

TELEPHONE SCRIPT
Follow-up Telephone Call

	CALLER GUIDELINES & NOTES
<p>1. INTRODUCTION</p> <p>1a. Introduction of Self; Length of Call</p> <p>Hello, may I speak with <first and last name of participant>? My name is <name> and I am calling from <site>. I want to thank you for your interest in the <name of study> and talk with you briefly about our next steps. Do you have a few moments to speak with me?</p> <p>GO TO 1B IF NO. GO TO 2A IF YES.</p> <p>1b. Not A Good Time for Participant</p> <p>Thank you. Is there a better time that I could reach you?</p>	<p><i>If caller asks how long call will take:</i></p> <ul style="list-style-type: none"> • <i>Approximately 20 minutes if self-administered questionnaires are NOT reviewed; and</i> • <i>Approximately 40 minutes if self-administered questionnaires are reviewed.</i> <p><i>RECORD BEST TIME TO CALL BACK</i></p>
<p>2. ENROLLMENT PACKET</p> <p>2a. Receipt of Enrollment Packet</p> <p>My supervisor may listen in from time to time to make sure that I am doing the best job that I can. If you agree to be interviewed, will it be OK for my supervisor to listen?</p> <p>IF NO: SET UP “NO MONITORING SIGNAL OR SIGN” FOR SUPERVISOR</p> <p>Thank you. By now you should have received an enrollment packet in the mail. The enrollment packet contains some information on the study for you to keep, some forms for you to complete and return, and a cheek swab kit for you to complete and return. Have you received this packet?</p> <p>GO TO 2B IF NO. GO TO 2C IF YES.</p> <p>2b. Participant Has NOT Received Packet</p> <p>I’ll make sure the packet is mailed to you as soon as possible. When you get the packet please be sure to complete and return the forms as soon as possible. You will</p>	<p><i>CONFIRM MAILING ADDRESS, ASK SPECIFICALLY ABOUT ANY APARTMENT NUMBER</i></p>

be compensated up to <amount> for the time and effort it takes to complete the enrollment packet.

I'll call back in a few days to see if you have received the packet.

GO TO 3A.

2c. Participant HAS Received Packet

Have you had a chance to complete and return the questionnaires and cheek swab kits?

GO TO 2D IF NO.

GO TO 2G IF YES.

2d. Participant HAS Received Packet but HAS NOT Returned Materials

Do you still have the materials that were sent to you?

GO TO 2E IF NO.

GO TO 2F IF YES.

2e. Participant DOES NOT Still Have Materials

I'll make sure the packet is mailed to you as soon as possible. When you get the packet please be sure to complete and return the forms as soon as possible. You will be compensated up to <amount> for the time and effort it takes to complete the enrollment packet.

I'll call back in a few days to see if you have received the packet.

GO TO 3A.

2f. Participant Does Still Have Materials

I realize that your time is valuable. All information gained in this study will help us learn more about autism and other developmental disabilities. Please complete and return these materials at your earliest convenience. You will be compensated up to <amount> for the time and effort it takes to complete the enrollment packet.

Are there any questions about the enrollment packet that I can answer for you at this time? Would you like for me to help you sort through the steps in the packet?

CONFIRM MAILING ADDRESS, ASK SPECIFICALLY ABOUT ANY APARTMENT NUMBER

<p>GO TO 2H IF PARTICIPANT HAS QUESTIONS ABOUT THE ENROLLMENT PACKET.</p> <p>GO TO 3A IF PARTICIPANT DOES NOT HAVE QUESTIONS ABOUT THE ENROLLMENT PACKET.</p> <p>2g. Participant HAS Received Packet and HAS Returned Materials</p> <p>Do you have any questions about the materials in the enrollment packet at this time?</p> <p>GO TO 2H IF PARTICIPANT HAS QUESTIONS ABOUT THE ENROLLMENT PACKET.</p> <p>GO TO 3A IF PARTICIPANT DOES NOT HAVE QUESTIONS ABOUT THE ENROLLMENT PACKET.</p> <p>2h. Enrollment Packet Review</p> <p><i>REVIEW NECESSARY FORMS.</i></p>	
<p>3. QUESTIONS</p> <p>3a. General Questions</p> <p>Are there any questions about the study that I can answer for you at this time?</p> <p>GO TO 4A.</p>	<p><i>ANSWER ALL QUESTIONS</i></p>
<p>4. NEXT STEPS</p> <p>4a. Describe Next Steps</p> <p>The next steps in the study involve parent interviews, a brief child exam, child developmental evaluation, and collecting a sample of blood from the birth parent(s) and the child, and a sample of hair from the child. There are many different options you can choose to complete these parts of the study. I will describe your options in detail as we schedule each individual component.</p>	
<p>5. PRIMARY CAREGIVER INTERVIEW</p>	

<p>5a. Description and Scheduling</p> <p>The first interview will focus on pregnancy factors and early developmental history. It will contain questions about the mother’s health before and during pregnancy. It will also ask about your child’s health and development after birth. It should take about 50 minutes to complete the interview.</p> <p>This interview will be conducted over the telephone by <site specific> at a time that is convenient for you.</p> <p>When is the best time to call?</p> <p>Thank you. I will note to call you on this day and time.</p> <p>IF SPEAKING WITH BIOLOGICAL MOTHER GO TO 5G. IF ANY OTHER GO TO 6A.</p> <p>5g. I would like to ask you some questions now that will help make the interview go faster.</p> <p>COMPLETE PREGNANCY REFERENCE FORM PACKET</p>	<p><i>RECORD APPOINTMENT DETAILS, IF R WON’T SCHEDULE, NOTE REASON AND WHETHER HARD OR SOFT REFUSAL FOR TELEPHONE INTERVIEW PIECE</i></p>
<p>6. Child Clinical: Parent Interviews</p> <p>6a. Description and Scheduling</p> <p>The second set of interviews will focus on your child’s behavior and development. It should take about 3 hours to complete all of the interviews. You can complete some or all of the interviews over the telephone. If the interviews are completed over the telephone it would be best for us to call at a time that you will be free from distractions. You can also come into a study clinic or study staff can come to your home in order to complete the interviews. Would like to schedule some or all of the interviews over the telephone?</p> <p>GO TO 6B IF YES. GO TO 6C IF NO.</p>	

GO TO 6E IF PARTICIPANT DOES NOT WANT TO COMPLETE INTERVIEWS.

6b. Telephone Scheduling

When is the best time to call?

How much time can you spend on the phone during this call?

Thank you. I will note to call you on this day and time.

GO TO 6D IF ADDITIONAL SCHEDULING NEEDED.

GO TO 7A IF NO ADDITIONAL SCHEDULING NEEDED.

6c. Clinic/Home Scheduling

Would you prefer to come to a study clinic or have study staff come to your home?

When would you like to schedule the appointment?

How much time can you spend during this visit?

Thank you. I will schedule an appointment on this day and time.

Please make sure that you return the clinic intake form 1 week before your visit. You may want to bring one of your child's favorite snacks in a small plastic container and one of his/her favorite toys to the visit.

GO TO 6D IF ADDITIONAL SCHEDULING NEEDED.

GO TO 7A IF NO ADDITIONAL SCHEDULING NEEDED.

6d. Additional Scheduling

When would you like to complete the remainder of the interviews?

Would you like to complete them over the telephone, at a clinic visit, or in your home?

RECORD APPOINTMENT DETAILS

RECORD APPOINTMENT DETAILS INCLUDING PLACE

<p><i>Schedule as appropriate.</i></p> <p>GO TO 7A.</p> <p>6e. Participant Does NOT Want to Complete Interviews</p> <p>Your participation in each part of the study is important. All of your answers may help us learn more about autism and other developmental disabilities. If you change your mind about participating in this part of the study, please call <name> at <number>.</p>	<p><i>RECORD APPOINTMENT DETAILS</i></p> <p><i>NOTE REASON AND WHETHER HARD OR SOFT REFUSAL FOR INTERVIEW PIECE</i></p>
<p>7. CHILD DEVELOPMENTAL EVALUATION</p> <p>7a. Description and Scheduling</p> <p>We would like to conduct a developmental evaluation on your child. In order to complete the evaluation, your child must be able to walk by him/herself and must not have any severe hearing or vision problems. The evaluation will be conducted by a trained professional who has experience working with children. It should take about (1 hour 20 min SUB/NIC/ 2 hours CASE) to complete. You will receive a letter about the results of the evaluation. Can you bring your child into a study clinic in order to complete the evaluation?</p> <p>GO TO 7B IF YES. GO TO 7C IF NO.</p> <p>7b. Clinic Visit</p> <p>When would you like to bring your child to the clinic in order to complete the evaluation?</p> <p>Thank you. I will schedule a clinic visit at this date and time.</p> <p>GO TO 8A7E.</p> <p>7c. Home Visit Description</p> <p>Would you allow project staff to come to your home in order to complete the evaluation?</p> <p>GO TO 7D IF YES.</p>	 <p><i>RECORD APPOINTMENT DETAILS INCLUDING PLACE</i></p>

GO TO ~~7E-7F~~ IF PARTICIPANT DOES NOT WANT TO COMPLETE DEVELOPMENTAL EVALUATION.

7d. Home Visit

When would be a good time for project staff to come to your home?

Thank you. I will notify the clinicians that you will be expecting them on this date and time.

GO TO 7E.

7e. Clinic Intake Questions

I would like to ask you some questions now that will help our clinician plan for the evaluation.

7e1. What is the primary language spoken to [CHILD] at home?

7e2. Does [CHILD] have any problems hearing?

IF YES:

Can you describe the problems?

7e3. Does [CHILD] have any problems seeing?

IF YES:

Can you describe the problems?

7e4. Does [CHILD] have food allergies or dietary restrictions?

IF YES:

Can you describe the allergies or restrictions?

Now I am going to ask you some questions about [CHILD'S] current language development.

7e5. Is [CHILD] babbling with no words?

7e6. Is [CHILD] using single words?

7e7. Is [CHILD] using two word phrases?

7e8. Is [CHILD] using full sentences?

RECORD APPOINTMENT DETAILS

RECORD CLINIC INTAKE ANSWERS

<p>7e9. Can [CHILD] have back and forth conversations?</p> <p>7e10. Can [CHILD] describe past events?</p> <p>7e11. Can [CHILD] follow two step directions?</p> <p>Now I have a few questions about any behaviors that may impact the evaluation.</p> <p>7e12. Does [CHILD] bite, hit, or scratch? IF YES: Can you describe the behavior(s)?</p> <p>7e13. Does [CHILD] throw tantrums? IF YES: Can you describe the tantrums?</p> <p>7e14. Does [CHILD] have preoccupations with topics or objects? IF YES: Can you describe the preoccupations?</p> <p>GO TO 8A</p> <p>7f. Participant Does NOT Want to Complete Developmental Evaluation</p> <p>Your participation in each part of the study is important. Results of the evaluation may help us learn more about how children develop differently. If you change your mind about participating in the evaluation, please call <name> at <number>.</p>	<p><i>NOTE REASON AND WHETHER HARD OR SOFT REFUSAL FOR DEVELOPMENTAL EVALUATION PIECE</i></p>
<p>8. Dysmorphology EXAM AND BLOOD DRAW</p> <p>8a. Description and Scheduling</p> <p>We would like to conduct a brief exam on your child. Trained professionals will measure your child's height and weight. They will take pictures of your child's hands and face. They will also measure your child's facial features, hands, and feet. This information will help us understand why children develop differently. We would also like to take a blood and hair sample from your child. The samples will help us understand the biology of developmental</p>	

<p>disabilities.</p> <p>GO TO 8B IF CHILD DEVELOPMENTAL EVALUATION HAS BEEN SCHEDULED.</p> <p>GO TO 8D IF CHILD DEVELOPMENTAL EVALUATION HAS NOT BEEN SCHEDULED.</p> <p>8b. Child Developmental Evaluation HAS Been Scheduled</p> <p>Let's try to schedule your child's exam and blood draw at the same time as the developmental evaluation.</p> <p>GO TO 8C IF YES.</p> <p>GO TO 8D IF NO.</p> <p>GO TO 8E IS PARTICIPANT DOES NOT WANT TO TAKE PART IN THIS COMPONENT OF THE STUDY.</p> <p>8c. Physical Exam and Blood Draw Scheduled Same Time as Developmental Evaluation</p> <p>I'll make a note that the exam and blood draw will be collected on the same day as the developmental evaluation.</p> <p>GO TO 9A.</p> <p>8d. Physical Exam and Blood Draw NOT Scheduled at the Same Time as Developmental Evaluation</p> <p>When would you like to schedule the exam and blood draw?</p> <p>Would you like for the visit to take place in a study clinic or in your home?</p> <p>Thank you. I will schedule an appointment on this day and time.</p> <p>GO TO 9A.</p> <p>8e. Participant Does NOT Want to Take Part in Child Physical Exam and Blood Draw</p> <p>Your participation in each part of the study is important.</p>	<p><i>RECORD APPOINTMENT DETAILS INCLUDING PLACE</i></p> <p><i>NOTE REASON AND WHETHER HARD</i></p>
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<p>Results of the exam and blood draw may help us learn more about how children develop differently and the biology and developmental disabilities. If you change your mind about participating in this part of the study, please call <name> at <number>.</p> <p>GO TO 9A.</p>	<p><i>OR SOFT REFUSAL FOR PHYSICAL EXAM AND BLOOD DRAW PIECE</i></p>
<p>9. PARENT BLOOD DRAW</p> <p>9a. Description and Scheduling</p> <p>We would also like to get a sample of blood from your child’s biological parents. The blood sample will help us understand the biology of developmental disabilities.</p> <p>GO TO 9B IF CHILD DEVELOPMENTAL EVALUATION HAS BEEN SCHEDULED.</p> <p>GO TO 9D IF CHILD DEVELOPMENTAL EVALUATION HAS NOT BEEN SCHEDULED.</p> <p>9b. Child Developmental Evaluation HAS Been Scheduled</p> <p>Let’s try to schedule your blood draw at the same time as your child’s developmental evaluation.</p> <p>GO TO 9C IF YES.</p> <p>GO TO 9D IF NO.</p> <p>GO TO 9E IS PARTICIPANT DOES NOT WANT TO TAKE PART IN THIS COMPONENT OF THE STUDY.</p> <p>9c. Blood Draw Scheduled Same Time as Developmental Evaluation</p> <p>I’ll make a note that your blood draw will be collected on the same day as your child’s developmental evaluation.</p> <p>GO TO 10A.</p> <p>9d. Blood Draw NOT Scheduled at the Same Time as Developmental Evaluation</p>	

<p>When would you like to schedule your blood draw?</p> <p>Would you like for this appointment to be at a study clinic or in your home?</p> <p>Thank you. I will schedule an appointment on this day and time.</p> <p>GO TO 10A.</p> <p>9e. Participant Does Not Want to Take Part in Parent Blood Draw</p> <p>Your participation in each part of the study is important. Results of the blood draw may help us learn more about how children develop differently and the biology and developmental disabilities. If you change your mind about participating in this part of the study, please call <name> at <number>.</p> <p>GO TO 10A.</p>	<p><i>RECORD APPOINTMENT DETAILS INCLUDING PLACE</i></p> <p><i>NOTE REASON AND WHETHER HARD OR SOFT REFUSAL FOR BLOOD DRAW PIECE</i></p>
<p>10. REMINDER CARDS AND PREP SHEETS</p> <p>10a. Notification of Reminder Card and Prep Sheet Mailing</p> <p>You will receive a reminder phone call before each telephone or face-to-face appointment. Preparation guides for the telephone interviews, child developmental evaluation, and parent and child biosampling are included in your enrollment packet. These materials will tell you what to expect and will let you know if you need to gather any information before the appointment.</p>	
<p>11. THANK YOU</p> <p>11a. Thank You</p> <p>Thank you for speaking with me today and for participating in this important study. If you have any questions about the study, you can call <name> at <number>. Thank you again for your time.</p>	