

SEED Follow-up – Call Script for SEED 1 Caregivers (2nd 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 time01[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 guardian02 [GO TO 2]
 NO, CHILD IS A LEGAL ADULT03 [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/ GRANDPARENT04 [GO TO 1c.]
LIVES W/ OTHER RELATIVE05 [GO TO 1c.]
LIVES W/ OTHER05 [GO TO 1c.]
LIVES ALONE06 [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
TO AA.C]
FOSTER CARE.....09 [INELIGIBLE GO TO AA.D]

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.

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, 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].