This document is scheduled to be published in the Federal Register on 2026-11-17 and available online at https://www.federalregister.gov/d/2026-23301, and on https://govinfo.gov

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[30Day-27-0017]

Agency Forms Undergoing Paperwork Reduction Act Review

In accordance with the Paperwork Reduction Act of 1995, the Centers for Disease Control and Prevention (CDC) has submitted the information collection request titled "Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT)" to the Office of Management and Budget (OMB) for review and approval. CDC previously published a "Proposed Data Collection Submitted for Public Comment and Recommendations" notice on January 27, 2026, to obtain comments from the public and affected agencies. CDC received two related to the previous notice. This notice serves to allow an additional 30 days for public and affected agency comments.

CDC will accept all comments for this proposed information collection project. The Office of Management and Budget is particularly interested in comments that:

(a) 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;

(b) Evaluate the accuracy of the agencies estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;

(c) Enhance the quality, utility, and clarity of the information to be collected;

(d) 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 submission of responses; and

(e) Assess information collection costs.

To request additional information on the proposed project or to obtain a copy of the information collection plan and instruments, call (404) 639-7570. Comments and recommendations for the proposed information collection should be sent within 30 days of publication of this notice to www.reginfo.gov/public/do/PRAMain. Find this particular information collection by selecting "Currently under 30-day Review - Open for Public Comments" or by using the search function. Direct written comments and/or suggestions regarding the items contained in this notice to the Attention: CDC Desk Officer, Office of Management and Budget, 725 17th Street, NW, Washington, DC 20503 or by fax to (202) 395-5806. Provide written comments within 30 days of notice publication.

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, 2, and 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 provider training, more benefits and insurance coverage, and 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 (ICR) is designed 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 another 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 1,867 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)
Caregivers of children ages 9-17 and young	Caregiver survey for children ages 9-17	1,400	1	30/60

adults who can't self-report				
Caregivers of young adults 18+	Caregiver survey for young adults 18+	1,600	1	10/60
Children and adolescents	Self-report Survey for children ages 9-17	1,000	1	15/60
Young adults who can self-report	Self-report survey for young adults 18+	1,300	1	30/60

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[FR Doc. 2026-23301 Filed: 11/16/2026 8:45 am; Publication Date: 11/17/2026]