

Study to Explore Early Development

Attachment 15.d.

Clinic Visit Prep Guide

The clinic visit consists of 4 parts: (1) conducting a developmental evaluation of your child, (2) conducting a brief physical exam of your child, (3) obtaining blood and saliva samples from your child and (4) obtaining blood and saliva samples from you and, if he is available, a saliva sample from your child's father. In some cases we may also want to ask more questions about your child's development. *<Optional: We created a picture story to help guide you and your child through the clinic visit.>* Please let us know if you have additional questions after you review *<optional: the picture story and>* this prep guide

It will take about 2 hours to complete the clinic visit. However, if we also need to spend some time completing any remaining study forms with you, the visit will take longer. The study forms were sent to you earlier. There were 6 in all. If we need to complete all of these forms with you, the visit might take an additional 1 ½ - 2 hours. Thus, we ask that you please complete all forms prior to the visit. *<Optional: We are happy to help you with these over the phone.>*

Please plan to arrive 15 minutes before your scheduled visit to help your child become familiar with the clinic. We ask that you meet us at *<Address of clinic: e.g., the Marcus Autism Center at 1920 Briarcliff Road NE in Atlanta, GA>* to complete this clinic visit. *<Optional: The visit is sometimes easier for children if seen in a clinic since there are few distractions in a clinic setting. As such, the child may perform better and the visit may take less time when performed in a clinic.>*

Home Visits (site specific)

<Optional: If you cannot come to the clinic, you can choose to have project staff come to your home to complete the clinic visit. In order to do the evaluation in-home, you must be able to provide a private and quiet area. This area must be free from distractions. It is preferred that you find childcare for your other children so that you can sit with your child during the evaluation.>

Project staff will need to look in your home for the most appropriate place to conduct the assessment. Staff will then need to set-up the room without your child present. After the room has been set-up, the evaluator will play with your child in order to make him/her more comfortable. The evaluation will begin after your child is comfortable with the evaluator.>

What to expect during the Developmental Evaluation:

A trained professional will conduct the evaluation. The evaluator will first introduce herself and answer any questions you may have. She will then play with your child in order to make him/her more comfortable. The evaluation will begin after your child is

comfortable with the evaluator. You can sit with your child during the evaluation in order to make him/her more comfortable. The evaluation will consist of one test that will take about 1 hour to complete. The test will involve asking your child some questions and engaging him/her in some structured play activities. Your child will be able to take a break if needed. You can come back at another time if your child cannot complete the evaluation.

How to prepare for the developmental evaluation:

Children must be able to walk by themselves in order to complete the evaluation. The evaluation also requires that your child does not have any significant and uncorrected hearing or vision impairments.

<Optional: You may want to review the picture story and bring one of your child's favorite toys for them to play with during breaks in the visit. You also may want to bring a favorite snack in a small plastic container. Please tell us if your child has any allergies to latex, foods or other things.>

What to expect during the form completion:

We have mailed forms to you to complete <Optional: on your own or over the phone with one of our staff members> prior to the clinic visit. These forms are about your child's development and your family's health.

How to prepare for the form completion:

If you are unable to complete these forms prior to the clinic visit, we will complete them with you in person. This can take up to an additional 1 ½ - 2 hours to do.

What to expect during the Physical Exam

We ask that you allow a project staff to conduct a brief exam on you and your child. A trained professional will measure your child's height, weight, and head circumference. We will also measure your height, and head circumference.

How to prepare for the physical exam

<Optional: You may want to review the picture story prior to the physical exam.>
We will ask you and your child to remove your shoes so we can obtain accurate height and weight measurements. If you or your child's hairstyle includes braids on their head, if possible, we ask you not to have them in at the time of the visit. The braids interfere with our staff obtaining an accurate measure of head size and height.

What to expect providing blood and saliva samples:

We ask that you allow us to get a sample of blood and saliva from you and your child, and a saliva sample from your child's father if he is available. These samples will help us learn more about the biology of developmental problems.

Saliva Samples: Each person will answer questions about when they last brushed their teeth and ate food. The clinic staff will assist you in collecting the samples using one of two methods. The first method is to collect saliva by spitting directly into a tube. The second method uses a small sponge to soak up saliva from your mouth. We will give you specific instructions for the method you choose. It can take about 10 minutes depending on how much saliva you make. You or the staff will collect your child's sample.

Blood Sample: A trained professional will wrap your arm with a latex band and insert a small needle into your arm to get the blood. Please tell us if you or your child has a latex allergy. We will do everything we can to make you feel at ease. If you decide to use the numbing cream for your child, we will first put the cream on your child's arm for a few minutes. The trained staff member who has experience working with children will then remove the cream and insert a small needle into your child's arm. We will do everything we can in order to make your child feel at ease. You can decide to stop at any point during the blood draw.

How to prepare for the blood and saliva samples:

You may want to <Optional: review the picture story and> talk with your child before the visit to explain the blood draw and saliva collection procedures. You may also want to tell staff which type of collection method you prefer; if you think your child will have difficulty with spitting into the tube then we can use the sponge method. We ask for you to wait at least 30 minutes after eating, drinking or chewing gum before we collect the saliva samples. <Optional: The picture story book is an excellent tool to review with your child before the visit.>

You may also want to bring a favorite snack or treat that can be given to your child after he/she has completed this part of the study.

You may want to wear, and dress your child in, a shirt or dress with sleeves that are loose fitting and can comfortably be pulled above your elbow. A loose long sleeve shirt may also be more comfortable for your child after the numbing cream is put on to distract your child from the cream.

Parent Interview

What to expect:

Study staff may want to ask you more questions about your child's development. All of the information you give will help us learn more about why children develop differently. The interview can be done either over the telephone or during a clinic visit. We will ask about your child's personal and social functioning and developmental skills. It will take

about 45 minutes to complete. You can skip any question that makes you feel uncomfortable.

How to prepare:

Please look through your child's baby book or baby calendar to recall when your child reached developmental milestones. Write down what age your child first rolled over, sat alone, crawled, walked, used single words, and spoke in phrases. If there was a period when your child seemed to lose skills, please write down what skills he/she lost and about how many months the skill was lost.