

Appendix B.1
Study to Explore Early Development
Primary Caregiver Interview Telephone Script

Hello, may I speak with <First and Last Name of Respondent (Caregiver)>? [RECORD NOTES AND TIME FOR NEXT CALL IF NOT AVAILABLE – GO TO BOX1]

My name is <Interviewer Name> and I am calling for the <Site> Study to Explore Early Development. In a recent phone call with our study staff you had agreed to participate in the study, including this telephone interview and had scheduled the interview for this time. Is this time still OK for you?

IF NO, DOES NOT WANT TO COMPLETE INTERVIEW NOW: When would be a convenient time to conduct the interview?

PROBES:

- We can start now and see how far we get.
- We can do the interview in short sections such as 10 or 15-minute sessions, if that would be more convenient.
- I can set an appointment up with you to call back at a convenient time.

[RECORD NOTES AND TIME FOR NEXT CALL IF NOT WILLING TO START – GO TO BOX1]

BOX1: IF NEED TO COMPLETE THE INTERVIEW AT ANOTHER TIME:

[RECORD DATE AND TIME (INCLUDING TIME ZONE).]

VERIFY PHONE NUMBER: I need to verify your telephone number where you can be reached for the interview.

CONFIRM: We have scheduled your appointment on <DAY, DATE> at <TIME>. Would you please call us at our toll-free number <xxx-xxx-xxxx> if you need to change your number?

Thank you for agreeing to participate in the Study to Explore Early Development.

IF YES, CAN START INTERVIEW NOW: READ INFORMED CONSENT TELEPHONE SCRIPT BELOW

This is an interview to discover some clues as to what causes autism and other developmental problems. Interviews are being conducted as part of the Study to Explore Early Development on child development and autism. I would like to give you a short introduction before we begin.

This interview takes about an hour (*but we can complete it in short sections if you prefer*). It covers a broad range of questions about:

- Your family background
- Your lifestyle,
- <Child's name> health after birth.
- (Your pregnancies)

- (Your health during your pregnancy with <child's name>, including prescription and non-prescription medications you might have taken)
- (<Child's name>'s biological father (*such as his background information and his use of medications to help you get pregnant*))

The questions cover many areas since we do not have a clear understanding of what factors are related to autism and child development. You may find some of the questions sensitive in nature but you can choose not to answer any question you wish.

There is little risk in taking part in the interview. You may feel uncomfortable answering sensitive questions or discussing your pregnancies. Again, you can choose not to answer any question that makes you feel uncomfortable.

Taking part in this interview will not benefit you or your family directly. Findings may help us learn more about what causes autism and other developmental problems. This may lead to better services and treatments for children with developmental disabilities. You can choose not to participate. There will be no bad effects from this decision; it will not affect the care or services you or your family receives. You are free to stop the interview at any time.

We understand that you may have concerns about your privacy. In order to protect the privacy of all participants, CDC applied for and received a Certificate of Confidentiality. A Certificate of Confidentiality guarantees that any information that is collected that could identify you or your child will be used only for this project. It cannot be given to anyone else unless you give your written consent or unless otherwise required by law.

If you have any concerns about the study or how it is conducted or if you feel you have been harmed by participating in the study, you may contact <PI for site> at <phone number of PI>. If you have questions about your rights as a research subject, you can call the Institutional Review Board representative < Representative's Name> at <Phone number of rep>.

My supervisor may listen in from time to time to make sure that I am doing the best job that I can. If you still agree to be interviewed, will it be OK for my supervisor to listen?

IF NO: SET UP “NO MONITORING SIGNAL OR SIGN” FOR SUPERVISOR

May we continue with the interview now?

IF YES TO CONTINUE WITH INTERVIEW:

[RECORD DATE AND TIME (INCLUDING TIME ZONE).]

Thank you for agreeing to participate in the Study to Explore Early Development.

IF NO, WILL NOT COMPLETE INTERVIEW: We would like to know for what reason or reasons you have decided to not participate in this interview (SPECIFY)

