

REVISED INTERVIEW QUESTIONS

I. Introduction

Concentrate on putting the interviewee and yourself at ease. Accept hospitality as offered. Spend a few minutes in social conversation (weather, children, home etc.), non-threatening small talk. This is also the appropriate time to review purpose and procedures of project, as needed.

II. Index Child

A. Tell me a little bit about "C".

- short {
1. Prompts: age, nickname, picture
 2. Prompts: How would you describe "C"? What is "C" like?
 3. Prompts: What does "C" enjoy? What does "C" dislike?

III. Effects of "C" on Individual Respondent/Family

A How has "C"'s presence affected your daily life?

- short - 40
1. Prompt: How do you spend your time on an average day?
 2. Prompt: How has this changed since before C was a part of your family?

B How has "C"'s presence affected your working/going to school?

- short - 5 min / long
1. Prompt: What changes have there been since "C" became part of your family?
 2. Prompt: Are these changes related to "C"'s being developmentally delayed or would you have made them in response to any child?

G How has "C" influenced your relationship with friends, neighbors?

- short -
1. Prompt: What was your social life like before "C"?
 2. Prompt: Do you think these changes are related to "C"'s being developmentally delayed? In what way?

K How has "C" had on your relationship with your spouse?

- * k
1. Prompts: Any negative? Any positive? Any additional stresses? Any increased closeness? Spend more time/less time together?

J How has "C" had on your relationship with your other children?

- short -
1. Prompts: Same as above D1

F In what ways do you think "C" affects your moods on a daily basis?

- short -
1. Prompts: Do you feel more stressed, more worried, happier?

C Are there any ways in which "C" has been a financial stress on you?

H How has "C" affected the amount of time you have for yourself?

L How were your initial feelings when you first learned about "C"'s condition?

- short -
1. Prompt: How have these feelings changed over time?
 2. Prompt: How did your spouse help improve/worsen these feelings?

M What kind of support did you need at that time?

- short -
1. Prompt: emotional, informational, logistical, financial, formal organization
 2. Prompt: What was available to you in terms of support?
 3. Prompt: How does that compare to now?

N How have you changed as a person as a result of having "C" as part of your family?

- short -
1. Prompt: Personality/character changes; attitude changes
 2. Prompt: Skills developed

H In what ways would you say your family is similar to or different from families of friends and neighbors with developmentally normal children?

- * H
1. Prompts: Way they spend their time; how family members get along

start *defunk*
 - 1 *11* Do you treat "C" the same or differently than your other children/ or than you would a developmentally normal child?

1. Prompt: Are your expectations different? In what ways?
2. Prompt: In what areas are these similarities/differences?

start *11* When you think of your own physical health, are there any ways in which you feel "C" has had an effect on you?

1. Prompts: More tired, any unusual physical symptoms
0. Do you sometimes feel that "C"'s needs are more than you can meet?

20 IV. Respondent's Perception of "C"'s Effect on Other Family Members

A. What have been siblings' reactions to "C"? (Ask separately for each child)

1. Prompts: Negative; positive; tell me more about this
2. Prompts: What kind of relationship would you say they have?
3. Prompt: Tell me something about how they play together.

*** B. Does "S" have any problems?

1. Prompts: At home? At school?
 2. Prompts: Behavior/discipline problems
 3. Prompts: Unusual number of illnesses, physical problems
 4. Prompt: Unusual personality characteristics: ie., very shy, aggressive
 5. Prompts: Fears, phobias, nightmares
- Is there one sibling who has special problems any problems*

*** C. What has your spouse's reaction to "C" been like?

1. Prompt: What is their relationship like?
2. Prompt: How much time do they spend together on a daily basis?
3. Prompt: How is this time spent? (What kind of activities?)
4. Prompt: How does spouse treat "C" compared to other children in family?

could cut - D. What has been grandparents' response to "C"?

1. Prompt: Negative; positive
2. Prompt: maternal/paternal grandparents
3. Prompt: What is their involvement with "C"? How often do they see "C"

V. Coping Resources and Responses

30 *** A. You mentioned

- problems in daily life (be specific)
- financial problems
- interpersonal problems
- personal problems

How have you dealt with each of these ? (get details)

*** B. Overall, what have you done, or thought, or felt to help you get through this experience?

C. What has been the most difficult thing about "C"'s condition for you?

1. Prompt: What have you worried about the most?
2. Prompt: What has troubled you the most?
3. Prompt: What has been most difficult for other family members/spouse?

D. How have you dealt with this?

1. Prompt: How successful have you been?

*** E. What do you think has helped you the most in dealing with "C"?

1. Prompts: past experience, social support, inner resources, faith tangible support

start F. Who in the family is involved in caring for "C"?

1. Prompt: spouse, extended family, neighbors, other people
2. Prompt: in what ways? who coordinates?

*** G. Do you think that dealing with a developmentally delayed child requires special coping skills or simply the same kinds of skills necessary to face any difficulty in life?

1. Prompt: What are these skills?

H. What advice would you give to a family in a similar situation to your own, to help them deal with the stresses and challenges of having a developmentally delayed child?

I. Who do you turn to most for support?

1. Prompt: How does this person help you?

10 VI. Meaning/Significance

A. Most people in your situation think about WHY this has happened in their lives, to their child. How do you answer this question for yourself?

B. Do you feel that there is any meaning or significance to be understood from "C"'s condition? If so, what?

C. Do you feel that "C" will have a better, worse, or essentially the same quality of life as other people? What makes you feel that?

D. In general, do you think things are improving in this country for individuals with mental and physical handicaps? In what ways?

E.

What thoughts do you have about "C"'s future?

1. Prompts: fears, worries; limitations

2. Prompt: What about the possibility of placement

Did anyone ever suggest?

3. Prompt: What do you think "C" might be doing in 10 years (school, home life, social life)

VII. Nature of Communication re "C"

10 * A. How often would you say you talk about "C" with your spouse? (times per week)

* B. Who usually initiates these talks?

* C. What kinds of things do you tend to talk about?

1. Prompt: problems in daily living.

2. Prompt: successes "C" has had

3. Prompt: decisions regarding "C"'s welfare

4. Prompt: transmitting information

5. Prompt: sharing negative/positive feelings

D. How comfortable are you talking to your spouse about "C"?

E. How often do you talk about "C" with other relatives; friends; neighbors?

F. ~~What kinds of things do you tend to talk about? (Prompts same as above)~~

G. How do you usually explain "C"'s condition to people who do not know "C"?

H. When you talk about "C" with your spouse, do the two of you generally tend to agree or disagree about things?

1. Prompt: What specific things do you have disagreements about?

Did you have any success.

When will you learn about father's feelings?

Reaction of child to world

could end

INTERVIEW QUESTIONS

1. Effects on individual/family related to P.

I'd like us to talk a bit about what having P as part of your family has been like.

How has P's presence in your family affected you personally?

PROMPTS: Negative effects

→ Positive effects

Developmental effects (historicity): How have feelings changed

over time? *How have resources*
etc. etc. etc.

Specific adaptive tasks: How have adaptive tasks changed?

emotional adaptation

instrumental problem-solving

financial problems

effect on work, daily life

How has P's condition affected your family as a whole?

2. Coping Responses

You've mentioned certain ways in which your life has been enriched by P's presence, and other ways in which it has been made more difficult, or at least has been challenged. Could we talk for a moment about some of the ways you've coped with the problems you mentioned earlier.

PROMPTS: Take specific adaptive tasks and ask about coping?

How have you coped as an individual?

How has your family coped?

What has been the most difficult thing about P's condition for you?
For other family members?

How have you dealt with this?

How successful have you been?

What do you think has helped you the most in dealing with P?

(PROMPTS: Past experience, social support, inner resources, faith)

What are other things that have helped you? In what ways?

What advice would you give to a family in a similar situation to your own, to help them deal with the stresses and challenges of having a developmentally delayed child?

3. Meaning/Significance?

Most people in your situation are forced to think about WHY this has happened in their lives, to their child. How do you answer this question for yourself? For other family members? For your child?

Do you feel that there is any meaning or significance to be understood in P's condition? If so, what?

Do you feel that a developmentally delayed person will have a better, worse, or essentially the same quality of life as most people? What makes you feel that?

What thoughts do you have about P's future?

(PROMPTS: specific fears, worries; limitations)

4. Nature of communication about P

How often would you say you talk about things concerning P with your husband? With the rest of the family?

Are any members of the family excluded from these discussions?

Who initiates these talks?

What is the content of these discussions?

Sharing of negative, positive emotions

Problem-solving, information-sharing

How open, and honest do you think this communication is?

How often do you talk about P with friends and neighbors?

(PROMPTS: same as above)

INTERVIEWER CHECKLIST

1. Introduce yourself to all family members present. State in simple language the purpose of the interview, and show the letter substantiating that you represent the University of California in this study.
2. Try to interview the respondent in private. This will not always be completely possible, as children and other members of the household may interrupt. However, the continuous presence of other family members will have a definite distorting effect on the interviewee's responses.
3. Put your interviewee at ease as much as possible. Reassure her that interruptions from children or other sources are allowed, and that you wish to inconvenience her as little as possible. Accept any hospitable gestures from the interviewee, such as offers of food or drink.
4. Be respectful and supportive at all times during the interview process. Be attentive to the respondent's comfort, and be sure that she understands that she may interrupt or leave the interview if she needs to at any time.
5. If all or any of her children are present, it is helpful in establishing a relaxed environment to acknowledge them by spending a few minutes talking or playing with them.
6. Have the respondent read and sign the consent form before you begin the interview. Give her the extra copy and the Human Subjects Experimental Bill of Rights to keep.
7. Be familiar with the interview form, so that you are able to maintain eye contact with the subject as much as possible. Familiarity with the interview is also important so that you do not make mistakes in asking the questions. Explain that the questions you are asking are written down, and that you will be referring to your papers from time to time. Offer to show her the interview schedule, as this will make it appear less intimidating.
8. Reiterate that if she is puzzled or confused by any question, she is free to ask you to repeat or clarify. Also reiterate that she has the right to refuse to answer any question, or to terminate the interview at any time.
9. Speak clearly and carefully when reading interview questions and statements.
10. Be sure to ask all questions in the same way as much as possible. Do not change the structure of questions, as this may affect the subject's response.
11. Be sure to ask all questions in a concerned and interested manner. This should not appear to be a mechanical task.
12. If the interviewee's response is unclear, be sure to clarify.
13. When you are writing out a summary of a respondent's statement, try to use her own words as much as possible. If you are paraphrasing her statement, be sure to confirm your paraphrase with her: "It sounds as though what you're saying is..."
14. If you are unable to code a response according to any of the categories indicated, simply note the actual response on the questionnaire.

INTERVIEWER CHECKLIST (continued)

15. Relevant information which the subject shares but which does not respond to any specific interview question should be noted at the end of the interview.
16. If the respondent begins to elaborate endlessly on a topic tangential to the interview, attempt to guide her gently back to the question at hand. While it is important to encourage the respondent to talk, it is also important to provide direction for the interviewer, so that the respondent is not tempted to avoid sensitive issues.
17. Pay special attention to interactions between mother and spouse/affected child/other children during the course of the interview. Note these and any other observations about the nature of the family at the end of the interview. We are interested in your subjective impressions of the family.
18. Avoid judgmental responses (For example, if a respondent states that her child was not vaccinated, do not tell her that she should have behaved more responsibly). Rather, create a supportive and open atmosphere. We are not interested in judging our subjects' behavior or feelings but in getting them to feel safe enough to share with us how they actually behaved and felt.
19. In the interview context, pity, in contrast to empathy, is not a productive or desirable response. Avoid comments such as, "It must be terrible for you to have a crippled child!" Comments such as these will not build trust, and in fact will create an emotional distance between you and the respondent.
20. Use all probes indicated. Especially when dealing with sensitive topics, respondents may initially be reluctant to disclose any information. It is easier for them to say "Not at all," in response to questions such as "How has this experience affected your family?" than to try to formulate a reply. If the interviewee spontaneously generates information relevant to a question to which she has previously given an unproductive response, be sure to note this.
21. In the event of any emotional display on the part of the interviewee, do not be bound by the interview format. Your primary concern must be the welfare of your subject. If the respondent starts to cry, or appears sad or distressed, empathetic comments are appropriate. Encourage her to talk more about her feelings, and let her know you are not embarrassed by her emotions. Continue the interview proper as appropriate.
22. Never leave any respondent in a state of extreme emotional distress. While this is not a likely development, should this occur, make an effort to calm the respondent. Be sure that when you leave, the spouse or a neighbor is present. Inform your supervisor, Estella Lopez, of all such occurrences.
23. If the respondent asks you any questions that you can't answer, tell her that you will get the information and contact her. Be sure you make a note of such questions and that you follow through on getting the necessary information.
24. At the conclusion of the interview, thank the respondent courteously for her help. Elicit any last thoughts and comments at this time.