

SEED Follow-Up Study: Adolescent Survey Supplement
(for SEED 2 Caregivers)

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A. Transitioning from High School

1. DURING THE PAST 12 MONTHS, has your child been enrolled in school? *If your child graduated or exited high school more than 12 months ago or participates in homeschool then check "no."*
 - € Yes
 - € No (**Skip to question 10**)

2. During either this year or the last school year your child was enrolled, did you or another adult in your household meet with teachers or school counselors to set goals for what your child will do after high school and create a plan for how to achieve them? Sometimes this is called a transition plan.
 - € Yes
 - € No
 - € Don't know

3. During either this school year or the last school year your child was enrolled, did your child meet with teachers or school counselors to set goals for what he/she will do after high school and create a plan for how to achieve them? Sometimes this is called a transition plan.
 - € Yes
 - € No
 - € Don't know

4. Does your child currently have a transition plan?
 - € Yes
 - € No (**Skip to question 10**)
 - € Don't know (**Skip to question 10**)

5. Did the school mostly come up with the goals for your child's transition plan or was it mostly you and/or your child who came up with the goals?
 - € Mostly the school
 - € Mostly myself and the school
 - € Mostly myself and my child
 - € A combination of all together
 - € Other, specify _____
 - € I don't know about any goals

6. Which of the following best describes your child's role in their own transition planning?
 - € My child was present in discussions but participated very little or not at all
 - € My child provided some input
 - € My child took a leadership role, helping set the direction of the discussions, goals and plans

- € My child was not involved in the transition planning
- € I don't know about any goals

7. How do you feel about your family's involvement in the decisions about your child's transition plan? Do you feel you...

- € Wanted to be more involved
- € Were involved about the right amount
- € Wanted to be less involved
- € No opinion

8. How useful has this planning been in helping your child prepare for life after high school? Would you say it has been...

- € Very useful
- € Somewhat useful
- € Not very useful
- € Not useful at all
- € Don't know

9. To what extent do you agree or disagree with the following statement: "My child's transition plan goals are challenging and appropriate"

- € Strongly agree
- € Agree
- € Disagree
- € Strongly disagree
- € No opinion

10. How often do you talk with your child about what they plan to be doing after high school?

- € Not at all
- € Rarely
- € Occasionally
- € Regularly
- € Don't know

B. Financial Planning

1. After graduation/high school completion, how do you want your child to be supported? (Check all that apply):

- Social Security/ SSI/ SSDI
- My child's own wages
- Government Benefits (food stamps, subsidized housing, etc.)
- Your financial support
- Other, specify: _____

2. Do you think that when your child turns 18 years old, your child will... (Check all that apply)

- Be their own legal guardian
- Need a guardian/conservator for financial decisions
- Need a guardian/conservator for medical decisions
- Need an advocate or personal representative
- Need a medical proxy
- Need Power of Attorney
- Need a legal guardian appointed
- Not sure/don't know

3. Have you prepared for the future support for your child (e.g., trust fund/special needs trust)?

- Yes
- No

4. Have you prepared a will that includes plans for your child?

- Yes
- No

C. Transitioning to Adult Health Care

1. At his or her LAST preventive check-up, did your child have a chance to speak with a doctor or other health care provider privately, without you or another adult in the room?

- Yes
- No

2. Has your child’s doctor or other health care provider actively worked with your child to:

	Yes	No	Don't Know
a. Think about and plan for their future? <i>For example, by taking time to discuss future plans about education, work, relationships, and development of independent living skills.</i>	q	q	q
b. Make positive choices about their health? <i>For example, by eating healthy, getting regular exercise, not using tobacco, alcohol or other drugs, or delaying sexual activity.</i>	q	q	q
c. Gain skills to manage their health and health care? <i>For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he/she may need.</i>	q	q	q
d. Understand the changes in health care that happen at 18? <i>For example, by understanding changes in privacy, consent, access to information, or decision-making.</i>	q	q	q

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Eligibility for health insurance often changes in young adulthood. Do you know how your child will be insured as they become an adult?

- Yes
- No

4. Do any of your child’s doctors or other health care providers treat only children?

- Yes
- No (**Skip to question 6**)

5. If yes, have they talked with you about when your child will need to see doctors or other health care providers who treat adults?

- Yes
- No

6. DURING THE PAST 12 MONTHS, how often has someone on your child’s care team explained to you who was responsible for different parts of your child’s care? (Check ONE)

- € Never
- € Rarely
- € Sometimes
- € Usually
- € Almost always
- € Always

7. DURING THE PAST 12 MONTHS, how often have you felt that your child's care team members thought about the "big picture" when caring for your child, meaning dealing with all of your child's needs?
(Check ONE)

- € Never
- € Rarely
- € Sometimes
- € Usually
- € Almost always
- € Always

D. Sexual Health and Education

1. Have you received guidance from a doctor, teacher, or other professional on how to talk about sexuality with your child?

Yes

No

2. Has your child received any form of sexual education, through informal conversation or in structured groups or classes?

Yes

No

3. Who do you feel should be the primary sexual educator for your child (Choose ONE)?

Parent or caregiver

Doctor

Teacher

Other professional, such as a psychologist

Sexual education should be a shared responsibility

4. Please answer the following:

		Yes	No	Don't Know
a.	I feel comfortable talking about sexuality with my child.	q	q	q
b.	I know the topics related to sexuality that I need to educate my child.	q	q	q
c.	I feel competent teaching my child about the reproductive system.	q	q	q
d.	I feel competent teaching my child about contraception and pregnancy.	q	q	q
e.	I feel competent teaching my child about sexually transmitted infections.	q	q	q
f.	I feel competent teaching my child about romantic relationships.	q	q	q

5. Has your child ever

	Yes	No	Don't Know
Expressed the desire for a relationship (dating, marriage, family)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shown or expressed attraction to anyone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had a sexual/romantic relationship with anyone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

E. Your Expectations for This Child

1. How likely do you think it is that your child will...

	DEFINITEL Y WILL	PROBABLY WILL	PROBABLY WON'T	DEFINITEL Y WON'T	DON'T KNOW	ALREADY HAS
a. Get a regular high school diploma? <i>This includes the standard high school diploma awarded to students after completing standard high school curriculum & exit exams OR students who received a "GED" but does not include a certificate of completion or a special diploma for students in special education.</i>	<input type="checkbox"/>					
b. Get an IEP modified high school diploma OR certificate of completion?	<input type="checkbox"/>					
c. Attend school after high school? <i>Including college, technical, or trade school.</i>	<input type="checkbox"/>					
d. Attend a special training program after high school for persons with intellectual disabilities?	<input type="checkbox"/>					
e. Complete a technical or trade school program?	<input type="checkbox"/>					
f. Immediately start working at a job (part or full-time) or volunteering right after high school?	<input type="checkbox"/>					
g. Graduate from a 2-year or community college? <i>This does not include a certificate of completion or a special diploma for students in special education.</i>	<input type="checkbox"/>					
h. Graduate from a 4-year college? <i>This does not include a certificate of completion or a special diploma for students in special education.</i>	<input type="checkbox"/>					
i. Get a driver's license?	<input type="checkbox"/>					
j. Eventually live away from home on their own without supervision?	<input type="checkbox"/>					
k. Eventually live away from home on their own with supervision?	<input type="checkbox"/>					
l. Eventually get a paid job? <i>This includes any paid job – child does not need to make enough to support self. This can include supported employment.</i>	<input type="checkbox"/>					
m. Earn enough to support him/herself without financial help from his/her family or government benefit programs?	<input type="checkbox"/>					
n. Get married or have a life partner?	<input type="checkbox"/>					
o. Have children?	<input type="checkbox"/>					

F. Special Skills

1. Does your child have any marked special skills that are above the skills of other children the same age?
(Check all that apply)

Skills	Yes	No	Don't Know	If YES, does your child use this skill in a meaningful way?
Art or drawing skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
Calendar calculating abilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
Mathematical skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
Mechanics or spatial skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
Memory skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
Musical abilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
Other, specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know

G. Social Responsiveness

[This is a place holder for the SRS-2]

You have reached the end of the survey.

Thank you for participating!

You and your child may also be eligible to take part in an in-person evaluation of learning abilities, at no cost to you. You might remember that your child received an in-person evaluation in the original SEED study. This second evaluation will help us learn how abilities change over time. Like the first evaluation, we will measure verbal and nonverbal abilities compared to other people the same age.

You and your child are under no obligation to take part in the in-person evaluation, but if you are interested and would like to learn more, please indicate your interest below.

- Yes, please contact me. I would like to learn more about this follow-up in-person evaluation.**
- No, I am not interested in learning more about this follow-up in-person evaluation.**

Note to CNI: *This final question is also included at the end of the Survey Supplement for SEED 1 Caregivers (i.e., Young Adult Supplement) and is only intended for SEED 1 & 2 families from the CO, GA, & MD SEED sites.*