Form Approved
OMB No. 0920-XXXX
Exp. Date XX/XX/XXXX

Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT): Caregiver Survey Version 2

This survey is intended to be administered online. This version of the survey is for caregivers of participants who are 18 years or older who can report on their own health history and needs. Questions in Section A and Section B are asked of all caregivers to determine which questionnaire they will be administered. It is expected to take no longer than 10 minutes to complete.

Thank you in advance for completing this survey. Results will help us learn how to best meet the healthcare needs of young adults with and without autism and other developmental disabilities. Please remember that your answers are voluntary and will remain private to the extent allowed by law. You do not need to answer any question that makes you feel uncomfortable. It should take no more than 10 minutes to complete.

Note that we use the term "participant" throughout the survey. This term is used to describe your child or relative regardless of age.

Section A: Age and Communication

A1. How old is the participant now? [Required – Input integer value]
Age in years:_____

A2. What is the participant's current method of verbal communication? Verbal

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 H21-8 Atlanta, Georgia 30329; ATTN: PRA (0920-XXXX)

The Centers for Disease Control and Prevention (CDC) is authorized to collect this information under Sections 301(a) [42 U.S.C. § 241(a)] and 317C of the Public Health Service Act [42 U.S.C. § 247b-4], as amended, including Public Law No. 106-310 (Children's Health Act of 2000), Public Law No. 109-416 (Combating Autism Act of 2006), and Public Law No. 118–180 (Autism CARES Act of 2024). CDC will use this information to support surveillance activities related to autism spectrum disorder (ASD), and to inform the development, implementation, and evaluation of public health programs and services aimed at improving outcomes for individuals with ASD and their families.

The Privacy Act of 1974, 5 U.S.C. §552a, governs the collection and use of this information. The information maintained by CDC will be covered by CDC's System of Records Notice (SORN) No. 09-20-0136, Epidemiologic Studies and Surveillance of Disease Problems. See 57 Fed. Reg 62811 (Dec. 31, 1992). CDC will only disclose information from the system outside the CDC and the U.S. Department of Health and Human Services as the Privacy Act permits, including in accordance with the routine uses published for this system in the Federal Register, and as authorized by law. These uses may include, but are not limited to, sharing information with authorized contractors, collaborating researchers, or other federal, state, or local agencies, as permitted by law. Providing this information is voluntary. There are no penalties for not participating. However, failure to provide requested information may limit the completeness or usefulness of the data for public health surveillance and program planning purposes.

communication means “with words.” (Choose 1 method used most often)? [radio button]

- ☐ Communicates using complex sentences (Go to A2a)
- ☐ Communicates using simple sentences of more than 3 words (Go to A3)
- ☐ Communicates using 2–3-word phrases (Go to A3)
- ☐ Communicates using single words (Go to A3)
- ☐ Communicates with noises (Go to A3)
- ☐ Does not verbally communicate (Go to A3)

A2a. Can you have a to and fro "conversation" with her/him that involves taking turns and building on what you have said? [radio button]

- ☐ Yes
- ☐ No

A3. Does the participant communicate with people using any of the following non-verbal methods of communication? Non-verbal means “without words.” (Select all that apply.) [Checkboxes]

- ☐ Simple hand movements, like waving or giving a “thumbs up”
- ☐ Facial gestures, like showing when angry, happy, or sad
- ☐ Eye Contact
- ☐ Lip reading
- ☐ Sign language

Provide these answer options only if participant does NOT communicate using complex sentences (A2)

- ☐ Picture exchange
- ☐ Communication board
- ☐ Other electronic device (e.g., uses a tablet, laptop, or smartphone to communicate without talking)
- ☐ Other nonverbal method (specify)_____ [text]

For A1 >= 18 (participant’s age >= 18 years), continue to section B. If A1 < 18 (participant’s age <18 years), administer survey in Attachment 5 (for children under 18 or who cannot self-report).

Section B: Ability to Self-Report and Intellectual Disability

B1. Do you think the participant is able to report on their own health history and needs? [radio button]

- ☐ Yes
- ☐ No

B2. Has the participant ever been diagnosed with an intellectual disability? [radio button]

☐ Yes

☐ No

Responses of Yes to B1 (ability to report on own health history and needs) and responses of No to B2 (no intellectual disability) continue with the rest of the survey. Responses of No to B1 or Yes to B2, administer survey in Attachment 5 (for children under 18 or who cannot self-report).

Section C: Questions for Caregivers of Adult Children (Ages ≥18)

C1. How often does the participant come to you for advice on each of the following? [radio button]

	Extremely Often	Very Often	Sometimes	Rarely	Never
Their financial situation					
Their career or job situation					
Their mental health					
Their physical health					
Their friendships					
Their dating life or relationships					
Parenting					

C2. How often do you and the participant <u>disagree</u> about each of the following? [radio button]

	Extremely Often	Very Often	Sometimes	Rarely	Never
Their financial choices					
Their views about religion					
Their political views					
Their career or job situation					
Their social life					
Their dating life or relationships					

C3. Overall, to what extent do you think you prepared the participant to be an independent adult? [radio button]

☐ A great deal
☐ A fair amount
☐ Some
☐ Not much
☐ Not at all

C4. Does the participant live with you? [radio button]

☐ Yes
☐ No

C5. In the past 12 months, did you give any financial help to the participant, including paying some of their bills? [radio button]

☐ Yes *(Go to C5a)*
☐ No *(Go to C6)*

C5a. In the past 12 months, how much has giving financial help to the participant hurt your personal financial situation? [radio button]

☐ A great deal
☐ A fair amount
☐ Some
☐ Not much
☐ Not at all

C6. In the past 12 months, did you receive any financial help from the participant? [radio button]

☐ Yes *(Go to C6a)*
☐ No *(Go to C7)*

C6a. Was the financial help you received for… [radio button]

☐ Special circumstances
☐ Recurring expenses
☐ Both

C7. How much do you think the participant's successes and failures reflect the job you have done as a parent? [radio button]

☐ A great deal
☐ A fair amount
☐ Some
☐ Not much
☐ Not at all

Section D: Demographics

D1. What is YOUR ethnicity? (radio button)

☐ Hispanic or Latino
☐ Not Hispanic or Latino

D2. What is YOUR race? (Select all that apply; you may report more than one answer) [Checkbox]

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Pacific Islander
☐ White

D3. What is THE PARTICIPANT's ethnicity? (radio button)

☐ Hispanic or Latino
☐ Not Hispanic or Latino

D4. What is THE PARTICIPANT's race? (Select all that apply; you may report more than one answer) [Checkbox]

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Pacific Islander
☐ White

D5. What is the highest degree or level of schooling that you have COMPLETED? (Check only one

box). (radio button)

☐ Less than high school
☐ High school graduate
☐ Some college
☐ College graduate
☐ Advanced degree (e.g., Master's, Professional, or Doctorate)

D6. How many children ages 0-17 years old (including the participant, if applicable) live or stay at this address? (Integer value – text)

Number of children_____

D7. How many of these children (including the participant, if applicable) have any disability, developmental delay, or special need? (Integer value – text)

Number of children_____

D8. Think about your total combined family income IN THE LAST CALENDAR YEAR for all members of the family. What was your yearly total household income before taxes? Include your income, your spouse's or partner's income, and any other income you may have received. (Integer value – text)

Total income_____

D9. If you are unable to provide a specific amount, please indicate an estimated range of total yearly income given the following options. (radio button)

☐ $0 to $16,000
☐ $16,001 to $20,000
☐ $20,001 to $24,000
☐ $24,001 to $28,000
☐ $28, 001 to $32,000
☐ $32,001 to $40,000
☐ $40,001 to $48,000
☐ $48,001 to $57,000
☐ $57,001 to $60,000
☐ $60,001 to $73,000
☐ $73,001 to $85,000
☐ $85,001 or more

D10. DURING THE LAST CALENDAR YEAR, how many people, including yourself and the participant, depended on this income? (For example, if you are married, and you care for the participant plus two other people, you have a total of 5 people who depend on this income.) (Integer value – text)

Number of people_____

Section E: Participant Strengths

E1. What does the participant do really well compared to his or her overall abilities? (open text)

E2. What does the participant enjoy? (text)

Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT): Caregiver 2 Survey

Some questions in the SPROUT caregiver 2 survey were selected from national surveys or the OMB approved Study to Explore Early Development Phase 1 (SEED 1; OMB #0920-0741), SEED 3; OMB #0920-1171), SEED Teen Survey (OMB #0920-1219), and SEED Follow-Up Survey (OMB #0920-1392).. National survey question sources for the SPROUT caregiver 2 survey are :

- *National Longitudinal Transition Study-2 (NLTS2) (http://www.nlts2.org/)*
- *National Survey of Children's Health (NSCH) (https://www.cdc.gov/nchs/slaits/nsch.htm)*
- *Pew Research Center (Pew Research Center)*

Additionally, questions from one validated, standardized instrument were embedded in the survey:

- *Social Communication Questionnaire (SCQ)*

SPROUT investigators were mindful of the benefits of using previously tested and/or OMB approved questions and developing new questions that offer unique information not available elsewhere. New questions were developed by SPROUT investigators after

reviewing the literature and considering priorities set forth by a federal autism advisory board (IACC | Interagency Autism Coordinating Committee).

Sources of each question in the caregiver 2 survey are provided in the following pages. New questions are highlighted in blue. Notes are highlighted in purple.

	Question Source(s)			
Question:	**SEED 1-3**	**SEED Teen**	**SEED Follow-Up**	**Other Source**
A1. How old is the participant now?	X			Adapted from "What is your child's date of birth?"
A2. What is the participant's current method of verbal communication? Verbal communication means "with words." (Choose 1 method used most often)?		X	X	Adapted from the National Longitudinal Transition Study-2 (NLTS2)
A2a. Can you have a to and fro "conversation" with her/him that involves taking turns and building on what you have said?				Social Communication Questionnaire: Social Communication Questionnaire (SCQ®)
A3. Does the participant communicate with people using any of the following non-verbal methods of communication? Non-verbal means "without words." (Check all that apply.)		X	X	Adapted from the National Longitudinal Transition Study-2 (NLTS2)
B1. Do you think the participant is able to report on their own health history and needs?				
B2. Has the participant ever been diagnosed with an intellectual disability?	X	X	X	Adapted from National Survey of Children's Health

C1. How often does the participant come to you for advice on each of the following?				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C2. How often do you and the participant disagree about each of the following?				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C3. Overall, to what extent do you think you prepared the participant to be an independent adult?				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C4: Does the participant live with you?				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C5: In the past 12 months, did you give any financial help to the participant, including paying some of their bills?				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C5a. In the past 12 months, how much has giving financial help to the participant hurt your personal financial situation?				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C6. In the past 12 months, did you receive any financial help from the participant?				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C6a. Was the financial help you received for…				Pew Research: ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
C7. How much do you think the participant's				Pew Research:

successes and failure reflect the job you have done as a parent?				ST_2024.01.25_Parents-Young-Adults_Topline-Parents.pdf
D1. What is YOUR ethnicity?	X			
D2. What is YOUR race? (Check all that apply).	X			
D3. What is THE PARTICIPANT 'S ethnicity?	X	X	X	National Survey of Children's Health
D4. What is THE PARTICIPANT 'S race? (Check all that apply).	X	X	X	National Survey of Children's Health
D5. What is the highest degree or level of schooling that you have COMPLETED? (Check only one box).	X	X	X	National Survey of Children's Health
D6. How many children ages 0-17 years old (including the participant, if applicable) live or stay at this address?	X	X	X	National Survey of Children's Health
D7. How many of these children (including the participant, if applicable) have any disability, developmental delay, or special need?	X	X	X	Adapted from the National Survey of Children's Health
D8. Think about your total combined family income IN THE LAST CALENDAR YEAR for all members of the family. What was your yearly total household income before taxes? Include your income, your spouse's or partner's income, and any other income you may have received.	X	X	X	National Survey of Children's Health

D9. If you are unable to provide a specific amount, please indicate an estimated range of total yearly income given the following options.	X	X	X	National Survey of Children's Health
D10. DURING THE LAST CALENDAR YEAR, how many people, including yourself and the participant, depended on this income? (For example, if you are married, and you care for the participant plus two other people, you have a total of 5 people who depend on this income.)	X	X	X	National Survey of Children's Health
E1. What does the participant do really well compared to his or her overall abilities?				
E2. What does the participant enjoy?				