


# FORWARD-MARCH Database & Registry

## First There Was FORWARD

Join FORWARD-MARCH study →

Since 2012 the CDC supported the development of FORWARD Fragile X studies to expand understanding of Fragile X syndrome (FXS). The NFXF has been coordinating study efforts since the beginning and has been vital in ensuring its success.

The first FORWARD (which stands for Fragile X Online Registry With Accessible Research Database) study was launched in 2008 and piloted an infrastructure to study FXS across multiple sites. The Fragile X Clinical and Research Consortium was established and consists of a network of FXS specialty clinics across the United States who engage in collecting data.

The second study piloted the infrastructure for a registry and for longitudinal data

collection to support analysis of data over time in a large cohort.

The third study expanded FORWARD infrastructure even further. The data collected in FORWARD advanced knowledge about FXS, its co-occurring conditions, and outcomes.

The FORWARD study created the largest database of information on FXS in the United States. On September 1, 2021, the CDC issued a five-year award to continue to build upon the foundation of the three prior FORWARD grants in collaboration with CDC's Study to Explore Early Development (SEED) follow-up study.

This current study is called FORWARD-MARCH.

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## What is FORWARD-MARCH?

FORWARD-MARCH is the next step following the highly successful FORWARD research study.

Data from the FORWARD study is being used by researchers to learn about the lives of people with FXS. Thanks to families who contribute to FORWARD, researchers are learning about important things like medication use, behaviors, and development over time. These findings are shared with other researchers and clinicians in order to help develop targeted therapies and treatments. FORWARD data can be used in a variety of ways:

- Help inform new treatments and therapies for individuals with FXS.
- Help develop resources to help families, such as the NFXF
- Treatment recommendation documents.
- Demonstrate the need and direction of future, more in-depth research.

The FORWARD-MARCH (Multiple Assessments for Research Characterization) project collects more detailed information from participants with FXS and add it to the existing FORWARD database. FORWARD-MARCH continues the mission of FORWARD to better understand FXS in order to improve the lives of children and adolescents with FXS and the lives of their families.

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## Who Can Participate in FORWARD-MARCH?

Individuals with FXS born between 2003 and 2020 are eligible to participate in FORWARD-MARCH. This includes participants who were previously enrolled in the FORWARD study and those new to FORWARD.

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## What Does Participation in the Study Look Like?

The FORWARD-MARCH project collects survey data from parents and caregivers and conducts several tests with participants to understand their cognition (thinking), language, behavior, and autism characteristics.

Combined with information already collected in the FORWARD study, FORWARD-MARCH will also better define paths of development in FXS.

This is important in understanding the long-term effects of interventions and treatments designed to help people with FXS develop to their full potential.

The more individuals who enroll and participate, the more helpful this study will become in helping researchers understand FXS across the human lifespan.

**Your child's participation will help healthcare professionals and educators create better therapeutic and educational programs that could benefit millions of individuals with FXS throughout the world.**

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## How Can I Enroll My Child in the Study?

Families who want to join FORWARD-MARCH should contact their nearest Fragile X clinic.

Please also visit Join FORWARD-MARCH! for more information, including frequently asked questions.

### Thank You

THANK YOU to all participating families for your willingness to share your life experiences for research. By giving families, doctors, scientific researchers, and policymakers an inside look into how FXS presents itself across the human lifespan, we can facilitate the actions needed to reach more positive health outcomes and an improved quality of life. Your participation in FORWARD will lead to better care and services for future generations affected by FXS.

### A Note about Privacy

Records of participation in this research study will be maintained and kept confidential as required by law. This research project has a Certificate of Confidentiality from the Centers for Disease Control and Prevention that provides additional protection from involuntary disclosure of information collected in the study.

This project was made possible by Cooperative Agreement 1 U01DD001298-01-00 from the Centers for Disease Control and Prevention.

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## Publications Resulting from FORWARD Data

view all

We are excited to share journal publications resulting from FORWARD data, with many more papers currently in development! The future for FXS research is bright as more rich data are gathered.



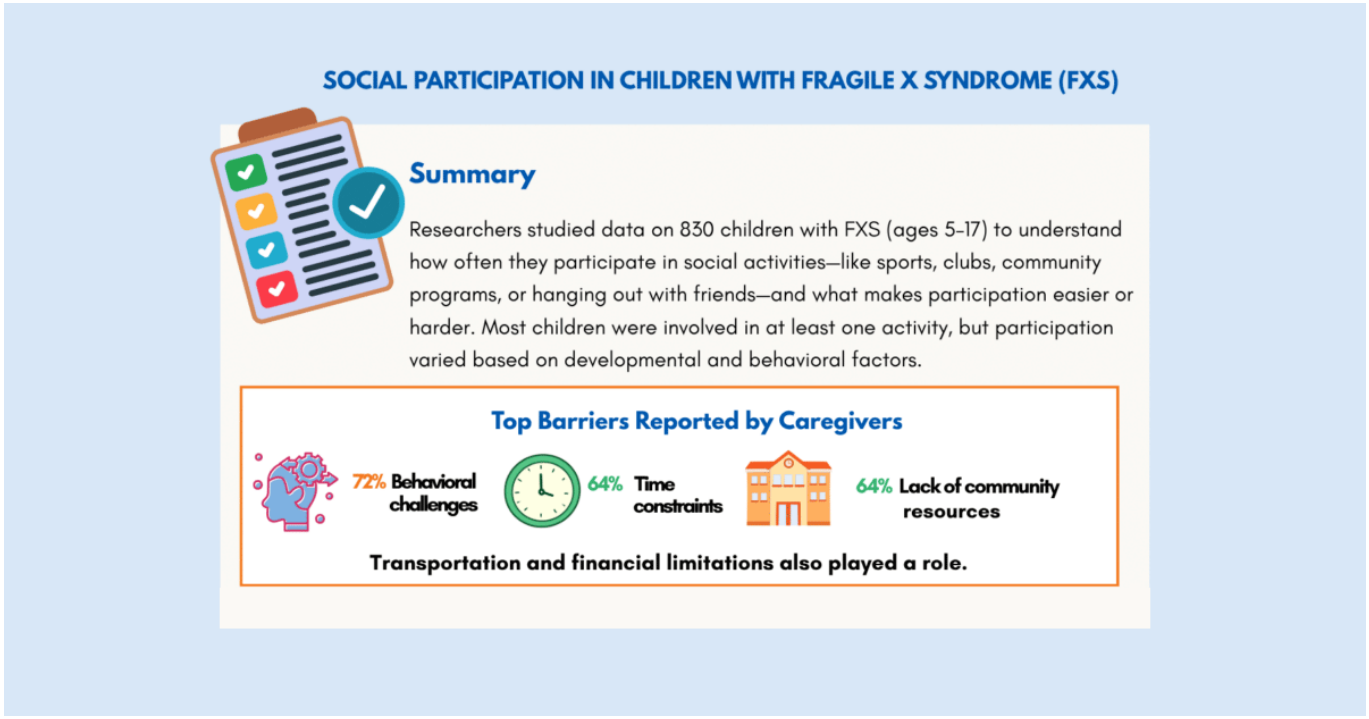

- Managing Behaviors
- Research

## Profile of Behavioral Comorbidities in Children With Fragile X Syndrome

October 22, 2026

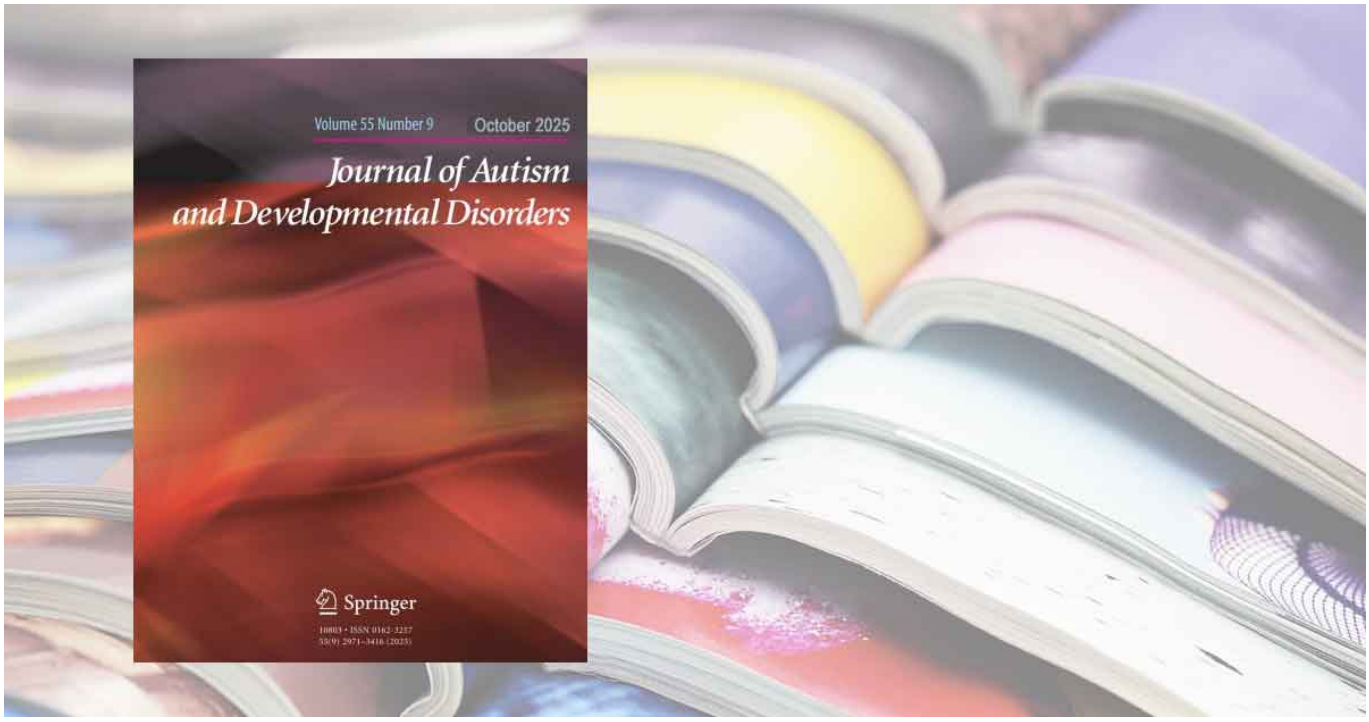
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## Relationship Between Intellectual Disability and Behavioral Comorbidity in Children with Fragile X Syndrome

November 12, 2025

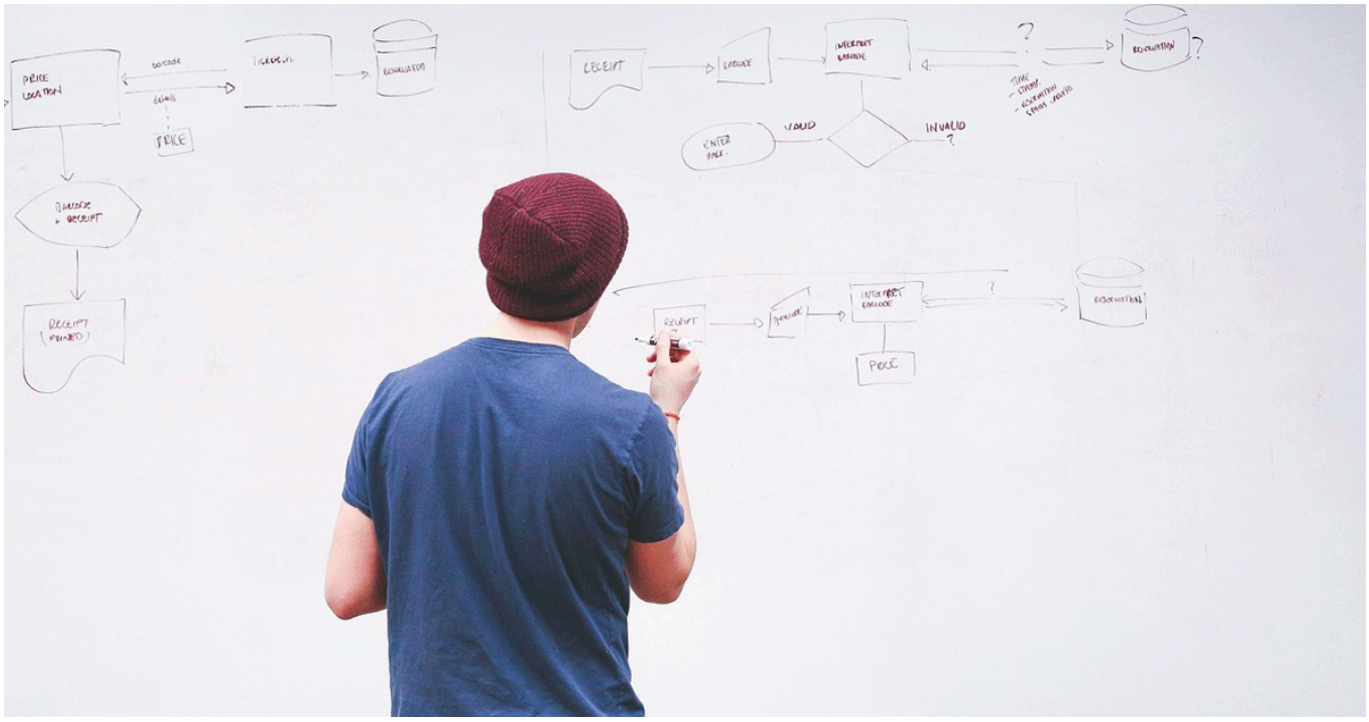
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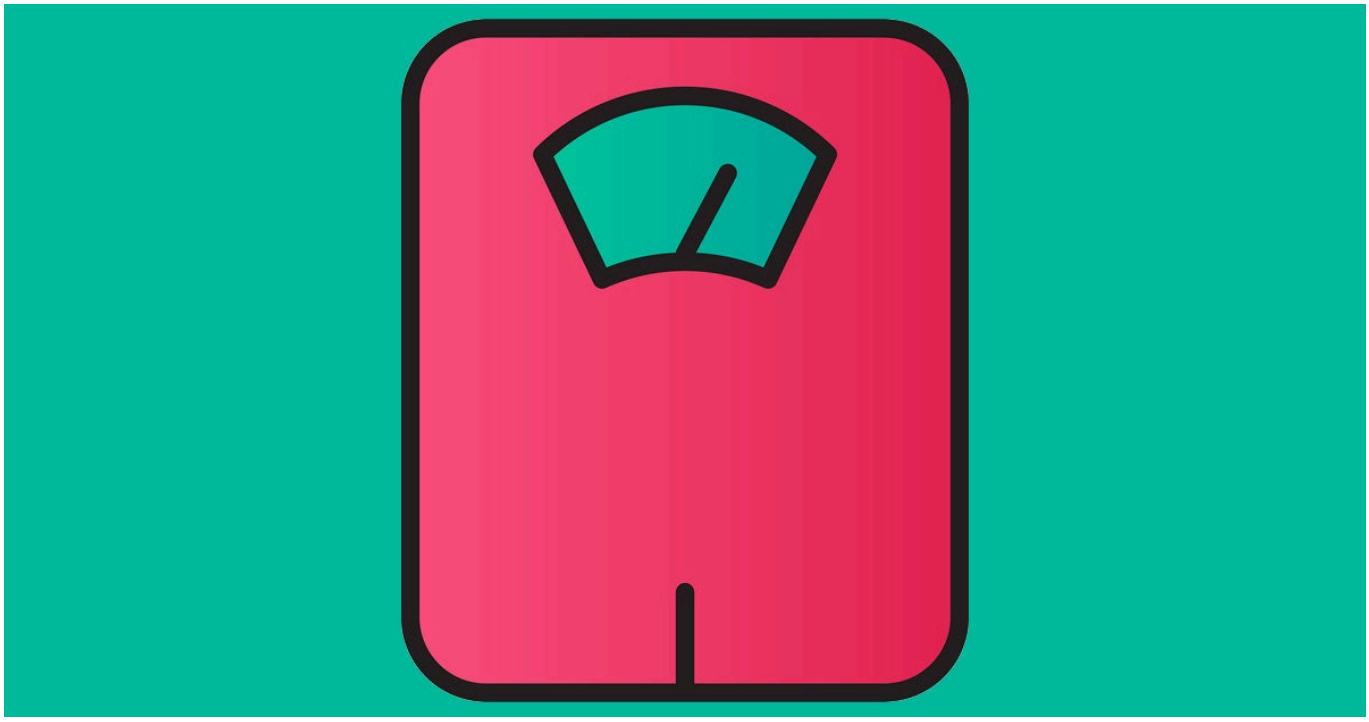
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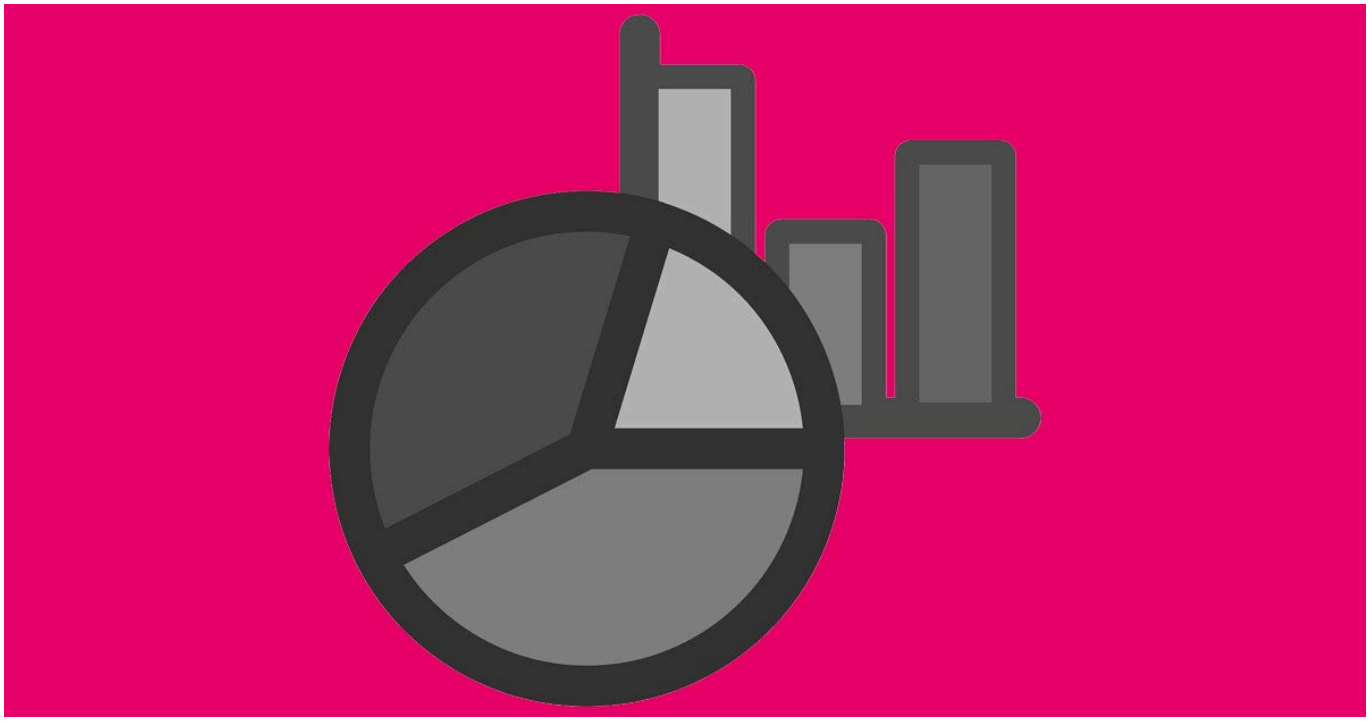
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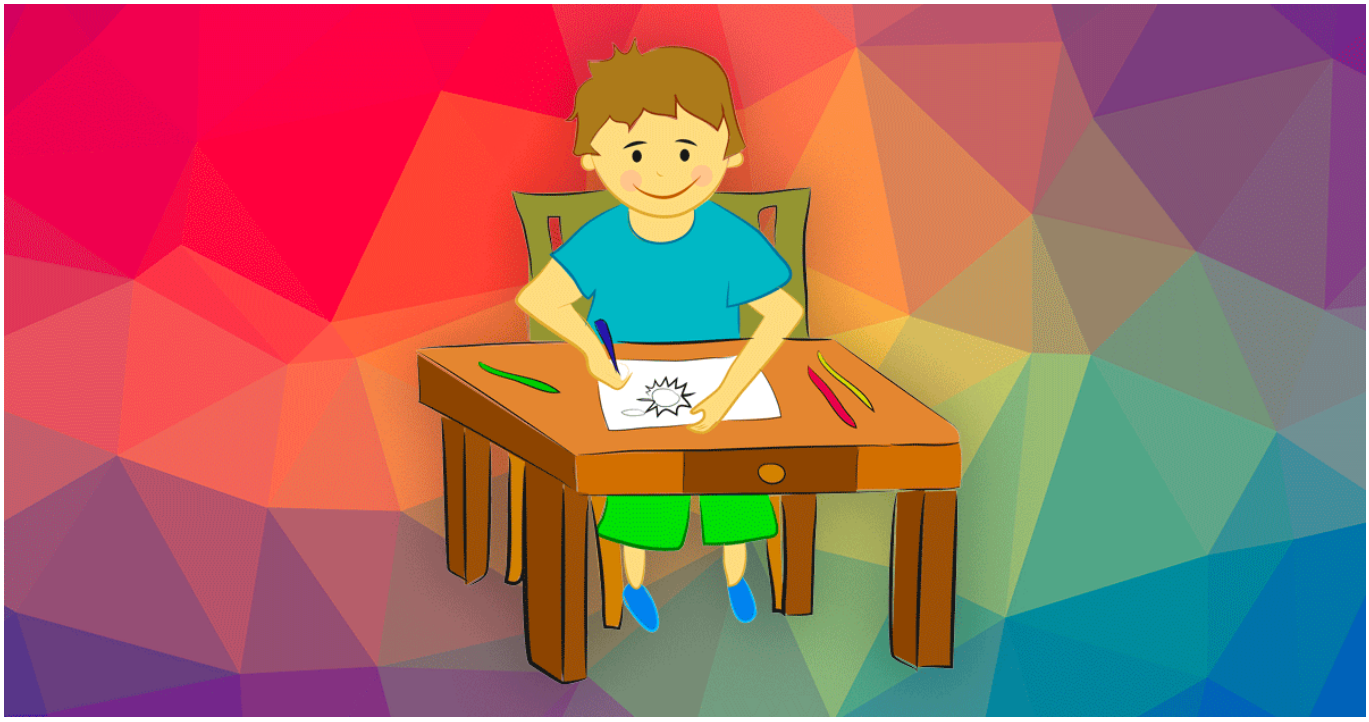
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# Find a Participating Clinic Near You

**This is a list of FXS clinics currently participating in the FORWARD-MARCH Study.** To search **all FXS clinics**, please visit our FXS Clinic Finder.