SEED Focus Groups Autism Society Annual Conference San Diego, CA. July 2012

## **Focus Group Moderator Guide**

Hi, my name is \_\_\_\_\_\_\_. I am conducting this Focus Group today on behalf of the Study to Explore Early Development ( or SEED) at the Centers for Disease Control and Prevention (CDC). Thank you for sharing your time with us. I am here because SEED would like to make sure its new brochures and other materials are useful for inviting families to be in the study. Please keep in mind that we are interested in your ideas and opinions—there are no right or wrong answers. Your participation in this focus group is voluntary. You can choose to end your participation at any time. 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 private and will only be used to help us improve our outreach efforts.

Could we go around the room and have each person answer the questions...

1. How old are your kids, and what is one thing you want to see or do in San Diego?

Here are some general questions about research.

1. Think back to a time when you had been asked to participate in a research study. Did you participate?

What were the reasons that you did or didn't participate in that study?

Who or what influenced your decision to participate?

2. How do you feel about health studies?

By health study, we mean any research study that was about learning more about human health or medicine.

Have you ever participated in a health study before?

What were the reasons that you did or didn't participate in that study?

Who or what influenced your decision to participate?

Potential follow-up questions

How would you respond if the study were done by [a university, government, provider, some other entity?]

Next we are going to hand out this packet and some paper and pens for notes. Take a couple minutes to review these materials and write down your thoughts. Afterwards we will share what we think.

The public reporting burden of this collection of information is estimated to average 1 hour 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)

[Present invitation packet and paper/ pencil for notes. Invitation packet includes brochure, invitation letter, beach ball toy, response card and return envelope.]

3. What do you think of these invitation materials?

Would you send back in the response card and want to be a part of the study?

What changes could we make to improve these materials?

What would make you want to participate?

Potential follow-up questions

What kind of invitation would you respond to?
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 it clear that this is a legitimate study and not junk mail?
Would you trust the study staff based on this invitation?
Is there other information you'd like to see included?
Is there another format you would suggest?

Now that you've been introduced to SEED, we wanted to share some of the other outreach materials [Hand out pictures of other materials if there is time left. Tabbed flyer, large response card, and pre-invitation post card.]

4. What do you think of these [materials]?

Would you respond to this [material]?

What changes could we make to improve these materials?

Potential follow-up questions

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?

To wrap up the focus group we want to ask each of you some closing questions since each of your opinions is important to us.

[Closing questions –ask each participant]

- 5. Of all the things we discussed what to you is the most important?
- 6. If you were in charge of the SEED study, what would you do to improve it?

Thank you so much for your time and willingness to talk with us today.