

# **Waisman Center University of Wisconsin – Madison**

*Dedicated to the advancement of knowledge about human development, developmental disabilities, and neurodegenerative disease.*

## **Study on Family Adaptation to Fragile X Syndrome**



### **Report 5: Social Activities and Friendships of Adolescents and Adults with Fragile X Syndrome**

#### **- Principal Investigators -**

**Marsha R. Mailick, PhD  
Jan S. Greenberg, PhD  
Leann S. DaWalt, PhD**

## Acknowledgements

This research was funded by ongoing grants from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development to support research on family adaptation to fragile X syndrome (R01 HD082110; P30 HD003100-S1) and to support research training in intellectual and developmental disabilities (T32 HD07489). It was additionally funded by grants from the National Institute on Aging (R01 AG08768) and Autism Speaks (AS#7724) to support longitudinal research on families of adolescents and adults with autism. We are also grateful for the support we received from the Waisman Center (U54 HD090256).

We are extremely grateful to the families who participated in this study; without their generous support and commitment, our research would not be possible. We also thank our staff, Renee A. Makuch, Jinkuk Hong, Ph.D, Arezoo Movaghar, M.S., and particularly Lauren V. Usher, Ph.D. for her hard work and expertise in preparing this report.

**Cover Art:** *Sea with Boats* by Peter from Denmark. The artwork is from the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities, sponsored by the Friends of the Waisman Center.

**Visit us at our website:** <http://www.waisman.wisc.edu/family>

## Table of Contents

<b>Section I: Introduction .....</b>	<b>1</b>
<b>Section II: Social Quality of Life for Adolescents and Adults with Fragile X Syndrome .....</b>	<b>2</b>
Social and Recreational Activities .....	4
Friendships .....	6
<b>Section III: Conclusions .....</b>	<b>9</b>

## **Section I: Introduction**

In our past reports, we have shared information about the daily life experiences of mothers who have a child with fragile X syndrome (FXS), as well as their health symptoms and emotional well-being. We have also reported on the way that daily living skills and behavior problems change over time for individuals with FXS during adolescence and adulthood.

Mothers participated in telephone interviews and completed mail-back questionnaires, reporting on multiple aspects of their children's lives. This family report presents data regarding social and recreational activities and friendships for individuals with FXS.

We are very grateful to the families who have provided us with this in-depth information about the lives of their adolescent and adult children. We hope our research not only will continue to inform understanding of the patterns of development for individuals with FXS but also will provide data to help shape new services and supports for them and for their families. We look forward to the opportunity to continue to partner with your family in this work in the future.

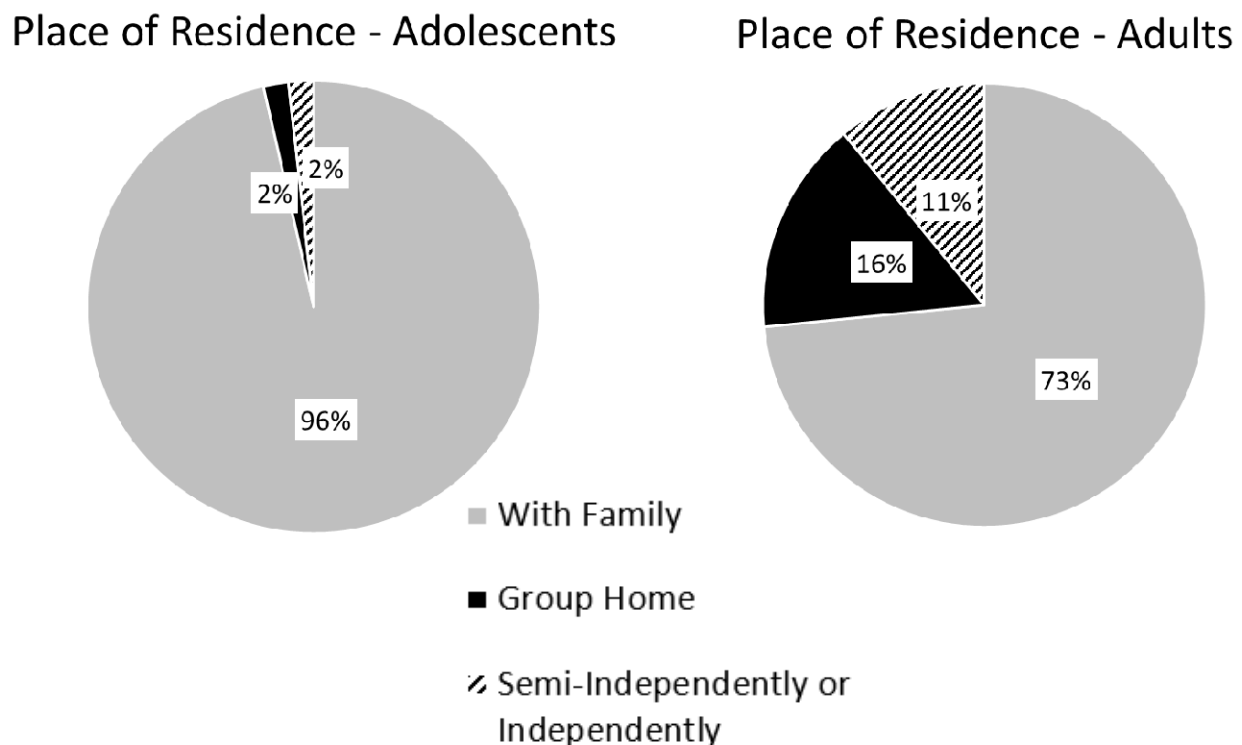
If you would like to learn more about the purpose of the study, our staff, and articles written about our Family Adaptation to FXS Study please visit the study website: [http://www.waisman.wisc.edu/family/study\\_frax.html](http://www.waisman.wisc.edu/family/study_frax.html)

## **Section II: Social Quality of Life**

This report includes data from 122 adolescents and adults with FXS and their families. Families in our study resided in 38 US states and one Canadian province. Almost half of the participants with FXS (46%) were 21 years old or younger (referred to as adolescents) and 54% were 22 years old or older (referred to as adults). Adolescents ranged from 15 to 21 years old (average age = 18.5) and 23.2% were female. Adults ranged from 22 to 47 years old (average age = 29.4) and 13.6% were female. We divided the study participants into these two age groups based on federal eligibility criteria for special education that specify that individuals with disabilities are able to receive public school services in the U.S. through age 21. Mothers of adolescents and adults with FXS ranged in age from 40 to 74 (average age = 54.4 years). Most mothers had a college or graduate degree (90%) and were married (83.2%).

Most adolescents and adults with FXS lived in with their families (see Figure 1), although in adulthood about one-quarter lived either independently or semi-independently, or in group homes.

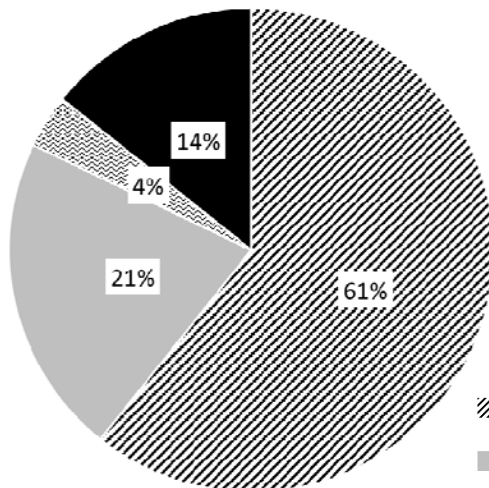
**FIGURE 1. Place of Residence for Adolescents and Adults with Fragile X**



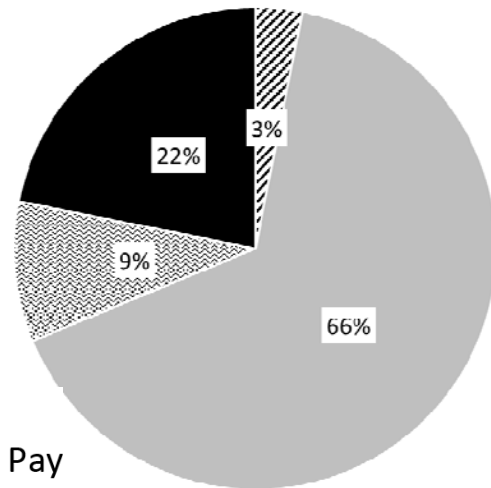
Most adolescents and adults with FXS were either working for pay (competitive or supported employment) or enrolled in school (see Figure 2). If the adolescent or adult with FXS was both in school and working for pay, working for pay was the activity reported below. Not surprisingly, adults were more likely to be working for pay, while adolescents were more likely to be enrolled in school.

**FIGURE 2. Daily Activities for Adolescents and Adults with Fragile X**

**Daily Activities - Adolescents**



**Daily Activities - Adults**



/ School  
 ■ Working for Pay  
 ■ None  
 ■ Other

**Comparison Group of Adolescents and Adults with Autism**

We selected a group of adolescents and adults with autism to serve as a comparison group with respect to the social and recreational activities and friendships of those with FXS. The comparison group was drawn from the Adolescents and Adults with Autism (AAA). Many of the questions that were asked of the mothers of children with FXS also were asked in the AAA study.

**Our Key Questions**

To understand social quality of life for adolescents and adults with FXS, we explored two key areas: social and recreational activities, and friendships. For each, we compared adolescents and adults with FXS to adolescents and adults with autism. We also examined what factors were associated with better outcomes in each area, including residential status (living with the family versus living away), age, and behavior problems. Findings for each outcome are presented below.

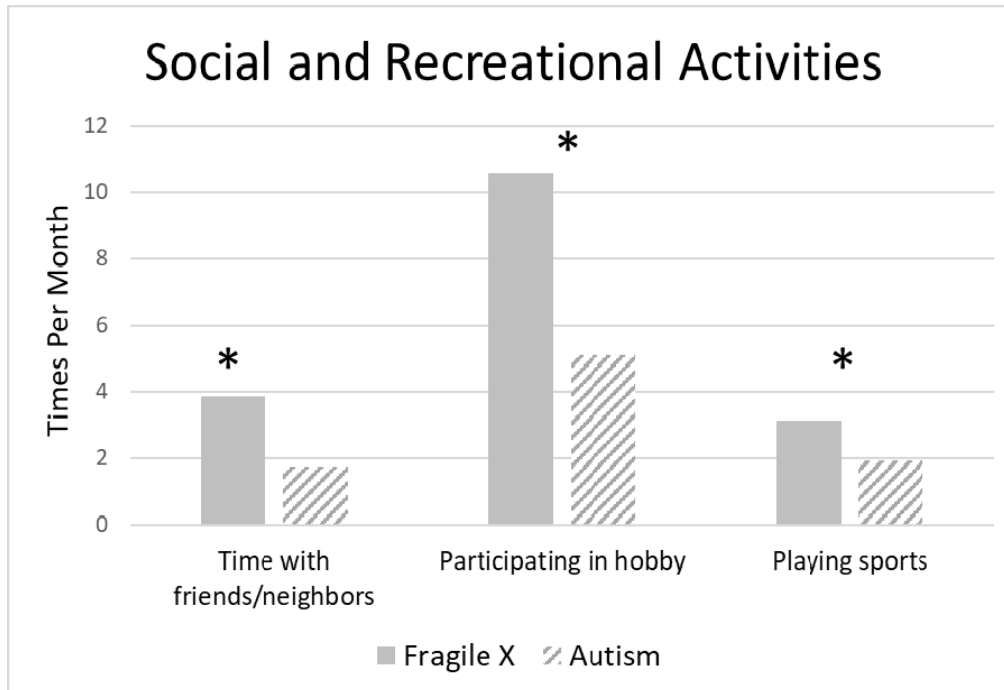
## Social and Recreational Activities

Mothers reported on the number of times per month their sons or daughters with FXS engaged in the following social and recreational activities:

- Spending time with relatives
- Spending time with classmates or coworkers
- Spending time with friends and neighbors
- Attending religious services
- Participating in activities such as bowling or watching movies
- Participating in hobbies such as video games
- Playing sports
- Exercising

As shown in Figure 3, compared to adolescents and adults with autism, adolescents and adults with FXS were more likely to spend time with friends and neighbors, to participate in a hobby, and to play sports. On average, adolescents and adults with FXS spent time with friends and neighbors about once a week, worked on a hobby more than twice a week, and played sports 3 times a month.

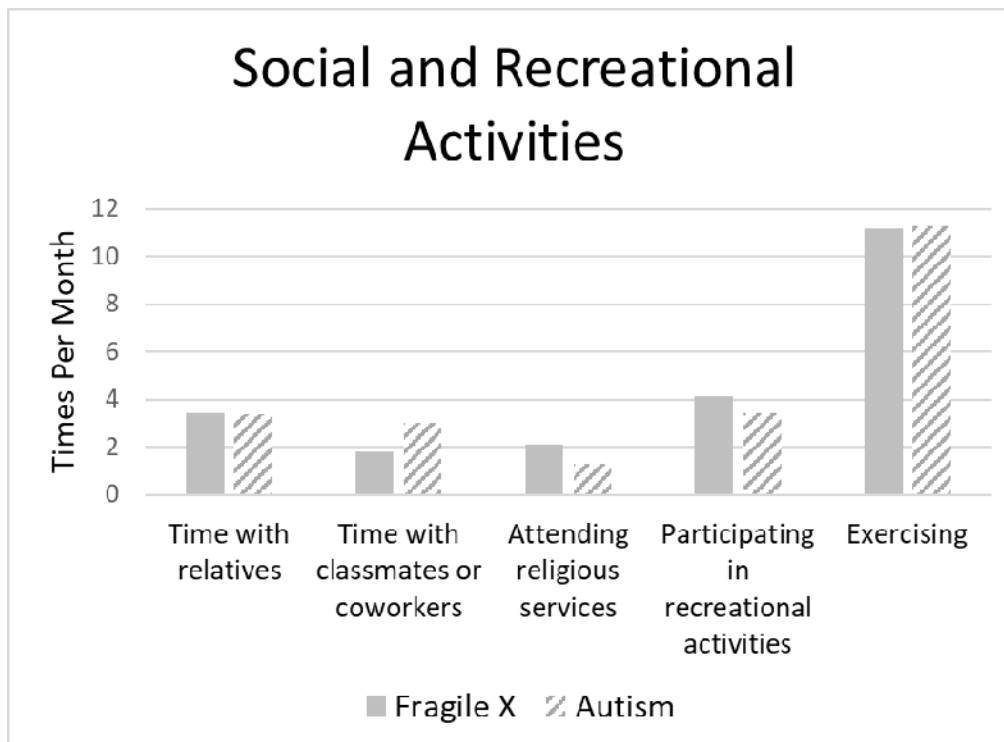
**FIGURE 3. Differences in Frequency of Social and Recreational Activities Per Month for Individuals with FXS and Individuals with ASD**



**Note.** \* indicates a statistically significant difference.

As shown in Figure 4, there were no statistically significant differences between individuals with FXS and those with autism with respect to the amount of time spent with relatives, with classmates or coworkers, attending religious services, participating in recreational activities, or exercising. Individuals with FXS and those with ASD spent time with relatives, classmates or coworkers, attended religious services, and participated in recreational activities once a week or less, and exercised more than twice a week.

**FIGURE 4. Similar Frequency of Social and Recreational Activities Per Month for Individuals with FXS and Individuals with ASD**



### ***What Predicts Participation in Social and Recreational Activities?***

We also were interested in what factors predict engagement in social and recreational activities for adolescents and adults with FXS. We examined residential status, age, and behavior problems as potential predictors.

We found that those who lived away from their family spent more social time with coworkers, were more engaged in recreational activities, and exercised more. In contrast, those who lived with their family had more involvement in religious services and in hobbies.



Adolescents were less likely than adults to spend time with relatives and with friends or neighbors. However, adolescents were more likely than adults to exercise.

We had expected that individuals who were experiencing high levels of behavior problems would be less likely to participate in social and recreational activities. Surprisingly, we found that the level of behavior problems was not associated with participation in social and recreational activities.

## **Friendships**

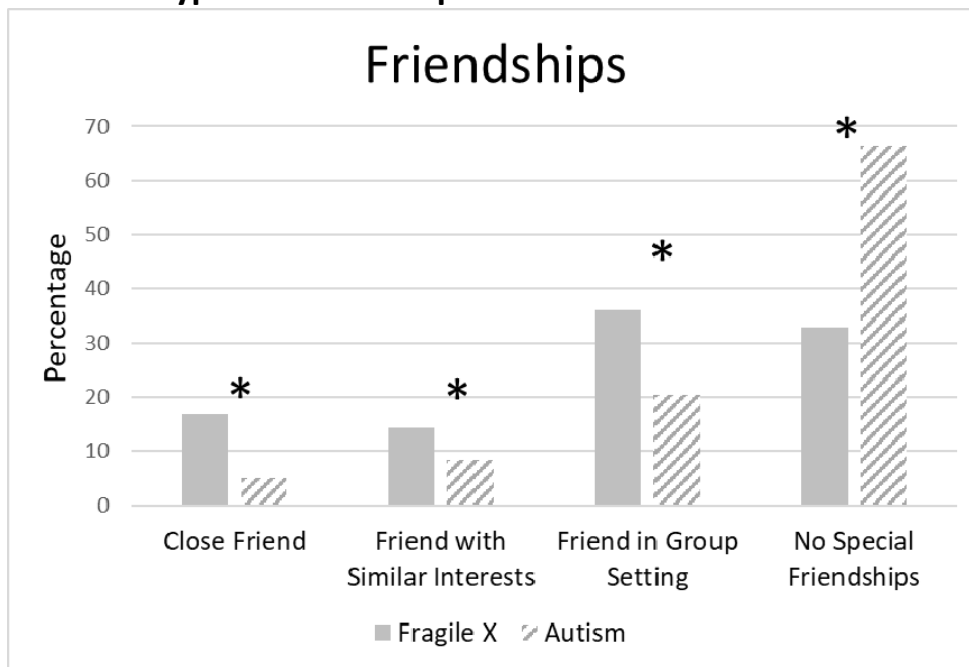
Mothers reported on the quantity and quality of their adolescent or adult child's friendships. Individuals were categorized into one of four groups according to their most common type of friendship:

1. **Close Friend(s):** Having one or more mutual friends in approximately the same age group with whom they share a variety of social activities;
2. **Friend(s) with Similar Interests:** Having one or more friends with a shared interest (for example, Pokémon);
3. **Friend(s) in Group Setting:** Having a friend in a group setting or at school/work;
4. **No Special Friendships:** Not having peer relationships that involve selectivity or sharing.

As shown in Figure 5, on average, the most common type of friendship for adolescents and adults with FXS was having a friend in a group setting. Also, individuals with FXS were almost twice as likely to have friends in each category, compared to those with autism.

Almost 40% of adolescents and adults with FXS had friends in group settings. Almost 15% had friends with similar interests, and over 15% had close friends. About one-third reported no special friendships. However, since most adolescents and adults attended school or had work activities, even those adults without special friendships had regular opportunities for social interaction.

**FIGURE 5. Percentage of Individuals with FXS and Individuals with ASD for Different Types of Friendships**



**Note.** \* indicates a statistically significant difference.

### ***Comments From Mothers***

We recorded mothers' responses about the friendships of their sons and daughters with FXS. Below are composite responses from mothers that we use to illustrate different types of friendships that adolescents and adults with FXS have.

#### **1. Close Friend(s):**

"He calls them or they'll call him. He talks to me about them. As a matter of fact we're going to a concert in a couple weeks with a couple of his friends. He wants to have someone over every weekend. So, he'll suggest it and if I'm open to it I'll call the mother and arrange it, or he might text the friend to see if they're even free to come over first."

#### **2. Friend(s) with Similar Interests:**

"They like to get together [to watch TV]. Other than the TV programs they watch, [they don't share other interests]. I think it's pretty centered on that."

### **3. Friend(s) in Group Setting:**

“Well, he talks about a few of them from the day program, but he doesn’t really talk to them outside of the program. He’s in a social group so they do a trip once a week. He considers some people to be his friends but only because he knows them through there. He has a rapport with people. It doesn’t translate into a friendship outside of that location. He’s not great without structure, so that’s better for him.”

### **4. No Special Friendships:**

“[He’ll talk about people at school] only if we really prod him. He doesn’t ask and he doesn’t call people or anything. He also does swimming... But he really does not socialize with [the other swimmers]. He does his own thing.”

### ***What Predicts Friendship Types?***

We also were interested in what factors predict having a friend for adolescents and adults with FXS. To explore this question, we examined whether age, residential status, and behavior problems were related to having a close friend, friend with similar interests, or a friend in group setting.

Our results indicated that having a close friend or a friend in group setting was predicted by having fewer behavior problems. Adolescents were more likely to have friends with similar interests than were adults. Also, individuals who lived away from the family were more likely to have a close friend or a friend with similar interests.

### **Section III: Conclusions**

In this report, we described the pattern of involvement in social activities and friendships of individuals with FXS in adolescence and adulthood. We also reported on the factors that predict favorable social outcomes.

When considering the frequency of engaging in various social and recreational activities, we found that in the course of a typical month, adolescents and adults with FXS exercised about twice a week, participated in a hobby also about twice a week, played sports about three times in the month, spent time with friends and neighbors about once a week, and once a week or less often spent time with relatives, classmates or co-workers, attended religious services, or participated in group recreational activities. Thus, their lives were rich with social and recreational activities. Indeed, they were more likely than those with autism to have a hobby, to spend time with friends and neighbors, and to play sports. Our data also suggest that, regardless of levels of behavior problems, the individuals with FXS in our study were engaged in social and recreational activities such as spending time with friends and neighbors and exercising.

We also observed age differences within the sample of participants with FXS. Adolescents were less likely than adults to spend time with relatives and with friends and neighbors, and were more likely to exercise.

We found that most individuals with FXS, regardless of age, were more likely to have friendships than were same-age peers with autism. The types of friendships varied, with some individuals having close friends, others having primarily friends with similar interests, and most having friends with whom they engaged in group settings only. Adolescents and adults with fewer behavior problems were more likely to have a friend.

These findings are encouraging as they demonstrate that the majority (about 70%) of individuals with FXS had friendships of one type or another. And since over 80% of adolescents with FXS and almost 70% of adults with FXS were engaged in school or work, the majority of adolescents and adults with FXS have opportunities for regular social interaction and friendships.

We aim to share these findings, along with future data, with researchers and practitioners to inform them of what we have learned about the social and recreational experiences of adolescents and adults with FXS. We also intend to gain a better understanding of health and well-being for mothers and how their own genetic status may interact with the stress of raising a child with FXS.