



CONSENT FORM

Expressive Language Sampling as an Outcome Measure in ASD - Parent

You and your child are invited to participate in a research study about how best to measure the language skills of children with autism spectrum disorder (ASD). You have been asked to participate because your child has been diagnosed with ASD and is between the ages of 6 and 23 years. Children, teens, and young adults between the ages of 6 and 23 years will participate in this study at three different sites, including the University of Minnesota-Twin Cities, University of California-Davis and University of Washington-Seattle. This study will include up to 50 children verbally expressive children with ASD and one of their primary caregivers. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Lizbeth H. Finestack, Ph.D., CCC-SLP in the Department of Speech-Language-Hearing Sciences at the University of Minnesota (phone: 612-624-6090; email: finestack@umn.edu). This study is also being conducted at the MIND Institute at the University of California in Davis, CA and The University of Washington in Seattle, WA.

Background Information

The purpose of the research is to better understand how the language individuals with ASD use changes based on the speaking situation. We are interested in how language is different when having a conversation, telling a story, or interacting with an adult. We also want to know how language used by individuals with ASD in these situations changes over time. In the future, it is possible that measures of spoken language production in one or more of these situations may be used to decide if a treatment is helping a child or adult to learn and use language more effectively.

Study Qualification

The study includes children and adults aged 6 to 23 years with ASD. Participants must have a documented diagnosis of ASD and no evidence of fragile X syndrome. Participants must use speech to communicate and use utterances that have at least 3 words. Participants must be native English speakers and have no serious hearing or visual impairments.

Procedures

If you decide that you and your child want to take part in this study, we will ask you to provide us with a copy of documents verifying your child's diagnosis of autism spectrum disorder. If you do not have a copy of this report, we may ask you to complete a separate release form so that we can obtain these records from your clinician. We also will ask you to provide us with a



report, such as a psychological report, an IEP, or other school record, indicating your child's developmental level.

Because we want to see how your child's language changes over time, you and your child will be asked to visit the University of Minnesota three times. At each visit, we will collect a sample of your child's language while interacting with an examiner in three different settings: a conversation, looking at a picture book, and participating in a series of interactive activities with an examiner. We will collect these language samples at your first visit, at your second re-test visit one month later, and 1 year later to see if the kind of language you use during these samples changes over a time. At the first visit, we also will administer additional tests that measure different aspects of your child's speech, language, and problem solving skills and we will ask you to fill out some questionnaires about your child's behavior and daily living skills. Each time you visit, the testing will take approximately one day.

If during any of the sessions your child appears to lose interest in the tasks and becomes disruptive or uncooperative, the researcher will end the session. You will have the option to either reschedule the session or discontinue participation, with no negative consequence.

Your child will be audio and video taped during each of the sessions. Only research staff associated with this project will have access to the audio and video recordings. The recordings will be used to code your child's responses for research purposes. We will share these recordings and copies of tests with our collaborating sites using secure servers. Only dummy codes will be used to identify files. The recordings will be destroyed 25 years after the close of the study.

Risks and Benefits of being in the Study

Participation in this study involves no unusual risks to you or your child. You or your child may become bored or frustrated and may feel uncomfortable answering some of the questions at times during the sessions. You and your child are encouraged to take breaks, as needed, and skip tasks, if desired.

There are no direct benefits to participation in this research. You or your child will not directly benefit from participating in this study. Information gained in this research study will be used develop measures to better understand changes in language skills of children and adults with autism spectrum disorder.

Compensation

You will receive a \$50 honorarium and your child will receive a \$5 gift card from a national retail store each time you visit. We will also reimburse you for your mileage to and from the University of Minnesota.

Confidentiality

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Research records will be stored securely and only researchers will have access to the records, including video and audio data. All files will be kept for 25 years after the close of the study.

Voluntary Nature of the Study

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you and your child are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions

The researcher conducting this study is Lizbeth H. Finestack, Ph.D., CCC-SLP from the Department of Speech-Language-Hearing Science at the University of Minnesota (phone: 612-624-6090; email: finestack@umn.edu). If you have any questions, **please** contact Lizbeth Finestack at any time.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; 612-625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent

I have read the above information. I have asked questions and have received answers. I **consent** to participate in the study.

Guardian's Name: _____

Child's Name: _____

Phone: _____

E-mail Address: _____

Mailing Address: _____

Signature of Parent or Guardian

Date

(Minors are involved)

Signature of Investigator

Date

I have read the above information. I **do not consent** to participate in the study at this time, but would like to receive for more information about the study.

Guardian's Name: _____

Child's Name: _____

Phone: _____

E-mail Address: _____

I have read the above information. I **do not consent** to participate in the study at this time.



ADDITIONAL RESOURCES

If you have concerns regarding your child's speech or language development now or in the future, we encourage you to contact your local school district. Other resources that may of benefit to you are listed below:

Julia M. Davis Speech-Language-Hearing Center

Speech-Language-Hearing Sciences Department

115 [Shevlin Hall](#), 164 Pillsbury Dr SE, Minneapolis, MN 55455

Phone: 612-624-3322

Fax: 612-624-7586

Email: slhs@umn.edu

Minnesota Speech-Language-Hearing Association (MSHA)

1821 University Avenue West, Suite S256

St. Paul, MN 55104

Phone: 651-999-5350

Email: office@msha.net

OPTIONAL

Audio & Video Consent Form

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The audio and video we collect during the tasks your child completes as part of this study are helpful in teaching future clinicians and practitioners. We may wish to present some of the tapes from this study in scientific presentations or as demonstrations in classrooms. No identifying names of people or places will be included in the files presented.

Whether you agree or do not agree to use audio and video recordings in the study will not affect your or your child's participation in the main study in any way. Please sign below **if you agree** that segments of the recordings made as part of this research may be used in educational settings and/or conference presentations, such as the education and training of future researchers/practitioners.

Printed name of **parent** or guardian: _____

Signature of **parent** or guardian: _____

Date: _____

Name of **child**: _____ Birth date: _____

OPTIONAL

Consent to Contact Form

Expressive Language Sampling as an Outcome Measure in ASD

We may be conducting other studies involving children with autism spectrum disorder in the future. Please let us know if you would like to be contacted in the future regarding another study that may be appropriate for your family. We will keep your contact information for no longer than 5 years and will not share your information with any other parties.

Whether you agree or do not agree to be contacted in the future will not affect your or your child's participation in the main study in any way. Please sign below **if you agree** to be contacted in the future by research staff from Lizbeth Finestack's Child Language Intervention Laboratory at the University of Minnesota.

Printed name of **parent** or guardian: _____

Signature of **parent** or guardian: _____

Date: _____

Name of **child**: _____ Birth date: _____

Contact Information:

Mailing Address: _____

Email: _____ Phone: _____

