Supporting Statement Part B

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

New

Seema Gupta, MPH
Public Health Analyst
Centers for Disease Control and Prevention
Email: sgupta3@cdc.gov
Phone: (770) 488-6527

October 21, 2026

Table of Contents

B1. Respondent Universe and Sampling Methods.....3

B.2. Procedures for the Collection of Information.....5

B.3. Methods to Maximize Response Rates and Deal with Nonresponse.....5

B.4. Tests of Procedures or Methods to be Undertaken.....6

B.5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data.....6

Attachments

Attachment 1. Authorizing Legislation (1a-1d)
Attachment 2. 60-day Federal Register Notice
Attachment 3. Public Comment 1
Attachment 4. Public Comment 2
Attachment 5. Caregiver survey for children ages 9-17
Attachment 6. Caregiver survey for young adults 18+
Attachment 7. Self-report survey for children ages 9-17
Attachment 8. Self-report survey for young adults 18+
Attachment 9. Research Determination
Attachment 10. Privacy Impact Assessment
Attachment 11. Invitation Letter for Caregivers
Attachment 12. Invitation Letter for Adolescents/Young Adults
Attachment 13. Participant Information Sheet for Caregivers
Attachment 14. Participant Information Sheet for Adolescents/Young Adults
Attachment 15. Thank You Letter
Attachment 16. References

B. Collection of Information Employing Statistical Methods

B1. Respondent Universe and Sampling Methods

The Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT) is a data collection effort to describe long-term outcomes among children, adolescents and young adults with and without autism who previously participated in a case-control study of autism at 2-5 years of age called the Study to Explore Early Development (SEED). SEED caregivers and their school-aged/adolescent/young adult child (henceforth referred to as youth) will serve as respondents for the SPROUT data collection effort. Given this is a longitudinal follow-up survey, statistical sampling methods will not be employed. Instead, all eligible caregivers and youth from SEED will be included.

Eligibility Criteria for Respondents

Eligible participants will be caregivers and youth who were classified as having autism spectrum disorder (ASD), other developmental disability (DD), indeterminate (INDT), or as general population controls (POP) at 2-5 years old as part of their participation in SEED 1-3. Additional eligibility criteria are as follows:

Criterion 1: Caregiver completed the caregiver interview and index child was classified as ASD, DD, INDT, or POP as part of their participation in SEED 1-3.

AND

Criterion 2a: If classified as ASD, other DD, or POP, caregiver provided consent for future contact. OR

Criterion 2b: If child classified as INDT, caregiver reported a previous ASD diagnosis (N= 714). This criterion only applies to the INDT group because caregivers did not have the opportunity to provide consent to future contact.

Approximately 7,400 families from SEED 1-3 meet these criteria. Based on the participation rates from a prior longitudinal follow-up of SEED 1-3 participants (SEED Follow-up), CDC estimates 4,500 caregiver respondents and 3,500 youth respondents will be recruited over the 3-year period covered by this Information Collection Request. Participating sites will be expected to complete data collection for SPROUT in 18 months to allow sufficient time for analysis before this 3-year coverage period ends.

Data Collection
SPROUT will conduct survey data collection with eligible SEED 1-3 caregivers and youth participants. Caregivers and youth will be asked to complete a 10–30-minute survey, yielding up to two surveys per family.

B.2. Procedures for the Collection of Information

Each site will identify SEED caregivers and youth who may be eligible to participate in SPROUT. Invitations to participate will either take place by mail, email, or text. Non-responders will be contacted by telephone. Invitations will include an introductory letter (**Attachments 11 and 12**) and participation information sheet that will provide information about the project, explain their rights as a respondent, and how the information collected will remain confidential and secure (**Attachments 13 and 14**).

After eligible caregivers or youth agree to participate, they will be sent an electronic survey (**Attachments 5-8**) via email or text.

B.3. Methods to Maximize Response Rates and Deal with Nonresponse

To maximize response rates, eligible participants will be notified in the invitation letter (**Attachments 11 and 12**) that they will receive a thank you letter (**Attachment 15**), including a $30 digital gift card, upon completion of the survey as a token of appreciation for their time and effort. Both caregivers and youth who respond to the surveys will receive their own gift card. Additionally, to enhance participation and mitigate nonresponse, recruitment, enrollment, and data collection will be conducted by funded sites that either previously collected data from SEED families or have cooperative agreements with former SEED sites to engage their prior participants.

Initially, all eligible SPROUT caregivers and youth will be invited to participate. However, information on age, sex, and race/ethnicity is included in existing SEED data sets to allow CDC to compare socio-demographic characteristics between those who agreed versus those who declined participation and/or did not complete the survey. This information will allow CDC to evaluate the presence of any non-response bias that could vary across socio-demographics.

B.4. Tests of Procedures or Methods to be Undertaken

Subject matter experts from across CDC, including experts in developmental disabilities, genetics, survey methodology, and health scientists, were involved in the development of SPROUT. CDC has ensured that the proposed topics align with priority areas and other autism partners.

Procedures for developing survey instruments included the following: 1) selecting individual questions from existing surveys that have already undergone cognitive testing; 2) selecting standardized assessments that have been previously validated and used in numerous studies and clinical evaluations of children.

The surveys have been evaluated by CDC project staff and pilot tested with a small group (<9) of parents and young adults with autism and other developmental disabilities to ensure comprehension of the questions, appropriate skip patterns, and determine the length of time required for completion. These surveys represent new survey material for data collection. The surveys that will be used in this data collection effort can be found in **Attachments 5-8**.

B.5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

The statistical aspects of the design of this project are the responsibility of the CDC Principal Investigator and Co-Investigators:

Patrick Powell, PhD
Health Scientist
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
404.498.2730

Lisa Wiggins, PhD
Health Scientist
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
404.498.3875

Seema Gupta, MPH
Public Health Analyst
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention
4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
770.488.6527

Katherine Overwyk, MPH
Health Scientist
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
404.718.6614

Aimee Alexander, MS CGC
Health Scientist
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
404.498.3870

Angela Thompson-Paul, PhD
Team Lead, Epidemiology Team
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
770.488.8536

Sarah Tinker, PhD
Senior Scientist, Child Development and Disability Branch
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
404.498.3509

Sherry L. Farr, PhD
Division Director (Acting)/Associate Director for Science
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

4770 Buford Hwy, MS: S106-4
Atlanta, GA 30341
404.498.3877

Data analysis is the primary responsibility of the funded sites and CDC staff in the Child Development and Disability Branch.