Project Determination

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

Project ID:	0900f3eb825d754e
Accession #:	NCBDDD-EPI-6/30/25-9ad93
Project Contact:	Seema Gupta
Organization:	OS/OS/OSI
Status:	Pending Regulatory Clearance
Intended Use:	Project Determination
Estimated Start Date:	07/01/26
Estimated Completion Date:	06/30/31
CDC/ATSDR HRPO/IRB Protocol#:	
OMB Control#:	
End of Human Research Date:	
OMB Discontinuation Date:	

Description

Priority

Standard

Date Needed

09/17/25

CDC Priority Area for this Project

Support for Young Families

Determination Start Date
09/05/25
Description
This surveillance project, the Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT), will utilize cohorts from the Study to Explore Early Development (SEED) Phases 1-3 (collected from 2007-2020), which were case-control studies of autism in children 2-5 years of age. SEED 1-3 participants will range from about 10-25 years of age when the funding for this project is anticipated to be awarded (Summer 2026). SPROUT will be comprised of caregiver and self-report surveys intended to offer unique information not available in other surveys, claims, or administrative data on (1) service and support needs and the impact of co-occurring conditions on autistic people and their families and (2) the educational, transitional, social, and/or vocational needs and experiences of autistic adolescents and young adults. The information collected from this population-based surveillance project is intended to provide data to inform ways to lessen individual, familial, and societal costs associated with autism, reduce morbidity and mortality, and improve health and well-being.
IMS/CIO/Epi-Aid/Lab-Aid/Chemical Exposure Submission
No
IMS Activation Name
Not selected
Submitted through IMS clearance matrix
Not selected
Primary Scientific Priority
Not selected
Secondary Scientific Priority (s)
Not selected
Task Force Responsible
Not selected
CIO Emergency Response Name
Not selected
Epi-Aid Name
Not selected
Lab-Aid Name
Not selected
Assessment of Chemical Exposure Name

Not selected

Goals/Purpose

The purpose of this surveillance project is to administer the Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT). SPROUT will utilize cohorts from the Study to Explore Early Development Phases 1-3 (collected from 2007-2020), which were case-control studies of autism in children 2-5 years of age. SEED 1-3 participants will range from about 10-25 years of age when funding for this project is anticipated to be awarded (Summer 2026). SPROUT will be comprised of caregiver and self-report surveys intended to offer unique information not available in other surveys, claims, or administrative data on (1) service and support needs and the impact of co-occurring conditions on autistic people and their families and (2) the educational, transitional, social, and/or vocational needs and experiences of autistic adolescents and young adults. These activities are intended to provide data to inform ways to lessen individual, familial, and societal costs associated with autism, reduce morbidity and mortality, and improve health and well-being.

Objective

Objective 1 - Identify resources and opportunities: Collect timely and unique data on co-occurring conditions (e.g., ADHD, anxiety, depression), resource needs (e.g., services, supports) and opportunities (e.g., education, employment, housing, social participation) for children, adolescents, and adults with autism. The data collected on these topics will be used to better inform healthcare professionals and service providers on the types of services and supports that are needed by individuals with autism across the lifespan.
Objective 2 - Promote health knowledge of autism: Translate data into high quality public health products covering a variety of topics (e.g., common co-occurring physical and mental health conditions, service and support needs) and disseminate to specific audiences (e.g., advocacy groups, parents, providers, & professional organizations). Broad dissemination of these public health products will foster greater health knowledge on autism and help strengthen capacity for parents, professionals and others to provide better supports for people with autism across the lifespan.

Does your project measure health disparities among populations/groups experiencing social, economic, geographic, and/or environmental disadvantages?

No

Does your project investigate underlying contributors to health inequities among populations/groups experiencing social, economic, geographic, and/or environmental disadvantages?

No

Does your project propose, implement, or evaluate an action to move towards eliminating health inequities?

No

Activities or Tasks

New Collection of Information, Data, or Biospecimens

Target Population to be Included/Represented

Children; Adult 18-24 years; Other-Parents/Caregivers

Tags/Keywords

Autism Spectrum Disorder; Adolescent; Young Adult; Adolescent Health; Adult Children; Child Health; Child Development

CDC's Role

Activity originated and designed by CDC staff, or conducted at the specific request of CDC, or CDC staff will approve study design and data collection as a condition of any funding provided; CDC employees will participate as co-authors in presentation(s) or publication(s); CDC employees will provide substantial technical assistance or oversight; CDC is providing funding; CDC is recipient of private data/specimens FROM an institution

Method Categories

Prospective Cohort Study; Survey

Methods

Eligible participants will be those who previously participated in SEED 1-3 (children were ages 2-5 years) and agreed to be contacted for future studies. SEED included children with autism, as well as a comparison group of children with other developmental disabilities and a comparison group of children without developmental disabilities from the general population. Awardees will work with CDC and each other to update contact information (contact tracing), recruit, and enroll caregivers and their minor and young adult children to participate in two surveys administered at separate times during the project period. SPROUT will be comprised of caregiver and self-report surveys intended to offer unique information not available in other surveys, claims, or administrative data on (1) service and support needs and the impact of co-occurring conditions on autistic people and their families and (2) the educational, transitional, social, and/or vocational needs and experiences of autistic adolescents and young adults.

Collection of Info, Data, or Bio specimens

Caregivers and their minor and/or young adult children will be separately administered two 20-30-minute online surveys, one in year 2 and one in year 4 of the project period. Sites will record and store data locally using a CDC-developed data collection and management system. The data will be de-identified and exported by the site periodically using a program developed by CDC and will be transferred to CDC via a secure file transfer protocol (SFTP) on a regular basis.

Expected Use of Findings/Results and their impact

CDC will produce two public health data briefs based on the identified focus of each survey. Data collected from the surveys may be used by partners to provide high-quality, timely, and actionable products; support awareness and implementation of impactful interventions; strengthen systems and supports for autistic people; and enhance coalitions and strategic partnerships. During the project period, awardees will be required to produce at least two high-quality public health products including but not limited to community reports, peer-reviewed papers, and awareness activities. The potential impacts are to improve the health and wellbeing of autistic people and their families, including reduced morbidity and mortality, and lessen the individual, familial, and societal costs associated with autism and its co-occurring conditions.

Could Individuals potentially be identified based on Information Collected?

Yes

Will PII be captured (including coded data)?

Yes

Does CDC have access to the Identifiers (including coded data)?

Yes

Is this project covered by an Assurance of Confidentiality?

No

Does this activity meet the criteria for a Certificate of Confidentiality (CoC)?

No

Is there a formal written agreement prohibiting the release of identifiers?

No

Funding

Funding Type	Funding Title	Funding #	Original Fiscal Year	# of Years of Award	Budget Amount
CDC Cooperative Agreement	Promoting Resources and Opportunities for People with Autism and Fragile X and their Families Across the Lifespan	CDC-RFA-DD-26-0025		5	

HSC Review

Regulation and Policy

Do you anticipate this project will require review by a CDC IRB or HRPO?

No

Will you be working with an outside Organization or Institution? Yes

Institutions

Institution	FWA #	FWA Exp. Date	Funding	Funding Restriction Amount
Institutions have not been awarded yet			Promoting Resources and Opportunities for People with Autism and Fragile X and their Families Across the Lifespan - CDC-RFA-DD-26-0025	

Institution	Funding Restriction Percentage	Funding Restriction Reason	Funding Restriction has been lifted
Institutions have not been awarded yet			

Institution	Institution Role(s)	Institution Project Title	Institution Project Tracking #	Prime Institution
Institutions have not been awarded yet	Receiving Direct HHS Support (Prime Awardee)			

Institution	Regulatory Coverage	IRB Review Status
Institutions have not been awarded yet	IRB Review is Not Required	

Institution	Registered IRB	IRB Registration Exp. Date	IRB Approval Status
Institutions have not been awarded yet			

Institution	IRB Approval Date	IRB Approval Exp. Date	Relying Institution IRB
Institutions have not been awarded yet			

Staff

Staff Member	SIQT Exp. Date	Citi Biomedical Exp. Date	Citi Social and Behavioral Exp. Date	Citi Good Clinical Exp. Date	Citi Good Laboratory Practice Exp. Date	Staff Role	Email	Phone #	Organization / Institution
AngelaThompson-Paul	08/17/2026	12/23/2027	12/21/2027	12/23/2027		Principal Investigator	eup4@cdc.gov	770-488-8536	EPIDEMIOLOGY TEAM

Staff

Staff Member	SIQT Exp. Date	Citi Biomedical Exp. Date	Citi Social and Behavioral Exp. Date	Citi Good Clinical Exp. Date	Citi Good Laboratory Practice Exp. Date	Staff Role	Email	Phone #	Organization / Institution
SeemaGupta	09/11/2026	03/31/2025		10/23/2027		Project Officer	cvk9@cdc.gov	770-488-6527	EPIDEMIOLOGY TEAM

DMP

Proposed Data Collection Start Date	07/01/26
Proposed Data Collection End Date	06/30/31
Proposed Public Access Level	Restricted
Data Use Type	
Data Use Type Data Use Type URL	
Data Use Contact	
Public Access justification	The data is restricted access due to the sensitive nature of the information being collected and the potential for participants to be identified. We plan to request an Assurance of Confidentiality (AoC) to protect the privacy of survey participants. An AoC is a formal confidentiality protection authorized under Section 308(d) of the Public Health Service Act that prevents information from being disclosed to any person or for any purpose other than which it was intended.
How Access Will Be Provided for Data	Only investigators affiliated with a participating SPROUT site or with CDC will have access to SPROUT data. They will be required to complete data security and confidentiality training and sign the SPROUT Data Use and Confidentiality Acknowledgment Form, which specifies how participant confidentiality is protected throughout the study. After each wave of data collection, sites will clean and remove personally identifiable information and transfer their de-identified data to CDC for analysis and for CDC to produce a data brief. After data collection is completed in 2031, CDC will clean and append the data from all sites into a consolidated dataset, which will then be made available to site investigators for analyses and use for their public health products. Data will be accessed through a CDC-approved mechanism (i.e., secure data file transfer protocol [sFTP] that sites currently have access to and are using) that meets Federal standards for

	security and confidentiality.
Plans for archival and long-term preservation of the data	Data will be archived and preserved in accordance with applicable federal records management requirements, working with the Agency privacy compliance unit.

Spatiality (Geographic Location)

Country	State/Province	County/Region

Determinations

Determination	Justification	Completed	Entered By & Role
HSC: **Does NOT Require HRPO Review**	Not Research - Public Health Surveillance *45 CFR 46.102(l)(2)*	09/04/25	Demissie_Zewditu (izj5) CIO HSC
PRA: **PRA Applies**		09/05/25	Tinker_Sarah (zzu9) OMB / PRA