Attachment 6.c.1
SEED Teen Health and Development Survey

(Reading level: 7.5)

[*add pictures or other graphics to cover page]*

Thank you for taking part in SEED Teen.

Please complete this survey about your child's health and development.

The survey should be completed by an adult who is familiar with this child's health, health care, education, and current activities.

The survey should be completed in dark blue or black pen. For each question, please check the box next to your answer or follow the directions included with the question. You may be asked to skip some questions that do not apply to you and your child.

If you make a mistake, please **cross out** the wrong answer, **fill in** the correct answer, and also **circle** the correct answer. Please do not use scribble marks to make a correction.

Participation in this survey is voluntary. There are no penalties for refusing to answer questions. However, your cooperation in obtaining this much needed information is very important to ensure complete and accurate results, and your participation is much appreciated.

The first two questions in this survey ask you to measure your child's height and weigh your child. Please ask your child if he or she agrees to these measurements. If your child says he or she does NOT agree or indicates that he or she does NOT agree (such as resisting you when you try to measure them), you should skip these measurements. However, you may still record the child's height and weight if you know them, for example if you know this information because your child was recently weighed and measured at the doctor's office.

All answers that you give will be kept private. Because sensitive health information is collected in this survey, *<site>* received a 'Certificate of Confidentiality.' This means that any information that *<site>* has that identifies you or your child will be used only for this project. It cannot be given to anyone else unless you give your written consent.

This Statement is provided pursuant to the Privacy Act of 1974 (5 U.S.C. § 552a):
The information you are being asked to provide is authorized to be collected under the System of Records Notices 09-20-0136, Epidemiologic Studies and Surveillance of Disease Problems. Providing this information is voluntary. The principal purpose(s) for which CDC will use the information that you provide for SEED Teen are to (1) understand the health and development of a group of U.S. adolescents with and without autism or other developmental disabilities, including adolescents from diverse population groups; (2) provide information that local, state, and federal organizations could use to allocate resources that help U.S. adolescents and adults with autism or other developmental disabilities; and (3) provide information that could be useful to clinicians who treat U.S. adolescents and adults with autism or other developmental disabilities. The information that you provide for SEED Teen will only be used to conduct the project. The information you provide will be included in a Privacy Act system of records, and will be used and may be disclosed for the purposes and routine uses described and published in the following System of Records Notice (SORN): 09-20-0136: Epidemiologic Studies and Surveillance of Disease Problems, [Federal Register: December 31, 1992 (Volume 57, Number 252)] [Notices] [Page 62812-62813].

If you have questions about the survey you can call <*site project coordinator*> at <*phone number*>. Please also call this number if you decide you would rather complete the survey over the phone with the assistance of a SEED staff member.

Nearly all questions (97%) in the SEED Teen Health and Development Survey instrument were selected from existing child health and development surveys or study questionnaires or adult surveys (for questions on caregiver, family, and household). These question sources include the following instruments:

- *National Survey of Children's Health (NSCH) (https://www.cdc.gov/nchs/slaits/nsch.htm)*
- *National Health Interview Survey (NHIS) (https://www.cdc.gov/nchs/nhis/)*
- *National Health and Nutrition Examination Survey (NHANES) (https://www.cdc.gov/nchs/nhanes/)*
- *Pregnancy Risk Assessment Monitoring System (PRAMS) (https://www.cdc.gov/prams/)*
- *Behavioral Risk Factor Surveillance System (BRFSS) (https://www.cdc.gov/brfss/)*
- *Infant Feeding Practices Study II (IFPS 11) and Year 6 Follow-Up (Y6FU), a U.S. nationally distributed longitudinal study of maternal health and infant health and feeding practices (https://www.cdc.gov/breastfeeding/data/ifps/index.htm)*
- *National Longitudinal Transition Study-2 (NLTS2) (http://www.nlts2.org/)*
- *Interactive Autism Network (IAN) (https://iancommunity.org/)*
- *SEED case-control study maternal and child health history forms*

Additionally, two standardized scales previously validated and used in numerous studies were embedded in the instrument:

- *Waisman Activities of Daily Living (W-ADL) Scale (18)*
- *Strengths and Difficulties Questionnaire (SDQ) (19)*

For most of the above instruments, extensive pilot and field testing was completed when the instruments were developed; additionally, all have been previously fully implemented in other surveys or research studies and, thus, offer benefits of having been scrutinized in light of past researchers' experience analyzing the data. In order to implement this first phase of SEED Teen within a 5-year funding cycle and collect data from participants when their children were aged 17 years or younger, the SEED Teen investigators faced a compressed timeline (which includes OMB review and approval) to develop the SEED Teen Health and Development Survey. We therefore were very mindful of the need to utilize the vast experience of other researchers who have previously developed and thoroughly tested questions that covered our research domains.

Moreover, many of the questions we used are from surveys of nationally-representative samples of US children. This holds an added benefit of allowing us to compare SEED Teen data obtained from all three study groups – ASD, DD, and POP – to external prevalence rates for health indicators in US children in the general population.

In compiling questions into a single SEED Teen instrument, we made only minor revisions to some of these existing questions. We made small non-substantive revisions such that we used the same verbiage style throughout the SEED Teen instrument. For example questions from various instruments used different phrasing to describe time period of interest, such as "DURING THE PAST 12 MONTHS" or "DURING THE PAST YEAR", or "IN THE LAST YEAR," and have typically placed this verbiage either at the beginning or the end of a question. In the SEED Teen instrument, we revised all applicable questions to use consistent phrasing, "DURING THE PAST 12 MONTHS" (or other timeframe of interest) and our default placement was the beginning of a question. In some instances we added an option to a multi-option question. For example we added an option on "use of special diet to help with behavioral problems" to a question on complementary and alternative health care treatments because we know this is a common alternative treatment used by families of children with developmental disabilities. We also changed the timeframes on a few questions to collect appropriate data for the population of children to be enrolled in SEED Teen. We developed very few truly new questions; we only developed new questions to capture information for which we could not find a suitable existing question. But even for these questions, we modelled the question verbiage on other existing questions of similar topics to the extent possible.

We have annotated the following instrument to indicate the source for each question (in red).

A. Child's Health

Height and Weight

1. How tall is this child now (without shoes)? **Source:** *Infant Feeding Practices Year 6 Follow-Up (Y6FU), a U.S. nationally distributed longitudinal study of maternal health and infant health and feeding practices*

   Please use the enclosed tape measure to measure the height. Have this child back up to a wall with the back of the head, shoulder blades, buttocks, and heels touching the wall. Lay a hard-backed book or other flat item from this child's head to the wall and level with the floor. Mark the wall under the book and then measure from the floor to the mark. Please tell us the height to the nearest quarter inch.

   If your child does not agree to be measured, please record the most recent height measure you recall.

   _____inches (measured with tape measure for this study)

   OR
   _____inches (recalled height from past measurement, such as doctor visit)

   OR
   _____I don't know

2. How much does this child weigh now (without shoes)? Please weigh this child on a scale if possible. If your child does not agree to be weighed, please record the most recent weight you recall. **Source:** *Infant Feeding Practices Year 6 Follow-Up (Y6FU)*

   _____ pounds (weighed on scale at home)

   OR
   _____ pounds (recalled weight from past doctor visit)

   OR
   _____ I don't know

General Health and Health Symptoms

3. In general, how would you describe this child's health? **Source:** *National Survey of Children's Health*

   € Excellent
   € Very Good
   € Good
   € Fair
   € Poor

4. DURING THE PAST 12 MONTHS, has this child had FREQUENT or CHRONIC difficulty with any of the following? **Source:** *National Survey of Children's Health*

	Yes	No
Breathing or other respiratory problems, (such as wheezing or shortness of breath)	❑	❑
Digesting food, including stomach/intestinal problems, constipation, or diarrhea	❑	❑
Toothaches	❑	❑
Bleeding gums	❑	❑
Decayed teeth or cavities	❑	❑

Question A: Has a doctor or other health care provider *ever* told you that this child has …		**Question B:** How old was this child when you were first told he or she had the condition? *(Write in 0 if less than 1 year)*	**Question C:** Does this child currently have the condition?
Attention deficit disorder or Attention deficit hyperactivity disorder (ADD or ADHD)?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Allergy, food? Specify type:_____	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Allergy, hay fever?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Allergy, skin? Specify type:_____	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Allergy, other? Specify type:_____	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Anxiety problems?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Arthritis?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Asthma?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Autism, Asperger's disorder, pervasive developmental disorder, or autism spectrum disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Behavioral or conduct problems?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Bipolar disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Brain injury, concussion or head injury?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Cancer?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Celiac disease?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Cerebral palsy?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Crohn's disease?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Cystic fibrosis?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Depression?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Developmental delay?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure

Physical Ability

1. Does this child have any of the following? **Sources:** *National Survey of Children's Health and National Longitudinal Transition Study-2 (NLTS2)*

	Yes	No
Serious difficulty walking or climbing stairs	❑	❑
Difficulty using his or her hands for things like using a spoon or holding a pencil	❑	❑
Deafness or problems with hearing	❑	❑
Blindness or problems with seeing, even when wearing glasses	❑	❑

2. Does this child use any equipment to help get around, such as crutches, a walker, a wheelchair, or a scooter? **Sources** *National Longitudinal Transition Study-2 (NLTS2)*
   - € Yes
   - € No

Communication

3. Does this child use verbal communication, such as words or noises, to communicate with people? **Source: adapted from** *National Longitudinal Transition Study-2 (NLTS2)*
   - Verbally communicates using words easily
   - Verbally communicates using words with a little trouble
   - Verbally communicates using words with a lot of trouble
   - Verbally communicates with noises
   - Does not verbally communicate

4. Does this child communicate with people using any of the following non-verbal methods of communication? **Source: adapted from** *National Longitudinal Transition Study-2 (NLTS2)*

	Yes	No
Sign language	❑	❑
Lip reading	❑	❑
Simple hand movements	❑	❑

Diabetes (uses insulin)?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Diabetes (does not use insulin)?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Eating disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Epilepsy or seizure disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Fragile X Syndrome?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Frequent or severe headaches, including migraine?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Heart condition?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Intellectual disability?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Irritable bowel syndrome?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Obsessive-compulsive disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Self-injurious behavior?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Sensory integration disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Sickle cell anemia/thalassemia/other hereditary anemias?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Substance abuse disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Tourette syndrome?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Ulcerative colitis?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Any other mental health disorder? _____	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Other genetic or inherited condition? _____	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Question A: Has a doctor or other health care provider or a school professional *ever* told you that this child has a …		**Question B:** How old was this child when you were first told he or she had the condition? *(Write in 0 if less than 1 year)*	**Question C:** Does this child currently have the condition?
Learning disability?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure
Speech or other language disorder?	❑Yes ❑No ❑Unsure	____ Years	❑Yes ❑No ❑Unsure

Medications

10. DURING THE PAST 12 MONTHS, has this child taken any **prescription** medication because of difficulties with any of the following (select all that apply): **Sources: adapted from several sources that included questions on medication use including:** *SEED Case-control Study Services and Treatment Questionnaire, National Survey of Children's Health,* **and** *National Health Interview Survey*

- € Behavioral problems
- € Anxiety
- € Depression
- € Attention or concentration
- € Autism
- € Seizures
- € Sleep problems
- € Asthma
- € Other chronic health conditions
- € Did not take medications in past 12 months for any of the above conditions

11. DURING THE PAST 12 MONTHS, has this child taken any **over the counter** (*non-prescription*) medications because of difficulties with any of the following (select all that apply): **Sources: adapted from several sources that included questions on medication use including:** *SEED Case-control Study Services and Treatment Questionnaire, National Survey of Children's Health,* **and** *National Health Interview Survey*

- € Behavioral problems
- € Anxiety
- € Depression
- € Attention or concentration
- € Autism
- € Seizures
- € Sleep problems
- € Asthma
- € Other chronic health conditions
- € Did not take medications in past 12 months for any of the above conditions

DURING THE PAST 12 MONTHS, has this child taken medication for gastrointestinal problems regularly?
Source: *SEED Case-Control Study Child Health History Form*

Regularly means at least once per month for at least 3 months within the past year.
This can include a medicine prescribed by a doctor or an over the counter medication, such as TUMS or Miralax.

- □ Yes
- □ No

Complementary and Alternative Health Care Treatments

12. DURING THE PAST 12 MONTHS, did this child use any type of complementary or alternative health care or treatment? Some therapies involve seeing a health care provider, while others can be done on your own. Select all that apply: **Source:** *National Survey of Children's Health* **with one addition from SEED Teen investigators to include special diet to help with behavioral problems. There are many anecdotal reports that parents of children with autism often use diet as a behavioral treatment and there is concern that this could lead to nutrient deficiencies. However, data on prevalence of use of diet for behavioral treatment are not available.**

€ Acupuncture
€ Chiropractic care
€ Relaxation therapies
€ Herbal supplements
€ Special diet to help with behavioral problems
€ Other (specify): _____
€ Did not use any complementary or alternative health care treatment

Food Allergies and Dietary Restrictions

13. Has this child EVER been taken to a medical doctor because of a possible food allergy? **Source:** *Infant Feeding Practices Year 6 Follow-Up (Y6FU)*

- Yes, within the past 12 months
- Yes, more than 12 months ago
- No

14. Do you currently avoid any foods or food ingredients for this child because of a known or suspected food allergy or intolerance? **Source:** *Infant Feeding Practices Year 6 Follow-Up (Y6FU)*

- Yes, diagnosed food allergy
- Yes, suspected allergy
- No **(Skip to question 17)**

15. Which foods or food ingredients do you currently avoid for this child? **(PLEASE "X" ALL THAT APPLY)** **Source:** *Infant Feeding Practices Year 6 Follow-Up (Y6FU)*

Cow's milk or other dairy products ..... ☐
Soy milk or other soy food ..... ☐
Eggs or egg products..... ☐
Peanuts, peanut butter, or peanut oil..... ☐
Nuts (like almonds, pecans, walnuts)..... ☐
Sesame seed or sesame seed oil..... ☐
Fish (like salmon, codfish, tuna)..... ☐
Crustacean shellfish (like shrimp, crab, lobster) .....☐
None of these..... ☐

Beef, pork, chicken, turkey or other animal meat..... ☐
Wheat, gluten, or wheat starch..... ☐
Other grain or cereal (like oats, barley) ..... ☐
Fruit or fruit juice..... ☐
Vegetables..... ☐
Artificial colors or flavors..... ☐
Sulfites..... ☐
Other, specify_____ ☐

Sleep

16. DURING THE PAST WEEK, how many hours of sleep did this child get on an average weeknight?
Source: *National Survey of Children's Health*

- € Less than 6 hours
- € 6 hours
- € 7 hours
- € 8 hours
- € 9 hours
- € 10 hours
- € 11 or more hours

17. The following statements are about this child's sleep habits and possible difficulties with sleep.
Source: *SEED Case-control Study Child's Sleep Habits Questionnaire*

*Think about the past week in this child's life when answering the questions. If last week was unusual for a specific reason, choose the most recent typical week. Answer USUALLY if something occurs **5 or more** times in a week; answer SOMETIMES if it occurs **2 to 4 times** a week; answer RARELY if something occurs never or 1 time during a week.*

	5-7 times / week Usually	2-4 times / week Sometimes	0-1 times / week Rarely
Child sleeps too little	❑	❑	❑
Child sleeps too much	❑	❑	❑
Child sleeps the right amount	❑	❑	❑
Child sleeps about the same amount each day	❑	❑	❑
Child wets the bed at night	❑	❑	❑
Child talks during sleep	❑	❑	❑
Child is restless and moves a lot during sleep	❑	❑	❑
Child sleep walks during the night	❑	❑	❑
Child grinds teeth during sleep (your dentist may have told you this)	❑	❑	❑
Child awakens during the night and is sweating, screaming, and inconsolable	❑	❑	❑
Child awakens alarmed by a frightening dream	❑	❑	❑

B. Child's Health Care Services

Services Used

1. DURING THE PAST 12 MONTHS, did this child see a doctor, nurse, or other health care professional for sick-child care, well-child check-ups, physical exams, hospitalizations or any other kind of medical care?
Source: *National Survey of Children's Health*

- € Yes
- € No **(Skip to question 4)**

2. If yes, DURING THE PAST 12 MONTHS, how many times did this child visit a doctor, nurse, or other health care professional to receive a PREVENTIVE check-up? A preventive check-up is when this child was not sick or injured, such as an annual or sports physical, or well-child visit. **Source:** *National Survey of Children's Health*

   € 0 Visits **(Skip to question 4)**
   € 1 visit
   € 2 or more visits

3. At his or her LAST preventive check-up, did this child have a chance to speak with a doctor or other health care provider privately, without you or another adult in the room? **Source:** *National Survey of Children's Health*

   € Yes
   € No

4. Is there a place that this child usually goes when he or she is sick or you need advice about his or her health? **Source:** *National Survey of Children's Health*

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

5. If yes, where does this child USUALLY go? (mark one only) **Source:** *National Survey of Children's Health*

   € Doctor's Office
   € Hospital Emergency Department
   € Hospital Outpatient Department
   € Clinic or Health Center
   € Retail Store or "minute clinic"
   € School (Nurse's Office, Athletic Trainer's Office, etc.)
   € Some other place

6. Is there one or more places that this child usually goes when he or she needs routine preventive care, such as a physical examination or well-child check-up? **Source:** *National Survey of Children's Health*

   € YES
   € No **(Skip to question 8)**

7. If yes, is that the same place where this child goes when he or she is sick? **Source:** *National Survey of Children's Health*

   € YES
   € No

8. DURING THE PAST 12 MONTHS, did this child see a dentist or other oral health care provider for any kind of dental or oral health care? **Source:** *National Survey of Children's Health*

€ Yes
€ No

9. DURING THE PAST 12 MONTHS, has this child received any treatment or counseling from a mental health professional? Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers. **Source:** *National Survey of Children's Health*

€ Yes
€ No, but this child needed to see a mental health professional
€ No, this child did not need to see a mental health professional **(Skip to question 11)**

10. How much of a problem was it to get the mental health treatment or counseling that this child needs? **Source:** *National Survey of Children's Health*

€ Not a problem
€ Small problem
€ Big problem

11. DURING THE PAST 12 MONTHS, did this child see a specialist other than a mental health professional? Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and others who specialize in one area of health care. **Source:** *National Survey of Children's Health*

€ Yes
€ No, but this child needed to see a specialist
€ No, this child did not need to see a specialist **(Skip to question 13)**

12. How much of a problem was it to get the specialist care that this child needs? **Source:** *National Survey of Children's Health*

€ Not a problem
€ Small problem
€ Big problem

13. DURING THE PAST 12 MONTHS, was there any time when this child needed health care 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. **Source:** *National Survey of Children's Health*

€ Yes
€ No **(Skip to question 16)**

14. If yes, which types of care were NOT received? Mark ALL that apply. **Source** *National Survey of Children's Health*

€ Medical Care
€ Dental Care
€ Vision Care

- € Hearing Care
- € Mental Health Services
- € Other, Specify _____

15. Which of the following contributed to this child not receiving needed health care services: **Source:** *National Survey of Children's Health*

	Yes	No
This child did not have health insurance that covered the services needed?	❑	❑
This child was not eligible for the services?	❑	❑
The services this child needed were not available in your area?	❑	❑
There were problems getting an appointment when this child needed one?	❑	❑
There were problems with getting transportation or child care?	❑	❑
The (clinic/doctor's) office wasn't open when this child needed care?	❑	❑
There were issues related to cost?	❑	❑
Other (Specify:_____)	❑	❑

16. DURING THE PAST 12 MONTHS, how often were you frustrated in your efforts to get health care services for this child? **Source:** *National Survey of Children's Health*

- € Never
- € Sometimes
- € Usually
- € Always

17. DURING THE PAST 12 MONTHS, how many times did this child visit a hospital emergency department? **Source:** *National Survey of Children's Health*

- € No visits
- € 1 visit
- € 2 or more visits

18. DURING THE PAST 12 MONTHS, how many times did this child visit an urgent care center? **Source: SEED Teen investigators developed this question using verbiage consistent with the emergency room question in the** *National Survey of Children's Health.* **Many children with developmental disabilities use urgent care centers for injuries that in the past would have necessitated an emergency room visit.**

- € No visits
- € 1 visit
- € 2 or more visits

Experience with Child's Health Care Providers

19. Do you have one or more persons you think of as this child's personal doctor or nurse? A personal doctor or nurse is a health professional who knows this child well and is familiar with this child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. **Source:** *National Survey of Children's Health*

- € Yes, one person
- € Yes, more than one person
- € No

20. DURING THE PAST 12 MONTHS, did this child need a referral to see any doctors or receive any services? **Source:** *National Survey of Children's Health*

- € Yes
- € No **(Skip to question 22)**

21. If yes, how much of a problem was it to get referrals? **Source:** *National Survey of Children's Health*

- € Not a problem
- € Small problem
- € Big problem

22. Answer the following questions only if this child had a health care visit IN THE PAST 12 MONTHS. Otherwise, SKIP to question 29 in this section.

DURING THE PAST 12 MONTHS, how often did this child's doctors or other health care providers:
Source: *National Survey of Children's Health*

	Never	Sometimes	Usually	Always
Spend enough time with this child?	❑	❑	❑	❑
Listen carefully to you?	❑	❑	❑	❑
Show sensitivity to your family's values and customs?	❑	❑	❑	❑
Provide the specific information you needed concerning this child?	❑	❑	❑	❑
Help you feel like a partner in this child's care?	❑	❑	❑	❑

23. DURING THE PAST 12 MONTHS, were any decisions needed about this child's health care services or treatment, such as whether to start or stop a prescription or therapy services, get a referral to a specialist, or have a medical procedure? **Source:** *National Survey of Children's Health*

- € Yes
- € No **(Skip to question 25)**

24. DURING THE PAST 12 MONTHS, how often did this child's doctors or other healthcare providers:
Source: *National Survey of Children's Health*

	Never	Sometimes	Usually	Always
Discuss with you the range of options to consider for his or her health care or treatment?	❑	❑	❑	❑
Make it easy for you to raise concerns or disagree with	❑	❑	❑	❑

recommendations for this child's health care?

Work with you to decide together which health care and treatment choices would be best for this child?	❑	❑	❑	❑

25. Does anyone help you arrange or coordinate this child's care among the different doctors or services that this child uses? **Source:** *National Survey of Children's Health*

- € Yes
- € No
- € Did not see more than one health care provider in past 12 months **(Skip to question 29)**

26. DURING THE PAST 12 MONTHS, have you felt that you could have used extra help arranging or coordinating this child's care among the different health care providers or services? **Source:** *National Survey of Children's Health*

- € Yes
- € No **(Skip to question 28)**

27. If yes, DURING THE PAST 12 months, how often did you get as much help as you wanted with arranging or coordinating this child's care? **Source:** *National Survey of Children's Health*

- € Usually
- € Sometimes
- € Never

28. Overall, how satisfied are you with the communication among this child's doctors and other health care providers? **Source:** *National Survey of Children's Health*

- € Very satisfied
- € Somewhat satisfied
- € Somewhat dissatisfied
- € Very dissatisfied

29. DURING THE PAST 12 MONTHS, did this child's health care provider communicate with this child's school, child care provider, or special education program? **Source:** *National Survey of Children's Health*

- € Yes
- € No **(Skip to question 31)**
- € Did not need health care provider to communicate with these providers **(Skip to question 31)**

30. If yes, overall, how satisfied are you with the health care provider's communication with the school, child care provider, or special education program? **Source:** *National Survey of Children's Health*

- € Very satisfied
- € Somewhat satisfied
- € Somewhat dissatisfied

€ Very dissatisfied

Adolescent transition services

31. Has the child's doctor or other health care provider actively worked with the child to:
Source: *National Survey of Children's Health*

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

32. Eligibility for health insurance often changes in young adulthood. Do you know how the child will be insured as he/she becomes an adult? **Source:** *National Survey of Children's Health*

€ Yes **(Skip to question 34)**
€ No

33. If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as the child becomes an adult? **Source:** *National Survey of Children's Health*

€ Yes
€ No

Health Insurance

34. Is this child currently covered by ANY kind of health insurance or health coverage plan? **Source:** *National Survey of Children's Health*

€ Yes
€ No **(Skip to question 37)**

35. If yes, please tell us which types of health insurance plans CURRENTLY include coverage for this child. **Source:** *National Survey of Children's Health*

	Yes	No
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 health care	❑	❑
Indian Health Service	❑	❑
Any other type of health insurance or health coverage plan: _____	❑	❑

36. Thinking specifically about this child's mental or behavioral health needs, how often does this child's health insurance offer benefits or cover services that meet these needs? **Source:** *National Survey of Children's Health*

- € This child does not use mental or behavioral health services
- € Always
- € Usually
- € Sometimes
- € Never

Providing for this Child's Health

37. In an average week, how many hours do you or other family members spend providing care at home for this child? **Source:** *National Survey of Children's Health*

Care might include changing bandages, or giving medication and therapies when needed.

- € No at home care is provided by me or other family members on a weekly basis
- € Less than 1 hour per week
- € 1-4 hours per week
- € 5-10 hours per week
- € 11 or more hours per week

38. IN AN AVERAGE WEEK, how many hours do you or other family members spend arranging or coordinating health or medical care for this child, such as making appointments or locating services? **Source:** *National Survey of Children's Health*

- € No health or medical care is arranged or coordinated by me or other family members on a weekly basis
- € Less than 1 hour per week
- € 1-4 hours per week
- € 5-10 hours per week
- € 11 or more hours per week

C. Child's Education

1. Which of the following best describes the school this child currently attends (or most recently attended)? **Source: SEED Teen Investigators reviewed a variety of questionnaires and spoke to individuals with expertise in school choices for children with developmental disabilities. They developed this question based on these sources of information.**

   If this child currently attends 2 schools, describe the school where he or she spent the most time.

- € A regular public school that serves a wide variety of students
- € A regular private school that serves a wide variety of students
- € A magnet school that specializes in a particular subject area or theme
- € A vocational/technical school (voc-tech)
- € A school that serves only children with disabilities
- € A charter school or alternative school
- € An "online" school
- € Home instruction by a professional
- € Home schooling by a parent
- € Medical or mental health facility, convalescent hospital, institution for people with disabilities, correctional or juvenile justice facility
- € Other (Specify) _____
- € Child is not attending school

2. Which of the following best describes this child's classroom setting: **Source: same as previous**

   - € Regular classroom with a wide variety of students
   - € Special education classroom for students with disabilities or special needs
   - € Mix of regular and special education classrooms
   - € Does not apply because this child is home-schooled or not attending school

3. Since starting kindergarten, has this child repeated any grades? **Source:** *National Survey of Children's Health*

   - € Yes
   - € No

4. Has this child ever changed schools or educational setting for any of the following reasons? **Source: SEED Investigators developed this question series based on comments that have come to them from various community partners. There is concern that children with developmental disabilities often change educational settings for reasons other than change in residence or parent/child preference.**

	Yes	No
The child's educational needs were not being met	❑	❑
All or some of the special education services this child needed were not provided or were not provided in a manner you agreed with	❑	❑

The child was bullied by other children ❑ ❑

IF CHILD NOT ATTENDING SCHOOL, SKIP TO QUESTION 8

5. What grade is this child currently in? (If summer, what is the highest grade level this child has already completed)? **Source:** *Infant Feeding Practices Year 6 Follow-Up (Y6FU)*

   _____

6. DURING THE PAST 12 MONTHS, about how many days did this child miss school because of illness or injury? **Source:** *National Survey of Children's Health*

   € No missed school days
   € 1-3 days
   € 4-6 days
   € 7-10 days
   € 11 or more days

7. DURING THE PAST 12 MONTHS, how many times has this child's school contacted you or another adult in your household about any problems he or she is having with school? **Source:** *National Survey of Children's Health*

   € No calls
   € 1 time
   € 2 or more times

8. Has this child EVER had any of the following special education or early intervention plans? (Check all that apply) **Source: SEED Teen investigators expanded a question that was included in the** *National Survey of Children's Health* **by providing additional options about certain plans children and teens with developmental disabilities are known to use.**

   € Individualized Family Service Plan or IFSP (*used for early intervention services in children younger than 3)*
   € Individualized Education Plan or IEP (*used for special education services in children 3 or older)*
   € 504 Plan (sometimes *used for special education services instead of or in addition to an IEP)*
   € Other Plan, Specify _____
   € No, my child has never had a plan for special education **(skip to next section)**

9. If yes, how old was this child at the time of the FIRST plan? **Source:** *National Survey of Children's Health*

   _____ Years

10. Is this child currently receiving services under one of these plans? **Source:** *National Survey of Children's Health*

    € Yes
    € No **(skip to next section)**

11. If yes, please tell us which plans this child currently has. (Check all that apply) **Source: SEED Teen investigators.**

- € Individualized Education Plan or IEP (*used for special education services in children 3 or older)*
- € 504 Plan (sometimes *used for special education services instead of or in addition to an IEP)*
- € Other Plan, Specify _____

12. Have you or another adult in the household met with teachers to set goals for what this child will do after high school and make a plan for how he or she will achieve them? **Source:** *National Longitudinal Transition Study-2 (NLTS2).*

Sometimes this is called a transition plan.

- € Yes
- € No

D. Child's Developmental Services

1. Please tell us whether this child has ever used any of the services or supports listed below. These types of services might be received through the school, a healthcare provider, or some other person or place such as an independent tutor.

*Please answer question **A** for all services and supports in the table below, even if the child does not use the service or support. Please answer questions **B** and **C** for only services and supports the child ever received.*

Sources: **Question verbiage is adapted from several sources. The main source was** *National Longitudinal Transition Study-2 (NLTS2).* **Other sources were:** *SEED Case-control study Services and Treatment Questionnaire and Infant Feeding Practices Year 6 Follow-Up (Y6FU),*		***If Question A is YES, please answer both Questions B and C.*** Has this child received the service or support DURING THE PAST 12 MONTHS?	
Question A: Has this child EVER received …		**Question B:** Received **THROUGH SCHOOL** DURING PAST 12 MONTHS?	**Question C:** Received **OUTSIDE OF SCHOOL** DURING PAST 12 MONTHS?
Speech or language therapy, or communication services?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Audiology services for hearing problems?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Psychological or mental health services or counseling?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Behavioral treatment specifically for Autism, ASD, Asperger's Disorder or PDD?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Physical therapy?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Occupational therapy or life skills therapy or training?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Personal assistant/or an in-the-home or in-the-	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure

classroom aide?			
Tutoring?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Reader or interpreter, including sign language?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Assistive technology services/devices, such as help getting/using any kind of equipment that helps people with a disability?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure
Other services_____?	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure	❑Yes ❑No ❑Unsure

E. Child's Abilities, Strengths, and Difficulties

Activities of Daily Living

1. We would like to know about this child'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.

Source: *Waisman Activities of Daily Living (W-ADL) Scale*

	Ability to perform task		
Please rate this child's level of independence in…	Does on own	Does with help	Does not do
Making his or 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. (Note: if he or she can do a portion but not all, mark 'does with help'.)	☐	☐	☐

Strengths and Difficulties

2. Here is a list of items that describe children. For each item, please tell us how true it has been for this child DURING THE PAST SIX MONTHS. It would help us if you answered all items as best you can even if you are not absolutely certain.

Source: *Strengths and Difficulties Questionnaire (SDQ)*

		NOT TRUE	SOMEWHAT TRUE	CERTAINLY TRUE
a.	Considerate of other people's feelings	☐	☐	☐
b.	Restless, overactive, cannot stay still for long	☐	☐	☐
c.	Often complains of headaches, stomach aches, or sickness	☐	☐	☐
d.	Shares readily with other youth, for example books, games, food	☐	☐	☐
e.	Often loses temper	☐	☐	☐
f.	Would rather be alone than with other youth	☐	☐	☐
g.	Generally well behaved, usually does what adults request	☐	☐	☐
h.	Many worries, or often seems worried	☐	☐	☐
i.	Helpful if someone is hurt, upset, or feeling ill	☐	☐	☐
j.	Constantly fidgeting or squirming	☐	☐	☐
k.	Has at least one good friend	☐	☐	☐
l.	Often fights with other youth or bullies them	☐	☐	☐
m.	Often unhappy, depressed, or tearful	☐	☐	☐
n.	Generally liked by other children	☐	☐	☐
o.	Easily distracted, concentration wanders	☐	☐	☐
p.	Nervous in new situations, easily loses confidences	☐	☐	☐
q.	Kind to younger children	☐	☐	☐
r.	Often lies or cheats	☐	☐	☐
s.	Picked on or bullied by other youth	☐	☐	☐
t.	Often offers to help others (parents, teachers, other children)	☐	☐	☐
u.	Thinks things out before acting	☐	☐	☐
v.	Steals from home, school, or elsewhere	☐	☐	☐
w.	Gets along better with adults than with other youth	☐	☐	☐
x.	Many fears, is easily scared	☐	☐	☐
y.	Good attention span, sees work through to the end	☐	☐	☐

F. Child's Activities

1. DURING THE PAST 12 MONTHS, did this child participate in: **Source:** *National Survey of Children's Health*

	Yes	No
A sports team or did he or she take sports lessons after school or on weekends?	❑	❑
Any clubs or organizations after school or on weekends?	❑	❑
Any other organized activities or lessons, such as music, dance, language, or other arts?	❑	❑

Any type of community service or volunteer work at school, church, or in the community?	❑	❑
Any work, including regular jobs as well as babysitting, cutting grass, or other occasional work?	❑	❑

2. Compared to other children his or her age, how much difficulty does this child have making or keeping friends? **Source:** *National Survey of Children's Health*

   € No difficulty
   € A little difficulty
   € A lot of difficulty

3. DURING THE PAST 12 MONTHS, has this child been invited by friends to social activities like over to their home or to a party? **Source:** *National Longitudinal Transition Study-2 (NLTS2)*

   € Yes
   € No **(Skip to question 5)**
   • I don't know **(Skip to question 5)**

4. If yes, about how often is this child invited to social activities by friends? **Source:** *National Longitudinal Transition Study-2 (NLTS2)*

   • Once a week or more
   • 1 to 3 times a month
   • Less than once a month
   • I don't know

5. DURING THE PAST WEEK, on how many days was this child physically active for at least 60 minutes per day? **Source:** *Infant Feeding Practices Year 6 Follow-Up (Y6FU)*

Add up all the time that he or she spent in any kind of physical activity that increased his or her heart rate and made him or her breathe hard some of the time.

   € 0 days
   € 1 day
   € 2 days
   € 3 days
   € 4 days
   € 5 days
   € 6 days
   € Every day
   € I don't know

6. ON AN AVERAGE WEEKDAY, about how much time does this child usually spend in front of a TV watching TV programs or movies? **Source:** *National Survey of Children's Health*

   € None
   € Less than 1 hour

- € 1 hour
- € 2 hours
- € 3 hours
- € 4 or more hours
- € I don't know

7. ON AN AVERAGE WEEKDAY, about how much time does this child usually spend with computers, cell phones, handheld video games, and other electronic devices, doing things other than schoolwork? **Source:** *National Survey of Children's Health*

- € None
- € Less than 1 hour
- € 1 hour
- € 2 hours
- € 3 hours
- € 4 or more hours
- € I don't know

G. Child's Safety and Stressful Life Events

1. Some children are likely to wander off and become so lost that it is necessary to search for them. Please tell us if this child wandered off or became lost from any of these places DURING THE PAST 12 MONTHS, even if it occurred just once. **Source:** *National Survey of Children's Health – pathways follow-up survey of children with special health care needs*

DURING THE PAST 12 MONTHS, has this child wandered off or became lost from…	**Yes**	**No**	**Unsure**
Your home?	☐	☐	☐
Someone else's home such as a relative, friend, neighbor, or babysitter?	☐	☐	☐
School, day care, or summer camp?	☐	☐	☐
A store, restaurant, playground, campsite, or any other public place?	☐	☐	☐

2. DURING THE PAST 12 MONTHS have you done any of the following to prevent this child from wandering off or to find them if they become lost? (Check all that apply). **Source:** *National Survey of Children's Health – pathways follow-up survey of children with special health care needs*

	Yes	No
Added fences or gates to your home	❑	❑
Added locks or alarms to your home	❑	❑

Added other barriers to your home	❑	❑
Placed a tracking device on this child	❑	❑
Used an APP or feature on the child's cell phone	❑	❑

3. Has this child EVER been bullied by another child? **Source:** *Interactive Autism Network (IAN)*

€ YES
€ NO **(Skip to question 6)**
€ I Don't Know **(Skip to question 6)**

4. DURING THE PAST 12 MONTHS, has this child been bullied by another child? **Source:** *Interactive Autism Network (IAN)*

€ YES
€ NO **(Skip to question 6)**
€ I Don't Know **(Skip to question 6)**

5. In what ways was this child bullied DURING THE PAST 12 MONTHS? **Source:** *Interactive Autism Network (IAN)*

	Yes	No	Unsure
Called bad names	☐	☐	☐
Threatened that they would be hurt or hit	☐	☐	☐
Teased, picked on, or made fun of	☐	☐	☐
Pushed or shoved	☐	☐	☐
Hit, slapped or kicked	☐	☐	☐
Someone texted, e-mailed, or posted something hurtful about him/her on the Internet (e.g. social media)	☐	☐	☐
Rumors or lies spread about them	☐	☐	☐
Ignored or left out of things on purpose	☐	☐	☐
Others stole their things	☐	☐	☐
Other - please specify _____	☐	☐	☐

6. Has this child EVER bullied another child? **Source:** *Interactive Autism Network (IAN)*

€ YES
€ NO
€ I Don't Know

The next question is about events that may have happened during this child's life. These things can happen to any family, but some people may feel uncomfortable with these questions. You may skip any questions you do not want to answer.

7. To the best of your knowledge, has this child ever experienced any of the following? **Source:** *National Survey of Children's Health*

	Yes	No
Parent/guardian divorced or separated	❑	❑
Parent/guardian died	❑	❑
Parent/guardian served time in jail	❑	❑
Was a victim of violence or witnessed violence in neighborhood	❑	❑
Lived with anyone who was mentally ill, suicidal, or severely depressed	❑	❑
Lived with anyone who had a problem with alcohol or drugs	❑	❑
Treated or judged unfairly because of his or her race or ethnic group	❑	❑

H. Your Expectations for This Child

1. Please check one box for each of the following questions. **Source:** *National Longitudinal Transition Study-2 (NLTS2)*

	Do you think this child…					
How likely do you think it is that this child will…	Definitely Will	Probably Will	Probably Won't	Definitely Won't	Don't Know	Already Has
Get a regular high school diploma? *A regular high school diploma includes a "GED" but does not include a certificate of completion or a special diploma for students in special education.*	☐	☐	☐	☐	☐	☐
Attend school after high school? *including technical or trade school*	☐	☐	☐	☐	☐	☐
Attend a special training program after high school for persons with intellectual disabilities?	☐	☐	☐	☐	☐	☐
Complete a technical or trade school program?	☐	☐	☐	☐	☐	☐
Graduate from a 2-year or community college?	☐	☐	☐	☐	☐	☐
Graduate from a 4-year college?	☐	☐	☐	☐	☐	☐
Get a driver's license?	☐	☐	☐	☐	☐	☐
Eventually live away from home on his or her own without supervision?	☐	☐	☐	☐	☐	☐
Eventually live away on his or her own with supervision?	☐	☐	☐	☐	☐	☐
Eventually get a paid job?	☐	☐	☐	☐	☐	☐

This includes any paid job -- child does not need to make enough to support self. This can include sheltered or supported employment.						
Earn enough to support himself or herself without financial help from his or her family or government benefit programs?	☐	☐	☐	☐	☐	☐

Section I: You and Your Family

About You

1. How are you related to this child? **Source:** *National Survey of Children's Health*

   - € Biological or Adoptive Parent
   - € Step-parent
   - € Grandparent
   - € Aunt or Uncle
   - € Other Relative
   - € Other Non-relative

2. What is your sex? **Source:** *National Survey of Children's Health*

   - € Male
   - € Female

3. What is your age? **Source:** *National Survey of Children's Health*

   __ __ (Print numbers)

4. What is the highest grade or year of school you have completed? **Source:** *National Survey of Children's Health*

   - € 8th grade or less
   - € 9th-12th grade; No diploma
   - € High School Graduate or GED Completed
   - € Completed a vocational, trade, or business school program
   - € Some College Credit, but No Degree
   - € Associate Degree (AA, AS)
   - € Bachelor's Degree (BA, BS, AB)
   - € Master's Degree (MA, MS, MSW, MBA)
   - € Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)

5. What is your marital status? **Source:** *National Survey of Children's Health*

   - € Married
   - € Not married, but living with a partner

- € Never Married
- € Divorced
- € Separated
- € Widowed

6. Are you currently…? **Source:** *Behavioral Risk Factor Surveillance System*

If more than one, select the category which best describes you.

- € Employed for wages
- € Self-employed
- € Out of work for 1 year or more
- € Out of work for less than 1 year
- € A Homemaker
- € A Student
- € Retired
- € Unable to work

About Your Health

7. In general, what is your physical health status? **Source:** *National Survey of Children's Health*

- € Excellent
- € Very Good
- € Good
- € Fair
- € Poor

8. In general, what is your mental or emotional health status? **Source:** *National Survey of Children's Health*

- € Excellent
- € Very Good
- € Good
- € Fair
- € Poor

9. Has a doctor or other healthcare provider EVER told you that you had any of the following? **Sources:** *SEED Case-control Study Maternal Health History Form* **and** *Behavioral Risk Factor Surveillance System*

	Yes	No
Attention deficit disorder or attention deficit hyperactivity disorder (ADD or ADHD)?	❑	❑
An anxiety disorder?	❑	❑

This includes acute stress disorder, anxiety, generalized anxiety disorder, obsessive-compulsive disorder, panic disorder, phobia, posttraumatic stress disorder, or social anxiety

disorder

Autism, Asperger's, pervasive developmental disorder, or autism spectrum disorder?	❑	❑
Bipolar disorder?	❑	❑
A depressive disorder? *This includes depression, major depression, dysthymia, or minor depression*	❑	❑
Schizophrenia	❑	❑

10. **DURING THE PAST 2 WEEKS, for about how many days have you felt very healthy and full of energy** **Source:** *Behavioral Risk Factor Surveillance System*

- Nearly every day
- More than half the days
- Few days
- No days

11. DURING THE PAST MONTH, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your breathing rate? **Source:** *National Health and Nutrition Examination Survey*

This may include sports, exercise, and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that may be part of your job.

_____ *days during the past month*

About Your Community

12. DURING THE PAST 12 MONTHS, was there someone that you could turn to for day-to-day emotional support with parenting or raising children? **Source:** *National Survey of Children's Health*

€ Yes
€ No **(Skip to question 14)**

13. If yes, did you receive emotional support from (check all that apply) **Source:** *National Survey of Children's Health*

	Yes	No
Spouse?	❑	❑
Other family member or close friend?	❑	❑
Health care provider?	❑	❑

Place of worship or religious leader?	❑	❑
Support or advocacy group related to specific health condition?	❑	❑
Peer support group?	❑	❑
Counselor or other mental health professional?	❑	❑
Other person, specify _____	❑	❑

14. Other than you or other adults in your home, is there at least one other adult in this child's school, neighborhood, or community who knows this child well and who he or she can rely on for advice or guidance? **Source:** *National Survey of Children's Health*

- € Yes
- € No

About You and This Child

15. How well can you and this child share ideas or talk about things that really matter? **Source:** *National Survey of Children's Health*

- € Very well
- € Somewhat well
- € Not very well
- € Not very well at all

16. DURING THE PAST MONTH, how often have your felt: **Source:** *National Survey of Children's Health*

	Never	Rarely	Sometimes	Usually	Always
That this child is much harder to care for than most children his or her age?	❑	❑	❑	❑	❑
That this child does things that really bother you a lot?	❑	❑	❑	❑	❑
Angry with this child?	❑	❑	❑	❑	❑

17. How well do you feel that you are coping with the day-to-day demands of raising children? **Source:** *National Survey of Children's Health*

- € Very well
- € Somewhat well
- € Not very well
- € Not very well at all

18. DURING THE PAST 12 MONTHS, have you ever: **Source: SEED Teen Investigators developed this question series based on a similar question series on delayed** Yes No

healthcare in *National Health Interview Survey*. **In addition to the impact of child care on parents meeting their own health care needs, SEED Teen Investigators were interested in child care impacts on behaviors important to caregiver physical and mental health. The need for data on the health and wellbeing of parents who care for children with autism and developmental disabilities is a theme we often here at autism and developmental disabilities conferences. This was also a key recommendation from the peer review committee who reviewed our activities on SEED.**

Delayed getting health care or dental care for yourself because of the time needed to care for this child?	❑	❑
Gotten less physical activity than you wanted because of the time needed to care for this child?	❑	❑
Limited your social life because of the time needed to care for this child?	❑	❑

About Your Family and Household

19. When our family faces problems we… **Source:** *National Survey of Children's Health*	All of the time	Most of the time	Some of the time	None of the time
Work together to solve our problems	❑	❑	❑	❑
Know we have strengths to draw on	❑	❑	❑	❑
Stay hopeful even in difficult times	❑	❑	❑	❑

20. DURING THE PAST WEEK, on how many days did all the family members who live in the household eat a meal together? **Source:** *National Survey of Children's Health*

- € 0 days
- € 1-3 days
- € 4-6 days
- € Every day

21. Have you or other family members living in your household EVER stopped working or cut down on the hours you work because of this child's health or health conditions? **Source: adapted from** *National Survey of Children's Health*

- € Yes
- € No **(Skip to question 23)**

22. If yes, have you or other family members living in your household stopped working or cut down on the hours worked DURING THE PAST 12 MONTHS? **Source:** *National Survey of Children's Health*

- € Yes
- € No

23. Have you or other family members living in your household EVER avoided changing jobs because of concerns about maintaining health insurance for this child? **Source: adapted from** *National Survey of Children's Health*

    € Yes
    € No **(Skip to question 25)**

24. If yes, have you or other family members living in your household avoided changing jobs because of concerns about maintaining health insurance DURING THE PAST 12 MONTHS? **Source:** *National Survey of Children's Health*

    € Yes
    € No

25. Which of these statements best describes the food situation in your household DURING THE PAST 12 MONTHS: **Source:** *National Survey of Children's Health*

    € We could always afford to eat good nutritious meals
    € We could always afford enough to eat but not always the kinds of food we should eat
    € Sometimes we could not afford enough to eat
    € Often we could not afford enough to eat

26. At any time DURING THE PAST 12 MONTHS, even for one month, did anyone in your family receive: **Source:** *National Survey of Children's Health*

	Yes	No
Cash assistance from a government welfare program?	❑	❑
Food Stamps or Supplemental Nutrition Assistance Program benefits (SNAP)?	❑	❑
Free or reduced-cost breakfasts or lunches at school?	❑	❑
Benefits from the Women, Infants, and Children (WIC) Program?	❑	❑

J. Household Information

1. How many children under the age of 18 are now living in the household, ***not including this child*** **Source: adapted from** *SEED Case-control Study Maternal Interview and National Survey of Children's Health*

   NUMBER OF CHILDREN _____ **(Skip to question 3)**

2. Do any of these children have any disability, developmental delay, special need, or condition? **Sources: adapted from** *SEED Case-control Study Maternal Interview and National Survey of Children's Health*

   € YES
   € NO

The next questions are about your total income in the last calendar year before taxes.

Income is important in analyzing the health information we collect. For example, with this information, we can learn whether persons in one income group use certain types of medical services more or less often than those in another group. Please be assured that, like all other information you have provided, these answers will be kept strictly confidential.

3. DURING THE LAST CALENDAR YEAR, what was your yearly total household income before taxes? **Source:** *Pregnancy Risk Assessment Monitoring System*

Include your income, your spouse's or partner's income, and any other income you may have received.

- $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

4. DURING THE LAST CALENDAR YEAR, how many people, including yourself and this child, depended on this income? **Source:** *Pregnancy Risk Assessment Monitoring System*

___ ____