Waisman Center
University of Wisconsin – Madison

Advancing knowledge of human development, developmental disabilities, and neurodegenerative diseases.

Study on Family Adaptation to Fragile X Syndrome

Report 6: Health and Vocational Activities of People with Fragile X Syndrome in Adulthood

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Section I: Introduction

This is the 6th Family Report we are sharing with families who have participated in our *Family Adaptation to Fragile X Syndrome* study during the past 10 years. 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 how daily living skills and behavior problems change over time for individuals with FXS during adolescence and adulthood.

For our study, mothers participated in telephone interviews and completed mail-back questionnaires, reporting on multiple aspects of their family and children's lives. This family report presents data regarding the health of their son or daughter with FXS as well as the vocational and employment activities that individuals with FXS engage in after they exit high school.

Because our study is longitudinal, spanning four interviews with families over nearly a decade, we are able to report how the health and daily lives of individuals with FXS change as they enter adulthood. This makes our study unique, and as we explain at the end of this report, we hope to continue to learn from you and your entire family.

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 knowledge about the course of FXS, but also will provide us with valuable information to share with professionals and policy makers to help shape new services and supports for individuals with FXS 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 read prior family reports or research publications, please visit the study website: **http://www.waisman.wisc.edu/family/study_frax.html**

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Section II: Health of Adolescents and Adults with FXS

This section of the report provides a description of the health of adolescents and adults with FXS. The questions in our study focused on health care utilization, ratings of general physical health, body mass index, specific health conditions, and the use of medications. Our goal was to identify what health problems are common in FXS, what medications are frequently used, and how health may change over time.

Physical Health

In each of the interviews, we asked mothers to tell us whether their son or daughter with FXS had received a complete physical examination and had been to the emergency room in the past year. It is encouraging that 91% of adolescents and adults with FXS had received a complete health exam/physical in the past year and only 12% had been to the emergency room.

Because we are interested in the overall health of the individuals in our study, in addition to questions on health care utilization, we asked mothers the following question: *How would you rate your son or daughter's physical health status at the present time (poor, fair, good, or excellent)?*

Figure 1 below shows how mothers rated the physical health of their sons and daughters at the first interview in 2008-2009.

- This figure shows that at the time of the first interview, the majority of mothers rated their son or daughter's health as good or excellent, while almost none of the sons and daughters were rated as having poor health.

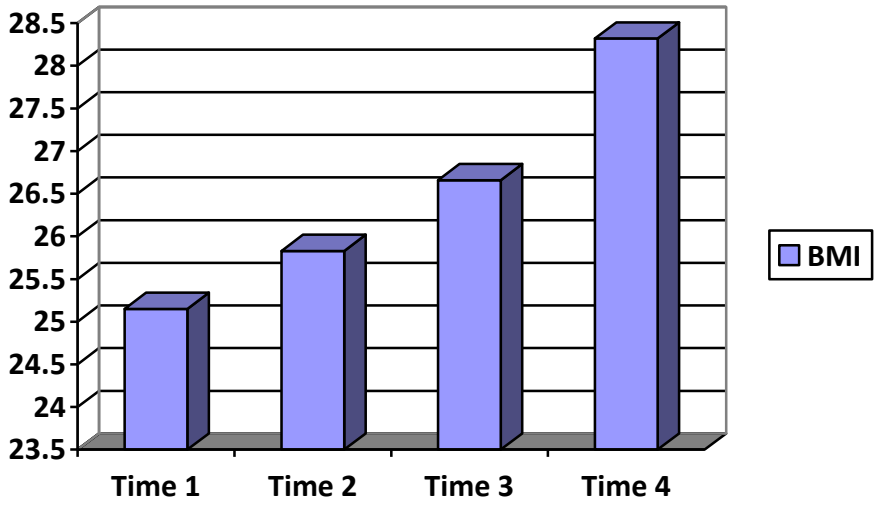
- A similar pattern of health was reported at each of the three later interviews, indicating stability in the health of individuals with FXS over 10 years.

Body Mass Index

In addition to asking questions about general health, we also were interested in knowing about possible obesity among adolescents and adults with FXS. Body Mass Index (BMI) was calculated for the adolescents and adults with FXS using mother's report of height and weight at each of the four interview time points (Time 1, Time 2, Time 3, and Time 4). BMI is a ratio of weight to height that is used as an index of healthy versus unhealthy body weight (National Institutes of Health 2006).

BMI of less than 18.5 indicates underweight, 18.5–24.9 indicates normal weight, 25-29.9 indicates overweight, and BMI of 30 or greater indicates obesity.

Figure 2 below shows average BMI for the adolescents and adults with FXS at each wave of the study.



- BMIs at each wave ranged from 14 to 50. At the start of the study, 13.5% were underweight, 42.1% had a normal weight, 22.6% were overweight, and 21.8% were obese.

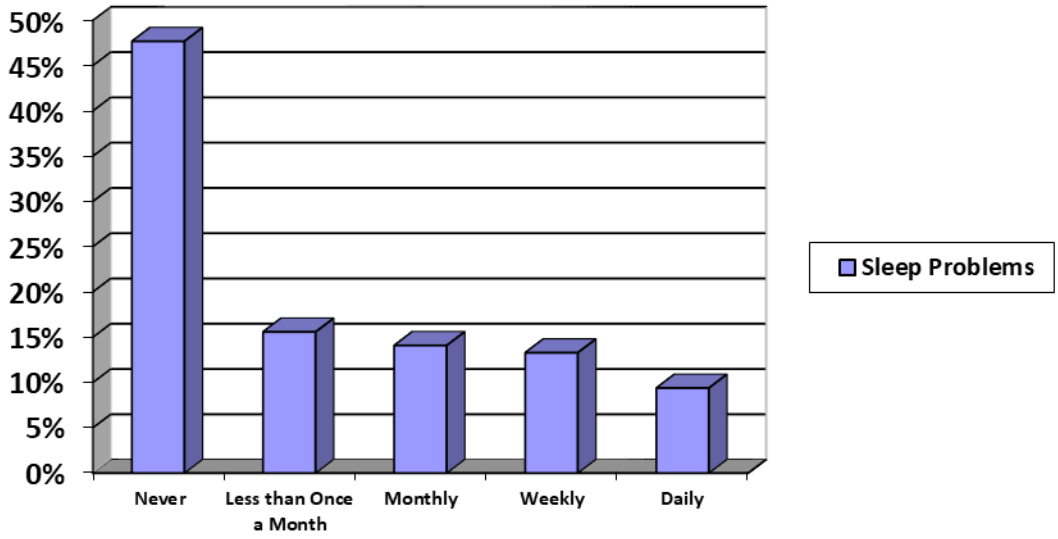
- On average, the BMIs of the individuals with FXS increased over the study, with 32.2% being overweight and 34.4% being obese by Time 4.

- Although many individuals with and without disabilities gain weight as they get older, the degree of weight gain observed in our study is concerning. Over two-thirds of the adults with FXS were overweight or obese at the time of the last interview, and the trends toward weight gain during adolescence and early adulthood suggest elevated risk of weight-related health problems during adulthood.

Specific Health Conditions

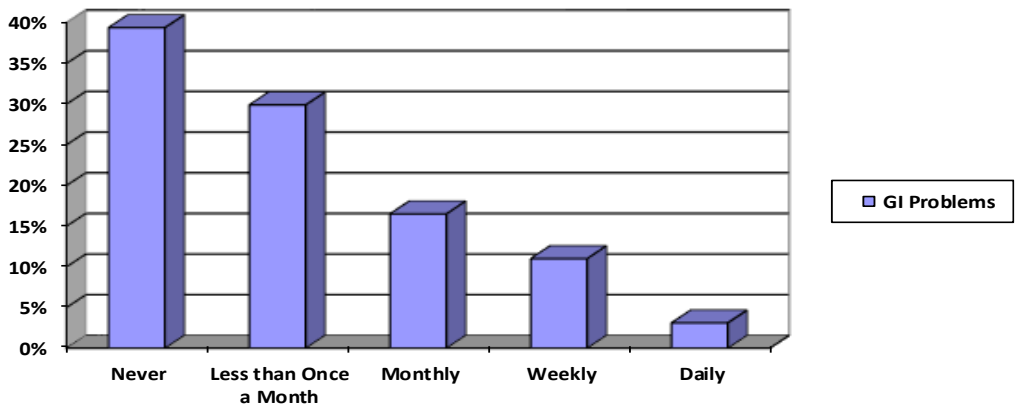
Many individuals with developmental disabilities have difficulties with sleep and also gastrointestinal problems. At our first interview we asked mothers to report how often their son or daughter with FXS had difficulty getting to sleep or staying asleep. We also asked mothers to report how often their son or daughter experienced indigestion, constipation, or other gastrointestinal problems.

Figure 3 below shows the frequency of sleep problems.



- As shown above, over half of the adolescents and adults with FXS experienced sleep problems, with over 20% experiencing these problems as at least once a week.

Figure 4 below shows the frequency of gastrointestinal problems.



- Over 60% of the adolescents and adults experienced gastrointestinal problems, with almost 15% experiencing these problems at least once a week.

We also asked mothers whether their son or daughter had experienced or been treated for any of a list of 36 health conditions within the past 12 months. This list included conditions such as allergies, persistent skin trouble, hypertension, sleep apnea, and thyroid disease.

- Of these 36 conditions, only one condition, allergies, was experienced by more than 10% of the adolescents and adults with FXS.

- Five other conditions were experienced by 5-10% of the sample: skin conditions, foot problems, high blood pressure, asthma, and high cholesterol.

- Similar patterns of health conditions were observed at each of the four data collection interviews.

Although these are common problems faced by adults who do not have FXS, the high degree of sleep and GI problems presents many challenges for families. Problems with blood pressure and high cholesterol are also concerning and may potentially be related to weight gain.

Medications

Over 70% of the individuals with FXS in our study take prescription medications. We asked mothers to provide information about those medications, including the primary reason why their son or daughter takes each medication. In response, the parents in our study provided information on nearly **700 prescription medications** that their sons and daughters were currently taking.

We divided the medications into two broad groups: psychotropic medications and non-psychotropic medications. Psychotropic medications are prescribed to alleviate symptoms of behavior problems and related conditions affecting the brain, while non-psychotropic medications are prescribed to alleviate or treat medical conditions.

- At the time of the first interview, 69% of adolescents and adults with FXS were taking psychotropic medications such as antidepressants, stimulants, and antipsychotics.

- Fully 18% of adolescents and adults with FXS were taking non-psychotropic medications such as anticonvulsants for seizures, birth control, and gastrointestinal medications.

Of those sons and daughters taking a prescription medication, the number of medications ranged from **1 to 12.** On average, parents reported that their sons and daughters were taking 1.5 prescription medications at the start of the study, with the most frequently prescribed type of medications being anti-depressants.

Over time, those adolescents and adults who initially took prescription medications were considerably more likely to remain on those medications than to stop taking such medications. Individuals with more autism symptoms, more behavioral problems, a mental health diagnosis, and greater family income were significantly more likely to be prescribed psychotropic medication over time Individuals who had more health problems, a mental health diagnosis, and were

female were more likely to be prescribed non-psychotropic medication over this time period.

Our study data indicates that by adolescence, most individuals with FXS take prescription medications, primarily psychotropic medications. This is likely because individuals with FXS experience symptoms of attention deficit, anxiety, depression, and aggressive and self-injurious behaviors. The medication patterns we observed are consistent with this profile.

Little previous research has studied non-psychotropic drug use among adolescents and adults with FXS, and our study provides new insights about the use of such medications among those with FXS. Research has indicated that individuals with FXS often experience physical health problems at higher rates than their typically developing peers, and thus may have elevated need for medication.

Section III: Educational and Vocational Activities of Adolescents and Adults with FXS

Educational and Vocational Activities

Our research also examined the educational and vocational activities of adults with FXS in the years after they left the school system. At the beginning of our study, 45 of the 137 individuals with FXS had exited high school. By our last wave of data collection, all but 8 individuals with FXS had exited high school. To answer our question about vocational activities, we focused our research on data collected at the Time 4 interview, when almost all individuals were out of high school.

We used a detailed record review to develop four categories of post-secondary activities. This was quite complicated, as many adults with FXS were involved in more than one type of day activity simultaneously, such as spending part of their week in a sheltered workshop, working with supports in the community, and also taking a college class.

The four categories we developed are as follows:

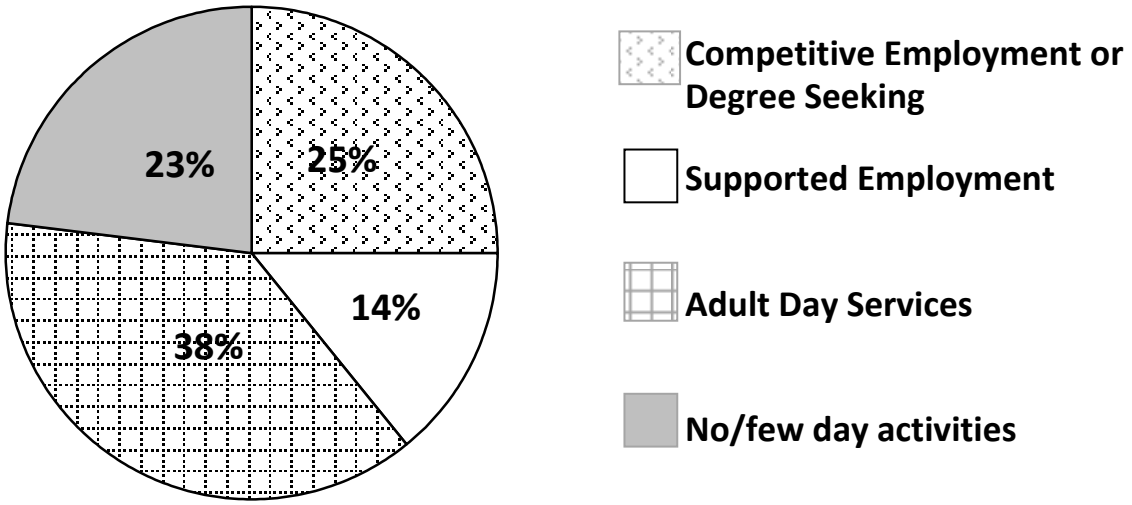
- **Competitive employment in the community or degree-seeking program**. This category included all adults who were competitively employed in the community, without receiving supports or adult day services. This category also included adults taking classes toward a post-secondary degree (regardless of their other occupational activities).

- **Supported employment**. This category represented adults who worked in the community with supports and who did not receive adult day services from a sheltered workshop or day activity center.

- **Adult day services.** Any adult who was attending sheltered workshops or day activity centers fit into this category.

- **No/few day activities**. This category was made up of adults who had vocational or educational activities that totaled less than 10 hours a week, or who were not engaged in any vocational or daytime activities out of the home.

Figure 5 below shows Postsecondary Vocational Activities



It is encouraging that fully a quarter (25%) of adults with FXS were competitively employed or in post-high school degree-seeking programs. Another 14% were participating in supported employment. For those not in the workplace, having access to adult day services is important, and these were accessed by more than one-third (38%) of those in our study. However, almost a quarter of the adults had no or few vocational or educational day activities once they left high school, which represents a significant unmet need.

Types of Community Employment

We also were interested in learning about the types of jobs adults with FXS were holding in the community. **Table 1** on the next page shows a list of the types of community employment held by adults with FXS.

Table 1. Types of Community Employment Held by Adults with FXS

Community Employment Type	%
Stocking	26.67 %
Cleaning and Maintenance	23.33 %
Retail	23.33 %
Food Service	16.67 %
Degree-Seeking Education Program	13.33 %
Other	16.67 %

Adults with FXS in our study who were employed held a range of types of jobs, from stocking items in stores, cleaning and maintenance, to retail positions and food service. Although most reported positions like these, a few individuals had unique experiences such as working in jobs involving caregiving, hospitality, and electronics. This range of options is encouraging.

Employment Stability

Next, we were interested in tracking stability in vocational activities over time. For this question, we examined a subset of the sample (95 adults) who were out of high school for at least two waves of data collection of the study. Based on the data, we categorized the adults into three employment groups:

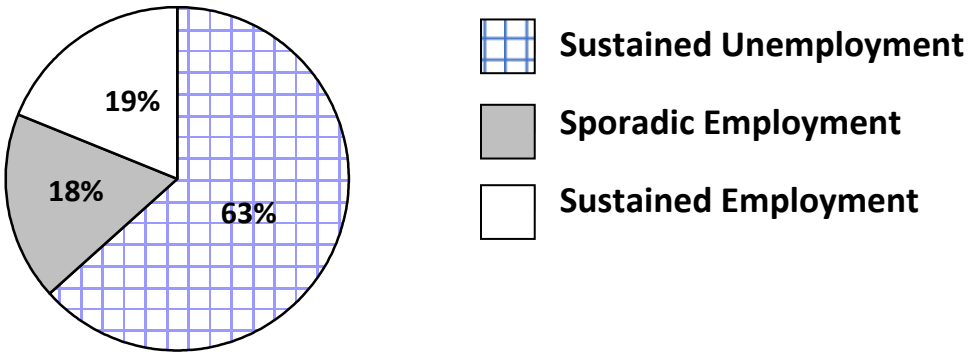
- **Sustained employment**. Individuals who were employed in the community (either competitive or supported employment) or participating in degree-seeking postsecondary education at all waves after high school exit.

- **Sporadic employment**. Individuals who were employed in the community (either competitive or supported employment) or participating in degree-seeking postsecondary education for some but not all waves after high school exit.

- **Sustained unemployment**. Individuals who were never employed in the community after high school exit. Although not employed in the community, these individuals may have been receiving adult day services.

As seen in **Figure 6** below, the majority (63.2%) of adults with FXS fell into the "sustained unemployment" category, meaning that they never held a job in the community after leaving high school, although they may have received adult day services.

Figure 6. Percentage of Adults with FXS in Each Employment Stability Group



Although many young adults experience periods of unemployment after high school, it is a serious concern that two-thirds of the adults with FXS in our study were unemployed over at least an 18 month period, which was the minimum duration included in this part of the study.

All adults, including those with FXS, want to feel useful and make a contribution, and the data we collected from you about the work-related activities of your son or daughter points to a need for improved vocational training and access to jobs for adults with FXS.

Some parents, whose son or daughter did not have access to formal day services or a job, organized daytime activities for their adult child. For example, some adults worked at a family business or volunteered for organizations with parental support such as delivering Meals on Wheels or helping at a local faith organization. These findings reflect the creativity and determination of families in supporting their adult children, but also the need for ongoing supports for adults with FXS and their families.

Section IV: Summary and Next Steps

Our study is one of the largest and longest-lasting studies of individuals with FXS in adolescence and adulthood and their families. You have helped us reach a new understanding of the characteristics and needs of individuals with FXS as they become adults. In this report, we focused on health and work, two of the most important factors that contribute to a high quality of life.

We learned that adults with FXS are mainly in good or excellent health, but there are some health concerns on the horizon, including an increased risk of being overweight or obese. We also learned that most of these individuals are prescribed medications and that once a class of medications is prescribed, it is likely to remain part of the individual's treatment regimen indefinitely. Finally, we learned that many of the most common health problems experienced by individuals with FXS during adolescence and adulthood are those not usually thought of as characteristic of FXS – such as allergies, skin problems, and asthma, as well as health problems that might be due to weight gain such as high blood pressure or high cholesterol. Parents often appreciate knowing that the health problems their son or daughter may experience are not unique but shared by others with FXS.

We also learned that some adults with FXS enter the workforce when they leave high school, but many do not. The range of jobs held by the adults in our sample is impressive, and this is a testament to the possibilities of those who have FXS to make a contribution to society through their work. It is also important for families to have access to adult services, especially for those adults who do not have conventional jobs in the labor market. The data suggest that there is much to be done to support adults with FXS and their families, and we aim for our study to make a contribution to a better future.

Next Steps for Our Study

We are very pleased to tell you that our study is continuing. We would like to conduct another interview with you to learn more about your son or daughter in adulthood. This will help us to advocate and inform both policy makers and clinicians about the needs of individuals with FXS in adulthood.

We also have embarked on a new component of our study that we are excited to tell you about. We would like to reach out and, with your permission, interview your brothers and sisters. Fragile X can affect the family as a whole and is thus a

family-wide experience. Some of your brothers and sisters might have a child with FXS, others might have a child with the premutation or carry the premutation themselves, while others may not be affected by expansions in the gene that causes FXS. Our goal is to gain a full understanding of "*Family Adaptation to FXS"* across the generations, and we hope you and your siblings will join us on this journey.

We will begin contacting you in the fall and will continue to do so into the spring. Before we call you, we will send you an information packet about this new phase of our study that explains what your participation would involve. At that time, we will also provide more information about contacting your sibling(s) and ask your permission about including them in the study.

We hope you are having a very enjoyable summer and we will be in touch soon!

Thank you very much!