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A Description of the Educational Setting Among Individuals With Fragile X Syndrome

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Abstract

Children with fragile X syndrome (FXS) display wide-ranging intellectual and behavioral abilities that affect daily life. We describe the educational setting of students with FXS and assess the relationships between school setting, co-occurring conditions, and functional ability using a national survey sample (n = 982). The majority of students with FXS in this sample have formal individualized education plans, spend part of the day outside regular classrooms, and receive modifications when in a regular classroom. Males with FXS and certain co-occurring conditions (autism, aggression, and self-injurious behavior) are more likely to spend the entire day outside

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regular classrooms, compared to males without these co-occurring conditions. Students who spend more time in regular classrooms are more likely to perform functional tasks without help.

Keywords

fragile X syndrome; education; support services; functional skills

Fragile X syndrome (FXS) is the most common known cause of inherited intellectual disability, with prevalence estimates ranging from 1 in 4,000–9,000 males and 1 in 8,000–11,000 females (Coffee et al., 2009; Crawford, Acuna, & Sherman, 2001; Hunter et al., 2014). In addition to intellectual disability, individuals with FXS can experience a wide range of other cognitive and behavioral symptoms such as attention problems, hyperactivity, aggression, and poor eye contact (Bailey, Raspa, Olmsted, & Holiday, 2008; Cohen, Vietze, Sudhalter, Jenkins, & Brown, 1989; Hatton et al., 2002). Many individuals with FXS also have a diagnosis of autism spectrum disorder (ASD; Clifford et al., 2007; Hall, Lightbody, & Reiss, 2008; Harris et al., 2008). Although the prevalence of ASD among individuals with FXS is not precisely known, current estimates range from 15% to 60% (Boyle & Kaufmann, 2010; Budimirovic & Kaufmann, 2011; McCary & Roberts, 2013). These estimates are even greater when considering the proportion of individuals who display autistic symptoms but do not have a diagnosis. Previous reports suggest up to 90% of males with FXS display at least one autistic behavior (Raspa, Wheeler, & Riley, 2017).

The educational setting plays an important role in addressing the unique behavioral and social challenges that students with intellectual and other developmental disabilities face. Individuals with FXS often qualify for school-based services through the Individuals with Disabilities Education Act (IDEA). One major component of IDEA is the development and implementation of individualized education plans (IEPs) for children ages 3 through 21 and individualized family service plans (IFSPs) for children younger than 3 years, which outline personalized goals for both the child and family as well as services and supports needed to reach each goal. In order to qualify for special education services under IDEA, children must have a diagnosed disability that impacts school performance. Children younger than 3 years old may qualify for early intervention programs with a general diagnosis of “developmental delay” (U.S. Department of Education). Through IDEA, individuals with FXS can receive a variety of services in addition to academic support, such as occupational therapy, physical therapy, and speech-language therapy, based on their distinct needs to improve learning and educational outcomes.

Several studies have shown that students with intellectual, developmental, or other special health care needs are at risk for poor outcomes both during and after schooling, which may lead to negative long-term effects on students’ ability to live an independent life (Bouck, 2014; Forrest, Bevans, Riley, Crespo, & Louis, 2011). Understanding the educational environment and how caregivers perceive this setting can assist parents and other stakeholders in helping students with FXS reach their full potential. Studies of the educational setting of children with FXS can help inform caregivers, educators, healthcare

providers, and researchers about the unique needs of this population and allow for future planning; however, data are limited in this area.

One prior study of a national sample of families affected by FXS in the United States found that the majority of respondents reported that their child with FXS received some type of therapy, with speech and occupational therapy being the most common. The location of therapy receipt varied (e.g., 38% of physical therapy but 56% of behavior management therapy occurred in a regular classroom at school or child care), but over 50% of individuals reporting therapy use received therapy in the school setting (Martin et al., 2013). Another study investigating the academic skills of 45 boys with FXS, ages 4 to 13 years old, found global deficits in both general skills (e.g., letter-word identification, math problem solving, writing skills) and knowledge (e.g., general information in science, humanities, and social studies; Roberts et al., 2005).

Due to the X-linked inheritance pattern of FXS, males can be more severely affected and typically have lower cognitive ability and more severe behavioral problems than females (Huddleston, Visootsak, & Sherman, 2014). For this reason, most studies of individuals with FXS have focused primarily—or exclusively—on males, resulting in a knowledge gap about many aspects of the lifespan for females with FXS. It is not well understood whether they need, or are accessing, the same educational services as males. Although the Martin et al. study (2013) showed that, among respondents, a greater proportion of males (72%) than females (47%) were reported to be receiving any therapy, nearly half of all females still received therapy. Previous studies have also shown that females with FXS have unique challenges in academic settings and also require support services. Deficits in academic skills, particularly in mathematics, have been documented in females with varying degrees of FXS severity (Bennetto, Pennington, Porter, Taylor, & Hagerman, 2001; Brainard, Schreiner, & Hagerman, 1991; Grigsby, Kemper, Hagerman, & Myers, 1990; Mazzocco, 2001; Murphy, Mazzocco, Gerner, & Henry, 2006). Other studies of school-aged children with FXS have suggested that both males and females affected with FXS display deficits in language and reading skills (Adlof, Klusek, Shinkareva, Robinson, & Roberts, 2015; Sterling & Abbeduto, 2012).

There is a limited understanding of the educational setting, including classroom placement and school performance, for individuals living with FXS, especially females. We analyzed data from a national survey of families affected by FXS to answer two research questions of interest. First, we wanted to describe the educational setting, classroom placement, caregiver perceptions, and skill performance among a cohort of individuals with FXS, including one-fifth of whom are females. Second, we assessed whether individuals with FXS who have another co-occurring condition (i.e., autism, attention deficit disorder, hyperactivity, aggressiveness, anxiety, or self-injurious behavior) were more likely to spend a greater proportion of the school day outside a regular classroom than individuals with FXS who do not have the same co-occurring condition. The presence of any co-occurring condition was used as a proxy for severity of the FXS phenotype, as these conditions would likely contribute to problems in the school environment. We also investigated functional skill ability in relation to the amount of time spent in the regular classroom.

Methods

Study Design

Researchers at RTI International (Research Triangle Park, NC) designed and implemented the large national survey of families affected by FXS, which was designed to better understand the nature and consequences of FXS. More details regarding sample recruitment, enrollment and survey design are offered in a previous publication (Bailey, Raspa, & Olmsted, 2010). The overall study included items on a variety of topics such as childhood physical activity, sleep, seizures, medication use, family impact, and educational setting and functional skills, which were used for this article. The survey was approved by the RTI International Institutional Review Board. Project staff obtained informed consent from all study participants prior to administering the survey questionnaire.

Families were recruited into the study through the combined efforts of foundations (National Fragile X Foundation and FRAXA Research Foundation), researchers, and clinicians. Any parent or caregiver (one per family) of an individual of any age with FXS was eligible to complete the survey. Approximately 80% of the participants completed the survey online and the remaining 20% participated via a call center. Two phases of data collection are used in this report (Phase I and Phase II), each of which had two components. For both phases, respondents first completed a short enrollment survey that included demographic and basic clinical information (e.g., diagnosis and co-occurring conditions). Approximately 6 months later, families completed a full survey, which focused on a variety of topics. Enrollment for Phase I was conducted in 2007–2008 and the full survey was administered in 2008. Enrollment for Phase II occurred during 2011–2012 and the full survey was administered in 2012. A total of 1,075 families (86% of the Phase I enrollment sample) completed both components of the Phase I survey and a total of 730 families (60% of the Phase II enrollment sample) completed both components of the Phase II survey. Families who participated in Phase I were also eligible to complete Phase II as the two surveys collected data on different subtopics; 459 families completed both Phase I and Phase II surveys, representing 718 individuals.

Participants

Analyses were restricted to responses of parents/caregivers of children for whom genetic testing revealed full mutation FXS ($n = 1,394$), according to the parent/caregiver. Because we were interested in describing the school services received by these children, we excluded responses with missing data regarding the child's school attendance ($n = 73$) or IEP/IFSP status ($n = 317$). The majority (86%) of the individuals for whom this information was missing were 22 years or older at the time of Phase I interview and, thus, their parent/caregiver was not asked to respond to questions about school attendance. We also excluded responses from parents/caregivers who resided outside of the United States ($n = 22$), resulting in survey records on 982 children with FXS for the school services analysis.

Demographic, family, economic, and geographic characteristics of the 982 children and their parents/caregivers are presented in Table 1. Notably, the majority of children with FXS in this study were male (80%) and non-Hispanic white (88%). Nearly two-thirds (65%) of the

children were between the ages of 6 and 17 years at the time of the Phase I survey; 24% were 5 years old and the remaining 12% were 18–21 years old. The caregivers who responded to the survey were mostly mothers (88%), college-educated (69%), employed at the time of survey enrollment (65%), reported an annual family income greater than \$50,000 (76%), and were geographically distributed throughout the United States.

Instruments

Caregivers were asked to respond to a variety of questions about their child's school experiences. In Phase I, items included questions about the school environment such as whether the child had an IFSP or IEP (yes/no) and the amount of time their child spends in the regular classroom (none of the time, 1 to 20% of the time, 21% to 60% of the time, 61% to 99% of the time, all of the time). In addition, Phase I asked about parents'/caregivers' perceptions about their involvement in the decisions surrounding the goals and services for the child (want to be more involved, involved the right amount, want to be less involved), agreement that the child's goals are challenging and appropriate (strongly agree, agree, disagree, strongly disagree), and whether the child has made progress toward the goals (a lot, some, not much, none). Respondents were also asked to rate their child's current academic performance (substantially below grade level, slightly below grade level, at grade level, slightly above grade level, substantially above grade level).

In Phase II, respondents were asked to rate their child's functional skill ability (e.g., reading restroom signs, following a schedule, deciding how to spend money). Functional skills were rated as "does not do this," "needs a lot of help," "needs a little help," or "does this without help." Specific functional skills questions are presented in Table 2. During enrollment for both surveys, co-occurring conditions were determined based on whether the child had ever been diagnosed or treated by a medical professional for any of the following conditions: anxiety, attention problems, hyperactivity, autism, aggression, self-injurious behaviors, depression, seizures, and developmental delay.

Data Analysis

All statistical analyses were conducted using SAS version 9.3 (English, Cary NC). Age for the school services descriptive analysis was categorized into four groups based on natural breaks in schooling, using the child's age at the time of the Phase I interview: 5 years, 6–10 years, 11–17 years, and 18–21 years. All analyses were stratified by sex. Subsequent analyses were limited by incomplete data and were therefore restricted to children who had responses to all questions being analyzed. Analysis of caregiver perceptions of the decisions and goals in their child's IEP/IFSP were limited to respondents whose child had an IEP/IFSP ($n = 872$). Analysis of school performance included responses from parent/caregivers who indicated their child was attending school and answered the questions regarding the child's performance in reading, writing, and math ($n = 672$).

Multivariable analyses were conducted using logistic regression to examine whether the six co-occurring conditions (autism, attention problems, hyperactivity, aggression, self-injurious behavior, and anxiety) were associated with time spent in the regular classroom. Six models were created, with each co-occurring condition serving as a binary predictor variable (i.e.,

not diagnosed/treated vs. diagnosed/treated), age as a covariate, and time spent in the regular classroom as the binary outcome variable (i.e., no time vs. any time spent in the regular classroom). An additional model was created using at least any two of the aforementioned co-occurring conditions as the outcome variable. Models were performed separately for males ($n = 542$) and females ($n = 124$).

We conducted a subanalysis of the participants who completed both surveys and had a child at least 6 years old at the time of the Phase I interview. The Phase I and Phase II surveys for these individuals were linked with a unique study ID that was the same for both surveys. Functional skill ability was assessed for those in the subanalysis who answered questions about various functional skills. For each of the 12 functional skills assessed (Table 2), ability to perform the task was dichotomized as more independent (“needs a little help” or “does this without help”) versus less independent (“needs a lot of help” or “does not do”). Then the distribution of more independent versus less independent for each age group was compared across categories of time spent in the regular classroom using Fisher’s exact test. The proportion in each category of time who were considered more independent were also presented graphically for each of the 12 functional skills. Age at time of Phase I survey and time spent in the regular classroom were collapsed into two (6–10 years and 11–21 years) and three categories (none, 1–60% of the time, and 61–100% of the time), respectively. Parents/caregivers for 234 males completed both surveys and answered the questions of interest. Due to the small sample size, results for females ($n = 37$) in this subanalysis were not reported.

Results

Tables 3a and 3b provide a description of the school setting by age for males and females, respectively. At the time of the Phase I survey, most respondents reported their children were currently attending school, with the lowest proportions for either sex reported for 18–21 year olds. The majority of children ≤ 5 years old who were attending school were in child care or early education and only about 40% reported the teacher was aware of the child’s FXS diagnosis. In contrast, most children >5 years were attending public school and $>90\%$ reported teachers were aware of the child’s FXS diagnosis, with the exception of females 18–21 years ($n = 12$), for whom only half of the respondents reported a teacher who was aware of the FXS diagnosis.

Across all age categories the majority ($>90\%$) of males currently attending school had an IEP or IFSP, whereas the proportion of female students with an IEP decreased with increasing age. The most commonly reported area of eligibility for an IEP/IFSP varied by age and sex, with “developmental delay” more common among children ≤ 5 years old and “mental retardation” (males) or “other health impairments” (females) more common among older students.

The majority (65%) of students spent at least some of their school day in a regular classroom (Tables 3a-b). The proportion of males who spent no time in a regular classroom increased with age (e.g., 24% among ≤ 5 years, 25% among 6–10 years, 41% among 11–17 years, and 50% among 18–21 years). A similar trend was not observed in females (e.g., 22% among ≤ 5

years, 8% among 6–10 years, 18% among 11–17 years, and 50% among 18–21 years). The majority of students who spent some time in a regular classroom also received at least one modification. The most common classroom modification for all age groups was the presence of a classroom aide. Some common responses in the “other” category for types of modifications included sensory tools (e.g., weighted backpacks, desk modifications, and sensory breaks) and modified curriculum or schoolwork.

Parents’/caregivers’ perceptions about child performance in school varied between male and female children. Across all age groups, the majority of parents/caregivers of male students reported that the child’s performance in reading, writing, and math was substantially below grade level, and this proportion generally increased with age (Figure 1A). In contrast, less than 50% of the respondents with female students reported performance substantially below grade level for writing and reading, and over 50% reported performance substantially below grade level for math. Among females, there was no significant difference in performance by age group for any school subject ($p = 0.24$ reading; 0.26 writing; 0.56 math). However, for all ages and subjects, the proportions of respondents that reported the child’s performance was substantially below grade level for females were lower than the corresponding proportions for males ($p < 0.01$ for all six comparisons; Figure 1B).

Parents’/caregivers’ perceptions about students’ school goals were similar for males and females (Table 4). The majority of respondents (70% for all age and sex categories) reported that they were involved “about the right amount” in decisions and believed their child made a lot or some progress towards their school goals. Caregivers also generally agreed that their child’s educational goals were challenging and appropriate and the majority believed their child made some or a lot of progress towards their goals. A small percentage of all caregivers answering the question (15%) disagreed to some extent (“disagree” or “strongly disagree”) that their child’s goals were appropriate and challenging, with caregivers of female students 11–17 years old reporting the highest percentage of disagreement (27%).

Table 5 presents results for the associations between various co-occurring conditions and time spent in a regular classroom. Males with co-occurring conditions of autism (aOR=1.8, 95% CI: 1.2–2.6), aggression (aOR=1.9, 95% CI: 1.3–2.8), or self-injurious behavior (aOR=1.8, 95% CI: 1.3–2.7) were significantly more likely to spend no time in a regular classroom than males without the respective co-occurring condition. Among females, self-injurious behavior (aOR=5.4, 95% CI: 1.7–17.5) and the presence of multiple co-occurring conditions (aOR=3.4, 95% CI: 1.1–11.1) were significantly associated with spending no time in a regular classroom.

Figure 2 demonstrates the association between functional skill ability (as reported in the Phase II survey, administered approximately four years after Phase I) and time spent in a regular classroom (as reported in the Phase I survey) among males, by age group. For young males, significant differences ($p < 0.05$) in ability across categories of time spent in the classroom at Phase I were found for the skills of writing name, copying shapes, counting to 10, adding and subtracting, reading a restroom sign, differentiating strangers, and reading a clock. The corresponding significant differences ($p < 0.05$) for older males were found for

writing name, adding and subtracting, and reading a restroom sign (Figure 2). Overall, a greater proportion of older male students were able to perform each functional skill with little or no help compared to younger students. Generally, male students spending more time in the regular classroom during Phase I were more likely to be able to perform a variety of functional skills with little or no help needed during Phase II.

This trend was evident in both age groups. For example, among male students who were 6–10 years old during Phase I, only 20% of those who spent no time in a regular classroom were able to read a clock with little or no help at the time of the Phase II survey, compared to 46% ($n = 27$) of those who spent up to 60% of time in a regular classroom, and 75% ($n = 15$) of those who spent 61–100% of time in a regular classroom ($p = 0.002$; Figure 2 and Table 6). Generally, as the skills became more complex, a greater proportion of males needed a lot of help or did not do that task.

Discussion

Findings from this analysis describe the school setting and caregiver perceptions related to their child's IFSP or IEP for a large, national sample of individuals with FXS whose caregivers were surveyed in 2008 and 2012. We also investigated the relationship between the time spent in a regular classroom and co-occurring conditions and the ability to perform various functional skills that may help determine a student's readiness for the transition towards independence. We found that the majority of students in our study were currently attending public school at the time of interview, had an IEP or IFSP in place, had teachers aware of their FXS diagnosis, and most spent at least some time in a regular classroom and had at least one classroom modification.

IDEA specifies that all children with disabilities, including intellectual and learning disabilities, should receive an appropriate education and that special education should occur in the least restrictive setting (Hurwitz, 2008; Individuals with Disabilities Education Act as amended through P.L. 114–95). Our findings showed that younger students were more likely to spend most or all of their day in a regular classroom, but older students often spent more time in a segregated setting. There are several possible explanations for this finding. One hypothesis is that students with FXS are outpaced by their typically developing peers and are unable to keep up with the academic expectations in a regular classroom. Several small studies (ranging from 10 to 56 subjects) of boys with FXS have found that cognitive development, measured by repeated IQ scores, slows with increasing age and plateaus during early adolescence (Dykens et al., 1989; Hagerman et al., 1989; Hodapp et al., 1990; Lachiewicz, Gullion, Spiridigliozzi, & Aylsworth, 1987). Another small study (45 males) found that academic growth slowed over time in boys with FXS, and was not associated with IQ. However, in this study, IQ was considered only as a fixed effect and was measured at different ages (Roberts et al., 2005). These observations suggest that the complex cognitive and academic skills required of older students could explain our age-related findings. Nevertheless, it is important to note the small and limited scope of these previous studies and the absence of an IQ measure in our analysis.

Another plausible explanation is that individuals with FXS have varying degrees of problem behaviors that impact their ability to be in a regular classroom, such as hyperactivity, motor stereotypies, and inappropriate speech (Baumgardner, Reiss, Freund, & Abrams, 1995; Hustyi, Hall, Jo, Lightbody, & Reiss, 2014; Sansone et al., 2012). As students get older and academic rigor increases, these behaviors may be viewed as more disruptive and become less likely to be tolerated in a regular classroom. However, behavioral interventions, many of which are administered in the school setting, could help with behavioral challenges associated with FXS, allowing students to spend more time with their typically developing peers. In particular, intensive early educational interventions may also improve behavior and cognitive ability in students with FXS (Hall, 2009; Hall, Maynes, & Reiss, 2009; Kurtz, Chin, Robinson, O'Connor, & Hagopian, 2015; Moskowitz & Jones, 2015; Weiskop, Richdale, & Matthews, 2005; Winarni, Schneider, Borodyanskara, & Hagerman, 2012). Providing additional support and/or classroom modifications to students early on in their academic careers may be one way to increase the amount of time students with FXS are able to spend in a regular classroom as they get older.

It is important to place our findings in the context of educational settings for the wider population of children with intellectual and other disabilities. According to the National Center for Education Statistics (Aud et al., 2013), nearly two-thirds of all students (ages 6 to 21 years) with disabilities spend 80% or more of their school day inside general classrooms, but this varies depending on the type of disability (ranging from 13% of students with 'multiple disabilities' to 65% of students with 'visual impairment'). In this NCES report, only 16% of students with intellectual disabilities spend the majority of their day inside general classrooms, which is lower than our findings for females of all ages, and males 10 years and younger, but higher than our findings for older males. It is important to note that our observed results for females and young males may be higher than the national estimates because individuals in these categories may not have a recognized intellectual disability.

The results of our study also confirmed the presence of educational differences between males and females. The proportion of females who received special education services was lower than that for males; this is likely due to females having less severe cognitive deficits and displaying fewer behaviors that may interfere with school performance. Caregivers of female students also reported better performance in school than did caregivers of male students. These findings are consistent with previous reports indicating males are more severely affected than females due to the X-linked inheritance pattern of FXS (Rinehart, Cornish, & Tonge, 2011). However, females with FXS can still have difficulties in an academic setting. Most females with FXS in our study sample had an IEP, and more than half were unable to be in a regular classroom for the entire school day. More than half of the parents/caregivers of females with FXS reported that their child's performance was substantially below grade level in math. Although females are often overlooked in other areas of FXS research, they likely have a unique profile of educational challenges that needs consideration.

In contrast to the differences between parent/caregiver perceptions of school services and performance for males and females, parent/caregiver perceptions of student progress and involvement in shared decision making were similar for both male and female students.

Other studies of family satisfaction with early intervention programs in children with disabilities found that most respondents reported being involved the right amount (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; Bailey, Skinner, Rodriguez, & Gut, 1999; Iversen, Shimmel, Ciacara, & Prabhakar, 2003). It is worth noting, however, that for parents/caregivers of children in all age groups, up to a quarter of respondents in our study reported that they wanted to be more involved. Future studies could try to understand potential barriers of family involvement in educational planning so that schools can ensure all families feel that they are taking an active role in educational decision making.

Earlier studies have found that students who have co-occurring diagnoses of FXS and autism spectrum disorder have lower skill competency than those without autism spectrum disorder, and that the presence of functional skills are strong predictors of independence in adult life, even though many males with FXS lack functional skills (Bailey, Raspa, Holiday, Bishop, & Olmsted, 2009; Hartley et al., 2011; Hatton et al., 2003; Hustyi et al., 2015). We found that males who spend more time in a regular classroom at a younger age were more likely to be able to perform various functional tasks later on. Additionally, students with certain co-occurring conditions were more likely to spend no time in a regular classroom than students without these conditions, suggesting that the amount of time spent in a regular classroom is affected by severity of disability. One implication that may arise from these results is that working with students to enable them to spend more time in a regular classroom, such as through management of co-occurring conditions or increased modifications including classroom aides, may help them be more independent later.

Although many special education programs, particularly at the secondary level, have separate programs in place that teach daily living skills, other programs are trending toward inclusion of students with intellectual disability in regular education classrooms (Kauffman & Hung, 2009). Although the majority of parents in our study reported that school goals were appropriate for their children, this may not be generalizable to all students with FXS or another form of intellectual disability. It is important for caregivers and educators to work together to determine the best placement for individual students based on their distinct needs and goals.

To our knowledge, this study represents the largest analysis of the educational setting among individuals with FXS. However, there are several limitations. Although data were collected as part of a national survey, the respondents were not sociodemographically diverse; 88% of respondents were White and over two-thirds had a college education. The relative homogeneity of our sample demographics represents a possible source of bias, as respondents were recruited through fragile X clinics and foundations, which may not be representative of all families and individuals with FXS. Studies have shown that minority children are more likely to have unmet therapy needs and are less likely to have appropriate diagnoses (Dickerson et al., 2017; Magnusson & Mistry, 2017). Further, caregivers responding to this survey may be more involved and vocal advocates for their child's education than caregivers who did not respond, which could potentially affect the amount and breadth of school services that their child received. It is possible that the average school setting looks very different for minority families or families in lower socioeconomic brackets. Although IDEA is federal legislation, IEP eligibility and special education services

vary by state and school district. Therefore, although we present broad results from a national survey, these results may not be indicative of the services available or provided to all students with FXS.

Other limitations of utilizing survey data to analyze educational services include the subjective nature of some questions, varying levels of understanding among respondents, and missing data for questions of interest. Lastly, it is important to note that given this was an online survey study and a direct IQ assessment was not possible, we were unable to analyze IQ level as a potential confounder of the relationship between time spent in a regular classroom and ability to perform functional skills.

Conclusions

Most students with FXS included in this national survey were accessing special education services, were spending at least some time in a regular classroom, and many were reported by parents/caregivers to be performing below grade level. Our finding that both males and females utilize special education services suggests that, although the focus of FXS research is often on males, females with FXS need support and consideration of their specific needs, particularly in an academic setting. We found that the ability to perform functional skills increased as more time was spent in a regular classroom, however we were unable to assess whether limited classroom time is a result of, a causal factor for, or incidental to having lower IQs or more behavioral challenges; further study could examine this relationship and its effect on functional skill ascertainment. Additionally, future studies could investigate potential barriers to family involvement in educational decision making to better understand how to help individuals affected by FXS reach their full potential.

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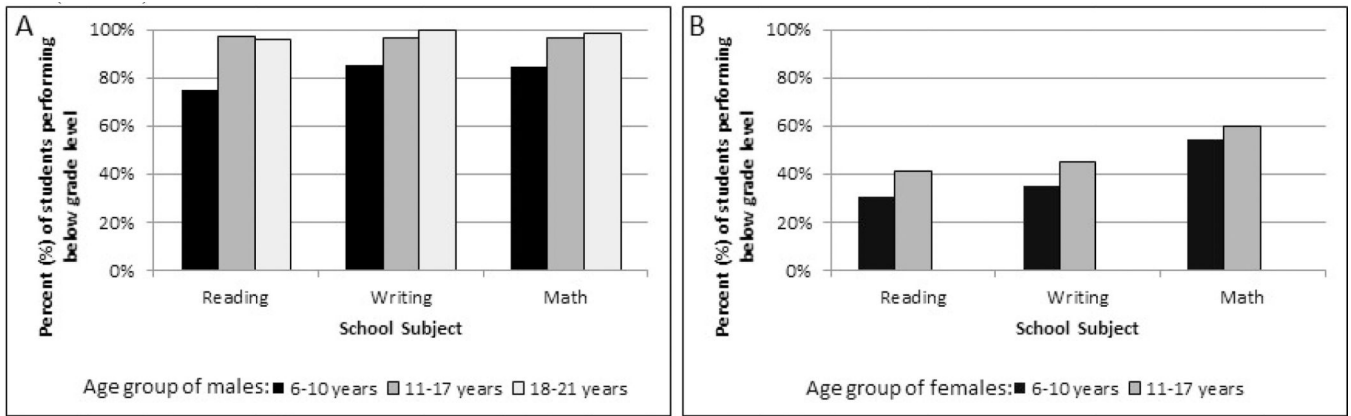


Figure 1.

The percent of students performing substantially below grade level by age category at time of Phase I survey and school subject among males (A) and females* (B) with fragile X syndrome from Phase I of a national survey of families affected by fragile X** ($N = 666$).

*Percentages for females 18–21 years are not reported due to small sample size ($n = 6$).

** Phase I (time spent in a regular classroom) conducted 2007–2008

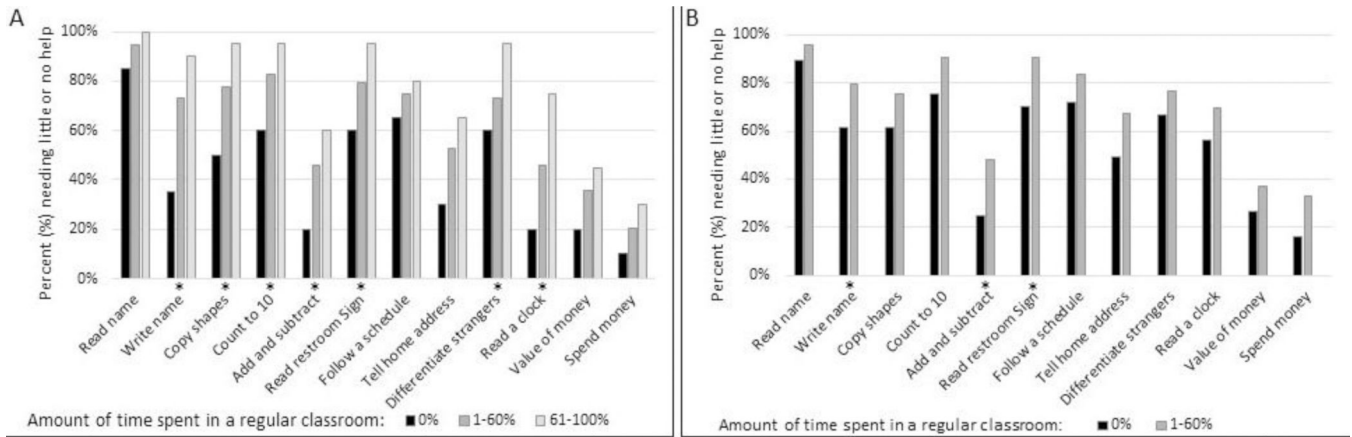


Figure 2.

The percent of students who can perform various functional tasks with little or no help by the amount of time spent in regular classroom (ascertained 3–4 years earlier) among males with fragile X syndrome who were 6–10 years old ($n = 99$; A) and 11–21 years old[^] ($n = 130$; B), from a national survey of families affected by fragile X^{^^}. Caregivers were asked to rate their child's ability on functional tasks as (1) unable to do this; (2) needs a lot of help; (3) needs a little help; or (4) no help needed. The functional tasks displayed in this figure correspond to the child's ability (rating of 3 or 4) to read or recognize their own first name (read name); write their own first and last name (write name); copy simple shapes (copy shapes); count up to 10 objects correctly (count to 10); add and subtract single digit numbers (add and subtract); in a new place, read or recognize signs to choose appropriate restroom (read restroom sign); follow a schedule; tell home address; appropriately differentiate between family/friends and strangers (differentiate strangers); read a clock; know value of coins and bills (value of money); and decide how to spend own money (spend money). Colored bars refer to the amount of time that respondents reported their child spent in the regular classroom during the Phase I interview and correspond to no time in a regular classroom (black bars), 1–60% of the time in a regular classroom (dark grey bars), or 61–100% of the time in a regular classroom (light grey bars).

[^]Percentages for males aged 11–21 years old who spent 61–100% of the time in a regular classroom are not reported due to small sample size ($n=5$)

^{^^}Phase I (time spent in a regular classroom) conducted 2007–2008 and Phase II (functional skills) conducted 2011–2012 *Fisher's exact test across categories of time spent in a regular classroom, $p < 0.05$

Table 1.

Demographic Characteristics of Parents/Caregivers and Children With Fragile X Syndrome From a National Survey of Families Affected by Fragile X (*N*= 982)

Demographic Characteristics of Survey Respondents	<i>n</i> (%)
Child's Sex	
Male	780 (79.4)
Female	202 (20.6)
Child's Race	
Non-Hispanic White	860 (87.6)
Non-Hispanic Black/African American	18 (1.8)
Non-Hispanic Other	16 (1.6)
Non-Hispanic Multiple Races	27 (2.7)
Hispanic	61 (6.2)
Child's Age at Phase 1 Survey	
5 years old	231 (23.5)
6–10 years old	302 (30.8)
11–17 years old	331 (33.7)
18–21 years old	118 (12.0)
Respondent relationship to Child	
Mother	863 (87.9)
Father	90 (9.2)
Other Family Member	29 (3.0)
Respondent Marital Status^{1,2}	
Married	854 (87.0)
Single	23 (2.3)
Other	104 (10.6)
Respondent Education^{1,2}	
Less than High School	6 (0.6)
High School Graduate or GED	98 (10.0)
Trade or Tech School Certificate	41 (4.2)
Some College	164 (16.7)
Two-year College Degree	93 (9.5)
Four-year College Degree	360 (36.7)
Graduate or Professional School	219 (22.3)
Respondent Currently Employed²	
Yes	635 (64.7)
No	347 (35.3)
Annual Household Income^{1,2}	
<\$25,000	48 (4.9)
\$25,000-\$49,999	158 (16.1)
\$50,000-\$74,999	224 (22.8)

Demographic Characteristics of Survey Respondents	<i>n</i> (%)
\$75,000-\$100,000	181 (18.4)
>\$100,000	339 (34.5)
Region of Residence^{1,2}	
Northeastern U.S.	232 (23.6)
Midwestern U.S.	305 (31.1)
Southern U.S.	278 (28.3)
Western U.S.	165 (16.8)

¹Sum<982 due to missing values

²Ascertained at time of Phase I survey enrollment (2007–2008)

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Functional Skill Ascertainment for Skills Analyzed in School Services Analysis From a Large Survey of Families Affected by Fragile X

Table 2.

Bottomic Question	Functional Skills Assessed	Variable in Analysis
How well does child / do each of the following reading tasks? If child / does not have the opportunity or is not allowed to do a task, please select "Does not do this."	Reads or recognizes first name In a new place, reads or recognizes signs to choose appropriate restroom Follows a schedule (can be written, picture, or object schedule) Reads a clock (either digital or clock with hands)	read name read restroom sign follow a schedule read a clock
How well does child / understand time and schedules?	Knows value of coins and small bills Decides how to spend/save own money	value of money spend money
How well does child / understand and use money? If child / does not have the opportunity or is not allowed to do a task, please select "Does not do this."	Counts up to 10 objects correctly Adds and subtracts single-digit numbers	count to 10 add and subtract
How well does child / do each of the following math tasks? If child / does not have the opportunity or is not allowed to do a task, please select "Does not do this."	Copies simple shapes (circle, triangle, square) Writes own first and last name (print or cursive)	copy shapes write name
How well does child / do each of the following writing tasks? If child / does not have the opportunity or is not allowed to do a task, please select "Does not do this."	Tells home address Appropriately differentiates between family/friends and strangers	tell home address differentiate strangers

/ **Child** was replaced with the **child**'s name piped from the beginning of the survey.

Table 3a. Description of School and Support Services by Age Category Among Males With Fragile X Syndrome From Phase I of a National Survey of Families Affected by Fragile X ($n = 780$)

Characteristics of school environment	Age of male child at time of Phase I interview (2007–2008)				Fisher's exact test p -value
	5 years old ($n = 174$) n (%)	6–10 years old ($n = 251$) n (%)	11–17 years old ($n = 257$) n (%)	18–21 years old ($n = 98$) n (%)	
Currently attending school					<0.001
Yes	162 (93.1)	249 (99.2)	251 (97.7)	80 (81.6)	
No	12 (6.9)	2 (0.8)	6 (2.3)	18 (18.4)	
Type of school (if attending school)					
Child care/early childhood education	138 (85.2)	19 (7.6)	–	–	
Public school	22 (13.6)	202 (81.1)	214 (85.3)	50 (62.5)	
Other type of school	2 (1.2)	28 (11.2)	37 (14.7)	20 (25.0)	
Postsecondary school	–	–	–	10 (12.5)	
Teacher aware of FXS diagnosis (if attending school)					0.163
Yes	68 (42.0)	245 (98.4)	250 (99.6)	80 (100.0)	
No	2 (1.2)	4 (1.6)	1 (0.4)	0 (0.0)	
Did not answer	92 (56.8)	0 (0.0)	0 (0.0)	0 (0.0)	
IFSP or IEP in place (if attending school)					0.203
Yes	155 (95.7)	244 (98.0)	248 (98.8)	78 (97.5)	
No	7 (4.3)	5 (2.0)	3 (1.2)	2 (2.5)	
Qualifying Category for IEP (if IEP in place)					
Developmental delay	49 (31.6)	34 (13.9)	47 (19.0)	8 (10.3)	
Autism	22 (14.2)	52 (21.3)	39 (15.7)	7 (9.0)	
Emotional disturbance	0 (0.0)	1 (0.4)	0 (0.0)	1 (1.3)	
Mental retardation	10 (6.5)	41 (16.8)	77 (31.0)	32 (41.0)	
Speech or language impairment	10 (6.5)	7 (2.9)	7 (2.8)	0 (0.0)	
Visual impairment	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Specific learning disability	7 (4.5)	10 (4.1)	4 (1.6)	2 (2.6)	
Multiple disabilities	12 (7.7)	29 (11.9)	35 (14.1)	9 (11.5)	
Other health impairment	9 (5.8)	57 (23.4)	30 (12.1)	13 (16.7)	

Characteristics of school environment	Age of male child at time of Phase I interview (2007–2008)				Fisher's exact test p-value
	5 years old (n = 174) n (%)	6–10 years old (n = 251) n (%)	11–17 years old (n = 257) n (%)	18–21 years old (n = 98) n (%)	
Don't know	6 (3.9)	13 (5.3)	8 (3.2)	6 (7.7)	
Did not answer	30 (19.4)	0 (0.0)	1 (0.4)	0 (0.0)	
Time spent in regular classroom (if attending school)¹					<0.001
None of the time	38 (23.5)	63 (25.3)	102 (40.6)	35 (50.0)	
1–20% of the time	22 (13.6)	80 (32.1)	94 (37.5)	28 (40.0)	
21–60% of the time	21 (13.0)	52 (20.9)	47 (18.7)	6 (8.6)	
61–99% of the time	23 (14.2)	35 (14.1)	2 (0.8)	1 (1.4)	
100% of the time	23 (14.2)	12 (4.8)	6 (2.4)	0 (0.0)	
Did not answer	35 (21.6)	7 (2.8)	0 (0.0)	0 (0.0)	
Received 1 regular classroom modification (if in regular classroom)¹					***
Yes	73 (82.0)	174 (97.2)	145 (97.3)	31 (88.6)	
No	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Did not answer	16 (18.0)	5 (2.8)	4 (2.7)	4 (11.4)	
Type of modification received (if received 1 modification)²					
Classroom aide	57 (78.1)	154 (88.5)	132 (91.0)	27 (87.1)	
Environmental modifications	37 (50.7)	87 (50.0)	64 (44.1)	16 (51.6)	
Assistance with transitions	57 (78.1)	123 (70.7)	87 (60.0)	18 (58.1)	
Adaptations to classroom schedule	35 (47.9)	85 (48.9)	67 (46.2)	14 (45.2)	
Behavior management system	33 (45.2)	78 (44.8)	55 (37.9)	10 (32.3)	
Peer tutoring or coaching	21 (28.8)	55 (31.6)	70 (48.3)	14 (45.2)	
Other	11 (15.1)	14 (8.0)	11 (7.6)	4 (12.9)	

Note. FXS=fragile X syndrome, IFSP=individual family service plan, IEP=individualized education plan.

*** Not computed because receiving 1 regular classroom modifications has less than two non-missing levels

¹ Students attending postsecondary school were not asked about time spent in the classroom

² Categories are not mutually exclusive, sum of proportions > 100%

Table 3b. Description of School and Support Services by Age Category Among Females With Fragile X Syndrome From Phase I of a National Survey of Families Affected by Fragile X ($n = 202$)

Characteristics of school environment	Age of female child at time of Phase I interview (2007–2008)					Fisher's exact test p -value
	5 years old ($n = 57$) n (%)	6–10 years old ($n = 51$) n (%)	11–17 years old ($n = 74$) n (%)	18–21 years old ($n = 20$) n (%)		
Currently attending school						<0.001
Yes	51 (89.5)	50 (98.0)	73 (98.6)	12 (60.0)		
No	6 (10.5)	1 (2.0)	1 (1.4)	8 (40.0)		
Type of school (if attending school)						
Child care/early childhood education	44 (86.3)	3 (6.0)	–	–		
Public school	5 (9.8)	41 (82.0)	53 (72.6)	3 (25.0)		
Other type of school	2 (3.9)	6 (12.0)	20 (27.4)	3 (25.0)		
Postsecondary school	–	–	–	6 (50.0)		
Teacher aware of FXS diagnosis (if attending school)						<0.001
Yes	20 (39.2)	46 (92.0)	70 (95.9)	6 (50.0)		
No	2 (3.9)	4 (8.0)	3 (4.1)	6 (50.0)		
Did not answer	29 (56.9)	0 (0.0)	0 (0.0)	0 (0.0)		
IFSP or IEP in place (if attending school)						0.054
Yes	44 (86.3)	41 (82.0)	56 (76.7)	6 (50.0)		
No	7 (13.7)	9 (18.0)	17 (23.3)	6 (50.0)		
Qualifying Category for IEP (if IEP in place)						
Developmental delay	18 (40.9)	8 (19.5)	9 (16.1)	1 (16.7)		
Autism	4 (9.1)	6 (14.6)	4 (7.1)	0 (0.0)		
Emotional disturbance	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)		
Mental retardation	0 (0.0)	3 (7.3)	5 (8.9)	1 (16.7)		
Speech or language impairment	6 (13.6)	0 (0.0)	3 (5.4)	0 (0.0)		
Visual impairment	1 (2.3)	0 (0.0)	0 (0.0)	0 (0.0)		
Specific learning disability	0 (0.0)	2 (4.9)	10 (17.9)	0 (0.0)		
Multiple disabilities	1 (2.3)	3 (7.3)	5 (8.9)	0 (0.0)		
Other health impairment	7 (15.9)	14 (34.1)	18 (32.1)	4 (66.7)		

Characteristics of school environment	Age of female child at time of Phase I interview (2007–2008)					Fisher's exact test p-value
	5 years old (n = 57) n (%)	6–10 years old (n = 51) n (%)	11–17 years old (n = 74) n (%)	18–21 years old (n = 20) n (%)		
Don't know	1 (2.3)	4 (9.8)	1 (1.8)	0 (0.0)		
Did not answer	6 (13.6)	1 (2.4)	1 (1.8)	0 (0.0)		
Time spent in regular classroom (if attending school)¹					0.020	
None of the time	11 (21.6)	4 (8.0)	13 (17.8)	3 (50.0)		
1–20% of the time	3 (5.9)	6 (12.0)	17 (23.3)	2 (33.3)		
21–60% of the time	0 (0.0)	9 (18.0)	6 (8.2)	0 (0.0)		
61–99% of the time	7 (13.7)	14 (28.0)	20 (27.4)	0 (0.0)		
100% of the time	19 (37.3)	15 (30.0)	17 (23.3)	1 (16.7)		
Did not answer	11 (21.6)	2 (4.0)	0 (0.0)	0 (0.0)		
Received 1 regular classroom modification (if in regular classroom)¹					***	
Yes	19 (65.5)	32 (72.7)	51 (85.0)	1 (33.3)		
No	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)		
Did not answer	10 (34.5)	12 (27.3)	9 (15.0)	2 (66.7)		
Type of modification received (if received 1 modification)²						
Classroom aide	10 (52.6)	22 (68.8)	32 (62.7)	1 (100.0)		
Environmental modifications	8 (42.1)	15 (46.9)	18 (35.3)	0 (0.0)		
Assistance with transitions	9 (47.4)	18 (56.3)	12 (23.5)	0 (0.0)		
Adaptations to classroom schedule	5 (26.3)	11 (34.4)	12 (23.5)	0 (0.0)		
Behavior management system	4 (21.1)	5 (15.6)	4 (7.8)	0 (0.0)		
Peer tutoring or coaching	6 (31.6)	15 (46.9)	13 (25.5)	0 (0.0)		
Other	8 (42.1)	7 (21.9)	13 (25.5)	0 (0.0)		

Note. FXS=fragile X syndrome, IFSP=individual family service plan, IEP=individualized education plan.

*** Not computed because receiving 1 regular classroom modifications has less than two non-missing levels

¹ Students attending postsecondary school were not asked about time spent in the classroom

² Categories are not mutually exclusive, sum of proportions > 100%

Table 4.

Caregiver Perceptions of School Services Among Caregivers of Children With Fragile X Syndrome* by Child Age Category From Phase I of a National Survey of Families Affected by Fragile X (N = 872)

Caregiver perceptions about child's goals	5 years old (n=199)		6-10 years old (n=285)		11-17 years old (n=304)		18-21 years old (n=84)	
	Male (n=155) n (%)	Female (n=44) n (%)	Male (n=244) n (%)	Female (n=41) n (%)	Male (n=248) n (%)	Female (n=56) n (%)	Male (n=78) n (%)	Female (n=6) n (%)
How do you feel about your involvement in the decisions about the goals and services provided for your child?								
I wanted to be more involved	39 (25.2)	7 (15.9)	63 (25.8)	7 (17.1)	57 (23.0)	15 (26.8)	12 (15.4)	NR
I was involved about the right amount	116 (74.8)	37 (84.1)	181 (74.2)	33 (80.5)	188 (75.8)	40 (71.4)	63 (80.8)	NR
I wanted to be less involved	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.8)	1 (1.8)	3 (3.8)	NR
Did Not Answer	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.4)	1 (0.4)	0 (0.0)	0 (0.0)	NR
To what extent do you agree or disagree with the following statement: child's educational goals are challenging and appropriate?								
Strongly agree	41 (26.5)	15 (34.1)	66 (27.0)	11 (26.8)	68 (27.4)	11 (19.6)	15 (19.2)	NR
Agree	90 (58.1)	27 (61.4)	143 (58.6)	25 (61.0)	141 (56.9)	30 (53.6)	53 (67.9)	NR
Disagree	19 (12.3)	2 (4.5)	27 (11.1)	2 (4.9)	30 (12.1)	13 (23.2)	7 (9.0)	NR
Strongly disagree	5 (3.2)	0 (0.0)	8 (3.3)	2 (4.9)	8 (3.2)	2 (3.6)	3 (3.8)	NR
Did Not Answer	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.4)	1 (0.4)	0 (0.0)	0 (0.0)	NR
In the past year, how much progress do you think your child has made towards meeting these goals?								
A Lot	85 (54.8)	23 (52.3)	96 (39.3)	16 (39.0)	74 (29.8)	19 (33.9)	25 (32.1)	NR
Some	56 (36.1)	19 (43.2)	117 (48.0)	18 (43.9)	139 (56.0)	31 (55.4)	44 (56.4)	NR
Not Much	14 (9.0)	2 (4.5)	28 (11.5)	6 (14.6)	31 (12.5)	4 (7.1)	7 (9.0)	NR
None	0 (0.0)	0 (0.0)	3 (1.2)	0 (0.0)	4 (1.6)	2 (3.6)	1 (1.3)	NR
Did Not Answer	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.4)	0 (0.0)	0 (0.0)	1 (1.3)	NR

* Restricted to parent/caregivers of children who reported that their child had an individual family service plan (IFSP) or individualized education plan (IEP) in place

NR=not reported because denominator < 10 subjects

Table 5.

Associations Between Co-Occurring Diagnoses in Children With Fragile X Syndrome and the Amount of Time Spent in a Regular Classroom by Sex From Phase I of a National Survey of Families Affected by Fragile X ($N = 666$)

Co-Occurring Conditions	Males ($n = 542$)		Females ($n = 124$)	
	n (%)	None vs. Any Time (ref) aOR ^I (95% CI)	n (%)	None vs. Any Time (ref) aOR ^I (95% CI)
Autism	254 (46.9)	1.8 (1.2, 2.6)	22 (17.7)	1.3 (0.4, 4.3)
Attention problems	468 (86.3)	1.0 (0.6, 1.7)	87 (70.2)	1.9 (0.6, 6.3)
Hyperactivity	366 (67.5)	1.2 (0.8, 1.7)	46 (37.1)	1.5 (0.6, 4.0)
Aggression	205 (37.8)	1.9 (1.3, 2.8)	21 (16.9)	3 (1.0, 9.5)
Self-injurious	231 (42.6)	1.8 (1.3, 2.6)	18 (14.5)	5.4 (1.7, 17.5)
Anxiety	391 (72.1)	1.4 (0.9, 2.1)	74 (59.7)	1.8 (0.6, 5.2)
2 of the above	472 (87.1)	1.7 (0.9, 3.0)	74 (59.7)	3.4 (1.1, 11.1)
None of the above ²	31 (5.7)	0.5 (0.2, 1.3)	25 (20.2)	0.4 (0.1, 1.9)

^I Adjusted for categorical age (6–10 years vs. 11–21 years)

² Includes people with other conditions (e.g., depression, seizures, gender development issues) as well as those with no other conditions

Table 6.

Functional Skills by Age at School Services Interview (Phase I) and Time Spent in Classroom Among Males with Fragile X Syndrome who Completed Both Surveys (n=234), from a National Survey of Families Affected by Fragile X*

Daily Functional Skill	Ability	6-10 year olds (n=99)						11-21 year olds (n=135)					
		Time Spent in Regular Classroom			p-value ²			Time Spent in Regular Classroom			p-value ²		
		No time (n=20) n (%) ^f	1-60% (n=59) n (%) ^f	61-100% (n=20) n (%) ^f				No time (n=57) n (%) ^f	1-60% (n=73) n (%) ^f	61-100% (n=5) n (%) ^f			
Reads or recognizes first name	Does not do this - needs a lot of help	2 (10.0)	3 (5.1)	0 (0.0)	0.289		5 (8.8)	3 (4.1)	NR				
	Needs a little help - no help needed	17 (85.0)	56 (94.9)	20 (100.0)			51 (89.5)	70 (95.9)	NR			0.483	
Writes own first and last name	Does not do this - needs a lot of help	12 (60.0)	16 (27.1)	2 (10.0)	0.002		21 (36.8)	13 (17.8)	NR				
	Needs a little help - no help needed	7 (35.0)	43 (72.9)	18 (90.0)			35 (61.4)	58 (79.5)	NR			0.047	
Copies simple shapes	Does not do this - needs a lot of help	9 (45.0)	12 (20.3)	1 (5.0)	0.007		21 (36.8)	18 (24.7)	NR				
	Needs a little help - no help needed	10 (50.0)	46 (78.0)	19 (95.0)			35 (61.4)	55 (75.3)	NR			0.239	
Counts up to 10 objects correctly	Does not do this - needs a lot of help	8 (40.0)	8 (13.6)	1 (5.0)	0.010		12 (21.1)	7 (9.6)	NR				
	Needs a little help - no help needed	12 (60.0)	49 (83.1)	19 (95.0)			43 (75.4)	66 (90.4)	NR			0.123	
Adds and subtracts single digit numbers	Does not do this - needs a lot of help	16 (80.0)	32 (54.2)	8 (40.0)	0.035		42 (73.7)	38 (52.1)	NR				
	Needs a little help - no help needed	4 (20.0)	27 (45.8)	12 (60.0)			14 (24.6)	35 (47.9)	NR			0.025	
In a new place, reads or recognizes signs to choose appropriate restroom	Does not do this - needs a lot of help	8 (40.0)	12 (20.3)	1 (5.0)	0.033		16 (28.1)	7 (9.6)	NR				
	Needs a little help - no help needed	12 (60.0)	47 (79.7)	19 (95.0)			40 (70.2)	66 (90.4)	NR			0.014	
Follows a schedule	Does not do this - needs a lot of help	7 (35.0)	15 (25.4)	4 (20.0)	0.567		16 (28.1)	12 (16.4)	NR				
												0.244	

Daily Functional Skill	Ability	6-10 year olds (n=99)						11-21 year olds (n=135)					
		Time Spent in Regular Classroom			p-value ²			Time Spent in Regular Classroom			p-value ²		
		No time (n=20) n (%) ¹	1-60% (n=59) n (%) ¹	61-100% (n=20) n (%) ¹				No time (n=57) n (%) ¹	1-60% (n=73) n (%) ¹	61-100% (n=5) n (%) ¹			
	Needs a little help - no help needed	13 (65.0)	44 (74.6)	16 (80.0)			41 (71.9)	61 (83.6)	NR				
Tells home address	Does not do this - needs a lot of help	13 (65.0)	28 (47.5)	6 (30.0)			28 (49.1)	23 (31.5)	NR				
	Needs a little help - no help needed	6 (30.0)	31 (52.5)	13 (65.0)	0.074		28 (49.1)	49 (67.1)	NR			0.076	
Appropriately differentiates between family/friends and strangers	Does not do this - needs a lot of help	8 (40.0)	16 (27.1)	1 (5.0)			18 (31.6)	15 (20.5)	NR				
	Needs a little help - no help needed	12 (60.0)	43 (72.9)	19 (95.0)	0.030		38 (66.7)	56 (76.7)	NR			0.188	
Reads a clock	Does not do this - needs a lot of help	16 (80.0)	31 (52.5)	5 (25.0)			25 (43.9)	21 (28.8)	NR				
	Needs a little help - no help needed	4 (20.0)	27 (45.8)	15 (75.0)	0.002		32 (56.1)	51 (69.9)	NR			0.178	
Knows value of coins and bills	Does not do this - needs a lot of help	16 (80.0)	38 (64.4)	11 (55.0)			41 (71.9)	45 (61.6)	NR				
	Needs a little help - no help needed	4 (20.0)	21 (35.6)	9 (45.0)	0.262		15 (26.3)	27 (37.0)	NR			0.475	
Decides how to spend own money	Does not do this - needs a lot of help	18 (90.0)	47 (79.7)	14 (70.0)			47 (82.5)	47 (64.4)	NR				
	Needs a little help - no help needed	2 (10.0)	12 (20.3)	6 (30.0)	0.303		9 (15.8)	24 (32.9)	NR			0.303	

* Phase I (time spent in a regular classroom) conducted 2007-2008 and Phase II (functional skills) conducted 2011-2012

¹ Proportions may not total 100% due to missing responses

² Fisher's exact test comparing distribution of ability across time spent in the regular classroom

NR=not reported because denominator < 10 subjects