

[Specific Word Interpretation]

In this question, what does the word “easy activities” mean to you?

In this question, what does the word “health stopping you” mean to you?

[Response Interpretation]

What does [selected response] mean to you?

[Definition Boundaries]

What kinds of things did you think about when we said “health stopping you from doing things”?

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[Interpretation Difficulty]

What kinds of things did you think about when we said “health stopping you”?

What kinds of things did you think about when we said “_____”?

Do you feel this is a question that people would or would not have difficulty understanding?

Which of the following would you also consider to be “_____”?

In answering this question about “_____”, did you think about?

APPENDIX B

Second Interview Modification Based on Conversational Analysis

1. Do you feel healthy?

Probes:

- *What does it feel like to be healthy?*
- *What does it feel like to be unhealthy (or instead of using “unhealthy” maybe say “not healthy”)?*

Original Question #1: In general would you say your health is: Very good, Okay, Bad.

Rationale for Changes: Listing the options of “very good, okay and bad” resulted in participants mirroring the interviewer; this was a leading question. In many interviews participants answered questions by repeating the interviewer’s last option.

Rational for Follow-Up Questions: It is important to keep the participant thinking about their own health rather than the health of others. Participants in the cognitive testing tended to answer questions by referencing other people instead of themselves.

Asking participants to talk about feeling healthy and unhealthy facilitated elaborations since most initially responded with a simple “yes” or “no”. The probe seeks to generate more conversation.

2. Does your health stop you from doing things?

Probes:

- *What does your health stop you from doing? OR if they answer “No” to the first question ask,*
- *Is it hard to do things when you are sick?*
- *What kinds of things is it hard to do?*

Original Questions #2 & #3: The following questions are about everyday activities you usually do. Does your health stop you from doing these activities? If so, how much?

Easy activities, such as moving a table, pushing a vacuum cleaner, bowling, or cleaning up your room? Options: Not at all, a little, a lot.

Hard activities, like walking up lots of stairs? Options: Not at all, A little, A lot.

Rationale for Changes: Generally, the participants gave good answers to this question when asked during the first round of interviews. The concept appeared relatively easy to understand. For this reason, the item was not dramatically changed. However, the sequence of “easy” followed by “hard” activities tended to be confusing and leading to the participants. By asking specific follow up questions we hope to get access the kinds of activities the participant is referencing when answering the question.

Rationale for Follow-Up Question: Participants often initially stated that their health did not stop them from doing things. But would later contradict themselves with some modest probing. Appeared to be an acquiescence bias. In order to attenuate this, we are having them elaborate on specific occurrences of their health stopping them from doing things.

3. Do you feel nervous?

Probes:

- When you feel nervous is it hard to pay attention to what you're doing?
- When you feel nervous is it hard to do things?

Original Questions #6 & #7: During the past four weeks, how often did you do things less carefully than usual because of bad feelings such as feeling sad or nervous? Options: Most of the time, Some of the time, None of the time.

During the past four weeks, how often did you get less done than you usually do because bad feelings such as feeling sad or nervous? Options: Most of the time, Some of the time, None of the time.

Rationale for Changes: In the revision we just ask about being "nervous" in order to reduce redundancy.

Participants were confused by the combination of the two emotional states, "sad" and "nervous" in the same question. In our cognitive interviews, participants had a difficult time articulating the meaning of "nervous," focusing on bodily movement or struggling to verbalize the concept. Responses to the general question were suppressed. We chose to query each separately.

Rationale for Follow-Up Questions: The original questions asks about "doing things less carefully" and "getting less done" when feeling nervous. These were difficult follow ups in the original interview sequence. We chose to keep the general concepts, but employed the phrases "paying attention" and "if things are hard to do," more concrete connections to the emotional state.

4. Do you feel pain ever?

Probes:

- Where do you feel pain?
- When you feel pain in your ____ is it hard to do things?
- What is hard to do?
- How often does pain make it hard to do ____?

Original Question #8: During the past four weeks, did pain make it hard for you to do your normal activities? Options: Most of the time, Some of the time, None of the time.

Rationale for Changes: We want to begin with a short and simple question about pain. In the interviews it was clear most of the participants understood the concept of pain, but the framing the question in terms of time was a distractor.

Rationale for Follow-Up Questions: Rather than time, more concrete questions will be employed. We will focus on location and consequences.

5. Do you feel calm and quiet?

Probes:

- When do you feel calm and quiet?
- How often does ____ make you feel calm and quiet?

Original Question #9: These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks have you felt calm and peaceful? Options: Most of the time, Some of the time, None of the time.

Rationale for Changes: The concept of "calm" was difficult; probes using the word "quiet" were more effective.

Rationale for Follow-Up Questions: Participants could directly speak to events or other issues that made them feel calm. We hope to get greater elaboration in the reports by asking what makes them feel calm.

6. Do you have a lot of energy? OR Are you active?

Probes:

- What do you do when you have energy?
- How often do you _____?

Original Question #10: These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

During the past four weeks, did you have a lot of energy? Options: Most of the time, Some of the time, None of the time.

Rationale for Changes: The concept of “energy” was difficult; probes using the word, “active” were more effective.

Rationale for Follow-Up Questions: When we asked about what energy meant, many were confused or felt the question was “tricky.” The revision simply makes the question more concrete by asking about activities they do when they have a lot of energy.

7. Do you ever feel sad?

Probes:

- What do you do when you feel sad? How often do you feel sad?

Original Question #11: These questions are about how you feel and how things have been with you during the past four weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

During the past four weeks, have you felt sad and depressed? Options: Most of the time, Some of the time, None of the time.

Rationale for Changes: Interviewees were fairly successful when talking about sad feelings; excluding the word “depressed” makes the query more direct.

Rationale for Follow-Up Questions: We hope to get more elaboration when asking about specific events related to feeling sad. While they were unable to fully articulate the idea of sadness, they were quite capable of relating their sad feelings and events related to the sadness.

Dropped Questions

Original Question #4: During the past 4 weeks, how often did your health cause you to get less done than you usually do? Options: Most of the time, Some of the time, None of the time.

Original Question #5: During the past 4 weeks, how often did you not do some things you wanted to do? Options: Most of the time, Some of the time, None of the time.

Rationale for dropping: The issues were often addressed in participants responses to question #2. The concepts of “get less done” and “stop” were difficult for our participants. The questions were negatively phrased questions, a difficult cognitive map for persons with intellectual disabilities.

Original Question #12: During the past four weeks, how much of the time has your health or feelings interfered with visiting friends or family or doing fun things with other people? Options: Most of the time, Some of the time, None of the time.

Rationale for dropping: The time frame confused respondents and answers were largely redundant to the queries about health stopping them from doing things.