Form Approved
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Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT): Caregiver Survey Version 1

This survey is intended to be administered online. This version of the survey is for caregivers of participants who are younger than 18 years old or caregivers of those older than 18 who are not be able to self-report. It is expected to take no longer than 30 minutes to complete.

Thank you in advance for completing this survey. Results will help us learn how to best meet the healthcare needs of children, adolescents, and 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. The survey should take no more than 30 minutes to complete. Please 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 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)*

Public reporting burden of this collection of information is estimated to average 30 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 30333; 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.

☐ 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 years, have caregiver answer B1A and then go to B2.
For A1 >= 18 (participant's age >= 18 years), have caregiver answer B1B then go to B2.

Section B: Ability to Self-Report and Intellectual Disability

B1A. Do you think the participant is able to report how they feel about life and deal with stress? [radio button]

☐ Yes
☐ No

B1B. 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

Section C: Co-Occurring Mental/Developmental Conditions

We would like to ask you about 11 other mental or developmental conditions that may apply to the participant

Note: The following questions will cycle through X=[condition], where X=

1. Autism spectrum disorder (including Autistic Disorder, Aspergers Disorder, or Pervasive Developmental Disorder)
2. Attention Deficit hyperactivity disorder (ADHD)*
3. Anxiety disorder (anxiety)
4. Bipolar disorder
5. Conduct or oppositional defiant disorder
6. Depression or mood disorder, not including bipolar disorder
7. Motor delay/disorder or developmental coordination disorder
8. Language delay or disorder
9. Learning disability (e.g., like dyslexia or a processing disorder, that is not due to intellectual disability)
10. Self-injurious behavior
11. Sensory integration disorder

*use ADHD for CXa-e

CX. Has a doctor or other healthcare provider told you that the participant has [condition_desc]?

Yes à CXa
No à Next condition
DK à Next condition

CXa. Does the participant currently have [condition]?

Yes à CXb
No à Next condition
DK à Next condition

CXb. How much does [condition] impact the participant's overall functioning?

Not at all
Very little

A moderate amount
Very much

If [condition]=("motor delay/disorder or developmental coordination disorder", "language delay or disorder", "a learning disability", "conduct or oppositional defiant disorder", or "sensory integration disorder") skip to CXd.

CXc. During the past 12 months, has the participant taken any prescription medication to help manage symptoms of [condition]?

Yes à CXc_1
No à CXd
DK à CXd

CXc_1. During the past 12 months, was any prescription medication helpful in managing symptoms of [condition]?

Yes
No
DK

CXd. During the past 12 months, has the participant seen any specialist to help manage symptoms of [condition]?

Yes à CXe
No à Next condition
DK à Next condition

CXe. During the past 12 months, was any specialist helpful in managing symptoms of [condition]?

Yes
No
DK

Section D: Co-Occurring Medical Conditions

Now we would like to ask you about 13 medical conditions that may apply to the participant.

Note: The questions in this section follow the same format as the previous section. The following questions will cycle through X=[condition], where X=

1. Allergies
2. Asthma
3. Autoimmune skin condition (e.g., eczema, psoriasis, or vitiligo)
4. Other autoimmune condition (e.g., lupus, multiple sclerosis, or rheumatoid arthritis)

5. Birth defect
6. Chronic migraines
7. Concussion or brain injury
8. Diabetes
9. Epilepsy or seizure disorder
10. Genetic disorder
11. Frequent or chronic constipation or diarrhea
12. Heart condition
13. Sleep disorder

DX. Has a doctor or other healthcare provider told you that the participant has [condition]?

Yes à DXa
No à Next condition
DK à Next condition

DXa. Does the participant currently have [condition]?

Yes à DXb
No à Next condition
DK à Next condition

DXb. How much does [condition] impact the participant's overall functioning?

Not at all
Very little
A moderate amount
Very much

if [condition]=("Birth Defect", "Genetic Disorder") add a text field to specify the condition and then skip to DXd

DXc. During the past 12 months, has the participant taken any prescription medication to help manage the symptoms of [condition]?

Yes à DXc_1
No à DXd
DK à DXd

DXc_1. During the past 12 months, was any prescription medication helpful in managing the symptoms of [condition]?

Yes
No
DK

DXd. During the past 12 months, has the participant seen any specialist to help manage the [condition]?

Yes à DXe
No à Next condition
DK à Next condition

DXe. During the past 12 months, was any specialist helpful in managing the [condition]?

Yes
No
DK

Section E: Healthcare Utilization

E1. DURING THE PAST 12 MONTHS, what type of care did the participant receive for routine check-ups when he/she was not sick or injured? [radio button]

	Yes	No	Don't Know
a. General physician or medical care	☐	☐	☐
b. Dental or oral care	☐	☐	☐
c. Mental health care	☐	☐	☐
d. Specialty hearing care	☐	☐	☐
e. Specialty vision care	☐	☐	☐
f. Other specialty care, from allergy or skin doctors	☐	☐	☐
g. Other (specify) _____ [text]*	☐ *	☐	☐

*Pop up text box if "Yes" is selected

E2. DURING THE PAST 12 MONTHS, what type of care did the participant receive when he/she was sick or injured? [radio button]

	Yes	No	Don't Know
a. General physician or medical care	☐	☐	☐
b. Dental or oral care	☐	☐	☐
c. Mental health care	☐	☐	☐
d. Specialty hearing care	☐	☐	☐
e. Specialty vision care	☐	☐	☐
f. Other specialty care, from allergy or skin doctors	☐	☐	☐
g. Other (specify) _____ [text]*	☐ *	☐	☐

*Pop up text box if "Yes" is selected

E3. DURING THE PAST 12 MONTHS, did the participant receive the following vaccines? [radio button]

	Yes	No	Don't Know
a. COVID-19	☐	☐	☐
b. Influenza/flu	☐	☐	☐

E4. Has the participant EVER received at least one dose of the following vaccines? *These vaccines are typically first offered between 11-12 years of age.* **[radio button]**

	Yes	No, but will receive	No, and will not receive	Don't Know
a. HPV (human papillomavirus) vaccine?	☐	☐	☐	☐
b. DtaP (tetanus, diphtheria, and pertussis) vaccine?	☐	☐	☐	☐
c. Meningococcal ACWY (meningitis) vaccine?	☐	☐	☐	☐

E5. DURING THE PAST 12 MONTHS, how many times did the participant visit a hospital

emergency department (not including urgent care)? [radio button]

☐ No visits *(Go to E6)*
☐ 1 visit *(Go to E5a)*
☐ 2 or more visits *(Go to E5a)*

E5a. Please indicate if the participant visited a hospital emergency department in the PAST 12 MONTHS for any of the following reasons. [radio button]

	Yes	No	Don't Know
a. Abdominal issue, including constipation, diarrhea, or pain	☐	☐	☐
b. Aggressive or behavioral outburst	☐	☐	☐
c. Headache, including migraine	☐	☐	☐
d. Mental health issue	☐	☐	☐
e. Seizure or convulsion	☐	☐	☐
f. Self-injurious behavior	☐	☐	☐
g. Sore throat	☐	☐	☐
h. Upper respiratory infection, like a cold, strep throat, or sinus infection	☐	☐	☐
i. Superficial injury, like a sprain, scratch, or minor cut or burn	☐	☐	☐
j. Major injury, like a broken bone or severe cut or burn	☐	☐	☐
k. Other (specify) _____ [text]*	☐ *	☐	☐

*Popup text box if "Yes" is selected

E6. DURING THE PAST 12 MONTHS, how many times was the participant hospitalized for any reason? *Hospitalized means the participant was admitted and stayed overnight.* **[radio button]**

☐ None *(Go to E7)*

☐ 1 time *(Go to E6a)*
☐ 2 or more times *(Go E6a)*

E6a. Please indicate if the participant was hospitalized DURING THE PAST 12 MONTHS for any of the following reasons. [radio button]

	Yes	No	Don't Know
a. Abdominal issue, including constipation, diarrhea, or pain	☐	☐	☐
b. Aggressive or behavioral outburst	☐	☐	☐
c. Mental health issue	☐	☐	☐
d. Seizure or convulsion	☐	☐	☐
e. Self-injurious behavior	☐	☐	☐
f. Surgery	☐	☐	☐
g. Upper respiratory infection, like a cold, strep throat, or sinus infection	☐	☐	☐
h. Major injury, like a broken bone or severe cut or burn	☐	☐	☐
i. Other (specify) _____ [text]*	☐ *	☐	☐

*Popup text box if "Yes" is selected

E7. Has the participant EVER been restrained during any hospitalization? *Restraint includes any method of restricting freedom of movement that is not part of a regular treatment plan. This includes physical holding, physical material or equipment, or medication intended to restrict movement in response to behavior.* **[radio button]**

☐ Yes
☐ No
☐ Don't Know
☐ Never Hospitalized

Section F: Service Needs

F1. DURING THE PAST 12 MONTHS, was there any time when the participant needed healthcare, but it was not received? *By health care, we mean medical care as well as other kinds of care like dental care, vision care, and mental health services.* **[radio button]**

☐ Yes *(Go to F1a)*
☐ No *(Go to F2)*
☐ Don't know *(Go to F2)*

F1a. Which of the following contributed to the participant not receiving needed healthcare services during the past 12 months? "Yes" means it was a factor in not receiving services and "No" means it was not a factor. *(Go to F1b)*

F1b. The services you needed were not available in your area. [radio button]

□ Yes *(Go to F1bi)*
□ No *(Go to F1c)*
□ Don't know *(Go to F1c)*

F1bi. If yes: What services were needed but not available in your area? (Check all that apply) [checkboxes]

☐ Dental care
☐ Medical care (routine well-child when not sick or injured)
☐ Medical care (specialist)
☐ Medical care (when sick or injured)
☐ Behavioral therapy
☐ Occupational therapy
☐ Mental health therapy
☐ Physical therapy
☐ Social skills training
☐ Speech-language therapy
☐ Other (specify): _____ [text]

F1c. There were problems getting an appointment when you needed one. [radio button]

- ☐ Yes *(Go to F1ci)*
- ☐ No *(Go to F1d)*
- ☐ Don't know *(Go to F1d)*

F1ci. If yes: How much would each of these factors help resolve problems getting an appointment? [radio button]

	Not at all	Somewhat	Very Little	Very much
A text messaging scheduling system	☐	☐	☐	☐
An online scheduling system	☐	☐	☐	☐
More general providers in my area	☐	☐	☐	☐
More providers willing to work with people with special needs[1]	☐	☐	☐	☐
More telehealth appointments	☐	☐	☐	☐
More walk-in appointments	☐	☐	☐	☐
Triaged (or prioritized) appointments based on need	☐	☐	☐	☐
Other (specify)_____ [text]	☐	☐	☐	☐

[1]Ask only if at least one mental/developmental or medical condition was endorsed in Section C or Section D

F1d. There were problems with transportation. [radio button]

- ☐ Yes *(Go to F1di)*
- ☐ No *(Go to F1e)*
- ☐ Don't know *(Go to F1e)*

F1di. If yes: How much would each of these factors help resolve problems you experienced with transportation? [radio button]

	Not at all	Somewhat	Very Little	Very much
Developmental disability training for public transport operators[1]	☐	☐	☐	☐
Help coordinating or scheduling transportation	☐	☐	☐	☐
Increased access to non-emergency medical transport	☐	☐	☐	☐
More information on transportation options	☐	☐	☐	☐
Reduced stigma about people with developmental disabilities[1]	☐	☐	☐	☐
Transportation vouchers reimbursement	☐	☐	☐	☐
Other (specify)_____ [text]	☐	☐	☐	☐

[1]Ask only if at least one mental/developmental condition was endorsed in Section C

F1e. There were issues related to the cost of the doctor's visit. [radio button]

- ☐ Yes *(Go to F1ei)*
- ☐ No *(Go to F1f)*
- ☐ Don't know *(Go to F1f)*

F1ei. If yes: How much would each of these factors help resolve issues related to cost? [radio button]

	Not at all	Somewhat	Very Little	Very much
More government supports, like supplemental income	☐	☐	☐	☐
More insurance coverage	☐	☐	☐	☐
More providers who accept insurance	☐	☐	☐	☐
Other (specify)_____ [text]	☐	☐	☐	☐

F1f. There were problems with navigating the healthcare system (e.g., like managing different services for different problems). [radio button]

- ☐ Yes *(Go to F1fi)*
- ☐ No *(Go to F2)*
- ☐ Don't know *(Go to F2)*

F1fi. If yes: How much would each of these factors help resolve problems with navigating the healthcare system? [radio button]

	Not at all	Very Little	Somewhat	Very much
A dedicated care navigator or social worker	☐	☐	☐	☐
Education on what services are available	☐	☐	☐	☐
Having visits for multiple providers at the same time	☐	☐	☐	☐
Having visits for multiple providers at the same location	☐	☐	☐	☐
Personal interaction between providers	☐	☐	☐	☐
Shared notes between providers	☐	☐	☐	☐
Other (specify)_____ [text]	☐	☐	☐	☐

F2. Have you or the participant EVER experienced any problems with service environments? *Service environments include waiting areas, appointment rooms, and check out desks.* [radio button]

☐ Yes *(Go to F2a)*
☐ No *(Go to F3)*
☐ Don't know *(Go to F3)*

F2a. If yes: How much would each of these factors help resolve the problems you experienced related to service environments? [radio button]

	Not at all	Very little	Somewhat	Very much
Access to fidget or sensory objects	☐	☐	☐	☐
Less crowded waiting area	☐	☐	☐	☐
Less noisy waiting area	☐	☐	☐	☐
Softer overhead lights	☐	☐	☐	☐
Reduced wait times	☐	☐	☐	☐
Other, specify _____ [text]	☐	☐	☐	☐

F3. Have you or the participant EVER experienced any problems with healthcare providers? **[radio button]**

☐ Yes *(Go to F3a)*
☐ No *(Go to F4)*
☐ Don't know *(Go to F4)*

F3a. If yes: How much would each of these factors help resolve problems related to healthcare providers? **[radio button]**

	Not at all	Very little	Somewhat	Very much
Consistency in provider(s) who deliver services	☐	☐	☐	☐
Extended visit times	☐	☐	☐	☐
Provider training on how to work with people with developmental disabilities[1]	☐	☐	☐	☐

Provider training on differences among people with developmental disabilities[1]	☐	☐	☐	☐
More collaborative or shared decision making between the provider and caregivers or patients	☐	☐	☐	☐
Written summaries of provider recommendations	☐	☐	☐	☐
Other, specify _____ [text]	☐	☐	☐	☐

[1]Ask only if at least one mental/developmental condition was endorsed in Section C

F4. DURING THE PAST 12 MONTHS, was this participant EVER covered by ANY kind of health insurance or health coverage plan? [radio button]

☐ Yes, this participant was covered all 12 months (Go to F5)
☐ Yes, but this participant had a gap in coverage (Go to F5)
☐ No (Go to F4a)
☐ Don't know (Go to F5)

F4a. If NO, what services were needed but NOT RECEIVED because they were not covered by health insurance in the PAST 12 months? (Select all that apply) [checkboxes]

☐ Dental care
☐ Medical care (routine well-child when not sick or injured)
☐ Medical care (specialist)
☐ Medical care (when sick or injured)
☐ Behavioral therapy
☐ Occupational therapy
☐ Mental health therapy
☐ Physical therapy
☐ Social skills training
☐ Speech-language therapy

☐ Other (specify): _____ [text]
☐ None
[any response SKIP TO F6]

F5. Is the participant CURRENTLY covered by ANY kind of health insurance or health coverage plan? [radio button]

☐ Yes *(Go to F5a)*
☐ No *(Go to Section G)*
☐ Don't know *(Go to Section G)*

F5a. If yes: What type of health insurance plan covers the participant ? [checkboxes]

☐ Insurance through a current or former employer or union
☐ Insurance purchased directly from an insurance company
☐ Medicaid, Medical Assistance, or any kind of government-assistance plan
☐ TRICARE or other military healthcare
☐ Indian Health Service
☐ Any other type of health insurance or health coverage plan (specify)_____ [text]
☐ Don't Know

F5b. Does the insurance plan meet the participant's needs? [radio button]

☐ Yes *(Go to Section G)*
☐ No *(Go to F5bi)*
☐ Don't know *(Go to Section G)*

F5bi. If no: How much would each of these factors improve health insurance to better meet the participant's needs? [radio button]

	Not at all	Very little	Somewhat	Very much
Increased annual coverage limits	☐	☐	☐	☐
Increased child age limits	☐	☐	☐	☐
Increased provider reimbursement so that more providers accept insurance	☐	☐	☐	☐
More mental health coverage	☐	☐	☐	☐
More pharmacy coverage	☐	☐	☐	☐
More physical health coverage	☐	☐	☐	☐

More types of other coverage (specify)_____ [text]	☐	☐	☐	☐
Number of approved in-network providers	☐	☐	☐	☐
Number of therapy hours or sessions covered	☐	☐	☐	☐
Reduced copayment or deductible requirements	☐	☐	☐	☐
Other:_____ [text]	☐	☐	☐	☐

Section G: Adaptive Abilities

We would like to know about the participant's <u>current</u> level of independence in performing activities of daily living. For each activity, please tell us which option best describes his or her ability to do the task.
Note that 'Does on own' means the participant is able to do the task without any help or assistance. If this child can do a portion but not all, mark 'does with help'.

Also note that we are asking about the participant's <u>ability</u> to do the task and not whether he or she actually completes the task. [radio button]

	Does on own [coded value of 2]	Does with help [coded value of 1]	Does not do [coded value of 0]
Making his/her own bed	☐	☐	☐
Doing household tasks, including picking up around the house, putting things away, light housecleaning, etc.	☐	☐	☐
Doing errands, including shopping in stores	☐	☐	☐
Doing home repairs, including simple repairs around the house, non-technical in nature; for example, changing light bulbs or repairing a loose screw	☐	☐	☐
Doing laundry, washing and drying	☐	☐	☐
Washing/bathing	☐	☐	☐
Grooming, brushing teeth, combing and/or brushing hair	☐	☐	☐
Dressing and undressing	☐	☐	☐
Toileting	☐	☐	☐

Preparing simple foods requiring no mixing or cooking, including sandwiches, cold cereal, etc.	☐	☐	☐
Mixing and cooking simple foods, fry eggs, make pancakes, heat food in microwave, etc.	☐	☐	☐
Preparing complete meal	☐	☐	☐
Setting and clearing table	☐	☐	☐
Drinking from a cup	☐	☐	☐
Eating from a plate	☐	☐	☐
Washing dishes (including using a dishwasher)	☐	☐	☐
Banking and managing daily finances, including keeping track of cash, checking account, paying bills, etc.	☐	☐	☐

Section H: Healthcare Team

H1. Does the participant have a healthcare team? *A healthcare team is a group of professionals who work together to care for the participant.* [radio button]

☐ Yes *(Go to H1a)*

☐ No *(**If the caregiver responded "No ID" to Question B2:***

- ***Pediatric population (Question A1 <18 years):** Go to Section I.*
- ***Young adult population (Question A1 ≥18 years) :** Go to Section L.*

***If the caregiver responded "ID" to Question B2:** Go to Section J.*

☐ Don't know *(**If the caregiver responded "No ID" to Question B2:***

- ***Pediatric population (Question A1 <18 years):** Go to Section I.*
- ***Young adult population (Question A1 ≥18 years):** Go to Section L.*

***If the caregiver responded "ID" to Question B2:** Go to Section J.*

H1a. Please select the types of professionals who are part of the participant's healthcare team. (Check all that apply) [checkboxes]

☐ Pediatrician/medical doctor
☐ Pharmacist
☐ Psychologist or mental health therapist
☐ Psychiatrist (who prescribes medication)
☐ Occupational therapist
☐ Speech/language therapist
☐ Nutritionist

☐ Behavior analyst
☐ Educational specialist
☐ Physical therapist
☐ Social worker
☐ Other (specify)_____ [text]

If the caregiver responded "No ID" to Question B2:

- ***Pediatric population (Question A1 <18 years):*** *Continue to Section I.*
- ***Young adult population (Question A1 ≥18 years):*** *Go to Section L.*

If the caregiver responded "ID" to Question B2: *Go to Section J.*

Section I: Pre-High School Transition (only for Caregivers of children with no ID)

I1. At his or her LAST preventive check-up, did the participant have a chance to speak with a doctor or other health care provider privately, without you or another adult in the room? [radio button]

☐ Yes *(Go to I2)*
☐ No *(Go to I1a)*

I1a. If no: Which of the following contributed to the participant not speaking with a doctor or other health care provider privately? (Check all that apply) [checkboxes]

☐ Time constraints (i.e., duration of visit was too short, doctor had competing time demands)
☐ Doctor did not offer to speak with my child privately
☐ Child refused to speak with doctor privately
☐ My child's behaviors limited the ability to speak privately
☐ Caregiver refused to allow child to speak with doctor privately (e.g., caregiver was uncomfortable with child speaking to doctor privately)

I2. Has the participant's doctor or other health care provider actively worked with the participant to: [radio button]

	Yes	No	Don't Know
Think about and plan for their future	☐	☐	☐
Make positive choices about their health	☐	☐	☐

Learn skills to manage their health and healthcare	☐	☐	☐
Understand the changes in healthcare that happen when they turn 18 years old and move to adult care	☐	☐	☐

I3. Eligibility for health insurance often changes in young adulthood. Do you know how the participant will be insured as they become an adult? [radio button]

☐ Yes
☐ No

I4. Which aspects of transitioning to adult health care are concerning to you and the participant? Please rate the level of concern you have about the following aspects of this transition. [radio button]

	No concern	Little concern	Some concern	Much concern
Leaving an established medical home. A medical home is a place the child usually goes for healthcare	☐	☐	☐	☐
Losing relationships with their current providers	☐	☐	☐	☐
Establishing a relationship with new providers	☐	☐	☐	☐
Seeing a doctor who doesn't know about my child's condition	☐	☐	☐	☐
Changing to a	☐	☐	☐	☐

new healthcare system/hospital system				
Transportation to doctor's office, clinic, or care center	☐	☐	☐	☐
Health insurance	☐	☐	☐	☐
Other concern (specify)_____ [text]	☐	☐	☐	☐

Section J: Future Planning (only for Caregivers of children with ID)

J1. Have you made plans for what will happen when you are no longer able to care for the participant? [radio button]

☐ Yes
☐ No

J2. Where will the participant live when this time comes? [radio button]

☐ Stay where he/she is currently living
☐ Move somewhere else (specify)_____ [text]
☐ I haven't yet decided

J3. Who will be responsible for the participant's decisions when you are no longer able to care for him/her? [radio button]

☐ Family member (specify)_____ [text]
☐ Friend
☐ Other (specify)_____ [text]
☐ Not yet decided

J4. Has an ABLE (Achieving a Better Life Experience) account been established for the participant? *An ABLE account is a tax-advantaged savings and investment account for eligible people with disabilities that can be used to pay for qualified disability-related expenses while*

helping preserve eligibility for certain public benefits. [radio button]

☐ Yes (Go to J4a)
☐ No (Go to J5)
☐ Don't know/Not familiar with ABLE accounts (Go to J5)

J4a. How old was the participant when the ABLE account was established?
[____years old] [text insert integer]

Age of child: _____ years old

J5. Has a special needs trust been established for the participant? *A special needs trust is an arrangement for the participant to receive financial support from a trust fund while still being eligible for public benefits like Medicaid.* **[radio button]**

☐ Yes *(Go to J5a)*
☐ No *(Go to J6)*

J5a. How old was the participant when the special needs trust was established? [text insert integer]

Age of child_____

J5b. Did you have an attorney establish the trust fund? **[radio button]**

☐ Yes *(Go to J5bi)*
☐ No *(Go to J6)*

J5bi. Approximately how much did it cost to prepare the trust fund? **[radio button]**

☐ Nothing
☐ Less than $1000
☐ $1001-$3000
☐ $3001 to $5000
☐ $5001-$7000
☐ More than $7000

J6. Have you prepared a will that includes plans for the participants' future? **[radio button]**

☐ Yes
☐ No

J7. How confident are you that the participant's welfare will be provided after you

are no longer able to care for your child? [radio button]

☐ Not very confident *(Go to J7i)*
☐ A little confident *(Go to J7i)*
☐ Somewhat confident *(Go to J7i)*
☐ Very confident *(Go to Section K)*

J7i. If J7 is answered anything other than "very confident": What needs do you think may not be met after you are no longer able to care for the participant? (Check all that apply). [checkboxes]

☐ Educational
☐ Financial
☐ Housing
☐ Physical
☐ Social/emotional
☐ Vocational

Section K: Parent Support (only for Caregivers of children with ID)

K1. Do you feel that you receive enough support from healthcare providers as a caregiver of the participant? [radio button]

☐ Yes *(Go to Section L)*
☐ No *(Go to K1a)*

K1a. How much could each of the following address your need for support from your healthcare providers? [radio button]

	Not at all	Very little	Somewhat	Very much
Being listened to by the participant's providers	☐	☐	☐	☐
Making collaborative decisions with the participant's providers	☐	☐	☐	☐
Receiving emotional support	☐	☐	☐	☐
Receiving information on respite services (or childcare) so I can attend to other needs	☐	☐	☐	☐

Being referred to parent training programs relevant to my needs	☐	☐	☐	☐
Other (specify)_____ [text]	☐	☐	☐	☐

Section L. Health Knowledge (only for Caregivers of Young Adults with no ID and who cannot Self-Report)

L1. Please answer these questions to help us learn what the participant knows about their health and health care. [radio button]

	Yes, the participant knows this	The participant needs to learn this	I need to learn this
Knows their medical needs	☐	☐	☐
Can tell other people what their needs are	☐	☐	☐
Knows what to do if they have a medical emergency	☐	☐	☐
Knows what medicines to take and what they are for	☐	☐	☐
Can take medicine on their own without a reminder	☐	☐	☐
Knows what medicines they should not take	☐	☐	☐
Knows what they are allergic to, including medicines	☐	☐	☐
Can name 2-3 people who can help them with their health goals	☐	☐	☐
Can explain to people how their beliefs affect their choices	☐	☐	☐
Knows or can find their doctor's phone	☐	☐	☐

number			
Makes their own doctor appointments	☐	☐	☐
Thinks about questions to ask before a doctor visit	☐	☐	☐
Has a way to get to the doctor's office	☐	☐	☐
Knows they should show up 15 minutes before the doctor visit to check in	☐	☐	☐
Knows where to get care when their doctor's office is closed	☐	☐	☐
Has a folder at home with their medical information, including their medical summary and emergency care plan	☐	☐	☐
Has a copy of their plan of care	☐	☐	☐
Knows how to fill out medical forms	☐	☐	☐
Knows how to ask for a form to be seen by other doctors or therapists	☐	☐	☐
Knows where the pharmacy is and what to do when they run out of their medicines (e.g., how to refill a prescription)	☐	☐	☐
Knows where to get a blood test or x-rays if the doctor orders them	☐	☐	☐
Carries health information with them every day (e.g.,	☐	☐	☐

insurance card, allergies, medications, and emergency phone numbers)			

Section M: Demographics

M1. What is YOUR ethnicity? (radio button)

☐ Hispanic or Latino
☐ Not Hispanic or Latino

M2. 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

M3. What is the participant's ethnicity? (radio button)

☐ Hispanic or Latino
☐ Not Hispanic or Latino

M4. 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

M5. 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)

M6. How many children ages 0-17 years old (including the participant, if applicable) live or stay at this address? [text insert integer]

Number of children_____

M7. How many of these children (including the participant, if applicable) have any disability, developmental delay, or special need? [text insert integer]

Number of children_____

M8. 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. [text insert integer]

Total income_____

M9. 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

M10. 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.) **[text insert integer]**

Number of people_____

Section N: Participant Strengths

N1. What does the participant do really well compared to his or her overall abilities? **[open text]**

O2. What does the participant enjoy? **[open text]**

Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT): Caregiver 1 Survey

Some questions in the SPROUT caregiver 1 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 1 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)*
- *National Immunization Survey (About the National Immunization Surveys (NIS) | NIS Information | CDC)*

Additionally, questions from three validated, standardized instruments were embedded into the survey:

- *Social Communication Questionnaire (SCQ)*
- *Waisman Activities of Daily Living Scale (W-ADL)*
- *GOT Transition Questionnaire (Got Transition®)*

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 1 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)
B1A. Do you think the participant is able to report how they feel about life and deal with stress?				
B1B. 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
Sections C and D. Has a doctor or other healthcare provider told you that the participant has [condition_desc]?	X	X	X	National Survey of Children's Health
Sections Ca and Da. Does the participant currently have [condition]?	X	X	X	National Survey of Children's Health
Sections Cb and Db. How much does [condition] impact the participant's overall functioning?				
Sections Cc and Dc. During the past 12 months, has the participant taken any prescription medication to help manage symptoms of [condition]?	X	X	X	National Survey of Children's Health *Wording and format for this question have changed throughout SEED phases; question(s) previously asked for limited conditions but now asked for all relevant conditions in SPROUT survey.*
Sections Cc_1 and Dc_1. During the past 12 months, was any prescription medication helpful in managing symptoms of [condition]?				

Sections Cd and Dd. During the past 12 months, has the participant seen any specialist to help manage symptoms of [condition]?	X	X	X	*Wording and format for this question have changed throughout SEED phases; question(s) previously asked for limited conditions but now asked for all relevant conditions in SPROUT survey.*
Sections Ce and De. During the past 12 months, was any specialist helpful in managing symptoms of [condition]?				
E1. DURING THE PAST 12 MONTHS, what type of care did the participant receive for routine check-ups when he/she was not sick or injured?		X	X	National Survey of Children's Health *Questions E1 and E2 (about routine check-ups and sick care) combined in previous surveys but separated in SPROUT survey. Wording of the question revised to focus on care and response options for vision/hearing are changed to indicate this is Specialty care.*
E2. DURING THE PAST MONTHS, what type of care did the participant receive when he/she was sick/injured?		X	X	National Survey of Children's Health *Questions E1 and E2 (about routine check-ups and sick care) combined in previous surveys but separated in SPROUT survey. Wording of the*

				question revised to focus on care and response options for vision/hearing are changed to indicate this is Specialty care.
E3. During the past 12 months did the participant receive the following vaccines?				Adapted from the National Immunization Survey
E4. Has the participant ever received at least one dose of the following vaccines? These vaccines are typically first offered between 11-12 years of age.				Adapted from the National Immunization Survey
E5. DURING THE PAST 12 MONTHS, how many times did the participant visit a hospital emergency department (not including urgent care)?		X	X	Adapted from the National Survey of Children's Health
E5a. Please indicate if the participant visited a hospital emergency department in the past 12 months for any of the following reasons.				*Questions about visits to a hospital emergency department were included in previous surveys; reasons for hospitalization added to SPROUT survey.*
E6. During the past 12 months, how many times was the participant hospitalized for any reason? Hospitalized means the participant was admitted and stayed overnight.		X	X	Adapted from the National Survey of Children's Health
E6a. Please indicate if the participant was				

hospitalized during the past 12 months for any of the following reasons.				
E7. Has the participant EVER been restrained during any hospitalization?				
F1. During the past 12 months, was there any time when the participant needed healthcare, but it was not received? By health care, we mean medical care as well as other kinds of care like dental care, vision care, and mental health services.		X	X	National Survey of Children's Health
F1a. Which of the following contributed to the participant not receiving needed healthcare services during the past 12 months? "Yes" means it was a factor in not receiving services and "No" means it was not a factor.		X	X	National Survey of Children's Health
F1b. The services you needed were not available in your area.		X	X	National Survey of Children's Health
F1bi. If yes: What services were needed but not available in your area? (Check all that apply)				
F1c. There were problems getting an appointment when you needed one.		X	X	National Survey of Children's Health
F1ci. If yes: How much would each of these				

factors help resolve problems getting an appointment?				
F1d. There were problems with transportation.		X	X	National Survey of Children's Health *Questions about problems with transportation and childcare combined in previous surveys but separated in SPROUT survey.*
F1di. If yes: How much would each of these factors help resolve the problems you experienced with transportation?				
F1e. There were issues related to the cost of the doctor's visit.		X	X	National Survey of Children's Health
F1ei. If yes: How much would each of these factors help resolve issues related to cost?				
F1f. There were problems with navigating the healthcare system.				
F1fi. If yes: How much would each of these factors help resolve problems with navigating the healthcare system?				
F2. Have you or the participant ever experienced any problems with service environments? Service environments include				

waiting areas, appointment rooms, and check out desks.				
F2a. If yes: How much would each of these factors help solve problems related to service environments?				
F3. Have you or the participant ever experienced any problems with healthcare providers?				
F3a. If yes: How much would each of these factors help resolve the problems you experienced related to healthcare providers?				
F4. DURING THE PAST 12 MONTHS, was this participant EVER covered by ANY kind of health insurance or health coverage plan?		X	X	National Survey of Children's Health
F4a. If NO, what services were needed but not received because they were not covered by health insurance in the PAST 12 months? (Select all that apply)				
F5. Is the participant CURRENTLY covered by ANY kind of health insurance or health coverage plan?		X	X	National Survey of Children's Health
F5a. If yes: What type of health insurance plan covers the participant?		X	X	National Survey of Children's Health

F5b. Does the insurance plan meet the participant's needs?		X	X	Adapted from the National Survey of Children's Health
F5bi. If no: How much would each of these factors improve health insurance to better meet the participant's needs?				
Section G: We would like to know about the participant's current level of independence in performing activities of daily living. For each activity, please tell us which option best describes his or her ability to do the task.		X		Waisman Activities of Daily Living Scale: Microsoft Word - W-ADL.doc
H1. Does the participant have a healthcare team? A healthcare team is a group of professionals who work together to care for the participant.				
H1a. Please select the types of professionals who are part of the participant's healthcare team. (Check all that apply)				
I1. At his or her LAST preventive check-up, did the participant have a chance to speak with a doctor or other health care provider privately, without you or another adult in the room?		X	X	National Survey of Children's Health
I1a. If no: Which of the following contributed to the participant not speaking with a doctor or other health care provider privately?				

(Check all that apply)				
I2. Has the participant's doctor or other health care provider actively worked with the participant to:…		X	X	National Survey of Children's Health
3. Eligibility for health insurance often changes in young adulthood. Do you know how the participant will be insured as they become an adult?		X	X	National Survey of Children's Health
I4. Which aspects of transitioning to adult health care are concerning to you and the participant? Please rate the level of concern you have about the following aspects of this transition.			X	
J1. Have you made plans for what will happen when you are no longer able to care for the participant?				National Fragile X Survey-II
J2. Where will the participant live when this time comes?				National Fragile X Survey-II
J3. Who will be responsible for the participant's decisions when you are no longer able to care for him/her?				Adapted from the National Fragile X Survey-II
J4. **Has an ABLE (Achieving a Better Life Experience) account been established for the participant?** *An ABLE account is a tax-*				* National Fragile X Survey-II – DC25

advantaged savings and investment account for eligible people with disabilities that can be used to pay for qualified disability-related expenses while helping preserve eligibility for certain public benefits.				
J4a. How old was the participant when the ABLE account was established?				* National Fragile X Survey-II – DC26
J5. Has a special needs trust been established for the participant? A special needs trust is an arrangement for the participant to receive financial support from a trust fund while still being eligible for public benefits like Medicaid.				National Fragile X Survey-II
J5a. How old was the participant when the special needs trust was established?				
J5b. Did you have an attorney establish the trust fund?				National Fragile X Survey-II
J5bi. Approximately how much did it cost to prepare the trust fund?				National Fragile X Survey-II
J6. Have you prepared a will that includes plans for the participant's future?				National Fragile X Survey-II
J7. How confident are you that the participant's welfare will be provided after you are no longer able to care for your child?				Adapted from the National Fragile X Survey-II
J7i. If J7 is answered anything other than "very confident": What needs do you think				

may not be met after you are no longer able to care for the participant? (Check all that)				
K1. Do you feel that you receive enough support from healthcare providers as a caregiver of the participant?				
K1a. How much could each of the following address your need for support from your healthcare providers?				
L1. Please answer these questions to help us learn what the participant knows about their health and health care.				GOT transition questionnaire: Got Transition®
M1. What is YOUR ethnicity?	X			National Survey of Children's Health
M2. What is YOUR race? (Check all that apply)	X			National Survey of Children's Health
M3. What is THE PARTICIPANT 'S ethnicity?	X	X	X	National Survey of Children's Health
M4. What is the PARTICIPANT's race? (Check all that apply)	X	X	X	National Survey of Children's Health
M5. 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
M6. 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

M7. 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
M8. 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
M9. 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
M10. 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
N1. What does the participant do really well compared to his or her overall abilities?				
N2. What does the participant enjoy?				
