

**Attachments 6b-7b: Enrollment Call Script for SEED 1 Caregivers and Young Adults**

Public reporting burden of this collection of information is estimated to average 10 minutes 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, GA 30333: ATTN: PRA (0920-xxxx).

**SEED Follow-up – Call Script for SEED 1 Caregivers (2<sup>nd</sup> Follow-Up)**

**SECTION A: Introduction**

**SECTION 1: Initial Contact**

**SECTION 1: NO ANSWER**

**Voicemail Script:**

Hi, my name is [NAME] and I'm calling on behalf of the Centers for Disease Control and Prevention. I am trying to reach [PARTICIPANT'S NAME]. I am sorry I missed you and will call you back later. You are also welcome to call us, toll-free at <CNI phone number>. Thank you.  
 [TERMINATE CALL] [DOCUMENT CALL IN DATABASE]

**SECTION 1: ANSWER**

**Contact Script:**

Hi, my name is [INTERVIEWER'S NAME] and I'm calling on behalf of the Centers for Disease Control and Prevention. May I please speak to [PARTICIPANT'S NAME]?

1. PARTICIPANT TEMPORARILY NOT AVAILABLE → CONTINUE TO A2
2. PARTICIPANT REACHED (CONTINUE) → GO TO A3
3. PARTICIPANT NO LONGER AT THIS NUMBER → GO TO A2.1

**Participant Temporarily Not Available:**

A2. I am sorry I missed [HER/HIM/NAME]. What is the best time to reach [HER/NAME]?  
 [SCHEDULE CALL BACK IN DATABASE]

**Participant No Longer At This Number:**

A2.1 Do you have [HER/HIS] contact information? [IF YES: THANK GATEKEEPER. UPDATE DATABASE WITH NEW CONTACT INFO] [IF NO: THANK GATEKEEPER. END CALL].

**SECTION A3: Introduction to the Study**

A4. Hi, [PARTICIPANT'S NAME]. I am calling because you recently participated in the Study to Explore Early Development or SEED Follow-up Study. We truly appreciate your previous contributions to SEED and are excited about the things we are learning from that research.

We had mentioned that we may contact you to participate in additional parts of the study. For this next part of the study, we are looking at changes in your child's services, supports, and social participation following exit from high school.

I would like to provide more information and describe the study in a little more detail. The call should only take about 10-15 minutes to complete. Have I reached you at a convenient time?

- YES [CONVENIENT TIME] ..... 1 [GO TO Section A6]  
 NO [NOT A CONVENIENT TIME] .....2 [GO TO Section A4]  
 NOT INTERESTED.....3 [GO TO Section A5]

[IF RECEIVED CONTACT INFO FOR LEGAL GUARDIAN FROM GATEKEEPER START HERE]

Hello, May I speak with [LEGAL GUARDIAN NAME]?

My name is [INTERVIEWER'S NAME] and I'm calling on behalf of the Centers for Disease Control and Prevention (CDC) regarding additional activities in the national research study called the Study to Explore Early Development or SEED Follow-up Study. We spoke with [you/contact's name] a few

weeks/months ago and you completed our survey. I would like to talk to you about another brief survey. The call should only take about 10-15 minutes to complete. Have I reached you at a convenient time?

YES [CONVENIENT TIME] ..... 1 [GO TO Section A6]  
NO [NOT A CONVENIENT TIME] .....2 [GO TO Section A4]  
NOT INTERESTED.....3 [GO TO Section A5]

**SECTION A4: Reschedule**

A4. When would be a convenient time for you to receive a callback?  
[TERMINATE CALL] [SCHEDULE CALL BACK IN DATABASE]

**SECTION A5: Response to Refusals**

[IF A REASON IS GIVEN FOR REFUSAL GO TO A5.a]

[IF A REASON IS NOT GIVEN FOR REFUSAL GO TO A5.b.]

**SECTION A5.a:** I understand you said ...

RESTATE REASONS AND USE TELEPHONE INTERVIEWING SKILLS TO ATTEMPT A CONVERSION

**SECTION A5.b:** May I ask why you do not want to participate?

[INTERVIEWER: USE TELEPHONE INTERVIEWING SKILLS TO RESPOND TO REASON FOR REFUSAL BY STATING THE BENEFITS]

**SECTION A6: Quality Assurance**

A6. Thank you! I would like to let you know that the call is being recorded for Quality Assurance purposes. Are you in a place where you can talk safely on the phone?

YES ..... 1 [GO TO SECTION B]  
NO ..... 2 [GO TO SECTION A4]

**SECTION B: Description of Study**

[FOR ALL RESPONDENTS]

We are asking you to participate in this part of the SEED Follow-up Study to learn more about experiences and challenges faced by young adults after leaving high school. We want to learn more about how services, supports, and activities changed after your child left high school. Your participation in the study will help us better understand these changes and identify the types of services and supports your child may continue to need after leaving high school.

It is important that we have parents of young adults with and without disabilities participate because it will help us find clues about why some young adults have different experiences after leaving high school than others.

Before we go over the details of the study and what you will be asked to do, would you mind if I ask you a few questions to make sure this study is right for you and your child?

**SECTION C: ELIGIBILITY SCREENING**

Now I have a few questions to help us determine your eligibility.

1a. Do you currently live with [CHILD]? YES, All of the time .....01[GO TO 1b]  
YES, Part of the time.....02 [GO TO 1b]  
NO, None of the time.....03 [GO TO 1b]

[If Respondent reports child is deceased express condolences, thank them for their time, END CALL.  
GO TO AA.A]

1b. Is your child 18 years or older? YES.....01 [GO TO 1c.]  
NO.....02 [GO TO 1d.]

1c. Are you still [CHILD's] legal guardian?  
YES.....01 [GO TO 1d]  
NO, someone other than me is legal guardian .....02 [GO TO 2]  
NO, CHILD IS A LEGAL ADULT .....03 [GO TO 1d]

1d. Has your child exited high school? YES.....01 [GO TO 1e.]  
NO.....02 [GO TO 1e.]

1e. What is [CHILD'S] current living situation? \_\_\_\_\_ [RECORD VERBATIM]

[IF NEEDED PROBE FOR RELATIONSHIP]

LIVES W/ BIOMOM..... 01 [GO TO 1c.]  
LIVES W/ BIODAD.....02 [GO TO 1c.]  
LIVES W/ STEP PARENT.....03 [GO TO 1c.]  
LIVES W/ GRANDPARENT .....04 [GO TO 1c.]  
LIVES W/ OTHER RELATIVE .....05 [GO TO 1c.]  
LIVES W/ OTHER .....05 [GO TO 1c.]  
LIVES ALONE .....06 [GO TO 3b.]  
LIVES IN DORM/APT/HOUSE WITH ROOMMATES  
..... 07 [GO TO 3b.]  
LIVES IN A RESIDENTIAL FACILITY...06 [GO TO 1d.]  
LIVES IN A JUV JUS/JAIL.....08 [INELIGIBLE GO  
FOSTER CARE.....09 [INELIGIBLE GO TO AA.D]

TO AA.C]

2. Who is the child's legal guardian?

FIRST NAME \_\_\_\_\_  
LAST NAME \_\_\_\_\_  
RELATION TO CHILD \_\_\_\_\_

2a. We would like to contact [CHILD's] legal guardian to see if they might be interested in participating in the follow-up study. Do we have your permission to contact the [CHILD'S LEGAL GUARDIAN RELATIONSHIP, E.G. CHILD'S FATHER, CHILD'S GRANDMOTHER]?

YES.....01 [GO TO 2b]  
NO.....02 [GO TO 2c]

2b. Can you provide [HIS/HER] contact information?

ADDRESS \_\_\_\_\_

PHONE NUMBER \_\_\_\_\_  
EMAIL ADDRESS \_\_\_\_\_  
DK CONTACT INFO..... [Thank GK END CALL, GO TO 2c]

Thank you for your help. We appreciate your time. [END CALL]

2c. That's fine, we understand. We would like to leave our contact information for you to pass on to [CHILD's] legal guardian if you change your mind. Would that be OK? [IF YES: give site contact information, thank gatekeeper, END CALL. INELIGIBLE GO TO AA.B [Can re-status family if receive call] IF NO: Thank gatekeeper for their time. END CALL. INELIGIBLE GO TO AA.B].

### SECTION D: STUDY STEPS OVERVIEW

You are eligible to participate in this part of the study. Next, I'd like to tell you some details about the study so you can make an informed decision whether or not you would like to participate. This study involves filling out a brief questionnaire about changes in your child's services, supports, social participation, and daily activities following their exit from high school. We estimate that it will take approximately 10 minutes total to complete. You will receive a \$5 gift card to thank you for your participation in the study.

You may choose to complete the questionnaire online via a weblink. If you choose to complete the questionnaire by web, we can email you a link to the survey.

If you prefer, you can also complete the questionnaire over the phone with a study team member. I can set up a time for someone to call you back – or if you have time now, I could also complete the survey with you now.

Do you prefer to complete the questionnaire online, or over the phone?

- ONLINE.....1 go to D.3
- PHONE.....2 go to D.3
- NEITHER....3 go to D.2

#### D.2 [ONLY OFFER IF PARTICIPANT INDICATES UNABLE TO COMPLETE BY WEB OR PHONE]

I am sorry that neither one of the options will work for you. Would you prefer to complete the questionnaire by mail?

If YES, verify contact information and notify SEED site:

Address: \_\_\_\_\_

Phone 1: \_\_\_\_\_

Phone 2: \_\_\_\_\_

Email: \_\_\_\_\_

#### D.3 Do you prefer to complete the survey in English or Spanish?

D.4 No matter how you complete the questionnaire, we will ensure you receive an information sheet for you to keep – it provides information on your rights as a research participant and also gives information about your participation in the SEED Follow-up Study. I can email a link for you to download this information sheet – or take your address and mail you a copy.

EMAIL.....1 record in database  
MAIL..... 2 Notify original site to mail

If you choose to complete the questionnaire by paper, we will also send you a packet of materials that contains:

- The questionnaire for you to fill out and mail back to us
- Prepaid envelope to mail the completed questionnaire back to us.

[READ TO ONLINE AND MAIL PARTICIPANTS]

If you find you have any questions about these forms as you complete them then you can call us. We may also contact you to set up a time to speak with you if we need to clarify any of your responses.

### SECTION E: VERBAL CONSENT TO ENROLL

Next, I will read the Verbal Consent regarding enrollment in this part of the SEED Follow-up Study. Afterwards, I am required to ask you for your decision so we can document your verbal consent for our records.

Your participation is voluntary. There is little risk in taking part in this study. You are free to skip any questions that you do not want to answer or that make you uncomfortable. All answers that you give will be kept private.

There is no personal benefit to you for taking part in the study. Your participation will help us understand experiences after high school for different types of people. The results of the study may help us learn more about how we can help individuals with ASD and other DD as they mature.

We understand that you may have concerns about your privacy. In order to protect the privacy of all participants, CDC received a Certificate of Confidentiality. The 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. However, by law, we must report to the State if you tell us you are planning to cause serious harm to yourself or others.

All answers that you give will be kept private. We will never use your name in any report. Information in reports or scientific papers from this study will be including only information from study participants combined together.

Rather than using your names, you will be given a study ID. The study ID will be recorded on all study forms. When we use data from the study to do analyses, only the study IDs will be used and not names. Only the necessary study staff will have access to your personal information.

If you have any concerns about the study, you may contact <site PI/PC and phone>. If you have any questions about completing the survey, you may contact <CNI staff and phone>. If you have questions about your rights as a research participant, you can call the <IRB office contact> at <phone number>. All of these contact numbers will be included in the packet we send you with information about the study and your rights as a participant.

Again, I want to remind you that your participation in this research study is voluntary. You are allowed to drop out of the study at any time without penalty. If you give your consent today, you can still decide at any time that you do not want to participate. To withdraw from this study, you may contact <CNI staff name and phone>. This number will also be included in the packet we send you.

March 2022

Now I need to ask for and document your verbal response to our request to consent.

ENROLLMENT CONSENT: Are you willing to enroll in this part of the study?

YES ..... 1 [GO TO SECTION F]  
NO .....2 [IS THERE ANY PARTICULAR REASON YOU ARE NOT INTERESTED IN PARTICIPATING?] [SPECIFY \_\_\_\_\_]

Thank you! If you change your mind about participating, please call us at <phone number>.

**SECTION F: CONTACT INFORMATION**

Thank you! Now I would like to verify your contact information.

Name: (First)\_\_\_\_\_ (Last) \_\_\_\_\_

Address: \_\_\_\_\_

Phone 1: \_\_\_\_\_

Phone 2: \_\_\_\_\_

Email: \_\_\_\_\_

**SECTION G: INCENTIVES**

As I mentioned before, you will receive a \$5 gift card to thank you for your participation in this part of the study. Would you prefer an electronic gift card that will sent to you by email, or a physical card that will be mailed to your address?

\_\_\_ Electronic gift card

\_\_\_ Physical gift card

**SECTION H: ELIGIBILITY SCREENING FOR ADULT CHILD**

One of the other additional study steps we may ask you to participate in is a questionnaire to be completed by your adult child. The survey includes questions about changes in service use and needs after high school exit. There are also questions about mental health, quality of life, gender identity, sexuality, and romantic relationships. This information will help us learn more about experiences and challenges faced by young adults after leaving high school. We want to learn more about individuals with ASD and other DD as they mature so they can get the services and supports they need. After you complete this questionnaire, we would like to contact your child to ask them about participating in this part of the study.

Your child will have the option to refuse participation in this part of the study, or agree to complete the questionnaires online or over the telephone with a study team member. If your child is unable to complete the survey online or over the phone, but could do so by mail, we may offer your child this option.

Based on the description of the study instruments your child will be asked to complete, do you feel that your child would be able to complete them independently or with some assistance? Or do you believe that your child would be unable to complete because of significant language or cognitive difficulties?

- Able to complete independently without assistance
- Able to complete with some assistance
- Unable to complete

[If child is able to complete questionnaire independently, ask for contact information for adult child.]

Name: (First)\_\_\_\_\_ (Last) \_\_\_\_\_

Address: \_\_\_\_\_

Phone 1: \_\_\_\_\_

Phone 2: \_\_\_\_\_

Email: \_\_\_\_\_

If assistance is needed, ask if they wish to be present on the phone when CNI contacts adult child.

If assistance is needed and parent is still child’s legal guardian, ask if they would be ok if we set up a call with them and their adult child so the legal guardian can provide consent on behalf of the adult child.

**SECTION I: END CALL**

Thank you for your time today.

If participant chooses to complete questionnaire online:

We will email you a weblink to complete the questionnaire online soon. The email will come from [CNI email] with the subject “SEED Survey.” We will follow-up in about a week or so to make sure you received the weblink and to answer any questions you may have. In the meantime, if you have any questions, please call us at <PHONE #>.

If participant chooses to complete questionnaire by phone:

Let’s go ahead and set up an appointment for us to complete the questionnaire with you by phone.

If participant chooses to complete questionnaire by mail:

You can expect to receive your packet in the mail soon. We will follow-up in about a week or so to make sure you received the packet and to answer any questions you may have. In the meantime, if you have any questions, please call us at <PHONE #>.

AA. INELIGIBLE/REFUSAL REASONS:

A. CHILD IS DECEASED. [Document call]



B. NO ACCESS TO LEGAL GUARDIAN. Unfortunately, your family is not eligible to participate. We must have permission from [CHILD's] legal guardian in order for your family to participate. Thank you for your time. [END CALL]

C. CHILD CURRENTLY IN JUVENILE JUSTICE SYSTEM/JAIL. Unfortunately, your family is not eligible to participate. Thank you for your time. [END CALL]

D. CHILD CURRENTLY IN FOSTER CARE. Unfortunately, your family is not eligible to participate. Thank you for your time. [END CALL]

E. LEGAL GUARDIAN WHO IS NOT FAMILIAR WITH CHILD'S HEALTH, HEALTH CARE, EDUCATION, AND CURRENT ACTIVITIES. Unfortunately, your family is not eligible to participate. Thank you for your time. [END CALL].

# SEED Follow-up – Call Script for Young Adults Who Previously Participated in SEED as Preschool-aged children

## SECTION A: Introduction

### SECTION 1: Initial Contact

#### SECTION 1: NO ANSWER

##### Voicemail Script:

Hi, my name is [NAME] and I'm calling on behalf of the Centers for Disease Control and Prevention. I am trying to reach [PARTICIPANT'S NAME]. I am sorry I missed you and will call you back later. You are also welcome to call us, toll-free at <CNI phone number>. Thank you.  
[TERMINATE CALL] [DOCUMENT CALL IN DATABASE]

#### SECTION 1: ANSWER

##### Contact Script:

Hi, my name is [INTERVIEWER'S NAME] and I'm calling on behalf of the Centers for Disease Control and Prevention. May I please speak to [PARTICIPANT'S NAME]?

- 1. PARTICIPANT TEMPORARILY NOT AVAILABLE → CONTINUE TO A2
- 2. PARTICIPANT REACHED (CONTINUE) → GO TO A3
- 3. PARTICIPANT NO LONGER AT THIS NUMBER → GO TO A2.1

##### Participant Temporarily Not Available:

A2. I am sorry I missed [HER/HIM/NAME]. What is the best time to reach [HER/NAME]?  
[SCHEDULE CALL BACK IN DATABASE]

##### Participant No Longer At This Number:

A2.1 Do you have [HER/HIS] contact information? [IF YES: THANK GATEKEEPER. UPDATE DATABASE WITH NEW CONTACT INFO] [IF NO: THANK GATEKEEPER. END CALL].

### SECTION A3: Introduction to the Study

A4. Hi, [PARTICIPANT'S NAME]. I am calling because when you were younger, you participated in the Study to Explore Early Development or SEED and your parent or guardian agreed to participate in future SEED studies. We truly appreciate your previous contributions to SEED and are excited about the things we are learning from that research.

We are now beginning a new phase of SEED – the SEED Follow-up Studies – and hope you will join us again. This study will help us understand the health and functioning of individuals with autism spectrum disorder (ASD), other developmental disabilities or delays as they mature into adolescents and young adults.

I would like to provide more information and describe the study in a little more detail. The call should only take about 10-15 minutes to complete. Have I reached you at a convenient time?

- YES [CONVENIENT TIME] ..... 1 [GO TO Section A6]
- NO [NOT A CONVENIENT TIME] .....2 [GO TO Section A4]
- NOT INTERESTED.....3 [GO TO Section A5]

[  
My name is [INTERVIEWER'S NAME] and I'm calling on behalf of the Centers for Disease Control and Prevention> regarding the national research study called the Study to Explore Early Development or

SEED. You participated in SEED when you were between the ages of 2-5. We are now conducting a follow-up study to SEED. This follow-up research study will help us learn more about experiences and challenges faced by young adults after leaving high school. Recently we spoke to your parent or another adult knowledgeable about your experiences. We would also like to learn about your experiences from your own perspective.

We are calling you to provide more information and describe the study in a little more detail. The call should only take about 10-15 minutes to complete. Have I reached you at a convenient time?

YES [CONVENIENT TIME] ..... 1 [GO TO Section A6]  
NO [NOT A CONVENIENT TIME] .....2 [GO TO Section A4]  
NOT INTERESTED.....3 [GO TO Section A5]

**SECTION A4: Reschedule**

A4. When would be a convenient time for you to receive a callback?  
[TERMINATE CALL] [SCHEDULE CALL BACK IN DATABASE]

**SECTION A5: Response to Refusals**

[IF A REASON IS GIVEN FOR REFUSAL GO TO A5.a]

[IF A REASON IS NOT GIVEN FOR REFUSAL GO TO A5.b.]

**SECTION A5.a:** I understand you said ...

RESTATE REASONS AND USE TELEPHONE INTERVIEWING SKILLS TO ATTEMPT A CONVERSION

**SECTION A5.b:** May I ask why you do not want to participate?

[INTERVIEWER: USE TELEPHONE INTERVIEWING SKILLS TO RESPOND TO REASON FOR REFUSAL BY STATING THE BENEFITS]

**A5.c. WAS A REFUSAL CONVERSION SUCCESSFUL?**

YES ..... 1 [GO TO A6]

NO ..... 2 [QUICKLY CHECK SAVED EXPORT TO DETERMINE IF FAMILY PREVIOUSLY AGREED TO STORE WITH IDENTIFIERS] [IF NO: Thank you! If you change your mind about participating, please call us at <phone number>.

**SECTION A6: Quality Assurance**

A6. Thank you! I would like to let you know that the call is being recorded for Quality Assurance purposes. Are you in a place where you can talk safely on the phone?

YES ..... 1 [GO TO SECTION B]

NO ..... 2 [GO TO SECTION A4]

**SECTION B: Description of Study**

[FOR ALL RESPONDENTS]

SEED staff from the Centers for Disease Control and Prevention and other SEED sites are working together to conduct the Follow-up Studies.

We are asking you to participate in the SEED Follow-up Study to help us learn more about experiences and challenges faced by young adults after leaving high school. We are also asking you to participate so that we can learn about certain topics – such as anxiety and depression, quality of life, gender  
March 2022

identify and sexuality – from your own perspective. We know that people may face challenges after leaving high school, such as people with autism spectrum disorder (ASD) and other developmental disabilities (DD). We want to learn more about individuals with ASD and other DD as they mature so they can get the services and supports they need. Your participation in the study will help us understand the changes in service use and needs after high school.

It is important that we have young adults with and without ASD and DD participate because it will help us find clues about why some young adults have different experiences after leaving high school than others.

The main task will be to complete a questionnaire online, or over the phone with a study team member. It should take about 40 minutes to complete the questionnaire. We know your time is valuable. You will be given a \$20 gift card to thank you for your time.

### **SECTION C: STUDY STEPS OVERVIEW**

Next, I'd like to tell you some details about the study so you can make a better-informed decision whether or not you would like to participate. This study involves filling out a series of questionnaires about the types of experiences and/or challenges faced by young adults. We estimate that it will take approximately 40 minutes total to complete. You will receive a \$20 gift card to thank you for your participation in the study.

These questionnaires should take about 40 minutes to complete.

You may choose to complete the questionnaires online via a weblink. If you choose to complete the questionnaire by web, we can email you a link to the survey.

If you prefer, you can also complete the questionnaires over the phone with a study team member. I can set up a time for someone to call you back – or if you have time now, I could also complete the survey with you now.

Do you prefer to complete the questionnaires online, or over the phone?

[ONLY OFFER IF PARTICIPANT INDICATES UNABLE TO COMPLETE BY WEB OR PHONE]

I am sorry that neither one of the options will work for you. Would you prefer to complete the questionnaire by mail?

Do you prefer to complete the questionnaires in English or Spanish?

No matter how you complete the questionnaire, we will ensure you receive an information sheet for you to keep – it provides information on your rights as a research participant and also gives information about your participation in the SEED Follow-up Study. I can email a link for you to download this information sheet – or take your email address to send you a copy.

If you choose to complete the questionnaire by paper, we will also send you a packet of materials that contains:

- The information sheet with your rights as a participant
- The questionnaire for you to fill out and mail back to us
- Prepaid envelope to mail the completed questionnaire back to us.

### **SECTION D: VERBAL CONSENT TO ENROLL**

Next, I will read the Verbal Consent regarding enrollment in the SEED Follow-up Study. Afterwards, I am required to ask you for your decision so we can document your verbal consent for our records.

Your participation is voluntary. There is little risk in taking part in this study. You may feel nervous answering some questions because they are sensitive or personal in nature. These questions may cause you to have negative feelings (like being embarrassed). You are free to skip any questions that you do not want to answer or that make you uncomfortable. All answers that you give will be kept private.

There is no personal benefit to you for taking part in the study. Your participation will help us understand experiences after high school for different types of people. The results of the study may help us learn more about how we can help individuals with ASD and other DD as they mature.

We understand that you may have concerns about your privacy. In order to protect the privacy of all participants, CDC received a Certificate of Confidentiality. The Certificate of Confidentiality guarantees that any information that is collected that could identify you 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. However, by law, we must report to the State if you tell us or say something that makes us think you might cause serious harm to yourself or others.

All answers that you give will be kept private. We will never use your name in any report. Information in reports or scientific papers from this study will be including only information from study participants combined together.

Rather than using your names, you will be given a study ID. The study ID will be recorded on all study forms. When we use data from the study to do analyses, only the study IDs will be used and not names. Only the necessary study staff will have access to your personal information.

If you have any questions or concerns about the study, you may contact <SEED site PI/PC and phone number>. If you have any questions about completing the survey, you may call <CNI staff name and phone number>. Both of these contact numbers will be included in the packet we send you.

Again, I want to remind you that your participation in this research study is voluntary. You are allowed to drop out of the study at any time without penalty. If you give your consent today, you can still decide at any time that you do not want to participate. To withdraw from this study, you may contact <CNI staff name and phone>. This number will also be included in the packet we send you.

Now I need to ask for and document your verbal response to our request to consent.

ENROLLMENT CONSENT: Are you willing to enroll in the study?

YES ..... 1 [GO TO SECTION F]  
NO .....2 [IS THERE ANY PARTICULAR REASON YOU ARE NOT INTERESTED IN PARTICIPATING?] [SPECIFY \_\_\_\_\_]

Thank you! If you change your mind about participating, please call us at <phone number>.

## SECTION E: OTHER PERMISSIONS

Next, I would like to ask for your permission on a few other things.

### E.1 Permission to contact you for future studies

Will you allow SEED staff to contact you for future studies? If you agree, then you are providing your permission for SEED staff to contact you by mail or telephone. SEED staff will explain the new study  
March 2022

and you can agree to participate. You can also decline participation. These studies would be related to ASD and/or other DD. SEED staff could be from Georgia SEED or another of the SEED sites could contact you. All SEED sites are held to the same confidentiality standards and are bound by the CDC Certificate of Confidentiality. SEED sites include representatives from California, Colorado, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, and Wisconsin.

YES, I AGREE to be contacted for future research studies.....

NO, I DO NOT WANT to be contacted for future research studies. ....

E.2 Permission to link your information in future studies

In the future, SEED researchers may want to link the information we collect about you with other data sets. For example, this could be census data or data on environmental chemicals in areas where you lived. If you agree, researchers from the SEED sites listed above may link your data with other data sets. We will not contact you again or ask you to give us more information for these linkages.

YES, I AGREE to allow my information to be linked in future research studies.

NO, I DO NOT WANT my information to be linked in future research studies.

**SECTION F: CONTACT INFORMATION**

Thank you! Now I would like to verify your contact information.

Name: (First) \_\_\_\_\_ (Last) \_\_\_\_\_

Address: \_\_\_\_\_

Phone 1: \_\_\_\_\_

Phone 2: \_\_\_\_\_

Email: \_\_\_\_\_

**SECTION G: INCENTIVES**

As I mentioned before, you will receive a \$20 gift card to thank you for your participation in the study. Would you prefer an electronic gift card that will sent to you by email, or a physical card that will be mailed to your address?

Electronic gift card

Physical gift card

**SECTION H: END CALL**

Thank you for your time today.

If participant chooses to complete questionnaire online:

We will email you a weblink to complete the questionnaire online soon. The email will come from [CNI email] with the subject "SEED Survey." We will follow-up in about a week or so to make sure you received the weblink and to answer any questions you may have. In the meantime, if you have any questions, please call us at <PHONE #>.

If participant chooses to complete questionnaire by phone:  
Let's go ahead and set up an appointment for us to complete the questionnaire with you by phone.

If participant chooses to complete questionnaire by mail:  
You can expect to receive your packet in the mail soon. We will follow-up in about a week or so to make sure you received the packet and to answer any questions you may have. In the meantime, if you have any questions, please call us at <PHONE #>.

AA. INELIGIBLE/REFUSAL REASONS:

A. YOUNG ADULT DECLINED TO PARTICIPATE.

B. YOUNG ADULT DOES NOT FULLY COMPREHEND THE INFORMATION PROVIDED IN THE CONSENT SCRIPT.