

SEED Follow-Up Study: Young Adult Survey Supplement
(for SEED 1 Caregivers)

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[Type here]

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 school 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. *(This may be part of an IEP - Individualized Education Program)*
 - 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. *(This may be part of an IEP - Individualized Education Program)*
 - Yes
 - No
 - Don't know

4. Does your child currently have a transition plan? *(This may be part of an IEP - Individualized Education Program)*
 - 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 transition planning?

[Type here]

- € 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

11. When do you expect your child to graduate or exit from high school? *If your child is no longer in high school, please provide the month and year your child graduated or exited high school.*

[Type here]

| | |
|-------|------|
| | |
| Month | Year |

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

[Type here]

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

[Type here]

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

8. We would like to better understand which aspects of transition to adult medical care are concerning to you and your child. Please rate the level of concern you have about the following aspects of this transition:

| | No Concern | Little Concern | Some Concern | Much Concern |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| Leaving an established medical home | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Losing the relationship with their current provider | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Establishing a relationship with a new provider | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Seeing a doctor who does not know about my child’s condition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Changing to a new health care system/hospital system | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Transportation to visits | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Health Insurance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (please describe): | | | | |

[Type here]

D. Transportation

1. How frequently does your child drive a car or other motor vehicle?

- Every day, or almost every day (**Skip to question 3**)
- Occasionally
- Seldom
- Never
- Don't Know (**Skip to question 3**)

2. Is this because of an impairment or health problem?

- Yes
- No
- Don't know

3. DURING THE PAST 12 MONTHS, has your child used local public transportation, such as a regular bus line, rapid transit, subway, or streetcar?

- Yes
- No
- Don't know

4. Does your child have any difficulty using the local public transportation service?

- Yes
- No (**Skip to Section E**)
- Don't know (**Skip to Section E**)

5. What types of difficulties does your child have using the local public transportation service (*check all that apply*)?

- Cognitive/mental problems (remembering where to go or knowing how to avoid trouble)
- Fear
- Vision difficulties
- Hearing difficulties
- Weather
- Difficulty walking/can't walk
- Wheelchair/scooter/access problems
- Problems with other medical/assistive devices
- Needs help from another person
- Hours inadequate
- Cost
- Don't know
- Other, specify: _____

[Type here]

E. Vocational Support and Training

The next questions are about services or training your child might have received to prepare them for finding and/or maintaining a job (*this applies to school or transition services*).

1. Has your child's school provided any of the following services? CHECK ALL THAT APPLY

| | Service | Yes | No | Don't know |
|----|---|--------------------------|--------------------------|--------------------------|
| a. | Testing to find out your child's work interests or abilities. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. | Training in specific job skills, for example food services, computer skills, or training for another kind of job. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. | Training in basic skills needed for work, like counting change, telling time, or using transportation to get to work. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. | Career counseling, like help in figuring out jobs your child might be suited to. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. | Help in learning how to search for available job positions online, write a resume, or prepare for a job interview. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. | Job shadowing, such as visiting a workplace and watching the way a job is done. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. | Apprenticeships or internships. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. | Other services or training? Specify: _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

2. Do you think your child is getting enough job or career training?

- Yes
- No
- Don't know

3. How useful do you think job or career training is in helping your child get a job?

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

4. Do you think your child needs additional job or vocational training they are not receiving now?

- Yes
- No (**Skip to Section F**)
- Don't know (**Skip to Section F**)

[Type here]

5. What other kinds of job training or help do you think your child needs? (*Check all that apply*)

- € Testing 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 learning to look for a job such as how to write a resume or interview for a job
- € Job shadowing, visiting a workplace and watching the way the job is done
- € Apprenticeships or internships
- € Help in finding a job such as learning how to search for available job positions online
- € Other, specify: _____
- € Don't know

[Type here]

F. Sexual Health and Communication

- 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. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. | I know the topics related to sexuality that I need to educate my child. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. | I feel competent teaching my child about the reproductive system. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. | I feel competent teaching my child about contraception and pregnancy. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. | I feel competent teaching my child about sexually transmitted infections. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. | I feel competent teaching my child about romantic relationships. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

[Type here]

| | 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 of the other sex? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Shown or expressed attraction to anyone of the same sex? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Had a sexual/romantic relationship with anyone of the other sex? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Had a sexual/romantic relationship with anyone of the same sex? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

5. Has your child ever
....

[Type here]

G. Your Expectations for Your child

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

| | DEFINITELY WILL | PROBABLY WILL | PROBABLY WON'T | DEFINITELY 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"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Get an IEP modified high school diploma OR certificate of completion? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Attend school after high school? <i>Including college, technical, or trade school.</i> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Attend a special training program after high school for persons with intellectual disabilities? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Complete a technical or trade school program? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Immediately start working at a job (part or full-time) or volunteering right after high school? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <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"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <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"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Get a driver's license? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Eventually live away from home on their own without supervision? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. Eventually live away from home on their own with supervision? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <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"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. Earn enough to support him/herself without financial help from his/her family or government benefit programs? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n. Get married or have a life partner? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o. Have children? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

[Type here]

H. 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 |

[Type here]

You have reached the end of the survey.

Thank you for participating!

By completing this survey, you and your child may be eligible for another survey opportunity. This second survey has two parts: one for caregivers and one for young adults. Both surveys will help us learn about the types of services and supports young adults need after leaving high school.

You and your child are under no obligation to be in this part of the study, but if you would like to learn more, please indicate your interest below.

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

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.**