



Informational Call for Potential Applicants

# Understanding and Promoting Resources and Opportunities for People with Autism and Fragile X Syndrome (FXS) and their Families Across the Lifespan **CDC-RFA-DD-26-0025**

Epidemiology Team  
Centers for Disease Control and Prevention  
National Center on Birth Defects and Developmental Disabilities

May 27, 2026



Components B and C



## Agenda

12:00 pm-1:00 pm ET

- 01 Award and Eligibility Information
- 02 Approach
- 03 Submission Procedures
- 04 Review and Selection Process
- 05 Question and Answers

# Award and Eligibility Information

Seema Gupta



## NOFO Summary

- This NOFO aims to better understand the resources and opportunities that people with autism or fragile X syndrome (FXS) and their families need in areas including education, transition into young adulthood, and services and supports
- Goal is to reduce morbidity and mortality, as well as improve long-term outcomes including health and wellbeing
- CDC will fund three components under this NOFO
  - Component A: Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT)
  - **Component B: Focus on Advancing Support and Transition with the Fragile X Online Registry With Accessible Research Database (FAST FORWARD)**
  - **Component C: Creating resources, support, and strengthening capacity for people with FXS**

## Award and Eligibility Information

- Type of Award: Cooperative Agreement
- Fiscal Year: 2026
- Total Period of Performance Length: 5 years (12-month budget periods)
- Number of Components: 3
- Approximate Number of Awards\*
  - Component A: Up to 7 (average amount per budget period: \$230K-\$650K)
  - **Component B: Up to 3 (average amount per budget period: \$333,333)**
  - **Component C: 1 (average amount per budget period: \$200K)**
- \*Applicants may apply for all three components if they have the capacity
- Eligible Applicants: Open competition

**Component B:  
Focus on Advancing Support and Transition  
with the Fragile X Online Registry With  
Accessible Research Database  
(FAST FORWARD)**

Marc Schweizer, Katie Overwyk, Angela Thompson-Paul



## Fragile X Syndrome

- Genetic disorder caused by FMR1 gene mutation; FMR1 makes FMRP, a protein needed for brain development
- Most prevalent known cause of inherited intellectual disability, and most common monogenic cause of autism
- Estimated to occur in 1 in 7,000 males & 1 in 11,000 females
- Males have more severe symptoms
- People with FXS more often have developmental delays, learning disabilities, and a variety of social and behavioral problems, compared to their peers
- FXS has no cure; however, early diagnosis & intervention may have a significant impact on the health & wellbeing of people living with FXS



## History of FXS Data Collection

CDC funded a series of FXS data collection efforts:



# Purpose of FAST FORWARD

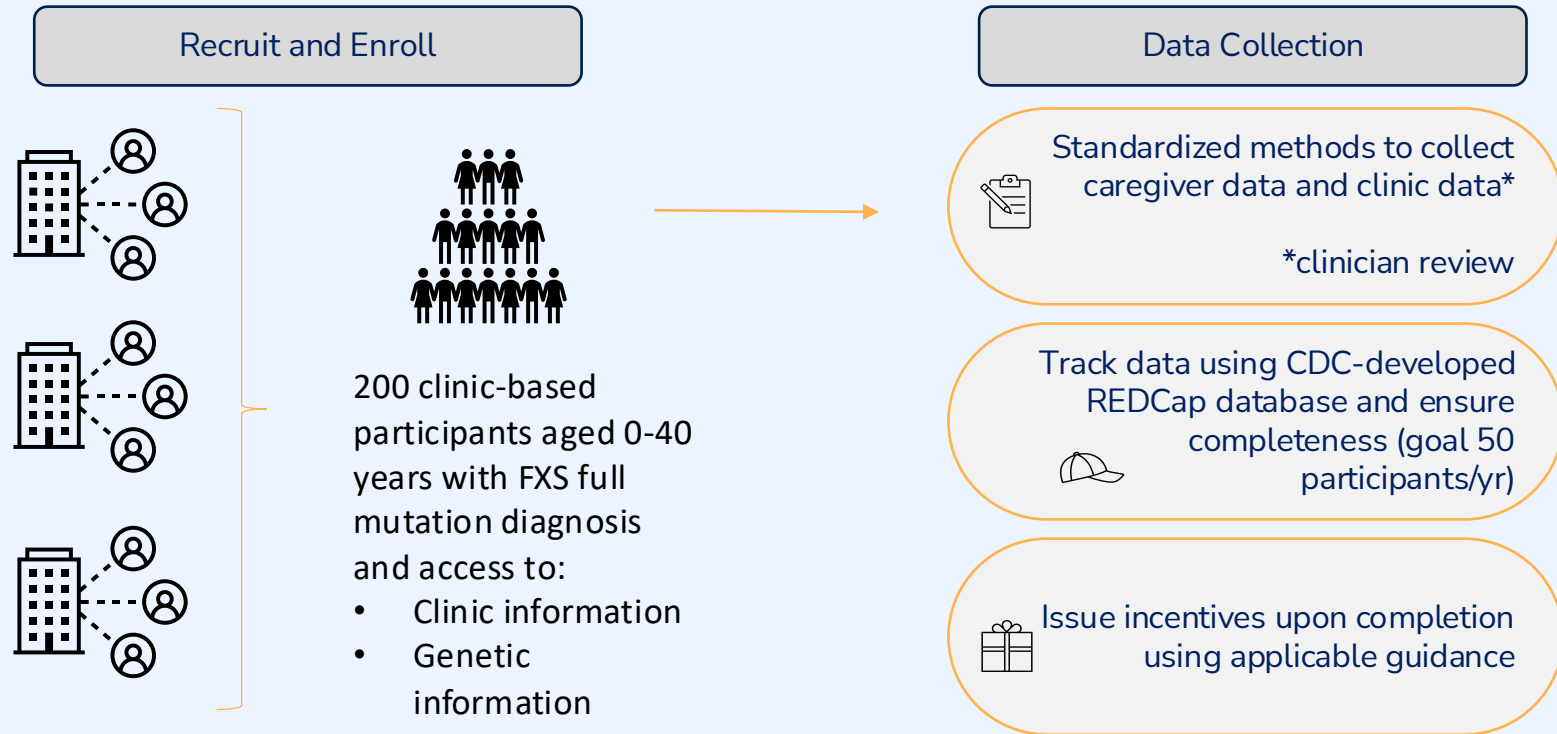
- Information will be collected on demographics, symptoms, co-occurring conditions, and service, support, and other needs and experiences of people with FXS and their families.
- Data will guide practices to increase access to services and supports, and improve health and other outcomes of people with FXS and their families
- Applicants must
  - Provide evidence of access to clinic-based samples of children, adolescents, and adults (ages 0-40 years) with FXS full mutation diagnosis
  - Demonstrate ability and capacity to collect data and access clinical records on a minimum of 200 unique people with FXS full mutation diagnosis

## **FAST FORWARD Strategies and Activities**

- **Strategy 1: Collect and manage timely, unique data on people age 0-40 years with full mutation FXS**
  - Activity 1: Recruit a minimum of 200 unique clinic-based participants
  - Activity 2: Collect data from caregivers and existing clinical data
  - Activity 3: Manage collected data
  - Activity 4: Clean and share de-identified data

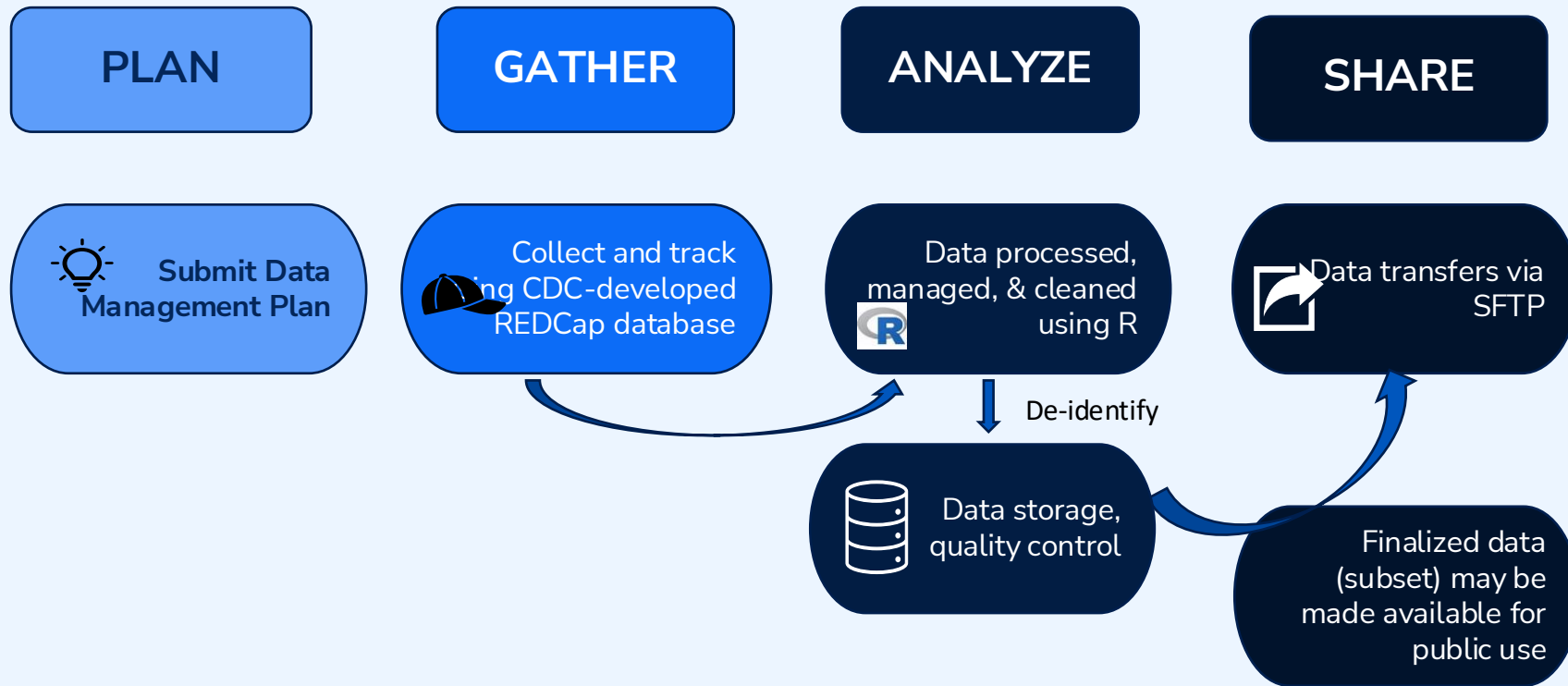
# FAST FORWARD Data Collection

Awardees are responsible for these activities and are expected to complete all activities in timeframe specified by CDC



# FAST FORWARD Data Management

Awardees are responsible for these activities and are expected to complete them in the timeframe specified by CDC



## **FAST FORWARD Strategies and Activities**

### **Strategy 2: Translate data into high quality public health products**

- Activity 1: Develop timely public health products
  - i.e., easy-to-read summaries, infographics, publicly accessible peer-reviewed publications, professional trainings

# Required Performance Measures for Strategy 1

Activity	Performance Measures	Frequency	Due Date/Start Date
1. Recruit a minimum of 200 unique clinic-based participants aged 0-40 years with FXS full mutation diagnosis	Report criteria used to determine participant eligibility and the total number of eligible FXS participants	Only once	Year 1, Quarter 1
	Provide clinic demographics to aid in refining projection for recruitment and enrollment estimated target rates	Quarterly	Year 1, Quarter 1
	Report number of eligible participants and other metrics in consultation with CDC	Monthly	Year 1, Quarter 3
2. Collect data	Report on key participation and completion milestones in consultation with CDC	Monthly	Year 1, Quarter 3
	Report on challenges and barriers to collecting survey data and proposed actions to overcome barriers to CDC	Monthly	Year 1, Quarter 3

## Required Performance Measures for Strategy 1 (cont'd)

Activity	Performance Measures	Frequency	Due Date/Start Date
3. Manage data collected	Provide statements of completion of confidentiality training for local investigators to CDC	Annually	Year 1, Quarter 2
	Ensure that at least one site representative is present on all FXS calls	Monthly	Year 1, Quarter 1
	Participate in principal investigator calls as needed	Monthly	Year 1, Quarter 1
4. Clean and share data	Upload/transfer de-identified data files via SFTP to CDC	Monthly	Year 1, Quarter 3
	Complete data cleaning procedures and submit final de-identified data files to CDC within the timeframe specified	One once	Year 5, Quarter 3

# Required Performance Measures for Strategy 2

Activity	Performance Measures	Frequency	Due Date/Start Date
<p>1. Develop timely public health products</p>	<p>Identify and develop at least one public health product, which can include but not limited to:</p> <ul style="list-style-type: none"> <li>- Easy to read summaries</li> <li>- Infographics</li> <li>- Publicly accessible peer reviewed publications, or</li> <li>- Professional trainings using FXS data</li> </ul>	<p>At least one</p>	<p>Anytime in years 1-5</p>
	<p>Report types of resource needs and opportunities</p>	<p>As needed</p>	<p>Anytime in years 1-5</p>

# Component C: Creating resources, support, and strengthening capacity for people with FXS

**Aimee Alexander, Angela Thompson-Paul**



## **FXS Information Dissemination**

### PURPOSE:

- Improve access to evidence-based information, support, and services for people with FXS, their families, and their communities
- Strengthen capacity among healthcare providers to appropriately support patients with FXS on a national level

### ACTIVITIES:

- Include dissemination of knowledge gained from previously funded data collections, such as FORWARD-MARCH.

# Strategies and Activities

## Strategy 3: Disseminate information to specific audiences

**Activity 1** - People with FXS and their families and communities

**Activity 2** - Healthcare providers

- Identify FXS priorities, gaps, education, and communication needs
- Develop or adapt programs, products, and tools
- Develop a dissemination plan and disseminate
- Evaluate and continuously improve items above
- Ensure developed products are responsive to diverse audience and communication needs

**Must share materials with CDC and incorporate current evidence for successful communication and dissemination in all activities proposed.**

## Component C Requirements

- Applicants must demonstrate ability and capacity to
  - Identify and reach people with FXS and their families and communities, across the United States
  - Reach healthcare providers, specifically those treating FXS patients
  - Generate new communication materials and continually identify and update resources for healthcare providers treating and people with FXS and their families and communities
  - Quantify metrics of impact (for example, tracking and reporting use)

# Required Performance Measures for Strategy 3

Activity	Performance Measures	Frequency	Due Date/Start Date
<p>1. &amp; 2. Create, disseminate, evaluate, and continuously improve tailored FXS communication and programs, products, tools, and supports that fill a demonstrated need related to FXS.</p>	<p>Include in evaluation plan and metrics:</p> <ul style="list-style-type: none"> <li>• Describe the needs identified</li> <li>• Itemize and describe products and plan created</li> <li>• Provide statistics and qualitative feedback (if available) on reach and outcomes</li> <li>• Provide info on barriers/facilitators                             <ul style="list-style-type: none"> <li>• Provide status of activities</li> </ul> </li> </ul>	<p>Annually for Activity 1 and for Activity 2</p>	<p>Years 1-5</p>

**Activity 1** - People with FXS and their families and communities

**Activity 2** - Healthcare providers



# Submission Procedures

Seema Gupta

## Letter of Intent (LOI) – Optional

- Requested but optional
- Due Date: June 1, 2026
- Allows CDC staff to estimate the number of applications and plan for their review
- Send LOI via email to Seema Gupta at [cvk9@cdc.gov](mailto:cvk9@cdc.gov) with the following information:
  - The funding opportunity number and title
  - Your organization's name and address
  - A contact name, phone number, and email address
  - The component(s) for which you are planning to apply – A, B, C

## Application Contents and Format

- Table of contents (no page limit)
- Project summary
- Project narrative
  - Page limit: 20
  - Content beyond the specified limits will not be reviewed
  - Text single-spaced, 12-point font (Calibri), 1-inch margins, number all pages
- Background and approach
- Evaluation and performance measurement plan
- Organizational capacity
- Budget narrative (not scored)
- Attachments

## Budget Narrative

- Supports information in Standard Form 424-A
- Explain and justify costs in budget
- Include the following:
  - Salaries and wages
  - Fringe benefits
  - Consultant costs
  - Equipment
  - Supplies
  - Travel
  - Other categories
  - Contractual costs
  - Total direct costs (total of all items)
  - Total indirect costs

## Component B Budget

- Salary and wages for staff, including a principal investigator, project coordinator, recruiters/interviewers, data management, outreach, and evaluation
- Recruitment support costs (e.g., community outreach, printing study materials, mailing invitation packets, photocopying, etc.)
- Participant incentives (\$60 gift card for each survey completed)
- Equipment: laptops/encrypted thumb drives/software and related IT needs
- Facility costs (rent, electricity, etc.)

## Component C Budget

- Salary and wages for staff, including a principal investigator/project director, project coordinator, outreach, and evaluation
- Equipment: laptops/encrypted thumb drives/software and related IT needs
- Facility costs (rent, electricity, etc.)



# Review and Selection Process

Seema Gupta

# Application Review

## Initial Review

- Office of Grants Services initially reviews for eligibility and completeness
- Non-responsive applicants will not advance to the next phase of review

## Scoring Process

- Panel reviews applications using criteria outlined in NOFO

## Risk Review

- Review the risk that recipient will not manage federal funds prudently

## Merit Review Scoring Criteria

- Background and Approach (45 points section total)
  - Background (5 points)
  - Strategies and Activities (20 points)
  - Outcomes (5 points)
  - Work Plan (15 points)
- Evaluation and Performance Measurement Plan (20 points section total)
- Organizational Capacity (35 points section total)

## Background and Approach

- Background (5 points)
  - Shows a clear problem your organization will address
- Strategies and Activities (20 points)
  - Achievable and consistent with the CDC logic model (10 points)
  - Demonstrate the ability and intent to adhere to standardized methods, including data collection, data transfer, making data publicly available in a manner consistent with CDC guidance, and making manuscripts publicly available immediately upon publication (10 points)
- Outcomes (5 points)
  - Consistent with the outcomes in the CDC logic model
- Work Plan (15 points)
  - Aligns with the strategies, activities, and performance measures in the program description and is consistent with the recommended content and format (10 points)
  - Proposed use of funds aligns with the work plan and is an efficient and effective way to carry out the strategies and activities and achieve the outcomes (5 points)

## Evaluation and Performance Measurement Plan

- Ability to collect the data needed for evaluation and performance measurement (5 points)
- Clear monitoring and evaluation procedures, and how your organization will incorporate evaluation and performance measurement into planning, implementing, and reporting project activities (5 points)
- How your organization will report and use performance measurement and evaluation fundings to demonstrate outcomes and for continuous program quality improvement (5 points)
- Data management plan (5 points)
  - Capacity to implement and manage appropriate software (e.g., REDCap, R software, Filezilla), access and confidentiality standards, and archival and long-term preservation plans, and data limitations
  - Ability to comply with CDC data privacy, confidentiality, and security guidelines, and ability to release a public use dataset

## Organizational Capacity

- Staffing plan – roles and responsibilities, organization chart sufficient to achieve the project outcomes (10 points)
- Relevant experience among project staff and capacity to implement the strategies and activities and achieve project outcomes (10 points)
- Collaborations that support the applicant's capacity or add value to the project (10 points)
- Experience or capacity to implement the evaluation plan (5 points)

## Selection Process

- Applications will be funded in order by the rank that the review panel determines
- When making funding decisions, we consider merit review results
  - Key in making decisions but not the only factor
- CDC may fund applications out of merit review order
  - Ensure demographic and geographic representativeness
  - Ability to access participant contact information
- CDC may
  - Fund applications in whole or in part
  - Fund applications at a lower amount than requested
  - Approve but not fund one or more components which could be funded in the next fiscal year
- The number of awards is subject to available funds and agency and program priorities.

## Award Notices

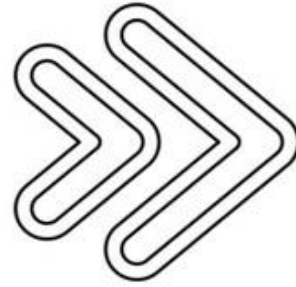
- If awarded, CDC will email a Notice of Award (NoA) to your authorized official
  - Only official award document
  - Amount of award, important dates, terms and conditions you need to follow
  - Work cannot begin until you receive the NoA
- We will notify you if your application is found not responsive or unsuccessful

## Key Dates

- **Optional letter of intent due:** June 1, 2026
- **Applications due:** June 15, 2026, 11:59 Eastern Standard Time
- **Tentative date for awards to be issued:** August 31, 2026
- **Project start:** September 30, 2026

## Agency Contacts

- **Programmatic Technical Assistance**
  - Seema Gupta, Project Officer
  - Email: [cvk9@cdc.gov](mailto:cvk9@cdc.gov)
- **Financial, Awards Management, or Budget Assistance**
  - Robyn Bryant, Grants Management Officer
  - Email: [ppa4@cdc.gov](mailto:ppa4@cdc.gov)
- **Submission Technical Assistance**
  - Grants.gov Contact Center
  - Phone: 1-800-518-4726



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## Questions and Answers

- Submit questions in the chat box.
- Deadline to submit questions (via [SPROUT@cdc.gov](mailto:SPROUT@cdc.gov)): June 9, 2026
- All questions and answers, as well as a recording of this call will be posted on the NOFO webpage:
- <https://www.cdc.gov/ncbddd/nofo-autism-fxs/index.html>

# Thank you.

For more information, contact CDC  
1-800-CDC-INFO (232-4636)  
TTY: 1-888-232-6348 <https://www.cdc.gov/>  
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