



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[60Day-26-0017; Docket No. CDC-2026-0067]

Proposed Data Collection Submitted for Public Comment and Recommendations

AGENCY: Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (HHS).

ACTION: Notice with comment period.

SUMMARY: The Centers for Disease Control and Prevention (CDC), as part of its continuing effort to reduce public burden and maximize the utility of government information, invites the general public and other Federal agencies the opportunity to comment on a proposed information collection, as required by the Paperwork Reduction Act of 1995. This notice invites comments on a proposed information collection project titled Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT). This follow-up survey will allow CDC to collect longitudinal data on prior participants in the Study to Explore Early Development (SEED) and family members in order to better understand the healthcare utilization, service and support needs, and impact of co-occurring conditions on autistic adolescents and young adults and their families, as well as the educational, social, and/or vocational needs and experiences of autistic adolescents and young adults.

DATES: CDC must receive written comments on or before [INSERT DATE 60 DAYS AFTER DATE OF PUBLICATION DATE IN THE FEDERAL REGISTER].

ADDRESSES: You may submit comments, identified by Docket No. CDC-2026-0067 by either of the following methods:

- Federal eRulemaking Portal: www.regulations.gov. Follow the instructions for submitting comments.

□ Mail: Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, NE, MS H21-8, Atlanta, Georgia 30329.

Instructions: All submissions received must include the agency name and Docket Number.

CDC will post, without change, all relevant comments to www.regulations.gov.

Please note: Submit all comments through the Federal eRulemaking portal

(www.regulations.gov) or by U.S. mail to the address listed above.

FOR FURTHER INFORMATION CONTACT: To request more information on the proposed project or to obtain a copy of the information collection plan and instruments, contact Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, NE, MS H21-8, Atlanta, Georgia 30329; Telephone: 404-639-7118; E-mail: omb@cdc.gov.

SUPPLEMENTARY INFORMATION: Under the Paperwork Reduction Act of 1995 (PRA) (44 U.S.C. 3501-3520), federal agencies must obtain approval from the Office of Management and Budget (OMB) for each collection of information they conduct or sponsor. In addition, the PRA also requires federal agencies to provide a 60-day notice in the *Federal Register* concerning each proposed collection of information, including each new proposed collection, each proposed extension of existing collection of information, and each reinstatement of previously approved information collection before submitting the collection to the OMB for approval. To comply with this requirement, we are publishing this notice of a proposed data collection as described below.

The OMB is particularly interested in comments that will help:

1. Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility;
2. Evaluate the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;
3. Enhance the quality, utility, and clarity of the information to be collected;

4. Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submissions of responses; and
5. Assess information collection costs.

Proposed Project

Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT) – New - National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

In 2022, an estimated one in 31 children eight years of age living in 16 communities across the United States had autism, a developmental disability that can cause significant social, communication, and behavior challenges. The Study to Explore Early Development (SEED) was implemented in 2006 to learn more about autism and other developmental disabilities in children 2-5-years of age. Extensive data, from interviews, in-person evaluations, and other sources were collected across three phases (SEED 1-3) in eight geographic areas (California, Colorado, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, and Wisconsin). SEED 1-3 collected data on 9,808 preschool-aged children with autism, another developmental delay or disability, or from the general population. To date, almost 100 analyses of SEED 1-3 data have been published in peer-reviewed journals.

To better understand transition and lifespan issues affecting people with autism as they age, caregivers of children enrolled in SEED 1 (2006-2011) were eligible to participate in a pilot follow-up survey when their child was between 12-16 years of age (2018-2021; SEED Teen). An important outcome of SEED Teen was to demonstrate that longitudinal data collection from

SEED participants is feasible (i.e., contact was established with approximately 97% of eligible participants and, of those, 64% enrolled in SEED Teen). SEED Follow-Up was thus initiated in 2021 to survey the broader cohort of SEED 1-3 participants on adolescent and young adult health and well-being. SEED Follow-Up is currently ongoing until June 2026.

The federal government identified a need to improve efforts to better understand lifespan issues among people with autism in the Autism CARES Act of 2024 and a report to Congress in 2017. Despite this, a recent portfolio analysis from the Interagency Autism Coordinating Committee (IACC), indicated that lifespan issues continue to receive the least amount of autism funding from federal agencies. Both the SEED Teen and SEED Follow-Up surveys helped identify healthcare needs and experiences among adolescents with autism. However, gaps in understanding remain in how we can best support adolescents and young adults with autism and their families.

Draft chapters of the 2024 IACC Strategic Plan Update emphasize the need for data on service and support needs and conditions that commonly co-occur with autism. On behalf of the IACC, the Office of National Autism Coordination (ONAC) released a Request for Public Comment on these topics from members of the autistic community. Some identified service and support needs were: 1) provider training; 2) more benefits and insurance coverage; and 3) help with system navigation. Some commonly reported co-occurring conditions were sensory and motor issues, anxiety disorder, sleep problems, attention deficits, hyperactivity, gastrointestinal issues, learning and memory issues, and suicidal ideation. Other topics identified as important to the autistic community are social, education, and vocational experiences and outcomes.

The current information collection request is to conduct longitudinal follow-up surveys that offer unique information about autistic adolescents and young adults, thereby addressing the priorities established in the Autism CARES Act of 2024 and draft 2024 IACC Strategic Plan. Given the size of the original SEED birth cohorts and the wealth of baseline and follow-up information collected, additional surveys of participants can help address critical information

gaps. Specifically, the information collected from the Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT) will allow us to better understand: 1) the healthcare utilization of, service and support needs of, and impact of co-occurring conditions on autistic people and their families; and 2) the educational, social, and/or vocational needs and experiences of autistic adolescents and young adults.

One survey will be administered to caregivers and a second is a self-report survey administered to children, adolescents and young adults age 9-27. The survey version will be based on the child participant’s age and ability to self-report on healthcare utilization, service and support needs, co-occurring conditions, and healthcare transition. CDC requests OMB approval for an estimated 1,510 annual burden hours. There are no costs to respondents other than their time to participate.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
Caregivers	Survey 1	1,310	1	30/60	565
Caregivers	Survey 2	180	1	30/60	90
Caregivers	Survey 3	90	1	30/60	45
Caregivers	Survey 4	1,600	1	10/60	266
Children and adolescents	Self-report Survey 1	575	1	15/60	144
Young adults	Self-report Survey 2	800	1	30/60	400
Total					1,510

Jeffrey M. Zirger,

Lead,

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Office of Public Health Ethics and Regulations,

Office of Science,

Centers for Disease Control and Prevention.

