

Socialization relative strength in fragile X longitudinal study

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Standard scores measuring "adaptive behavior" in boys with fragile X syndrome tend to decline during childhood and adolescence, the largest longitudinal study of the inherited disorder to date has found.

Adaptive behavior covers a range of everyday social and practical skills, including communication, socialization, and completing tasks of daily living such as getting dressed. In this study, socialization emerged as a relative strength in boys with fragile X, in that it did not decline as much as the other two domains of [adaptive behavior](#) measured: communication and daily living skills.

Fragile X syndrome is the leading inherited cause of intellectual disability and the leading single-gene risk factor for [autism spectrum disorder](#). It affects one in 4000 boys and one in 8000 girls, and boys tend to be more severely affected, because boys have just one X chromosome while girls have two. Measured IQ shows a range from average to severe intellectual disability, with an average IQ of 40 in males who have complete silencing of the FMR1 gene.

The results are published in the journal *Pediatrics*.

The study's findings will help child development specialists refine educational programs for individuals with fragile X syndrome, and could inform the design of clinical trials now underway for drugs that target the molecular deficiencies arising in fragile X syndrome.

Adaptive behavior is often studied in individuals with intellectual disability, because it indicates someone's ability to function independently.

"Adaptive behavior is separate from measures of intelligence such as IQ, but it can be a more important predictor of success," says lead author Cheryl Klaiman, PhD, formerly of the Stanford University Center for Interdisciplinary Brain Sciences Center, now senior psychologist at Marcus Autism Center and assistant professor of pediatrics at Emory University School of Medicine.

"Our findings highlight the need for continued attention to adaptive behavior skills for individuals with fragile X syndrome, in both special education programs and home-based care."

Researchers from Stanford and the University of North Carolina followed the families of 275 children and adolescents with fragile X syndrome (186 were boys) and 225 typically developing children and adolescents. 60 percent of the typical controls were siblings of study participants with fragile X.

Study participants' caregivers were interviewed using the Vineland Adaptive Behavior Scales every two to four years. The Vineland framework asks caregivers whether the child never, sometimes/partially or always performs a given task, and was divided into socialization, communication and daily living realms.

For typically developing children, their average standard score in each area was around 100 and the average generally remained steady with age. For boys with fragile X, the average standard score for all three areas starts at around 60 in early childhood and declines significantly into the teens. Daily living skills did increase in males with fragile X after 14 years of age. This gain could perhaps be due to the increased efforts

focused on teaching these skills prior to graduating from high school.

The decline doesn't mean that boys with fragile X are losing skills over time, Klaiman says.

"It does mean that they are not keeping pace with their typically developing peers of the same age, or expectations based on their initial scores in early childhood," she says.

Adaptive behavior scores for girls with fragile X start lower, compared to typically developing children, but do not decline as much as males' scores do over time. As a group, their scores also have a wider range. For girls, communication declines more than other domains.

Provided by Emory University

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