

Informal Focus Groups for ADDM Network
Autism Society of America Conference
July 25-28, 2012
San Diego, California

Moderator's Guide

Introduction/Warm-Up

Hi, my name is _____. I am conducting this Focus Group today on behalf of the Centers for Disease Control and Prevention (CDC). Thank you for sharing your time with us. I am here because the CDC would like to make ADDM Network data more useful for you. Your participation in this focus group is voluntary. You can choose to end your participation at any time. Please keep in mind that we are interested in your ideas and opinions—there are no right or wrong answers. We have asked for our discussion to be recorded so that we can concentrate on talking with you. I want to assure you, however, that all of your comments will be kept secure and will be used to help us improve our health communication efforts. We would like to begin by asking each of you some general questions. Could we go around the room and have each person answer the questions...

1. What is your role or interest in the autism community and what is one thing you want to see or do in San Diego?

Current Knowledge

2. When you think about the Centers for Disease Control and Prevention, or CDC, and autism what is the first thing that comes to mind?

[Prompt]

Is CDC an agency that you think of when you think about autism?

3. Are you familiar with the estimated number of children identified with autism spectrum disorders, or ASDs, the US? This is also referred to as the prevalence of ASDs.

[Prompt]

Can anyone tell me what the prevalence is?

Where did you hear the information about the 1 in 88 estimate?

CDC estimates that 1 in 88 children has been identified as having an autism spectrum disorder. This estimate is provided by CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. This estimate is also comparable to those from nationally representative U.S. surveys from the same time period.

The public reporting burden of this collection of information is estimated to average 45 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to - **CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333 ATTN: PRA (0920-0919)**

4. Are you familiar with any of the characteristics of children with ASDs?

[Prompt]

For example, which groups of children are more likely to be identified with ASDs?

For example, at what age most children are likely to be diagnosed with ASDs?

5. Has anyone heard of the Autism and Developmental Disabilities Monitoring Network, or ADDM Network?

[Prompt]

What do you think the purpose of the ADDM Network is?

In your opinion, is this what the ADDM Network should be doing?

6. Are you familiar with any studies being conducted in your area that are related to the ADDM Network?

Information Needs, Preferences, and Past Uses

7. What are some of the reasons you would seek out information on the estimated number (prevalence) and characteristics of children with ASDs?

8. What does knowing the estimated number (prevalence) and characteristics of children with ASDs do for you, your family, your work, your community, or others?

[Prompt]

Does it influence your work?

Has it changed anything you are doing?

Has it had an impact on state/ local policy?

Has it helped the autism community?

9. How can CDC get the most up-to-date and accurate information to you on the estimated number (prevalence) and characteristics of children with ASDs?

[Prompt]

Are there channels or modes of communication that you prefer?

What do you think is the best mode of communication for this information?

10. Do you know if your state collects data on the estimated number (prevalence) and characteristics of children with ASDs?

[Prompt]

Do you use state level data on the prevalence of ASD?

What additional state level data would be useful?

Evaluation of Current Materials

Now we are going to give each of you a copy of CDC's Community Report on ASD. Some of you may already be familiar with the Community Report and for some of you this may be your first time seeing it. Please take about five minutes to skim it. Once you've looked over the Community Report, I'd like to talk with you about your overall reactions. [Allow time for participants to look through Community Report]

11. Now let's talk about the Community Report. What's your general reaction to the Community Report?

[Prompt]

Is there anything you especially like about it?

Is there anything you especially dislike about it?

Is anything confusing?

Are the pictures and colors appealing?

Is the layout organized and easy to follow?

Is there other information you'd like to see included?

Is there another format you would suggest?

12. Where, when, or how could you see yourself using the Community Report?

Please turn to page 18 and 19 of your copy of the Community Report. I would like to talk about your reactions to the state pages. This page on Georgia's ADDM Network site is just an example. Please take a moment to review it. [Allow time for participants to look over the Georgia state page]

13. Now let's talk about this example of a state page. What's your general reaction to the state page?

14. Where, when or how could you see yourself using a state page?

Thank you. That was great feedback. Let's turn to the Table of Contents for a moment. It's on the first page inside the front cover.

15. Of all the sections included in the Community Report, which one do you think you would use the most?

Now we are going to give each of you a copy of the ADDM Network fact sheet. Again, some of you may already be familiar with the ADDM Network fact sheet and for some of you this may be your first time seeing it. Please take about a minute to read it. Once you've looked over the fact sheet, I'd like to talk with you about your overall reactions.

16. Now let's talk about the ADDM Network fact sheet. What's your general reaction to the fact sheet?

[Prompt]

Is there anything you especially like about it?

Is there anything you especially dislike about it?

Is anything confusing?

Are the pictures and colors appealing?

Is the layout organized and easy to follow?

Is there other information you'd like to see included?

Is there another format you would suggest?

17. Where, when, or how could you see yourself using the fact sheet?

Well, that is the last of our questions. Do you have any final comments or questions? [Pause a moment to give the opportunity for participants to comment/ask questions.] Thank you so much for your

participation. We will surely use your feedback to improve our health communication efforts and make CDC's ADDM Network data more useful for you. Thanks again!