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Factors associated with social participation among children with fragile X syndrome

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Abstract

Background: Social participation may increase quality of life for children with disabilities. However, few studies have explored social participation among children with fragile X syndrome (FXS).

Objectives: The objectives of this analysis were to describe social participation among children with FXS, associations with demographic and clinical characteristics, and caregiver-reported barriers to social participation.

Methods: Children with FXS aged 5–17 years were identified using data collected 2011–2021 in the Fragile X Online Registry With Accessible Research Database. Caregivers reported on types of social activities the child was involved in and specific barriers to social participation. Chi-square tests of independence were used to compare distributions by sex and modified Poisson regression was used to estimate unadjusted and adjusted prevalence ratios (aPRs) and 95% confidence intervals (CI).

Results: Among children with FXS (n = 830), 81.7% participated in at least one social activity; physical (65.8%) and work or volunteer activities (2.0%) were the most and least common. Children with severe to profound intellectual disability (ID; aPR = 0.57, CI = 0.43–0.77) and emotional dysregulation behaviors (aPR = 0.93, CI = 0.87–1.00) were less likely to participate

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Conflict of interest

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CRediT authorship contribution statement

Maria G. Gonzalez: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **April D. Summers:** Writing – review & editing, Writing – original draft, Validation, Supervision, Methodology, Conceptualization. **Lisa D. Wiggins:** Writing – review & editing, Methodology. **Marc A. Schweizer:** Writing – review & editing, Methodology. **Angela M. Thompson-Paul:** Writing – review & editing, Methodology. **Sarah C. Tinker:** Writing – review & editing, Supervision, Methodology.

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in a social activity relative to children without these characteristics. Demographic and clinical differences were observed for social participation by activity type. Caregivers most often reported behavioral issues (72.2%), time constraints (64.4%), and lack of community resources (64.2%) as barriers to social participation.

Conclusion: Increasing adaptive program availability, activity staff training, and respite support services may improve social participation.

Keywords

Fragile X syndrome; Social participation; Developmental disabilities

1. Introduction

Social participation, defined as a person's involvement in activities providing interactions with others in society or the community,¹ has positive associations with quality of life for children with disabilities; it provides the basis for creating social connections, encouraging community participation, providing social identity, and developing new or existing skills (e.g., emotional and behavioral control, physical coordination, pragmatic communication, social cooperation).²⁻⁷ Examples of social participation include participation in physical activities or group sports, outings with friends, classes or lessons (e.g., music lessons), religious organizations, volunteer work, or employment.⁸⁻¹⁰ However, studies have shown children with fragile X syndrome (FXS) and other developmental disabilities (DD) such as autism spectrum disorder (ASD), intellectual disability (ID), developmental delay, speech/language impairment, and cerebral palsy, participate in social and recreational activities at lower rates and have fewer social relationships than their typically developing peers.^{2,10-14}

Myriad factors affect social participation for individuals with ID and DD. For example, Buttner and Tierney⁸ found that students with mild to moderate ID reported time constraints, lack of transportation, and feeling restricted by parents from engaging in activities as barriers to leisure participation. A study by Smith et al.¹⁵ exploring social participation experiences of families raising children with ASD found that the child's difficulty in understanding or meeting social expectations, along with the community's lack of sensitivity to family circumstances, and the family's difficulty in managing their child's behaviors served as barriers to social participation. Merrells et al.⁵ investigated social inclusion experiences from the perspective of young adults with ID and found that social participation and friendships may be negatively influenced by a lack of integrated programs providing interaction with people without DD, exclusion or rejection from employment opportunities, and lack of access to communication devices (e.g., cell phones, social media). However, some participants in this study indicated preferring isolation or not having access to these devices, suggesting social participation may also rely on the individual's interests. Other factors potentially impacting social participation include availability and adequacy of resources such as programs, services or finances, the individual's ability to meet activity demands, and support from friends, family, or the community.^{6,7,10,16}

FXS is the leading single-gene cause of ID and ASD¹⁷ and is commonly associated with behavioral and emotional conditions such as attention problems, hyperactivity, anxiety,

hyperarousal, irritability, aggression, self-injurious behaviors, and obsessive-compulsive disorder (OCD) or perseverative behaviors.^{18–20} FXS is also characterized by social avoidance (e.g., poor eye contact), social withdrawal, sensory integration dysfunction, and language deficits, which can interfere with appropriate social behaviors and persist into adulthood.¹⁹ Studies have shown that conditions such as anxiety or depression (among females with FXS), aberrant behaviors such as lethargy, irritability, or hyperactivity, and delayed social or functional skills are associated with reduced quality of life and can predict level of independence for individuals with FXS in adulthood.^{21–23} However, studies have shown involvement in social activities is associated with fewer depressive symptoms among adolescents with ASD²⁴ and young adults with DD.²⁵ Additionally, participating in group social activities provides an opportunity for children with disabilities to develop and strengthen the skills necessary for independence. Adolescents with disabilities have reported feeling more independent and self-reliant after participating in summer camp activities as they had to manage their daily living skills and explore their physical ability without the help of a caregiver.⁷

1.1. Purpose of this analysis

Social participation plays a critical role in fostering the development of interpersonal and functional skills associated with independence and increased quality of life in adulthood. Previous research suggests individuals with DD have similar desires to participate in social activities as their typically developing peers.⁵ While factors and barriers affecting social participation have been explored extensively for other populations, little is known about the specific factors and barriers for individuals with FXS.

The objectives of this analysis were to describe social participation among children with FXS, including potential associations with demographic and clinical characteristics, and to describe caregiver-reported barriers to social participation.

2. Methods

2.1. FORWARD study

This analysis used 2011–2021 clinician- and caregiver-reported data from the longitudinal component of Fragile X Online Registry With Accessible Research Database (FORWARD). FORWARD is a multisite, observational study that includes data from individuals with FXS and their family members, collected by 30 established fragile X clinics across the United States.²⁶ It comprises two main components: the registry (n = 3769), which collects primarily demographic information from families with FXS and other fragile X-associated disorders, and the longitudinal database (n = 1834), which collects data from only individuals with full mutation FXS. For a detailed description of FORWARD, see Sherman et al.²⁶

2.2. Sample

Children who participated in the longitudinal study between the ages of 5–17 years, who had both a clinician- and caregiver-report form record available, and non-missing data for sex were considered eligible for inclusion in the analysis sample (n = 830/1834 longitudinal

participants [45.3%]).^c Participants may have had multiple study visits; the latest participant record, on or before age 17 years, was used for analysis.

2.3. Clinician and caregiver report forms

Data in the longitudinal database are collected by clinicians using the clinician-report form and by caregivers using the caregiver-report form and other standardized behavioral assessments. Both forms contain questions designed by FORWARD investigators or selected from other national FXS surveys (e.g., Our Fragile X World's National Fragile X Survey). The clinician report form, associated with physical examination at the participant's most recent clinical visit, collects the following information used in these analyses: age in years at the latest clinical visit (categorized as 5–10, 11–13, 14–17), ever diagnosed with ASD (diagnosis was based on the examining clinician's judgment using DSM-5 diagnostic criteria or previous diagnosis documented in medical records), current level of intellectual disability (i.e., developmental delay [as a pre-ID designation of intellectual disability for children under age 6 years], no ID, borderline or mild ID, moderate ID, severe or profound ID; level of ID was based on the examining clinician's judgment using DSM-5 severity levels; IQ assessment data may have informed clinical judgment but were not used alone to categorize ID), and current behavioral or emotional problems (i.e., attention problems or hyperactivity, hyper-sensitivity including overreaction to stimuli and emotional reactivity, anxiety, OCD or perseverative behavior, mood swings or depression, and emotional dysregulation behaviors, specifically irritability, aggression, agitation, and self-injury behaviors; diagnoses based on the examining clinician's judgment using DSM-5 diagnostic criteria or previous diagnosis documented in medical records). The following information from the caregiver-report form was also used in these analyses: primary caregiver education, child social participation, and child barriers to social participation. Other information used in these analyses include child race and ethnicity (i.e., Hispanic, and non-Hispanic, White, Black, other race [including Asian, American Indian/Alaskan Native, Native Hawaiian or Pacific Islander, unspecified race], and multi-race) and sex, collected in the FORWARD registry.

2.4. Measures

2.4.1. Social participation: Caregivers were asked “*In what type of activities is the child involved?*” and were provided the following response options: *physical activities not specific to special needs individuals (e.g., sports, walking, hiking, fitness center); physical activity programs specific to special needs individuals (e.g., Special Olympics); social activities (e.g., hanging out with friends, play dates, sleepovers); religious activities (e.g., attending services, youth group); school-related clubs and activities (e.g., chorus, band); before or after school program run at school; art, music, parks and recreation classes; non-school group activities open to all types of individuals (e.g., Scouts); organized buddies/friends programs (e.g., Best Buddies); work; other (specify); none; don't know.* Due to the similarities in response options, these responses, including written-in responses for the *other* category, were recategorized into the following groups: *physical activities, peer*

^cThe longitudinal component of FORWARD included 1834 participants. Of these, 1117 (60.9%) were between the ages of 5–17 years at the time of the latest clinician visit (on or before 17 years), 831 (74.4%) had both a clinician- and caregiver-report form record, and 830 (99.9%) had non-missing data for sex.

activities, religious activities, school-based clubs and programs, community-based activities and therapies, volunteer and work activities, and overall participation in social activities. Supplemental Table 1 provides details on the activities included for each group. Participants who responded *don't know* (n = 3), only selected *other* and did not specify an activity (n = 9), or did not select any response options (n = 22) were excluded from social activity outcomes.

2.4.2. Barriers to social participation: Caregivers were asked to select a response of *no barrier, little barrier, moderate barrier, or huge barrier* for each of the following issues: *financial constraints, lack of resources in the community, transportation limitations, time constraints, child's behavioral issues, and other.*

2.5. Statistical analyses

Counts and percentages were calculated for demographic and clinical characteristics, any social activity engagement and type, and caregiver-reported barriers to social participation. Chi-square tests of independence were used to compare distributions by sex and p-values were reported. Missing values were not included in hypotheses testing.

Modified Poisson regression models with robust error variance were used to estimate prevalence ratios (unadjusted [PR] and adjusted [aPR]) and 95% confidence intervals (CI).²⁷ Selection of demographic and clinical characteristics as covariates was informed by previous studies,^{2,13,14,22} prevalence of co-occurrence with FXS,²⁰ and potential for confounding. Characteristics that were moderately to strongly correlated based on Spearman's rho ($r_s \geq 0.4$), or had >10% missing data were not included in the models.

The first regression model examined the association of demographic and clinical characteristics with any social participation. This model was conducted within the total sample and, separately, stratified by sex. Model covariates included the primary caregiver's education level and the child's age in years at the latest clinical visit, race and ethnicity, intellectual function, ASD diagnosis, and behavioral or emotional conditions.

The second set of models examined the association of demographic and clinical characteristics with each type of social activity (physical, peer, school-based, community-based, religious), within the total sample. *Work* as an outcome was not assessed due to low prevalence. For these models, the primary caregiver's education level and the child's age in years at the latest clinical visit, race and ethnicity, sex, ASD diagnosis, and behavioral and emotional conditions were included as covariates. Intellectual function was not included as a covariate due to its moderate correlation with child sex ($r_s = -0.420$, $p < .0001$).

Although data on current school enrollment status was unavailable, a sensitivity analysis was conducted to assess the association between demographic and clinical characteristics with school-based clubs and programs among children ever enrolled in school.

All analyses were completed using SAS 9.4.

3. Results

Demographic and clinical characteristics for the 830 FORWARD participants with FXS are shown in Table 1 (75.8% male; 72.2% non-Hispanic [NH] White, 13.2% Hispanic, 6.8% NH Black, 4.7% NH other race, 3.1% NH multi-racial). Almost all males (97.8%) and 75.0% of females had DD or ID. About two thirds of males and one third of females had co-occurring ASD. Although nearly all males and females had at least one co-occurring behavioral or emotional condition (99.1% and 98.4%, respectively), males tended to have a higher cumulative number of these conditions. Attention problems or hyperactivity, hypersensitivity, OCD or perseverative behavior, and emotional dysregulation behaviors were more common in males; mood swings or depression were more common in females.

Among children with FXS, 81.7% participated in at least one type of social activity. The most common type of social activity was physical (65.8%), followed by peer (39.9%) and religious (31.3%). A higher percentage of female children participated in peer activities (49.5% vs. 36.9%), religious activities (37.6% vs. 29.2%), community-based activities and therapies (32.0% vs. 20.3%), and school-based clubs and programs (33.0% vs. 17.9%) compared to male children (Table 1).

Results for the model examining the associations between demographic and clinical characteristics and overall social participation are shown in Table 2 among the 690 children with no missing data on variables in the model; results stratified by sex are available in Supplemental Table 2. Adjusted model results showed no significant differences in overall social participation by child's age group, race/ethnicity, or ASD status, in total or stratified by sex. However, children whose caregivers had less than or equal to a high school diploma (aPR = 0.74, 95% CI = 0.62–0.88) or some college (aPR = 0.91, 95% CI = 0.83–1.00) were less likely to participate in social activities compared to children whose caregivers had an advanced degree. Level of intellectual function and behavioral and emotional conditions were also associated with social participation. Children with severe to profound ID (aPR = 0.57, 95% CI = 0.43–0.77) or moderate ID (aPR = 0.92, 95% CI = 0.83–1.02) were less likely to participate in social activities relative to children with no ID. Children with hypersensitivity were more likely to participate in social activities relative to peers without hypersensitivity, within the total (aPR = 1.10, 95% CI = 1.02–1.20; Table 2) and male (aPR = 1.14, 95% CI = 1.03–1.28; Supplemental Table 2) samples. Children with anxiety (aPR = 1.13, 95% CI = 1.01–1.27) were also more likely to participate in social activities than children without anxiety. Lastly, children with emotional dysregulation behaviors (aPR = 0.93, 95% CI = 0.87–1.00) were less likely to participate in social activities than children without these conditions. Except for hypersensitivity, aPRs stratified by sex were similar to overall aPRs, although with lower precision due to smaller sample sizes. Unadjusted analyses indicated Hispanic race, borderline or mild ID, ASD diagnosis, and OCD or perseverative behaviors had significant associations with social participation; similar estimates to adjusted analyses were observed for all other characteristics.

Demographic characteristics associated with social participation varied by type of activity among the 714 children with no missing data on variables in the model (Table 3; Supplemental Table 3). Children ages 14–17 were more likely to participate in physical

activities than children ages 5–10 (aPR = 1.12, 95% CI = 1.00–1.25; Table 3). Children ages 11–13 (aPR = 1.79, 95% CI = 1.23–2.62) and ages 14–17 (aPR = 2.40, 95% CI = 1.75–3.28) were more likely to participate in school-based clubs and programs than children ages 5–10. Results were similar in sensitivity analyses restricted to children (n = 690, 96.7% overall; ages 5–10 years: 97.2%; 11–13: 96.2%; 14–17: 96.1%) who were ever in school (data not shown).

Hispanic children were less likely to participate in physical (aPR = 0.74, 95% CI = 0.60–0.91) and religious activities (aPR = 0.59, 95% CI = 0.36–0.94) than White, NH children. Black, NH children were more likely to participate in religious activities (aPR = 1.50, 95% CI = 1.07–2.09) and less likely to participate in school-based clubs and programs (aPR = 0.33, 95% CI = 0.11–1.02) than White, NH children. Female children were more likely to participate in school-based clubs and programs (aPR = 1.57, 95% CI = 1.19–2.06) and community-based activities and therapies (aPR = 1.51, 95% CI = 1.12–2.03) and less likely to participate in physical activities (aPR = 0.89, 95% CI = 0.79–1.01) than male children. Lower educational level of the primary caregiver was associated with lower participation in each type of activity.

Several clinical characteristics were also associated with specific types of social participation (Table 3). Children diagnosed with ASD were less likely to participate in physical activities (aPR = 0.92, 95% CI = 0.83–1.03), peer activities (aPR = 0.74, 95% CI = 0.61–0.90), school-based clubs and programs (aPR = 0.61, 95% CI = 0.46–0.83), and religious activities (aPR = 0.66, 95% CI = 0.52–0.85) compared to children not diagnosed with ASD. Children with attention problems or hyperactivity were less likely to participate in physical activities (aPR = 0.83, 95% CI = 0.73–0.93), peer activities (aPR = 0.79, 95% CI = 0.63–0.98) and religious activities (aPR = 0.75, 95% CI = 0.56–1.00) compared to children without these conditions. Children with hypersensitivity were more likely to participate in physical (aPR = 1.18, 95% CI = 1.04–1.33) and peer activities (aPR = 1.30, 95% CI = 1.06–1.60) compared to children without hypersensitivity. Children with anxiety were more likely to participate in peer (aPR = 1.39, 95% CI = 1.05–1.84) and religious activities (aPR = 1.46, 95% CI = 1.02–2.07) than children without anxiety. Children with OCD were less likely to participate in physical activities than children without OCD (aPR = 0.89, 95% CI = 0.80–1.00). Lastly, emotional dysregulation behaviors were associated with decreased participation in peer activities (aPR = 0.73, 95% CI = 0.60–0.90). Unadjusted analyses produced similar estimates to adjusted analyses for most covariates; unadjusted associations between activity types and hypersensitivity and anxiety were not statistically significant (Supplemental Table 3).

Distributions of caregiver-reported barriers are shown in Table 4. Within the total sample, caregivers most frequently reported behavioral issues (72.2%), time constraints (64.4%), and lack of community resources (64.2%) as barriers to social participation (Table 4). Comparisons by sex indicated caregivers more frequently reported behavioral issues and lack of community resources as barriers to social participation for male children.

Table 5 depicts the prevalence of caregiver-reported child behavioral issues as a barrier to social participation stratified by the child's intellectual function, overall, and further

stratified by sex. Behavioral issues were moderate to huge barriers for 59.0% of children with moderate ID and 75.9% of children with severe to profound ID, with similar results for males and females. For children with DD, 61.5% of caregivers reported behavioral issues as a moderate to huge barrier to social participation, primarily among males.

4. Discussion

Social participation has positive associations with quality of life for children with disabilities, and while most children with FXS in this study participated in at least one activity, those with more severe clinical characteristics were less likely to engage socially. Our findings suggest severe or profound ID and emotional dysregulation behaviors, specifically irritability, aggression, agitation, and self-injury, are significant barriers to participation. These insights not only expand on prior research but also highlight the need for targeted public health interventions, such as adaptive programs, that promote inclusive social activities for children with FXS.

While nearly all children (96.7%) were currently or previously enrolled in school, children participated in school- and community-based activities less often than other activities, indicating an opportunity to increase adaptive programming at easily accessible locations. Creating adaptive programs or modifying existing programs to accommodate and meet the interests of children with ID and/or regulatory issues may support families and children seeking to participate in social activities. Implementation of evidence-based practices such as cooperatively structured activities and peer network interventions into adaptive programs can further promote social inclusion at school and within the community.^{28,29} These practices provide an opportunity for individuals with ID to engage with individuals without ID by encouraging collaboration and social connectedness through staff-facilitated activities.

Caregivers most often reported behavioral issues as a barrier to social participation, followed by lack of community resources and time constraints. Some evidence-based strategies to address behavioral issues are environmental modification, mindfulness approaches, and positive behavioral supports.³⁰ Educating and training activity staff on these strategies may help reduce behavioral interference with social participation for children with FXS. Lack of community resources may refer to a lack of access to or availability of programs, services, information, or social support.^{10,31} Time constraints may be in the form of time spent caring for the person with a disability, competing priorities such as work or attending medical appointments or therapies over social activities, and time spent traveling to the location of activities.^{8,32} Informal respite services, such as caregiver cooperatives, may be beneficial for families of children with FXS interested in participating in social activities. Through caregiver cooperatives, families create support systems with other families who are familiar with their child's needs and routines. Families can provide support by sharing information, running errands, or providing childcare or transportation. Formal respite services, such as group respite or day care programs, can provide additional opportunities for children with special healthcare needs to socialize with other children with similar needs while providing caregivers with relief.³³ Group respite programs often take place in community-based locations, such as assisted living facilities or community centers, and offer a variety of social, recreational, and therapeutic activities facilitated by trained professionals.

Demographic differences were observed for social participation by activity type. Previous literature suggests activity participation decreases with age among children³⁴ and adults³⁵ with disabilities. However, the results of this analysis indicate younger children were less likely to participate in physical and school-based activities compared to older children. Results restricted to children ever enrolled in school showed similar associations between age and school-based activities among children. Therefore, lower participation among younger children may be due to a lack of available resources such as programs or services, the programs' age requirement for participation, or the ability to meet the demands of the activity. Research has shown adolescents with disabilities participating in social activities have an opportunity to develop and strengthen the social and daily living skills necessary for independence in adulthood.⁷ For children interested in social activities but whose social anxiety or sensory integration problems may pose as barriers, intensive therapy focused on improving social deficits and strengthening language or motor abilities may be beneficial. Further investigation is needed to better understand the barriers experienced by younger children with FXS.

Although school enrollment was similar across race and ethnicities, Black, NH children were less likely to participate in school-based activities. However, they were more likely to participate in religious activities, suggesting participation in certain activity types may be influenced by the individual's preferences and cultural background. Resource availability may also vary by racial-ethnic group³⁶ and may further explain the lower social participation rates observed for Hispanic and NH Black children in this analysis.

Adjusted regression models indicated children with clinical characteristics such as hypersensitivity and anxiety were more likely to participate in social activities, specifically in physical, peer, and religious activities, than children without these conditions. However, previous studies examining activity participation among children with ASD have shown sensory sensitivities and anxiety may interfere with activity participation.^{37–39} Factors such as the location of activities (e.g., in the home versus community), the type of sensory sensitivity (e.g., tactile, auditory, visual) or anxiety symptoms (e.g., performance, separation, uncertainty), or the severity of symptoms have been shown to play a role in activity participation. These results should be interpreted with caution given we did not have detailed information on the specific activity, the child's symptoms, or the temporality of hypersensitivity and anxiety presentation and social activity participation; additionally, hypersensitivity and anxiety were not significantly associated with physical, peer, and religious activities in unadjusted models. It is possible that children in this analysis may have increased anxiety or hypersensitivity because they were participating in social activities, their symptoms were ameliorated by the structure or setting of the activity (i.e., where the environment is controllable and predictable), or that their symptoms did not limit their participation in these types of activities. Although our data cannot answer these questions, additional research is needed to understand how these factors affect social participation among children with FXS and hypersensitivity or anxiety.

4.1. Limitations

This analysis is subject to several limitations. Due to data missingness, other potentially important contributing factors to social participation were not examined, such as presence of motor, communication, or social interaction delays. The analysis was also limited by the scope, detail, and clarity of the study questions on social participation; caregivers were not asked about the frequency, intensity, or duration by type of activity and children were not asked about their own activity engagement or barriers to social participation. Details on activity eligibility criteria and current school enrollment were not reported, which may have influenced a child's participation in activities such as group sports, community-based activities, or school-based programs. Some questions, for example asking about the impact of the lack of community resources on the ability to participate in an activity, did not clearly define terms such as "resources" and are therefore open to interpretation. Lastly, the exclusion of eligible children due to missing data, and the FORWARD study being limited to those who receive care at FXS specialty clinics, may create sampling bias that reduces generalizability.

Despite these limitations, FORWARD is one of few sources of information on social participation and FXS and is the largest database of clinical- and caregiver-reported data for the FXS population in the United States. These data allowed researchers to consider many demographic and clinical characteristics associated with social participation and report results by sex.

5. Conclusion

Most children with FXS participated in one or more activity, with physical activities most common and other school- and community-based activities least common. Factors such as having severe or profound ID or emotional dysregulation behaviors were associated with lower social participation, and caregivers often reported behavioral issues, lack of community resources, and time constraints as barriers. Increasing adaptive program availability, activity staff education and training, and respite support services may increase social participation among children with FXS. These findings can be used to support inclusive programs and practices to help all children with FXS thrive.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Appendix A.: Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2026.102069>.

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Table 1

Characteristics of Fragile X Online Registry With Accessible Research Database participants, aged 5–17 years.

<i>Demographic and clinical characteristics^a</i>	Total (n = 830) n (%)	Males (n = 629) n (%)	Females (n = 201) n (%)	p-value^b
<i>Child's age at most recent clinical visit, in years</i>				
5–10	376 (45.3%)	282 (44.8%)	94 (46.8%)	0.891
11–13	161 (19.4%)	123 (19.6%)	38 (18.9%)	
14–17	293 (35.3%)	224 (35.6%)	69 (34.3%)	
<i>Child's race and ethnicity</i>				
White, non-Hispanic	597 (72.2%)	452 (72.0%)	145 (72.9%)	0.067
Black, non-Hispanic	56 (6.8%)	46 (7.3%)	10 (5.0%)	
Other race, non-Hispanic	39 (4.7%)	34 (5.4%)	5 (2.5%)	
Multi-racial, non-Hispanic	26 (3.1%)	15 (2.4%)	11 (5.5%)	
Hispanic	109 (13.2%)	81 (12.9%)	28 (14.1%)	
<i>Primary caregiver education</i>				
≤ High school diploma or equivalent	91 (11.2%)	69 (11.2%)	22 (11.1%)	0.541
Some college	200 (24.5%)	157 (25.5%)	43 (21.6%)	
Bachelor's degree	268 (32.9%)	204 (33.1%)	64 (32.2%)	
Advanced degree	256 (31.4%)	186 (30.2%)	70 (35.2%)	
<i>Child's region of residence</i>				
Northeast	110 (14.7%)	79 (14.0%)	31 (16.9%)	0.610
Midwest	298 (39.9%)	223 (39.5%)	75 (41.0%)	
South	210 (28.1%)	160 (28.4%)	50 (27.3%)	
West	129 (17.3%)	102 (18.1%)	27 (14.8%)	
<i>Child's health insurance</i>				
Public only	216 (26.3%)	174 (28.1%)	42 (21.0%)	<0.001
Private only	412 (50.2%)	280 (45.2%)	132 (66.0%)	
Both public & private	184 (22.4%)	160 (25.8%)	24 (12.0%)	
No insurance	8 (1.0%)	6 (1.0%)	2 (1.0%)	
<i>Child's current intellectual function</i>				
No ID	61 (7.7%)	13 (2.2%)	48 (25.0%)	<0.001
Developmental delay ^c	29 (3.7%)	26 (4.3%)	3 (1.6%)	
Borderline or mild ID	286 (36.2%)	174 (29.1%)	112 (58.3%)	
Moderate ID	353 (44.7%)	333 (55.7%)	20 (10.4%)	
Severe or profound ID	61 (7.7%)	52 (8.7%)	9 (4.7%)	
<i>Child's autism spectrum disorder diagnosis</i>				
Current or past diagnosis	492 (61.3%)	421 (69.5%)	71 (36.0%)	<0.001
Never diagnosed	311 (38.7%)	185 (30.5%)	126 (64.0%)	
<i>Child's number of current co-occurring behavioral or emotional conditions</i>				
No conditions	8 (1.0%)	5 (0.9%)	3 (1.6%)	0.001
1–2 conditions	172 (22.1%)	111 (18.9%)	61 (31.8%)	
3–4 conditions	329 (42.2%)	255 (43.4%)	74 (38.5%)	

Demographic and clinical characteristics^a	Total (n = 830) n (%)	Males (n = 629) n (%)	Females (n = 201) n (%)	p-value^b
5 or more conditions	271 (34.7%)	217 (36.9%)	54 (28.1%)	
<i>Child's current behavioral or emotional conditions</i>				
Attention problems or hyperactivity	693 (84.7%)	548 (88.4%)	145 (73.2%)	<0.001
Hypersensitivity ^d	554 (68.2%)	441 (71.8%)	113 (57.1%)	<0.001
Anxiety	697 (85.4%)	528 (85.6%)	169 (84.9%)	0.821
OCD or perseverative behaviors	460 (57.3%)	372 (61.3%)	88 (44.9%)	<0.001
Mood swings or depression	170 (21.3%)	111 (18.3%)	59 (30.3%)	<0.001
Emotional dysregulation behaviors ^e	433 (53.7%)	350 (57.7%)	83 (41.7%)	<0.001
<i>Types of social activities child is involved in</i>				
≥1 type	650 (81.7%)	488 (81.1%)	162 (83.5%)	0.445
Physical activities	524 (65.8%)	404 (67.1%)	120 (61.9%)	0.180
Peer activities	318 (39.9%)	222 (36.9%)	96 (49.5%)	0.002
Religious activities	249 (31.3%)	176 (29.2%)	73 (37.6%)	0.028
Community-based activities and therapies	184 (23.1%)	122 (20.3%)	62 (32.0%)	<0.001
School-based clubs and programs	172 (21.6%)	108 (17.9%)	64 (33.0%)	<0.001
Work or volunteer activities	16 (2.0%)	13 (2.2%)	3 (1.5%)	0.597

Abbreviations: ID = intellectual disability; ASD = autism spectrum disorder; OCD = obsessive-compulsive disorder.

^aNumber of participants missing data for: *Child's race/ethnicity* (Total = 3, Males = 1, Females = 2); *Primary caregiver education* (Total = 15, Males = 13, Females = 2); *Child's region of residence* (Total = 83, Males = 65, Females = 18); *Child's health insurance* (Total = 10, Males = 9, Females = 1); *Child's current intellectual function* (Total = 40, Males = 31, Females = 9); *Child's ASD diagnosis* (Total = 27, Males = 23, Females = 4); *Number of current co-occurring behavioral conditions* (Total = 50, Males = 41, Females = 9); *Attention problems or hyperactivity* (Total = 12, Males = 9, Females = 3); *Hypersensitivity* (Total = 18, Males = 15, Females = 3); *Anxiety* (Total = 14, Males = 12, Females = 2); *Obsessive-compulsive disorder* (Total = 27, Males = 22, Females = 5); *Mood swings or depression* (Total = 30, Males = 24, Females = 6); *Emotional dysregulation behaviors* (Total = 24, Males = 22, Females = 2); *Types of social activities child is involved in* (Total = 34, Males = 27, Females = 7).

^bComparison of demographic and behavioral characteristics by child's sex using Chi-square test of independence.

^cQuestion instruction limited response to children under age 6 years; however, 7 children ≥6 years old were also included.

^dIncludes overreaction to stimuli and emotionally reactive behaviors.

^eIncludes irritability, aggression, agitation, and self-injury behaviors.

Table 2

Association between demographic and clinical characteristics and prevalence of overall social activity participation among Fragile X Online Registry With Accessible Research Database participants, aged 5–17, 2011–2021.

<i>Demographic and clinical characteristics</i>	<i>Child participated in any type of social activity^a</i>	
	<i>Total (n = 690)^b</i>	
	<i>PR (95% CI)</i>	<i>aPR^c (95% CI)</i>
<i>Child's age at most recent clinical visit, in years</i>		
5–10 (<i>ref.</i>)	-	-
11–13	1.01 (0.92, 1.11)	1.03 (0.94, 1.14)
14–17	1.01 (0.94, 1.09)	1.03 (0.95, 1.11)
<i>Child race and ethnicity</i>		
White, non-Hispanic (<i>ref.</i>)	-	-
Black, non-Hispanic	0.95 (0.82, 1.10)	0.98 (0.84, 1.14)
Other race, non-Hispanic	1.06 (0.94, 1.19)	1.05 (0.93, 1.18)
Multi-race, non-Hispanic	0.86 (0.67, 1.12)	0.88 (0.71, 1.09)
Hispanic	0.85 (0.74, 0.98)	0.91 (0.80, 1.04)
<i>Primary caregiver education</i>		
≤ High school diploma	0.68 (0.57, 0.83)	0.74 (0.62, 0.88)
Some college	0.88 (0.80, 0.97)	0.91 (0.83, 1.00)
Bachelor's degree	0.96 (0.89, 1.03)	0.96 (0.90, 1.03)
Advanced degree (<i>ref.</i>)	-	-
<i>Child's current intellectual function</i>		
No ID (<i>ref.</i>)	-	-
Developmental delay ^d	0.91 (0.75, 1.09)	0.97 (0.80, 1.18)
Borderline or mild ID	0.94 (0.86, 1.02)	0.95 (0.87, 1.04)
Moderate ID	0.89 (0.82, 0.98)	0.92 (0.83, 1.02)
Severe or profound ID	0.53 (0.40, 0.70)	0.57 (0.43, 0.77)
<i>Child's autism spectrum disorder diagnosis</i>		
Current or past diagnosis	0.92 (0.86, 0.99)	0.99 (0.92, 1.06)
Never diagnosed (<i>ref.</i>)	-	-
<i>Child's current behavioral conditions</i>		
<i>Attention problems or hyperactivity</i>		
Yes	0.96 (0.88, 1.04)	0.95 (0.87, 1.04)
No (<i>ref.</i>)	-	-
<i>Hypersensitivity^e</i>		
Yes	1.05 (0.97, 1.14)	1.10 (1.02, 1.20)
No (<i>ref.</i>)	-	-
<i>Anxiety</i>		
Yes	1.13 (1.00, 1.27)	1.13 (1.01, 1.27)
No (<i>ref.</i>)	-	-

<i>Demographic and clinical characteristics</i>	<i>Child participated in any type of social activity^a</i>	
	<i>Total (n = 690)^b</i>	
	<i>PR (95% CI)</i>	<i>aPR^c (95% CI)</i>
OCD or perseverative behaviors		
Yes	0.95 (0.89, 1.02)	0.98 (0.91, 1.05)
No (<i>ref.</i>)	-	-
Mood swings or depression		
Yes	0.91 (0.82, 1.00)	0.93 (0.84, 1.02)
No (<i>ref.</i>)	-	-
Emotional dysregulation behaviors ^f		
Yes	0.89 (0.84, 0.96)	0.93 (0.87, 1.00)
No (<i>ref.</i>)	-	-

Abbreviations: Ref = reference category; PR = unadjusted prevalence ratio; aPR = adjusted prevalence ratio; CI = confidence interval; OCD = obsessive-compulsive disorder; ASD = autism spectrum disorder; ID = intellectual disability.

^a Bolded values indicate statistically significant results, where the confidence interval does not include 1. Borderline significant results, defined as 0.97 to 1.03, were also bolded.

^b Participants with missing data for one or more variables included in the table were excluded from the models (n = 140/830).

^c Regression models adjusted for all other variables included in the table.

^d Question instruction limited response to children under age 6 years; however, 7 children ≥6 years old were also included per clinician designation.

^e Includes overreaction to stimuli and emotionally reactive behaviors.

^f Includes irritability, aggression, agitation, and self-injury behaviors.

Table 3

Association between demographic and clinical characteristics and prevalence of participation in specific activities among Fragile X Online Registry With Accessible Research Database participants, aged 5–17, by activity type, 2011–2021.

Demographic and clinical characteristics ^a	Child participated in ^b			
	Physical activities (n = 714) ^c	Peer activities (n = 714) ^c	School-based clubs and programs (n = 714) ^c	Community-based activities and therapies (n = 714) ^c
	aPR ^d (95% CI)	aPR ^d (95% CI)	aPR ^d (95% CI)	aPR ^d (95% CI)
<i>Child's age at most recent clinical visit, in years</i>				
5–10 (<i>ref.</i>)	-	-	-	-
11–13	1.08 (0.95, 1.24)	0.98 (0.77, 1.25)	1.79 (1.23, 2.62)	0.82 (0.58, 1.18)
14–17	1.12 (1.00, 1.25)	1.02 (0.84, 1.24)	2.40 (1.75, 3.28)	0.82 (0.61, 1.11)
<i>Child race and ethnicity</i>				
White, non-Hispanic (<i>ref.</i>)	-	-	-	-
Black, non-Hispanic	0.91 (0.72, 1.15)	0.86 (0.56, 1.32)	0.33 (0.11, 1.02)	0.67 (0.34, 1.35)
Other race, non-Hispanic	0.98 (0.79, 1.22)	0.83 (0.53, 1.29)	1.51 (0.93, 2.46)	1.47 (0.92, 2.35)
Multi-race, non-Hispanic	0.75 (0.51, 1.12)	0.87 (0.53, 1.44)	1.24 (0.61, 2.55)	1.34 (0.77, 2.33)
Hispanic	0.74 (0.60, 0.91)	0.78 (0.57, 1.06)	1.00 (0.66, 1.53)	0.84 (0.52, 1.35)
<i>Child sex</i>				
Male (<i>ref.</i>)	-	-	-	-
Female	0.89 (0.79, 1.01)	1.18 (0.97, 1.43)	1.57 (1.19, 2.06)	1.51 (1.12, 2.03)
<i>Primary caregiver education</i>				
≤ High school diploma	0.62 (0.48, 0.80)	0.59 (0.39, 0.90)	0.54 (0.30, 0.97)	0.46 (0.25, 0.85)
Some college	0.85 (0.75, 0.98)	0.66 (0.51, 0.85)	0.40 (0.25, 0.64)	0.72 (0.51, 1.01)
Bachelor's degree	0.92 (0.82, 1.03)	0.84 (0.69, 1.03)	0.86 (0.65, 1.14)	0.65 (0.47, 0.89)
Advanced degree (<i>ref.</i>)	-	-	-	-
<i>Child's autism spectrum disorder diagnosis</i>				
Current or past diagnosis	0.92 (0.83, 1.03)	0.74 (0.61, 0.90)	0.61 (0.46, 0.83)	1.07 (0.79, 1.46)
Never diagnosed (<i>ref.</i>)	-	-	-	-
<i>Child's current behavioral conditions</i>				
Attention problems or hyperactivity	0.83 (0.73, 0.93)	0.79 (0.63, 0.98)	0.90 (0.65, 1.26)	0.98 (0.66, 1.46)
Yes				0.75 (0.56, 1.00)

Demographic and clinical characteristics ^a		Child participated in ^b				
		Physical activities (n = 714) ^c	Peer activities (n = 714) ^c	School-based clubs and programs (n = 714) ^c	Community-based activities and therapies (n = 714) ^c	Religious activities (n = 714) ^c
		aPR ^d (95% CI)	aPR ^d (95% CI)	aPR ^d (95% CI)	aPR ^d (95% CI)	aPR ^d (95% CI)
No (<i>ref.</i>)		-	-	-	-	-
Hypersensitivity ^e						
Yes		1.18 (1.04, 1.33)	1.30 (1.06, 1.60)	1.17 (0.87, 1.58)	1.01 (0.74, 1.37)	1.23 (0.95, 1.59)
No (<i>ref.</i>)		-	-	-	-	-
Anxiety						
Yes		1.04 (0.90, 1.20)	1.39 (1.05, 1.84)	0.89 (0.63, 1.25)	1.19 (0.79, 1.82)	1.46 (1.02, 2.07)
No (<i>ref.</i>)		-	-	-	-	-
OCD or perseverative behaviors						
Yes		0.89 (0.80, 1.00)	0.97 (0.80, 1.18)	1.00 (0.74, 1.34)	1.14 (0.85, 1.55)	0.89 (0.70, 1.13)
No (<i>ref.</i>)		-	-	-	-	-
Mood swings or depression						
Yes		0.92 (0.80, 1.07)	0.86 (0.66, 1.12)	0.80 (0.55, 1.17)	0.91 (0.64, 1.30)	1.07 (0.81, 1.40)
No (<i>ref.</i>)		-	-	-	-	-
Emotional dysregulation behaviors ^f						
Yes		0.94 (0.84, 1.04)	0.73 (0.60, 0.90)	0.83 (0.62, 1.12)	0.84 (0.62, 1.13)	0.97 (0.76, 1.24)
No (<i>ref.</i>)		-	-	-	-	-

Abbreviations: Ref = reference category; aPR = adjusted prevalence ratio; CI = Confidence interval; OCD = obsessive-compulsive disorder; ID = intellectual disability.

^a Intellectual disability status was not included due to correlation with child sex ($r_s = -0.420$, $p < .0001$).

^b Bolded values indicate statistically significant results, where the confidence interval does not include 1. Borderline significant results, defined as 0.97 to 1.03, were also bolded.

^c Participants with missing data for one or more variables included in the table were excluded from the models (n = 116/830).

^d Regression models adjusted for all other variables included in the table.

^e Includes overreaction to stimuli and emotionally reactive behaviors.

^f Includes irritability, aggression, agitation, and self-injury behaviors.

Table 4

Caregiver-reported barriers to social participation, overall and by participant sex among Fragile X Online Registry With Accessible Research Database participants, aged 5–17, by activity type, 2011–2021.

<i>Barriers to social participation^a</i>	Total (n = 830) n (%)	Males (n = 629) n (%)	Females (n = 201) n (%)	<i>p-value^b</i>
Behavioral issues	558 (72.2%)	461 (78.9%)	97 (51.3%)	<0.001
Time constraints	497 (64.4%)	382 (65.4%)	115 (61.2%)	0.291
Lack of community resources	492 (64.2%)	393 (68.5%)	99 (51.6%)	<0.001
Financial constraints	381 (49.4%)	285 (49.1%)	96 (50.3%)	0.788
Transportation	222 (29.3%)	173 (30.3%)	49 (26.2%)	0.286

^aNumber of participants missing data for: *Behavioral issues* (Total = 57, Males = 45, Females = 12); *Financial constraints* (Total = 59, Males = 49, Females = 10); *Lack of community resources* (Total = 64, Males = 55, Females = 9); *Time constraints* (Total = 58, Males = 45, Females = 13); *Transportation* (Total = 72, Males = 58, Females = 14).

^bComparison of barriers to social participation by child's sex using Chi-square test of independence.

Table 5

Caregiver-reported behavioral issues as a barrier to social participation and child's intellectual function among Fragile X Online Registry With Accessible Research Database participants, aged 5–17, by activity type, 2011–2021.

<i>Current Intellectual function</i>	Behavioral issues as a barrier to social participation					
	Total (n = 738)^a		Males (n = 557)		Females (n = 181)	
	Little to No Barrier	Moderate to Huge Barrier	Little to No Barrier	Moderate to Huge Barrier	Little to No Barrier	Moderate to Huge Barrier
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
No ID	43 (78.2%)	12 (21.8%)	4 (36.4%)	7 (63.6%)	39 (88.6%)	5 (11.4%)
Developmental delay ^b	10 (38.5%)	16 (61.5%)	8 (34.8%)	15 (65.2%)	2 (66.7%)	1 (33.3%)
Borderline to mild ID	183 (67.8%)	87 (32.2%)	101 (62.3%)	61 (37.7%)	82 (75.9%)	26 (24.1%)
Moderate ID	135 (41.0%)	194 (59.0%)	127 (40.8%)	184 (59.2%)	8 (44.4%)	10 (55.6%)
Severe to profound ID	14 (24.1%)	44 (75.9%)	13 (26.0%)	37 (74.0%)	1 (12.5%)	7 (87.5%)

Abbreviations: ID = Intellectual disability.

^aParticipants missing responses for current intellectual function or behavioral issues as a barrier were excluded (n = 92/830).

^bQuestion instruction limited response to children under age 6 years; however, 7 children ≥6 years old were also included per clinician designation.