

**Attachments 4a-4b: First Follow-up Survey Supplement for Caregivers of Adolescents**

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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>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. 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.	<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"/>



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 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"/>

## E. Your Expectations for This 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 &amp; 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 <b>without</b> 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 <b>with</b> 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"/>



## 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.*

Social Responsiveness Scale  
Second Edition

# SRS-2

John W. Cunningham, III  
and Christopher R. Linstead, PhD



Child's name \_\_\_\_\_ Child's age in years \_\_\_\_\_ Date of rating \_\_\_\_\_
Rater's name \_\_\_\_\_ Relationship to rated individual  Mother  Father  Other custodial adult

PARENT REPORT

This profile for the SRS-2 is designed to aid in diagnosis and treatment planning. The user should be familiar with the materials presented in the SRS-2 Manual (WPS Product No. W-608M). See Chapter 3 of the manual for additional interpretation of scores. No diagnostic or treatment decisions should be made solely on the basis of this report without confirming information from independent sources.

SRS-2 TOTAL SCORE RESULTS table with columns for T-score and Total raw score, ranging from 30 to 123.

TOTAL SCORE DISCUSSION table with three sections: 59T and below (Normal limits), 60T to 65T (Mild range), and 66T to 75T (Moderate range).

TREATMENT SUBSCALES table with columns for T-score, Amr, Cog, Com, Mot, RRB, and T-score, ranging from 30 to 90.

DSM-5 COMPATIBLE SCALES table with columns for SCI and RRB, each with T-score and Raw score, ranging from 30 to 90.

EXAMINER: REMOVE THIS SHEET BEFORE COMPLETING FORM.

**SRS-2 Profile Sheet**

**School-Age**

**MALE**

Child's name \_\_\_\_\_ Child's age in years \_\_\_\_\_ Date of rating \_\_\_\_\_

Rater's name \_\_\_\_\_ Relationship to rated individual  Mother  Father  Other custodial adult

**PARENT REPORT**

This profile for the SRS-2 is designed to aid in diagnosis and treatment planning. The user should be familiar with the materials presented in the SRS-2 Manual (WPS Product No. W-608M). See Chapter 3 of the manual for additional interpretation of scores. No diagnostic or treatment decisions should be made solely on the basis of this report without confirming information from independent sources.

SRS-2 TOTAL SCORE RESULTS	
T-score	Total raw score
≥90	≥134
89	131-133
88	129-130
87	126-128
86	124-125
85	121-123
84	119-120
83	116-118
82	113-115
81	111-112
80	108-110
79	106-107
78	103-105
77	101-102
76	98-100
75	96-97
74	93-95
73	91-92
72	88-90
71	86-87
70	83-85
69	81-82
68	78-80
67	76-77
66	73-75
65	71-72
64	68-70
63	66-67
62	63-65
61	61-62
60	58-60
59	56-57
58	53-55
57	50-52
56	48-49
55	45-47
54	43-44
53	40-42
52	38-39
51	35-37
50	33-34
49	30-32
48	28-29
47	25-27
46	23-24
45	20-22
44	18-19
43	15-17
42	13-14
41	10-12
40	8-9
39	5-7
38	3-4
37	0-2
36	.
35	.
34	.
33	.
32	.
31	.
30	.

TOTAL SCORE DISCUSSION	
<b>597 and below—Within normal limits</b>	
Scores in this range are generally not associated with clinically significant autism spectrum disorders.	
<b>607 to 657—Mild range</b>	
Scores in this range indicate deficiencies in reciprocal social behavior that are clinically significant and may lead to mild to moderate interference with everyday social interactions.	
<b>667 to 757—Moderate range</b>	
Scores in this range indicate deficiencies in reciprocal social behavior that are clinically significant and lead to substantial interference with everyday social interactions. Such scores are typical for children with autism spectrum disorders of moderate severity.	
<b>767 or higher—Severe range</b>	
Scores in this range indicate deficiencies in reciprocal social behavior that are clinically significant and lead to severe interference with everyday social interactions. Such scores are strongly associated with clinical diagnosis of an autism spectrum disorder.	

TREATMENT SUBSCALES						
T-score	Awr	Cog	Ces	Met	RRB	T-score
≥90	117	123	117	120	125	≥90
89	115	121	115	118	123	89
88	113	119	113	116	121	88
87	111	117	111	114	119	87
86	109	115	109	112	117	86
85	107	113	107	110	115	85
84	105	111	105	108	113	84
83	103	109	103	106	111	83
82	101	107	101	104	109	82
81	99	105	99	102	107	81
80	97	103	97	100	105	80
79	95	101	95	98	103	79
78	93	99	93	96	101	78
77	91	97	91	94	99	77
76	89	95	89	92	97	76
75	87	93	87	90	95	75
74	85	91	85	88	93	74
73	83	89	83	86	91	73
72	81	87	81	84	89	72
71	79	85	79	82	87	71
70	77	83	77	80	85	70
69	75	81	75	78	83	69
68	73	79	73	76	81	68
67	71	77	71	74	79	67
66	69	75	69	72	77	66
65	67	73	67	70	75	65
64	65	71	65	68	73	64
63	63	69	63	66	71	63
62	61	67	61	64	69	62
61	59	65	59	62	67	61
60	57	63	57	60	65	60
59	55	61	55	58	63	59
58	53	59	53	56	61	58
57	51	57	51	54	59	57
56	49	55	49	52	57	56
55	47	53	47	50	55	55
54	45	51	45	48	53	54
53	43	49	43	46	51	53
52	41	47	41	44	49	52
51	39	45	39	42	47	51
50	37	43	37	40	45	50
49	35	41	35	38	43	49
48	33	39	33	36	41	48
47	31	37	31	34	39	47
46	29	35	29	32	37	46
45	27	33	27	30	35	45
44	25	31	25	28	33	44
43	23	29	23	26	31	43
42	21	27	21	24	29	42
41	19	25	19	22	27	41
40	17	23	17	20	25	40
39	15	21	15	18	23	39
38	13	19	13	16	21	38
37	11	17	11	14	19	37
36	9	15	9	12	17	36
35	7	13	7	10	15	35
34	5	11	5	8	13	34
33	3	9	3	6	11	33
32	1	7	1	4	9	32
31	0	5	0	2	7	31
30	0	3	0	0	5	30

DSM-5 COMPATIBLE SCALES			
SCI		RRB	
T-score	Raw score	T-score	Raw score
≥90	≥109	≥90	≥28
89	107-108	89	27
88	105-106	88	26
87	103-104	87	25
86	101-102	86	24
85	99-100	85	23
84	97-98	84	22
83	95-96	83	21
82	93-94	82	20
81	91-92	81	19
80	89-90	80	18
79	87-88	79	17
78	85-86	78	16
77	83-84	77	15
76	81-82	76	14
75	79-80	75	13
74	77-78	74	12
73	75-76	73	11
72	73-74	72	10
71	70-72	71	9
70	68-69	70	8
69	66-67	69	7
68	64-65	68	6
67	62-63	67	5
66	60-61	66	4
65	58-59	65	3
64	56-57	64	2
63	54-55	63	1
62	52-53	62	0
61	50-51	61	.
60	48-49	60	.
59	46-47	59	.
58	44-45	58	.
57	42-43	57	.
56	40-41	56	.
55	38-39	55	.
54	36-37	54	.
53	34-35	53	.
52	32-33	52	.
51	30-31	51	.
50	28-29	50	.
49	26-27	49	.
48	24-25	48	.
47	22-23	47	.
46	20-21	46	.
45	18-19	45	.
44	16-17	44	.
43	14-15	43	.
42	12-13	42	.
41	10-11	41	.
40	8-9	40	.
39	6-7	39	.
38	4-5	38	.
37	2-3	37	.
36	0-1	36	.
35	.	35	.
34	.	34	.
33	.	33	.
32	.	32	.
31	.	31	.
30	.	30	.

EXAMINER: REMOVE THIS SHEET BEFORE COMPLETING FORM.