

**FOCUS GROUPS ABOUT WOMEN'S PERCEPTIONS OF DOWN SYNDROME
FOCUS GROUP GUIDES****Segment 1: Women who have a young child or children without Down syndrome****A. Background**

Hello. My name is ____ and I work with RTI International, a not for profit research company. Thank you for participating today. We are working on a project sponsored by the U.S. Centers for Disease Control and Prevention, or CDC, in Atlanta to learn about women's views about Down syndrome. Ultimately CDC would like to use this information to develop better health messages about this issue.

Before coming into the room, each of you completed the consent form and had an opportunity to ask questions. Later, you can contact the RTI's Office of Research Protection toll-free at 1-866-214-2043 about any questions or concerns that you have related to your participating today. That number is listed on your copy of the consent form.

At this time, I want to review what will happen next. Who has participated in a focus group before? [Wait for response.] My role is to guide our discussion today and to assure that everyone has a chance to share their thoughts and ideas on the topics that I ask about. Therefore, we will follow some general rules for our discussion.

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Our group discussion will take about 75 minutes. The discussion will be recorded so that I can give my full attention to what you are saying. Even though there is also a note taker in the observation room, we want to assure that we do not miss any of your comments. At the end, we will ask you to complete a short form and we will provide your incentive (\$75.00). Again, your participation in this discussion is voluntary and you can end your

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participation and leave the group at any time. Any questions? [Wait a moment. Respond to any questions.]

Okay, let's get started. I will turn on the recorder now. [TURN ON THE RECORDER. RECHECK TO BE SURE THAT THE RECORDER IS RECORDING!]

B. Participant Introductions and Ice Breaker

Now, I would like each of you to introduce yourself—FIRST NAME ONLY PLEASE—and tell us something you like to do for fun. [Pass around name tags.] Please write your FIRST NAME ONLY on the name tag. That will help me to address you by name.

Icebreaker: Does anyone have any experience with people with Down syndrome?

C. Discussion

I. Knowledge about Down syndrome

We're going to begin our discussion by talking about what you know about Down syndrome.

1. What thoughts come to mind when you think about Down syndrome?
2. What types of things have you heard or do you know about Down syndrome? How would you describe it?
3. What have you heard about how Down syndrome is caused?
4. What about how common it is?
5. What do you know about how Down syndrome is treated?
6. What have you heard about the effects of Down syndrome?

PROBES: Can you describe what person with Down syndrome is like
mentally?
Physically?

7. What types of things have you heard about how long people with Down syndrome live?
8. What are some risks for having a child with Down syndrome?

II. Perceptions of Quality of Life

9. What would life be like if you had a child with Down syndrome?

PROBES: What changes would have to be made?
What things would you have to do differently?

10. How do you think having a child with Down syndrome would affect your personal life? Your other children? Your relationship with your significant other? Your job?

11. What do you think the life of someone with Down syndrome is like?

PROBE: How do you perceive the quality of life of someone with Down syndrome? Why do you say that?

12. What are your attitudes/thoughts about persons with Down syndrome?

PROBES: In schools/your child's class?
At your workplace?
In your community?

13. What do you think about the ability of children with Down syndrome to develop like other children?

PROBES: For example, their ability to speak, to be toilet trained, to learn to walk.
For example, their ability to go to school.

14. What do you think about the ability of adults with Down syndrome to live like other adults?

PROBE: For example, their ability to work and live independently.

15. How do you think persons with Down syndrome are viewed by others?

PROBES: In schools?
At your workplace?
In your community?

16. How do you think someone with Down syndrome would be treated by others?

PROBES: In schools?
At your workplace?
In your community?

17. Have/would concerns about having a child with Down syndrome affected your thoughts about when to start having children?

III. Information Sources

18. Where do you get information about health?

PROBES: Media?
Family?
Church?
Internet?

19. Out of these sources, which one do you tend to use most often to get health information?

PROBES: Which of these sources do you trust or feel is most likely to be right?
Why?

20. Where have you heard or received information about Down syndrome?

PROBES: Personal experience?
Media images?
Health care providers?

21. What information, if any, did you receive about Down syndrome when you were pregnant?

22. What kinds of information about Down syndrome would you like to know or would be good to know?

PROBES: Causes of Down syndrome?
How common it is?
Effects?
Treatment?
Quality of Life?

23. What are the most important messages to communicate about Down syndrome to someone like you?

24. What information would you need if you found out your newborn baby had Down syndrome?

25. What information would you need if your child was at a higher risk of developing Down syndrome?

26. In what format would you prefer to receive information about Down syndrome?

PROBES: Brochure/pamphlet?
Fact sheet?
CD/DVD?
Website?

27. If you wanted more information about Down syndrome, where would you go?

PROBE: Who or what would be a trusted source of information?

28. What would be good places to put information about Down syndrome to reach women like yourself?

29. Where would you expect to find information about Down syndrome?

30. When is the best time to give mothers/parents information about Down syndrome? Why do you say that?

PROBES: Prenatal care providers?
After birth in the hospital?

IV. WRAP UP

31. What recommendations do you have for designing materials about Down syndrome for parents?

32. Does anyone else have any thoughts on any of the issues we've discussed?

Thanks so much for your time and help! We plan to use this information to provide a report to CDC to help inform the development of materials about Down syndrome.

Now we are going to ask you to complete a short survey to provide us some basic information about you.

FOCUS GROUPS ABOUT WOMEN'S PERCEPTIONS OF DOWN SYNDROME FOCUS GROUP GUIDES

Segment 2: Women without children but who plan to have children in the future

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Hello. My name is ____ and I work with RTI International, a not for profit research company. Thank you for participating today. We are working on a project sponsored by the U.S. Centers for Disease Control and Prevention, or CDC, in Atlanta to learn about women's views about Down syndrome. Ultimately CDC would like to use this information to develop better health messages about this issue.

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Icebreaker: Does anyone have any personal experience with people with Down syndrome?

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PROBES: Can you describe what person with Down syndrome is like mentally?
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What things would you have to do differently?

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- your other children?
- your relationship with your significant other?
- your job?

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PROBES: How do you perceive the quality of life of someone with Down syndrome?
Why do you say that?

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