

Appendix C: Focus Group Protocols

Idaho Parents of Children Ages 0-8 Focus Group Moderator's Guide

I. WELCOME/BACKGROUND INFO (10 minutes)

Welcome to our group discussion. Thank you for taking the time to participate in our focus group discussion about young children. My name is _____, I am here with my colleague _____ and we work for Health Systems Research, Inc. based in Washington, DC. Our company is working with the Idaho Department of Health and Welfare. As a requirement for receiving Federal funding, Idaho and all other States are required to examine the needs of families and children in the State every five years.

As part of this needs assessment, they are seeking to learn more about the experiences of families with young children. This information will be used to assist them in improving services and resources for families.

The purpose of focus groups is to get the honest opinions of small groups of people about a specific topic. These topics may range from what people think about a particular soft drink, soap product, or in our case, services for young kids and their families.

I would like to review the ground rules for our discussion:

- There are no right and wrong answers. Remember, I do not work for the State of Idaho, so please tell me your thoughts, whether they are positive or negative.
- It is ok to disagree with one another. We want to hear everyone's point of view. If you disagree, please do so respectfully.
- Only one person should talk at a time. We are tape recording this session so that we do not miss anything important. If two people talk at once, we can not understand what anyone is saying. I may remind you of this during the group.
- We would like everyone to participate. You each do not have to answer every question. If, however, some of you are shy or I really want to know what you think about a particular issue, I may ask you about it.
- We have a lot that we want to talk about tonight. So, do not be surprised if at some point I interrupt the discussion and move to another topic. But, do not let me cut you off. If there is something important you want to say, let me know and you can add your thoughts in before we change subjects.
- We will be using first names only today. Everything you say is confidential. After we conduct several of these group discussions across the state, we will write a report for the Idaho Department of Health and Welfare. Your name will not appear anywhere in the report. What you say today will not be attached to your name at any point. Nothing that you say will affect your eligibility for or the services you receive

through any of the programs we talk about today.

- Do not worry about offending us. We really want to learn from you and find out what you think about the issues we talk about tonight. Please tell us your honest opinions.
- I want to make a couple more points related to the tape recording. Please speak up. If you speak too quietly, it will be too difficult to hear you later on the tape. Also, please do not bump the table or tap your hands on the table. Anything close to the microphones sounds incredibly loud on the tape and it will drown out your voices. _____ is also taking notes in case the tapes do not come out clearly and she will be handling the tape recorders.

The group will last two hours. You will not get out any later than _____. We will not be taking a formal break, but if you need to leave for a restroom break, the bathrooms are _____.

(If someone unexpectedly came with a child and on-site child care was not arranged in advance: If your child begins to get too noisy, please take them out of the room until they are quiet again. Then, come back into the room. Again, with tape recording, we need to keep the room relatively quiet.)

At the end of the session, we will give you \$20 cash for your time and expenses associated with coming tonight (child care and transportation). We will also ask you to complete a short anonymous survey.

II. INTRODUCTIONS

(5 minutes)

Let's get started. Please remember that the focus of this group discussion is young children from birth to eight years old, so please limit your comments to that age group.

Start with the participant to your right. Have them respond in round robin fashion.

1. Please tell me your name, how many children you have, and their ages.

III. FOCUS GROUP QUESTIONS

A. What Concerns Families About their Children Age Birth to Eight Years? (15 minutes)

I would like to begin our discussion with some general questions about children age eight or younger.

1. What worries you about caring for and raising young children, that is babies and kids up to age 8?

Probe for:

- health needs (health insurance, finding a provider, cost of care, getting sick, safety issues - getting hurt)
- development (are they growing OK? Issues with eating, temper tantrums, sleep)
- who will take care of them (childcare arrangements, availability, cost, quality)
- family relationships (sibling rivalry, stress on family unit, current and future financial concerns)
- adequacy as a parent

2. What concerns you the *most*? Why?
3. Who do you turn to for help with things that worry you?

B. Pregnancy and Childbirth

(20 minutes)

Now I would like those of you who are biological parents to think back to when you were pregnant.

1. What was good about the care you received when you were pregnant?
2. What could have been better?
3. How pregnant were you when you first started receiving care?

Probe: [If they started care after the first trimester (the 4th month or later)]:
Any reasons you didn't see a doctor or nurse earlier?

4. While you were pregnant what information did you receive about what things would be like once you had a child? How helpful was this information?
5. Now I want you to think about when your child was born, where was your child born?
6. What was this experience like?

Probe: What was good about it? What could have been better?

7. After your child was born what follow-up care did you receive? What was good about it? What could have been better?
8. What help and support were you offered with breastfeeding? What help and support could you have used that you didn't receive?

C. Healthcare

(20 minutes)

I want to turn to the healthcare you receive for your child or children.

1. First I have a question about health insurance. Can you raise your hand if your child has health insurance coverage? What is good and what is bad about the health insurance coverage you have for your child?
2. **(If anyone does not have coverage)** What has been your experience in obtaining health care without insurance?
3. **(For everyone)** Are you able to see a doctor when you feel you need to?

Listen for:

- issues related to finding, paying, timeliness of availability
- other barriers (e.g. transportation)

4. During visits what does the doctor or nurse talk with you about?

Probe for:

- child development (Does the doctor tell you what age you can expect your child to accomplish a particular task)
- child rearing (eating, sleeping, play, temper tantrums)
- family concerns (stress on parent, sibling rivalry)
- does the doctor suggest and/or refer you to other resources or services?

5. What kinds of things *would* you like to discuss with your child's health care provider?

Listen for:

- health issues, development, parenting advice, resource information, family issues, behavioral issues, and level of comfort with talking with provider

6. If you could change one thing about the healthcare you receive for your child what would it be?

D. PARENTING

(20 minutes)

Now let's go on and talk about parenting. Babies and young children do not come with instruction manuals, let's talk about how and where you learn to be a parent starting with:

1. Where do you go to for answers about your parenting questions or concerns?

Probe for:

- What information or advice they were seeking
- How useful was the information or advice
- What made it useful

2. What are the child rearing areas and issues where you think parents and families need the most information and guidance?

3. What services in your community currently help parents in these areas?

Probe for:

- What are they look like?
- What is good and bad about them?

4. What services are needed that aren't currently available?

Probe for:

- What should they look like?
- What are some strategies that could be used to help parents strengthen their parenting skills?

E. FAMILY SUPPORT

(15 minutes)

Caring for little ones, managing a home and supporting a family can be a handful and sometimes parents need some help.

1. What kinds of supports do families of young children need?

(Try not to use but if parents get stuck and need some explanation: “these are programs or services which help parents raise their children or help with particular family issues, including things such as financial issues, stress, parent support groups, balancing work and family”)

2. What kinds of supports are currently available to families in your community?

3. How could these supports and services be improved?

4. What is the best way to for people to learn about family support issues and services available in the community?

Probe: Community meetings or lunches? Mailings? Email? The internet?
Flyers in doctor's offices or daycare?

C. SUMMARY ISSUES

(15 minutes)

1. Thinking about all the areas and services we have discussed, what would make it easier for you and your family to:

a) Do a good job raising your children?

- b) Feel more confident in raising your children?
- c) Find services needed?
- d) Use services needed?

Probe for: warm lines, info directories, co-located services, Family Centers, services connected to church, childcare/Head Start, health care,

- 2. If there was one thing you could change about the services available in your community to parents of very young children, what would it be?
- 3. What is the best part of being a parent to children under age 5?
(want to end with happy thoughts)

IV. CLOSING

(5 MINUTES)

Check for questions or follow-up from co-moderator.

Thank you very much for coming tonight. We enjoyed the discussion and have learned a lot from your comments and suggestions.

Is there anything I haven't asked about that you would like to tell me related to the topics we have discussed?

Please complete the form with a few questions about you.....be sure NOT to include your name. Also please sign a receipt for the \$30.

Idaho
CSHCN Focus Group
Moderators Guide

A. INTRODUCTION

(10 MINUTES)

Welcome to our group discussion. Thank you for taking the time to participate in this discussion to share your thoughts and experiences around services for children with special needs. By that we mean children and adolescents with a chronic health problem, behavioral problem, or disability. My name is _____ and I work for Health Systems Research. My co-worker's name is _____. Our company is working with the Idaho Department of Health and Welfare. As a requirement for receiving Federal funding, Idaho and all other States are required to examine the needs of families and children in the State every five years.

As part of this needs assessment they are seeking to learn more about the experiences of families of children with special needs. This information will be used to assist them in improving services and resources for children and teens with special needs.

This discussion is called a “focus group.” The purpose of focus groups is to get the honest opinions of small groups of people about a specific topic. These topics may range from what people think about a particular soft drink, soap product, or in our case, services for children with special needs.

I would like to review the ground rules for our discussion:

- There are no right and wrong answers. Remember, we don't work for any state agency, so please tell us what you honestly think.
- It is OK to disagree with one another. We want to hear everyone's point of view. If you disagree, please do so respectfully.

Only one person should talk at a time. We are tape recording this session so that we don't miss anything important. If two people talk at once, we can't understand what anyone is saying. We may remind you of this during the group.

- We would like everyone to participate. But, you each don't have to answer every question. If, however, some of you are shy or I really want to know what you think about a particular question, I may call on you.
- We have a lot that we want to talk about tonight. So, don't be surprised if at some point we interrupt the discussion and move to another topic. But, don't let us cut you off. If there is something important you want to say, let us know and you can add your thoughts in before we change subjects.
- We want to talk with you about services for children with special needs. Also, we are more interested in some aspect of the topic than others. If the group starts to talk

about any other issues, we will remind you to stay on topic.

- We will be using first names only today. Everything you say is confidential. After we conduct several of these group discussions across the state, we will write a report to the Idaho Department of Health and Welfare. Your name will not appear anywhere in the report. What you say today will not be attached to your name at any point. **Nothing that you say will affect the services you receive now or in the future.**
- We really want to learn from you and find out what you think about the issues we talk about. Please tell us your honest opinions.
- We want to make a couple more points related to the tape recording. Please speak up. If you speak too quietly, it will be too hard to hear you later on the tape. Also, please don't bump the table or tap your hands on the table. Anything close to the microphones sounds incredibly loud later on and it will drown out your voices.
- _____ is taking notes in case the tapes don't come out clearly and she will be handling the tape recorders. At the end of the session, she will provide a brief summary of what you all said tonight, so that you can correct anything we have misunderstood or clarify important points.

The group will last no more than two hours. You will not get out any later than _____. We will not be taking a formal break. If you need to leave for a restroom break, the bathrooms are _____.

If someone unexpectedly came with a child and on-site child care was not arranged in advance: If your child begins to get too noisy, please take them out of the room until they are quiet again. Then, come back into the room. Again, with tape recording, we need to keep the room relatively quiet.

At the end of the session, we will give you \$20 cash for your time and expenses associated with coming tonight (child care and transportation). We will also ask you to complete a short anonymous demographic form that asks some basic information about your family.

Let's get started. I'd like to start out by going around the table and having each of you tell us a little about yourself. Again, my name is _____.

Start with the participant to your right. Have them respond in round robin fashion.

B. CURRENT UTILIZATION OF SERVICES

(30 MINUTES)

1. Please tell me your name, how many children you have and their ages, and what kind of insurance you have. We are particularly interested in your experiences caring for your child with special needs (child with a chronic health or disabling condition) so would you tell us the nature of your child's special need.
2. Who would you consider to be your child's primary/regular doctor?

Probe:

- A specialist, a primary care/pediatrician?
- Has your child's primary doctor changed over the years?

3. In addition to your primary doctor, what are the other health care providers that you have used for your child/teen in the last year?

Probe:

- specific medical specialists
- OT, PT, Speech therapist
- dentist
- nutritionist
- counselor, mental health
- walk-in clinics
- emergency room
- local public health department
- other

4. What other (non-medical) services have you used for your child or teen in the past year?

Probe:

- education
- social services
- counseling/mental health
- support
- respite

5. What have been your experiences in obtaining day care or schooling for your child?

Probe:

- What has worked well about this?
- What could be better?

6. Does your child or teen need medical care while at school? At day care?

Probe:

- What kind?
- How is this managed?

C. SURVEILLANCE AND INITIAL ASSISTANCE

(20 MINUTES)

Please think back to when you found out your child had a special need.

1. Can you describe how you found out?
2. What help were you offered in understanding what your child would need at that point?

3. What services were you connected to?
4. What helped were you offered in terms of how this affected your family?
5. Thinking of all that happened when you first found out about your child's special needs, what was useful about the help you received? What could have been better?

D. SEEKING SERVICES AND CARE COORDINATION (45 MINUTES)

1. What have been your experiences in finding the services your child needs?

Probe:

- Explore experiences with different agencies/systems (education, early intervention, medical [primary care, specialty care], nutrition, pharmacy, durable medical equipment, supplies, etc.)

2. Who helps you find the services your child needs?

Probe :

- Primary doctor?
- Does family do this - if so who?
- An agency (education, social services)?
- Various agencies depending on need or service? If so, who is the *most* involved?

3. What help do you receive in determining and understanding what services your child needs?

4. What do you feel is working well within your community in regards to finding, determining and understanding the services your child needs?

5. What makes it hard to get services for your child or teen?

Probe:

- Availability of services/providers
- Accessibility of services/providers
- Lack of knowledgeable providers
- Health Insurance Issues/out-of-pocket costs

6. What is the *most* serious problem you and your family face in trying to get and use care for your child with special needs and your family?

Probe:

- Lack of communication, coordination, or cooperation between service providers
- Cost of services
- Problems finding home or community-based services
- Problems scheduling services or getting/using appointments (wait times)
- Not knowing what services are available
- Needed services are not available in my community
- Geographic distance to service
- Lack of reliable transportation

7. What would make it easier to get/use care for your child or teen?

Probe:

- Having one person to assist family with coordination of care
- Having multiple services available in one place
- Having one place to get information about services and financing of care

8. What *one* thing would make the system better for you and your family?

9. Caring for a child or teen with special needs can affect the entire family. Tell if you agree or disagree with the following statements.

a) My child's health problems are causing financial problems for our family.

b) My child's health conditions are causing disagreements within our family.

c) I need additional support to care for my child.

d) I have cut down the hours I work or have stopped working because of my child's health condition.

e) (If has not surfaced) What are the positive impacts on the family of caring for a special needs child?

10. What is the *one* thing that would help the impact on your family of caring for your child or teen with a special need?

E. CLOSING

(10 MINUTES)

Thank you very much for coming. We enjoyed the discussion and have learned a lot.

Is there anything I haven't asked about that you would like to tell me about?

Ask the co-moderator if they have any questions.

Have participants complete short demographic form.

Pass out the envelopes with the \$20 and ask them to sign a sheet saying they got their money.

Encourage them to take home whatever food remains.

Idaho Adolescent Health Focus Groups Teen Protocol

I. BACKGROUND

(10 MINUTES)

Welcome to our group today. Thank you for taking the time to participate in this afternoon's discussion. My name is _____ and I work with Health Systems Research. My co-worker's name is _____. The State of Idaho's Division of Health is interested in finding out more about your opinions of the health care services and supports available to you. Your ideas will be used to educate providers on the types of health issue teenagers have, and what types of services they want to meet their needs.

I would like to review the ground rules for our discussion:

- There are no right or wrong answers. Remember, I don't work for the State of Idaho, the Idaho Migrant Council, the county, or the school system. I will not be speaking to your parents so please tell me your thoughts, whether they are positive or negative.
- It is ok to disagree with one another. We want to hear everyone's point of view. If you disagree, please do so respectfully.
- Your participation in today's focus group is voluntary. You are free to leave at any time. However, pizza will be served midway through our meeting and the \$20 in cash will only be given to those who stay until the end.
- Only one person should talk at a time. We are tape recording this session so that we don't miss anything important. If two people talk at once, we can't understand what anyone is saying. I may remind you of this during the group.
- I would like everyone to participate. But, you each don't have to answer every question. You don't have to raise your hand either. If, however, some of you are shy or I really want to know what you think about a particular question, I may call on you.
- I have a lot that I want to talk about this afternoon. So, don't be surprised if at some point I interrupt the discussion and move to another topic. But don't let me cut you off. If there is something important you want to say, let me know and you can add your thoughts in before we change subjects.
- We will be using first names only today. Everything you say is confidential. We will write a report for the State to use in its adolescent health planning. Your name will not appear anywhere in the report. We also ask that you don't tell other people what was said by specific people during the group. What you say today will not be attached to your name at any point. Nothing that you say will be repeated to teachers or your parents.

- Don't worry about offending me. I don't have a vested interest in anything that is said here tonight. I really want to learn from you and find out what you think about the issues we talk about this afternoon. Please tell me your honest opinions.
- As I mentioned the session is being recorded, in order to ensure that the tapes are as clear as possible I would ask that you do not tap on the table and that you speak up when you talk.

The group will last two hours. We will need to talk while you are eating later so that the group ends on time. We will not be taking a formal break. If you need to leave for a restroom break, the bathrooms are _____.

Do you have any questions before we begin?

II. INTRODUCTIONS

(5 MINUTES)

Let's get started. I'd like to start out by going around the table and having each of you tell us a little about yourself. Again, my name is _____.

Start with the participant to your right. Have them respond in round robin fashion.

1. Please tell me your name, how old you are, and what you most like to do for fun?

III. FOCUS GROUP QUESTIONS

(15 MINUTES)

A. TEEN ATTITUDE ON HEALTH CARE

I would like to begin today's discussion with some general questions about being a teenager.

1. What are some of the things that you worry about as a teenager (*Listen for health and health insurance issues*)?
2. What do you think are your parent's/guardian's biggest worries about you?
3. What types of health services do you think are most important for teens your age?

PROBE: What are some reasons why you or your friends go to the doctor or nurse?

4. How do people stay healthy?

B. HEALTH ACCESS

(20 MINUTES)

1. When you have questions about a health issue, where do you go for information?
2. What do you do when you don't feel well? (*Listen for what kids do/try, self-care, etc.*)

PROBE: Who usually makes the decision on whether or not you go to the doctor?

PROBE: Where do you go?

- Do you go to your parents doctor or clinic?
- Do you go to the school nurse?
- What is it about that place that makes you want to go there for health care?

3. If you could create the perfect doctor's office or clinic to go to what would it be like?

PROBE: How do you want them to treat you?

- What kinds of services or information would you want them to have?
- What would you want them to say? What would you *not* want them to say--
- Have any of your peers ever delayed seeing a health care provider because of fear that their parents would find out? (*Listen for confidentiality issues*)

4. If you want to see a doctor or nurse, what are some of the things that make it hard for you to get in to see them? What makes it easy for you?

5. What about dental care? Are you able to see the dentist when you need to?

C. HEALTH TOPICS

(45 MINUTES)

Now I would like to focus in more detail on some of the areas we have touched on and ask you about your thoughts and experiences.

1. Let's begin with one of my favorite topics – food! (and exercise)

- 1.1 What are some of your favorite foods and snacks?
- Which of these foods do you consider 'healthy'?
- 1.2 What do you see as the benefits of eating healthy?
- 1.3 If you wanted to eat more healthy foods, what one thing would you want to change now?
- 1.4 Where do you get information about food or nutrition? Do you believe the information?
- 1.5 What exercise/physical activity are you already doing?
- 1.6 What are some of the reasons teens don't exercise? What kinds of exercise/physical activity would you like to do or be interesting in doing?

1.7 How would you find out about what is available?

2. Now let's move on to alcohol, drug and tobacco use.

2.1 At what age do youth in your community start drinking or using drugs?

2.2 What percent of the teenagers you know drink or use drugs?

2.3 What are some of the reasons that people start drinking or using drugs?

2.4 What percent of the teenagers you know smoke cigarettes or use chewing tobacco?

2.5 Thinking about other Hispanic teens you've known who did not use drugs or alcohol... Why Didn't they (Prompt: What was it about them, their family, or their environment?)

2.6 What could be done to keep kids from drinking, taking drugs, smoking cigarettes, or chewing tobacco?

3. Reproductive Health

3.1 Do you think teen pregnancy is a problem in your community? Why or why not?

3.2 Where do young people get information about preventing pregnancy? Do you trust the information?

3.3 What information do you have to prevent sexually transmitted diseases such as chlamydia, gonorrhea, syphilis or AIDS?

4. Emotional Health

4.1 If kids are feeling really, really sad or angry or worried what do they usually do?

PROBE: Who can they talk to?

Where can they find help?

Is there anything that can be done to better help kids who feel this way?

5. Violence

5.1 What types of violence do the young people in your community experience or witness? PROBE: At home? In school? At work?

5.2 What do you think could be done to reduce violence?

E. HEALTH CARE PROMOTION

(15 MINUTES)

We want to get your opinions on the best ways for health and social service groups to reach teens.

1. What's the best way to reach teenagers for groups that want to help young?

PROBE: Where do teens like to go to hangout?

What do teens like to do?

- Magazines?
- Radio stations?

2. Tell me about any health-related activities or programs that you participated in or heard about.

PROBE: What is it about that activity or program that made it stand out?

Would you participate in it again?

What is it about that activity or program that would make you want to participate in it or not participate in it again?

3. Be creative – tell me what other kinds of health programs or activities would be most interesting to you or your friends?

PROBE: Have you ever signed up or participated in something for the incentives or giveaways?

-What was the incentive/giveaway?

- Money?
- Food?
- T-Shirts?

F. CONCLUSION

(10 MINUTES)

1. If you could change one thing about how health care services are provided to teens, what would it be and why?
2. Is there any other information you would like to share about teenagers in your community?

I want to thank you for participating in the group today. The confidential information you have provided will be of great help to the State of Idaho as it makes plans to improve the health care of all teenagers in the state. We appreciate you taking the time to share your opinions with us and we wish you good luck and good health. I have envelopes to give you with your \$20 to thank you for your time.