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Attachments 6b-6d: Enrollment Call Script and Second Follow-up Survey for SEED 1 Caregivers

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 (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]	
NOT INTERESTED	-

[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	-

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 INTERVIEW ING 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			
NO	2 [GO T	TO SECTION A4]

SECTION B: Description of Study

IFOR 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.

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1a. Do you currently live with [CHILD]?	YES, All of the time
[If Respondent reports child is deceased ex GO TO AA.A]	press condolences, thank them for their time, END CALL.
1b. Is your child 18 years or older?	YES01 [GO TO <mark>1c</mark> .] NO02 [GO TO <mark>1</mark> d.]
1c. Are you still [CHILD's] legal guardian?	
	is legal guardian02 [GO TO 2] JLT03 [GO TO 1d]
1d. Has your child exited high school?	YES01 [GO TO <mark>1e</mark> .] NO02 [GO TO <mark>1</mark> e.]
1e. What is [CHILD'S] current living situation	n? [RECORD VERBATIM]
[IF NEEDED PROBE FOR RELATION	ONSHIP]
TO AA.C]	LIVES W/ BIOMOM
2. Who is the child's legal guardian?	
	NAME NAME FION TO CHILD
participating in the follow-up study. ['s] legal guardian to see if they might be interested in Do we have your permission to contact the [CHILD'S LEGAL CHILD'S FATHER, CHILD'S GRANDMOTHER]?
	01 [GO TO 2b] 02 [GO TO 2c]
2b. Can you provide [HIS/HER] cont	act information?
ADDRESS	

PHONE NUMBER				
EMAIL ADDRESS				
DK CONTACT INFO.	[Thank GK EN	D 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.

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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.

IREAD 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 r need to ask for and document your verbarresponse to our request to consent.		
ENROLLMENT CONSENT: Are you willing to enroll in this part of the study?		
YES		
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?

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Able to complete independently to the complete with some assistant of the completeUnable to complete	
[If child is able to complete questionnair	e 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 Study: Second Follow-up Survey of Parents of Young Adults (Parent-Report)

Contents

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A. Exit from High School

1. When did your child complete their high school education??

Month	Year

2. When your child left high school, did your child...

Receive a regular diploma
Receive an occupational diploma
Receive a certificate of completion
Take a test and receive a GED without completing all classes
Drop out or stop going
Get expelled (or suspended but did not return)
Other specify:

3. Since leaving high school, has your child...(check all that apply)

Attended a 2 year or community college
Graduated with a diploma, certificate, or license from a 2 year or community college
Attended a vocational, business, or technical school after high school
Graduated with a diploma, certificate, or license from a vocational, business, or technical schoo
Attended a 4-year college
Graduated with a diploma, certificate, or license from a 4-year college
Attended a graduate program (e.g., master's or doctoral program)
Graduated with an advanced degree (e.g., master's or doctoral degree)

- 4. Is your child currently enrolled in college or planning to attend college?
 - □ No
 - ☐ Yes, Part-time
 - ☐ Yes, Full-time

B. Living Situation

1.	wh	Independently (alone) with some assistance Independently (alone) with no assistance Independently (with spouse or roommate) With parent(s) or foster parent(s) With an adult family member who is not a parent (e.g., sibling, aunt, uncle, cousin, etc.) Specify relationship: With a legal guardian who is not a family member In a group home within the community In a residential facility separated from the community Other (Specify, please print): [Specify please print]: [Specify please p
2.	Ho	w satisfied do you think your child is with the conditions of their living situation?
		Very Dissatisfied
		Fairly Dissatisfied
		Neither Satisfied nor Dissatisfied
		Satisfied
		Very Satisfied

C. Daily Activities and Social Participation

1. Since leaving high school, has your child participated in:

				Yes	No		Oon't now	
	A sports team or taken sport lessons?							
	Any clubs or organizations?							
	Any other organized activities or lessons, such as manage?	nusic, da	nce or					
	Any type of community service or volunteer work a or in the community?	at schoo	l, church,					
	Any work, including regular jobs as well as babysitt or other occasional work?	ing, cutt	ing grass,					
2.	IN THE LAST 6 MONTHS, how often does your	child de	o any the	following:				
		Never	At least once	Every other month	Monthly	Weekly	Daily	
	Get together socially with friends or neighbors?							
	Call or text friends on the phone?							
	Use email, instant messaging, Skype, texting, Facebook/Instagram/Snapchat messaging or taken part in chat rooms?	٥						
	Gotten together with ANY relatives, not including those who live with you?							
	Gone to church, temple, or another place of worship for services or other activities?							
	Gone to a show or movie, sports events, club meeting, or another group event?							
	Gone out to eat at a restaurant?							
3.	physical activity, which was enough to raise the brisk walking or cycling for recreation or to get physical activity that may be part of their job.	neir brea t to and	athing rat	e? This ma	y include	sports, e	exercise,	ana
	Number of days of exercise during the past m	nonth: _						

4. ON AN AVERAGE WEEKDAY, about how much time does your child usually spend watching TV

programs or movies, including streaming services such as Netflix, Hulu, Apple+?

	□ None
	□ Less than 1 hour
	□ 1 hour
	□ 2 hours
	□ 3 hours
	☐ 4 or more hours
	□ I don't know
5.	ON AN AVERAGE WEEKDAY, about how much time does your child usually spend playing on an electronic device? This does NOT include doing schoolwork or watching TV shows, movies, or videos on YouTube/TikTok.
	□ None
	□ Less than 1 hour
	□ 1 hour
	□ 2 hours
	□ 3 hours
	☐ 4 or more hours
	□ I don't know

D. Health & Health Care Service Use and Need

1.	Which of the following best describes your child's general health? Please mark ONE	Вох.		
	 Excellent Very good Good Fair Poor 			
2.	Since leaving high school, was there any time when your child needed health care, be health care, we mean medical care as well as other kinds of care like dental care, visit services.			-
	☐ Yes ☐ No (Skip to Section E)			
3.	If yes, which types of care were NOT received? (Mark ALL that apply)			
	 □ Dental Care □ Hearing Care □ Medical care, routine preventive □ Medical care, routine sick or urgent care □ Medical care, hospital emergency □ Medical care, specialist □ Medical services for diagnosis or evaluation related to a disability □ Mental Health Services, counseling, or psychological services □ Vision Care □ Other, Specify 			
4.	Which of the following contributed to your child not receiving needed health			
	My child did not have health insurance that covered the services needed.	Yes	No 🗆	
	My child was not eligible for the services.			
	The services my child needed were not available in my area.			
	There were problems getting an appointment when my child needed one.			
	There were problems with getting transportation or childcare.			
	The (clinic/doctor's) office wasn't open when my child needed care.			
	There were issues related to cost.			
	There were concerns or issues related to being exposed to others with an illness (e.g., concerned about being around others at doctor's office who may have been exposed to COVID-19, influenza, etc.)	٥		
	Other Specific			

E. Educational & Developmental Services

1. Since leaving high school, has your child received any of the services listed in the table below? *Do not include services/help received from family or friends*.

	Yes, received after high school	No, did not receive after high school	If no, did your child need this service?
Financial aid, like paying for college classes or training.			☐ Yes ☐ No
Educational assistance or tutoring.			☐ Yes ☐ No
Reader or interpreter, such as a sign language interpreter.			☐ Yes ☐ No
Independent living or occupational therapy (like help with doing things such as managing money, cooking, or housekeeping).			□ Yes □ No
Childcare services or parenting skills training.			☐ Yes ☐ No
Social work services.			☐ Yes ☐ No
Physical therapy.			☐ Yes ☐ No
Devices or assistive technology services (like a special calculator, reading machine, or communication device).			☐ Yes ☐ No
Other services (Please specify):			☐ Yes ☐ No

2.	Overall, how satisfied have you been with all services your child has received since leaving high school?
	□ Very dissatisfied
	□ Dissatisfied
	☐ Neither satisfied nor dissatisfied
	□ Satisfied
	□ Very Satisfied

F. Vocational Support and Training

2.

3.

4.

5.

The next questions are about services or training your child might have received after high school exit to help them find and/or keep a job.

1. After your child exited high school, did your child receive any of the following services? (Check all the apply)

	Service	Yes	NO	Don't K	
a.	Testing to find out your child's work interests or abilities.				
b.	Training in specific job skills, for example food services, computer skills, or training for another kind of job.				
C.	Training in basic skills needed for work, like counting change, telling time, or using transportation to get to work.				
d.	Career counseling, like help in figuring out jobs that might best suit your child.				
e.	Help in learning how to search for available job positions online, write a resume, or prepare for a job interview.				
f.	Job shadowing, such as visiting a workplace and watching the way a job is done.				
g.	Apprenticeships or internships.				
h.	Other services or training? Specify:				
 Yes No Don't know How useful do you think job or career training is in helping your child get a job?					
	□ Somewhat useful □ Not very useful □ Not at all useful				
Do	you think your child needs job training or additional training tha	t is not provi	ided now?		
What other kinds of job training or help do you think your child needs? (Check all that apply)					
Tes	ting to find out his/her/their work interests or abilities				

	Training in specific job skills, for example food services, computer skills, or training for another kind of job
	Training in basic skills needed for work like counting change, telling time, or using transportation to get to work
	Career counseling like help in figuring out jobs your child might be suited to
	Help in finding or applying for a job such as learning how to search for available job positions online, write a resume, or prepare for a job interview
	Job shadowing, visiting a workplace and watching the way the job is done
	Apprenticeships or internships
	Other, specify:
	Don't know
6.	Guardianship gives a designated person the legal right to make certain decisions on behalf of an adult child. Have you considered guardianship for your child?
	□ Yes
	□ No (Skip to end of survey)
7.	If yes and your child is 18 years or older, have you obtained guardianship for your child?
	□ Yes
	□ No
8.	If yes, what types of decisions does the guardian make for your child? (Check all that apply)
	□ Healthcare
	☐ Housing
	□ Finances
	☐ Daily activities
	□ Plans for the future
	☐ Other specify:

You have reached the end of the survey.

Thank you for participating!