

Future Opportunities

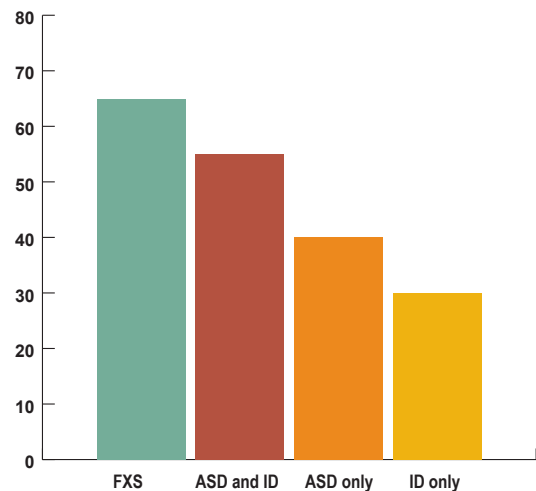
- There is limited information about whether the number of people affected by FXS varies by race or ethnicity. A large-scale study could provide a more specific estimate of how many people live with FXS. A large-scale study could also yield more information on the relationship between changes in genetic material and symptoms faced by people with FXS and [fragile X-associated disorders](#).
- Healthcare professionals, researchers, and families have shown an interest in screening newborns for FXS as a way to identify FXS as early as possible. To date there has not been a study comparing people who receive care and services for FXS shortly after birth with those who receive care and services for FXS after they develop symptoms of the condition. A study of this type could assess whether people with FXS do better when medications and therapies begin in the newborn phase or when these begin later.

What is CDC doing?

- **Building evidence through public health research.** CDC funds the collection of data for public health use from people receiving care at FXS specialty clinics across the United States.
 - Examples of these data include age at diagnosis, the age when a child reaches milestones like walking and toilet training, level of intellectual ability, care and services received by each person, and each person's access to preventive services. CDC scientists and research partners can use this information to
 - » Describe the symptoms and challenges of FXS across the lifespan; and
 - » Identify the care and services provided to people with FXS and measure how well that care is working for them.
- **Using data to address the impact of FXS on people and their families.** CDC scientists and research partners are using existing data to
 - » Report on school services used by individuals with FXS, such as how many school-aged children with FXS are
 - Receiving instruction in a regular classroom setting;
 - Assisted by a personal aide at school; and
 - Receiving occupational therapy, speech therapy, and/or physical therapy
 - » Report on the reasons why people with FXS go to the emergency room.
- **Collaborating with partners.** CDC collaborated with the American Academy of Pediatrics to develop and distribute educational materials to healthcare professionals and families. These materials are designed to raise awareness of FXS and encourage early diagnosis so that people with FXS can receive appropriate care and services.

Percentage of families reporting excessive financial expense

A comparison of family, financial, and employment effects of fragile X syndrome, autism spectrum disorder, and intellectual disability¹



More families caring for a child with FXS reported excessive financial expense as compared to families caring for a child with autism spectrum disorder (ASD), intellectual disability (ID), or those caring for a child with both ASD and ID.¹

Reference

Ouyang L, Grosse SD, Riley C, Bolen J, Bishop E, Raspa M, Bailey DB. [A comparison of family financial and employment impacts of fragile X syndrome, autism spectrum disorders, and intellectual disability](#). Research in Developmental Disabilities. 2014 Jul;35(7):1518-27.

For more information visit <http://www.cdc.gov/fragileX> or call 1-800-CDC-INFO