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ABSTRACT

This final report reviews the second phase of a life-span study of boys with fragile X syndrome (FSX), the most common known inherited cause of mental retardation. Males with the syndrome are more severely affected than females and in males, delays are usually evident in all the developmental domains, although cognitive and communication skills are likely to be most affected. The project studied 61 elementary school aged boys and their families. Approximately 25% of the boys were found to also meet diagnostic criteria for autism. It was noted that when autistic behavior and FXS co-occur, the effect on development appears to be additive. The heart rates of the boys with FXS were significantly higher than of typically developing children, and their visual-motor skills were less than half than would be typically expected. Achievement test scores showed wide variability. The children with FXS were found to be hypersensitive to their environment and about 43% had clinically significant behavior problems in the classroom. By third grade, 85% of the children were in self-contained, rather than inclusive classrooms. Teachers reported that 55% of the children had at least one friend at school and parents reported that 72% had at least one friend in or out of school. In most cases, the friend was another child with a disability. In addition to these findings, strategies to teach reading skills are discussed in the report. Data were collected on families' needs and supports, but have not yet analyzed. Budget information, a list of presentations, and a list of published articles related to the study are included. (SG)

FINAL REPORT

Elementary School and Boys with Fragile X Syndrome

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Introduction

Fragile X Syndrome (FXS) is the most common known inherited cause of mental retardation. A single-gene disorder located on the X chromosome, the syndrome results from a change in the typical DNA sequence at the xq27.3 location on the long arm of the X chromosome. A series of three nucleotides (CGG) in the DNA is greatly expanded beyond its normal size, disrupting the normal messages that need to be sent and shutting down the production of FMRP, a protein assumed to be essential for normal brain function.

Clinical signs of the syndrome are not typically present in carrier males and females. However, when the gene expands into the full mutation, developmental disabilities are apparent. Males with the syndrome are more severely affected than females. Most males exhibit mental retardation that ranges from mild to severe, but typically falls in the moderate range; whereas about one-third of females will exhibit learning disabilities and one-third will have mental retardation. In males, delays are usually evident in all the developmental domains, although cognitive and communication skills are likely to be most affected. Affected males may seem shy and often have problems with social skills and attention. One feature that is frequently described is *hyperarousal*, which refers to the fact that these individuals can easily become overstimulated and may appear to overreact to changes in environment, routines, or expectations. Males also have several distinguishing physical features. They often have large ears, loose connective tissue in joints and muscles, and an elongated face. After puberty, males usually have testicles that are unusually large.

Study Rationale

Literally hundreds of studies have been published about fragile X syndrome; however, most of these have focused on its genetic features. Little practical research is available to help special educators and allied health professionals plan appropriate educational and therapeutic interventions. A careful and comprehensive review of the literature revealed five key limitations of the existing developmental and behavioral research: lack of longitudinal research, limited outcome measures, a lack of treatment studies, a deficit orientation to research, and lack of attention to family variables and outcomes.

In 1993, we were awarded a Field-Initiated Research grant to begin a life span, longitudinal study of the development of boys with fragile X syndrome and their families. Our interest in this project evolved from the Principal Investigator's experiences as the parent of a child with fragile X syndrome and extensive discussions with other parents and professionals. From these experiences and discussions, the dearth of educationally relevant information became clear. We decided that rather than doing a fragmented, age-specific study, we would start with the earliest years of life and trace the development of a cohort of boys with the syndrome from the early childhood years, through the elementary, middle, and high school period, and on into early adulthood. The data on the children in the preschool years suggested that fragile X syndrome exerts a powerful influence on a child's development, placing the child at substantial risk for specific developmental delays. Throughout our longitudinal study of preschool males with FXS, we documented the therapeutic services they were receiving in their communities and we found that all of the children had participated in early intervention programs. However it is clear all will face special challenges in succeeding in the elementary school environment.

For the project just completed we requested funds to conduct the second phase of a life-span study of boys with fragile X syndrome and their families in order to advance our understanding of the nature and trajectory of development for these boys and their families during the elementary school period. Eight specific goals were identified for the Elementary School grant:

(1) Describe the development and educational achievement of boys with FXS during their elementary school years;

(2) Identify factors that account for the variability in the development and educational performance of boys with FXS;

(3) Describe the elementary age social relationships of boys with FXS;

(4) Identify factors that influence variability in elementary age social relationships of boys with FXS;

(5) Describe the school experiences of boys with FXS in the elementary years within the standard array of labels and services;

(6) Describe the needs and concerns of elementary teachers working with boys with FXS;

(7) Identify the most effective treatments for enhancing development, school performance, and peer socialization for boys with FXS;

(8) Identify the needs, resources, and priorities of families of elementary age boys with FXS.

Study Overview

Subjects. We enrolled 61 boys during the course of the study. Of this number, 53 (87%) were white, 7 (11%) were African American, and 1 (2%) was Hispanic. The mean age at study entry was 105 months, but the range was from 72 to 181 months.

Procedures. Once families agreed to participate in the project, each child was assessed and each family interviewed within 3 weeks of his birthday or 12-month anniversary following his most recent previous assessment. Assessments were subsequently re-administered once each year. Recruitment of subjects and repeated assessments at 12-month intervals continued throughout the course of the project. Tests were administered by project staff members who had extensive training and experience in administering the measures and in working with young children with disabilities and their families. A total of 186 assessment occasions occurred during the course of this project. The mean number of assessments per child was 3, with a range of 1 to 6. Assessments were conducted at times and locations selected by parents as most likely to yield a representative sample of the child's competence. Families received payment for each assessment session and a report summarizing their child's status and performance. A toll-free number was established so that parents call at any time to discuss the project or their child.

This project was designed to describe growth, educational, and social experiences of boys with fragile X syndrome during the elementary years. The goals and procedures for the project can be clustered around four major activities: (1) monitoring development and educational achievement over time; (2) studying social competence and behaviors; (3) describing and evaluating services and concerns; and (4) understanding family coping and adaptation.

Study Series 1: Monitoring Development and Educational Achievement Over Time

The preschool age study provided a detailed description of the early development of boys with fragile X syndrome. This phase of the elementary study continued the collection of comprehensive demographic, developmental, and behavioral data. For those children in the elementary study whose performance on the BDI suggested readiness to participate in more advanced standardized measures, the *Woodcock-Johnson Psychodeducational Battery-Revised* (WJ-R; Woodcock & Johnson, 1990) was also used as our measure of academic achievement and cognitive ability.

Instruments. We had used the *Battelle Developmental Inventory* (BDI; Newborg, Stock, Wnek, Guidobaldi, & Svinicki, 1984) for all children participating in the preschool age project and decided to continue using the BDI as our primary measure of children's development for all children until they reached their ninth birthday. It was chosen because it covers five key areas of development (cognitive, language, motor, adaptive, and personal-social) and because it spans the age range from birth to 96-months. Because the BDI norms extend through 96 months, and because the level of the delay evidenced by the children in our study thus far suggests their performance will continue to be covered by the BDI beyond a chronological age of 96 months, we continued to use this instrument for an additional year. As noted above, the WJ-R (Woodcock & Johnson, 1990) was used as our primary measure of academic achievement and cognitive ability and was administered to all participants whose verbal abilities and overall performance on the BDI indicated sufficient skills to respond to tasks on the WJ-R. We also continued to collect and update extensive demographic data on our participants and their families and to collect data on temperament and behavioral style on each child. We have drawn on the measures developed by Carey, et al.—i.e., the *Behavioral Style Questionnaire* (for ages 3 through 7 years) and the *Middle Childhood Temperament Questionnaire* (for ages 8 through 12 years), (Hegvik, McDevitt, & Carey, 1980) and the *Rothbart, Children's Behavior Questionnaire* (for ages 3 through 7 years), (Rothbart, 1996) for measurement of temperament and behavioral style. Families completed the Carey and Rothbart measures. In addition, families completed the *Family Needs Survey* (Bailey & Simeonsson, 1988), the *Families Index* (Simeonsson & Bailey, 1987), and the *Family Support Scale* (Dunst, Jankins, & Trivette, 1988) upon entrance into this study. Both parents and teachers completed the appropriate versions of the *Child Behavior Checklist* (CBCL; Achenbach, 1991). Finally, annual interviews were conducted with each family, utilizing the *Vineland Adaptive Behavior Scales* (Sparrow, Balla, & Cicchetti, 1984) and a focused update developed by our team regarding school changes, medications, therapeutic services, and any significant events or changes in the family upon entrance into the study and at points of transition in school (e.g., change to new school, new classroom, triennial assessment). (A copy of this instrument is included in Appendix A.)

We also collected data regarding autism status utilizing the *Children's Autism Rating Scale* (CARS; Schopler, Reichler, & Renner, 1988). A series of papers published by our group indicated that 25% of our sample fell in the autistic range (Bailey, Mesibov, Hatton, Clark, Roberts, & Mayhew, 1998) and that boys with full mutation FXS who had scores of 30 or higher on the CARS (indicating autism status) were substantially more delayed than children with either FXS or autism alone (Bailey, Hatton, Mesibov, Ament, & Skinner, 2000). Consequently, we also continued to collect a minimum of two data points utilizing the CARS for the children participating in the Elementary Study in order to identify those participants who appeared to have both diagnoses and to look for stability and variability in the earlier published findings.

The comprehensive developmental assessment described above was conducted once a year for each of the 61 participants. We had originally intended to see participants twice a year, focusing on general development in the fall and academic and cognitive skills in the spring. However, the additional travel expenses and potential stress to families being asked to participate twice a year, led us to design a longer, more comprehensive assessment once each year.

Subsequent additional measures and studies. After the preschool age study had been initiated, we realized other domains of behavior and diagnosis needed to be assessed as well. Supplemental funding was obtained during that project to study heart rate and arousal in children with FXS. Comparing young boys with FXS to normal controls, initial findings suggested increased heart rate and different patterns of nervous system response to experimental challenges between the two groups (Roberts, Boccia, Bailey, Hatton, & Skinner, 2001). Therefore, it was deemed important to continue collecting the physiological heart rate and arousal data for a subset of children with FXS over time. Supplemental funding from the Charles A. Dana Foundation, the Ronald McDonald House Charities, and OSEP was also obtained to collect blood from each child and his mother to determine more accurately the child's genetic status and to get an estimate of the amount of FMRP expressed in the child's blood. The assessment of FMRP was done in order to address the extent to which developmental status is associated with FMRP.

Study Series 2: Social Competence and Peer Relations

Parents with whom we have talked have indicated a substantial concern regarding their child's social competence and peer relations. Data collected in the preschool study indicated that study participants have significant delays in social skills as measured by the BDI and as observed during home visits. In the elementary study, we addressed these issues through longitudinal repeated measures, descriptive studies based on classroom observation, and parent and teacher interviews.

Instruments. We continued use of the Personal-Social domain of the BDI through the child's ninth birthday to document attainment of basic social competencies. During the second year of the project, the examiner completed a classroom observation that included observation of the target child in both a free play context and a group learning activity. The field notes from these observations were transcribed and summarized for each child. The information provided by both parents and teachers from the *Child Behavior Checklist* (CBCL) also identified strengths and difficulties in the child's social and interactive skills. The Socialization and Communication subscales from the *Vineland Adaptive Behavior Scales* were obtained during interview with the parent annually and also provided longitudinal data on evolving social and peer interaction skills. We interviewed teachers regarding each child's social and communication skills. Finally, portions of the in depth phone interviews conducted with teachers and therapists and described below in Study Series 3 provided information on intervention goals and practices focused on developing the child's social communication and interactive competencies.

Study Series 3: Educational and Therapeutic Services and Concerns

A broad set of concerns expressed by parents relates to the educational and therapeutic services their child receives. We addressed these concerns through ongoing descriptive analysis of educational variables pertinent to the nature and quality of services provided for each child across the elementary grades and through detailed phone interviews.

Instruments. We continued to collect data annually on each child's diagnostic label, classroom placement, class size, inclusion opportunities both inside and outside of school, and nature and frequency of therapeutic services provided. We developed a 4-page teacher/therapist interview and conducted these interviews over the phone with each child's teacher and therapists in order to document intervention goals, preferred strategies, and perceived effectiveness of interventions during year two. (A copy of this interview form may be found in Appendix A.) In addition, families were interviewed annually to ascertain satisfaction with services and to identify changes they would like to see in services for their children.

Study Series 4: Family Coping and Adaptation

The final set of studies continued the investigation started in the early childhood study of family coping and adaptation. We continued to address these issues with repeated formal surveys and scales.

Instruments. Our families continued to fill out the Family Needs Survey, the Famies Index, and the Family Support Scale at their initial entry into our study and during periods of transition. Each year our families also participated in a focused interview and update designed to document changing concerns and strategies utilized by families to cope or intervene.

Results

We were able to collect a large amount of data during this project. The following sections summarize some of our major findings as they relate to the four major activities of the study described above:

Study Series 1: Monitoring Development and Educational Achievement Over Time

FMRP, autism, and development. In a longitudinal analysis through age 8, we examined the role of FMRP protein and autism status in the development of males with FXS. Immunocytochemistry of peripheral blood smears was used to determine the percentage of lymphocytes expressing FMRP. For our entire sample, FMRP expression ranged from 1-40% and accounted for a small but significant amount of variance in level, but not rate of development. This finding was true for overall development as well as development in the five domains assessed: motor, social, adaptive, cognitive, and language development. Autistic behavior was not related to FMRP expression, but was a significant predictor of both developmental status and developmental change. No autistic behavior and FMRP interaction was found.

These data were published in the *Journal of Autism and Developmental Disorders* (Bailey, Hatton, Skinner, & Mesibov, 2001). The findings lend support to the hypothesis that when autistic behavior and FXS co-occur, the effect is additive in its impact on development. In addition, these data as well as data from our group's earlier publications related to the autistic behaviors found in boys with FXS and the many issues still being investigated in regard to the similarities and differences from "classic" autism as it is expressed in children with FXS are discussed in a chapter on fragile X syndrome and autism (Hatton & Bailey, 2001).

Achievement. A paper on achievement of our study participants in specific academic skills (e.g. reading, writing, math) and broad knowledge subject areas (e.g. science, social studies, humanities) is currently in preparation. Longitudinal analysis of these data indicate wide variability was evident in the achievement test scores of the sample on the Woodcock-Johnson Tests of Achievement-Revised. For example, at an average chronological age of 108 months (9 years), age equivalent scores in Early Skills (letter and word identification, applied problems, dictation) ranged from 27 months to 80 months. The average developmental age was 65 months or about half that of typically developing children. Wide across-domain variability was seen in Early Skills, with letter-word identification a relative strength across the age span and applied problems a relative weakness. Age equivalent scores on average continued to increase until children reached an age equivalent of 74 months, after which little change was evident. Standard scores showed a more variable pattern, but declined slightly overall to between 30 and 45. In the domain of Broad Knowledge (science, social studies, humanities), at 108 months chronological age, the average developmental age was 68 months, also about half of normal achievement. However, age equivalent scores continued to increase to an average level of more than 90 months. Relatively equivalent patterns of progress were seen across domains when looking at age equivalent scores, but standard scores for humanities were consistently higher than social studies and science. We are in the process of analyzing and writing up these results for publication.

Physiological Arousal. This series of research studies was conducted in collaboration with funds from FRAXA, a private research foundation. In the studies analyzed thus far, arousal was measured via heart rate. During their assessment, children wore an elastic belt around their chest wall and the electrodes on the belt sent continuous digital information about heart rate to a remote logger worn by the child in a fanny pack or set on the table near the child during testing. Results of these studies indicate that physiological arousal is related to attention, motor activity, and IQ level in boys who are not prescribed medication such that lower levels of arousal are associated with greater attention, less motor activity, and higher IQ levels. However, arousal does not appear to be related to FMRP (i.e., protein level). In addition, higher activity and lower attention are associated with and may be predictive of stimulant medication use in that boys with these characteristics appear to be the ones later prescribed stimulant medication. These result have been published in Developmental Psychobiology (Roberts, Boccia, Bailey, Hatton, & Skinner, 2001).

Visual-motor integration. Because we observed significant problems in the handwriting of boys with FXS, we assessed their visual-motor integration skills. In our preliminary analysis of those scores we found that at an average assessment age of 102 months, the age equivalent for visual-motor integration was about 48 months, less than half the motor integration age expected based on chronological age. We are in the process of analyzing and writing up these results for publication.

Study Series 2. Studying Social Competence and Behaviors

Classroom behavior. An observational study of classroom behavior found moderate levels of engagement during periods of academic instruction (average of 66% of the time). This level was comparable to that of other peers with disabilities in the class. Child factors (e.g., autism, severity of delay, medication status) did not predict variation in engagement, but classroom quality did, with higher quality classrooms producing higher levels of engagement.

Teacher ratings of classroom behavior indicated that about 43% of the children had clinically significant behavior problems in the classroom and that these were primarily related to social and attention issues. This study was published in *The Journal of Special Education* (Symons, Clark, Roberts, & Bailey, 2001).

Problem Behavior. Behavioral difficulties have been reported across many contexts in the literature and in our discussions with both parents and teachers. One of the measures utilized in this study that documented behavior across contexts and modalities was the *Child Behavior Checklist* (Achenbach, 1991). Both parents and teachers completed this measure annually. Findings based on the *Child Behavior Checklist* were reported in *The American Journal of Medical Genetics* (Hatton, Hooper, Bailey, Skinner, Sullivan, & Wheeler, 2001). Approximately 49% of the boys scored within the borderline or clinical range on Total Problem Behavior, while 56% to 57% scored in the borderline or clinical range on the Attention and Thought Problems subscales, and 26% scored in this range on the Social Problems subscale. With a mean of 2.5 assessments per child, behavior problems were found to be stable during the three-year period of study. Total problem behavior was higher for children who displayed autistic behavior, had mothers with higher education levels, and who were on medication. Mothers with more education also rated their children as having more attention, thought, and total problems. Low adaptability and more autistic characteristics predicted thought problems.

Self-Injurious Behavior. Little detailed information is available about the nature of associated behavior disorders reported to occur quite often among individuals with mental retardation. We surveyed the families of 67 young boys with FXS to determine the prevalence, onset, form, function, location, and correlates of self-injurious behavior. Fifty-five surveys were completed (82%). Self-injurious behavior (SIB) was reported for 58% of the participants with a mean age of onset of 31 months. The mean number of forms of self-injury was 2 per participant. Self-biting was the most common form of self-injury reported and the fingers and back of the hand were disproportionately targeted as the most prevalent self-injury body site. SIB was reported as most likely to occur following the presentation of a difficult task or a change in routine. When boys with self-injury were compared to boys without self-injury, significant group differences were found for overall ratings of problem behavior. The groups did not differ on measures fragile X mental retardation protein (FMRP), autism status, adaptive behavior, or age first medicated. These results were reported in an article that has been submitted to a peer-reviewed journal (Symons, Clark, Hatton, Skinner, & Bailey, under review).

Friendships. Parents and teachers were both asked to complete surveys regarding friendships. Initial analysis of that data indicated teachers reported that 55% of the students had at least one friend at school who in turn thinks of the child as his or her friend. In all of the cases the friend was another child with a disability. Parents reported that 72% of the students had at least one friend in or outside of school who in turn thinks of their child as a friend. In 64% of the cases, the friend was another child with a disability.

Sensory processing. A study of sensory processing found that boys with FXS tend to be hyperresponsive to the sensory features in their environment, possibly reflecting a lower threshold for sensory stimulation. Children with sensory processing problems were likely to be rated by teachers as having more social-behavioral problems in the classroom. A paper discussing these findings has been submitted for publication (Baranek, Chin, Greiss, Yankee, Hatton, & Hooper, under review).

Study Series 3. Educational and Therapeutic Services and Concerns

Eligibility labels and classroom placements. Although all the children in this project have the same disorder (FXS), when they enter kindergarten they are assigned a wide variety of eligibility labels, including developmental delay, mental retardation, other health impaired, learning disabled, and multiply handicapped. This variability in labels is in part a function of state and local variation in practices and policies, and in part a reflection of parent preferences. Descriptive analysis of the data we have collected on classroom placements and eligibility labels for our 61 boys with FXS in elementary schools indicated that by third grade, the variability in labels was somewhat reduced, with three primary categories being used: mental retardation (50%), other health impaired (29%), and multiply handicapped (21%).

Inclusion. As we have already indicated, the parents of our study children have repeatedly expressed concerns about the need for their children to spend significant portions of the school day in inclusive environments with typically developing children. At each of the follow-up assessments conducted during the preschool and kindergarten years and during the current study of elementary grades, we collected information on inclusion opportunities provided for each of our study participants. Descriptive analysis of the combined data indicated that beginning as early as kindergarten, most (i.e., 79%) of the boys in our study were in self-contained classes. By third grade, this percentage increased to 85%. Although some inclusion experiences were incorporated into the self-contained classroom, the children spent most of their time in one room with other children with disabilities. The remainder of the children had a regular class placement with considerable amounts of time spent in resource room placements. By third grade, no child met the regular class placement definition (i.e., less than 20% of time spent outside the regular classroom) used by OSEP in its annual report to Congress. Thus while nationally about 40% of all children with mental retardation ages 6-11 years are served in regular class or resource room environments, in our sample only 15% of the children were served in such an environment by third grade.

Teaching Reading Skills. Another concern frequently expressed by both parents and teachers of the children in this project was related to teaching functional reading skills. Many of the children evidenced a strong interest in books, a fascination with letters, and some knowledge of environmental print. Typically, the same children had much more difficulty with phonetic approaches to teaching word attack and beginning reading skills. Two intervention studies were conducted in three classrooms where four students were enrolled during the spring semester of the 1997-1998 school year. These studies were predicated on fairly extensive evidence in the literature that visual, wholistic approaches (i.e., as opposed to auditory, sequential approaches) are typically more successful when teaching academic skills to boys with FXS.

The first study was designed to investigate the effects of direct instruction and observational learning on the acquisition of sight words. Four triads of students participated (i.e., one student with FXS and two other special education students in each grouping). Results indicated that direct instruction resulted in substantial increases in correct performance for 11 of the 12 participants. For 3 of 4 students with FXS, observational learning was greater when they observed but were not taught directly. These findings provide guidance for structuring observational learning for in small group instruction for children with FXS. This data was summarized in an article that is currently being revised for publication (Clark, Erba, Symons, & Wolery, under revision).

The second study investigated the use of attending cues to support the acquisition of sight words. The study compared two specific attending cues/responses while teaching word reading to seven elementary-age students with disabilities. Three of the participants had FXS. The attending cues were: (1) matching the word to be read (simultaneous instruction) and (2) tracing the letters of the word to be read (sequential instruction). The findings indicated that (1) both attending cues/responses were effective with most students, (2) the matching attending cue resulted in more efficient learning for students without FXS and the data were mixed for students with FXS, and (3) observational learning occurred for all students and was not differentially affected by the type of cue or response. A manuscript is currently being written that summarizes this data (Symons, Clark, Erba, & Wolery, in preparation).

Study Series 4: Understanding Family Coping and Adaptation

Family Needs. All of the families who participated in the elementary age study completed the Family Needs Survey as a part of their child's initial assessment in this study. The data from this measure have not yet been analyzed but will provide valuable insights into the types of information families were most interested in accessing, the difficult issues families faced on a daily basis, and the most pressing financial concerns faced by families of children with FXS.

Family Supports. Each of the families who participated in the elementary age study completed the Family Support Scale and the Families Index in conjunction with their child's initial assessment in this study. The Family Support Scale asked parents to indicate how helpful various individuals or groups (e.g., husband, wife, grandparents, co-workers, church group members) had been to the family during the 6 months prior to filling out the form. The Families Index asked parents to rate various statements about resources and attitudes (e.g., financial resources, motivation for change and adaptation) as similar or dissimilar to their own family. These data have not yet been analyzed, but the information will be published and should provide useful insights into the nature of the support systems developed by families with children with FXS and the ways in which these support systems evolve over time.

Other Studies to be Completed

Data analysis and manuscript preparation are currently underway to present findings related to the visual-motor integration issues that appear to cause special difficulties for this population as documented by our longitudinal use of the *Developmental Test of Visual-Motor Integration* (VMI) and to discuss our findings related to academic achievement that we have documented longitudinally through the *Woodcock-Johnson Tests of Achievement-Revised* (WJR). In addition to these major findings and reports, we have also collected data on heart rate, school experiences, speech and communication skills development, and strategies for enhancing achievement and behavioral coping. A paper on adaptive behavior is now being written and should be submitted for peer review by November 1, 2001.

Dissemination

Publications

As of this report, 19 peer-reviewed journal articles and one book chapter have been published or accepted for publication:

Bailey, D.B., Hatton, D.D., Skinner, M., & Mesibov, G. (2001). Autistic behavior, FMRP, and developmental trajectories in young males with fragile X syndrome. Journal of Autism and Developmental Disabilities, 31, 165-174.

Bailey, D.B., Hatton, D.D., Tassone, F., Skinner, M., & Taylor, A.K. (2001). FMRP and early development in fragile X syndrome. American Journal on Mental Retardation, 106, 16-27.

Bailey, D. B., Hatton, D. D., Mesibov, G., Ament, N., & Skinner, M. (2000). Early development, temperament, and functional impairment in autism and fragile X syndrome. Journal of Autism and Developmental Disorders, 30, 49-59.

Bailey, D. B., Skinner, D., Hatton, D., & Roberts, Jane. (2000). Family experiences and factors associated with diagnosis of fragile X syndrome. Journal of Developmental and Behavioral Pediatrics, 21, 315-321.

Bailey, D. B., Mesibov, G., Hatton, D. D., Clark, R. D., Roberts, Jane E., & Mayhew (1998). Autistic behavior in young boys with fragile X syndrome. Journal of Autism and Developmental Disorders, 28, 499-508.

Bailey, D. B., Hatton, D. D., & Skinner, M. (1998). Early developmental trajectories of males with fragile X syndrome. American Journal on Mental Retardation, 103, 29-39.

Boccia, M. L., & Roberts, Jane E. (2000). Behavior and autonomic nervous system function assessed via heart period measures: The case of hyperarousal in boys with fragile X syndrome. Behavior Research Methods, Instruments, and Computers, 32, 5-10.

Hatton, D. D., & Bailey, D. B. (2001). Fragile X syndrome and autism. In L. Marcus, E. Schopler, C. Shulman, & N. Yirmiya (Ed.), The research basis of autism intervention outcome. New York: Kluwer Academic/Plenum Publishers.

Hatton, D. D., Bailey, D. B., Hargett-Beck, M. Q., Skinner, M., & Clark R. D. (1999). Behavioral style of young boys with fragile X syndrome. Developmental Medicine and Child Neurology, 41, 625-632.

Hatton, D. D., Bailey, D. B., Roberts, J. P., Skinner, M., Mayhew, L., Clark, R. D., Waring, E., & Roberts, Jane E. (2000). Early intervention services for young boys with fragile X syndrome. Journal of Early Intervention, 23, 235-251.

Hatton, D. D., Buckley, E., Lachiewicz, A., & Roberts, Jane E (1998). Ocular status of boys with fragile X syndrome: A prospective study. Journal of the American Association for Pediatric Ophthalmology and Strabismus, 2, 298-302.

Hatton, D. D., Hooper, S.R., Bailey, D.B., Skinner, M., Sullivan, K., & Wheeler, A. (in press). Problem behavior in boys with fragile X syndrome. American Journal of Medical Genetics.

Hooper, S.R., Hatton, D.D., Baranek, G.R., Roberts, J.P., & Bailey, D.B., Jr. (2000). Nonverbal assessment of cognitive abilities in children with fragile X syndrome: The utility of the Leiter International Performance Scale-Revised. Journal of Psychoeducational Assessment, 18, 255-267

Jackson, S. C., & Roberts, Joanne E. (1999). Family and professional congruence in communication assessments of preschool boys with fragile X syndrome. Journal of Early Intervention, 22, 137-151.

Roberts, Jane E., Boccia, M. L., Bailey, D. B., Hatton, D. D., & Skinner, M. (2001). Cardiovascular indices of physiological arousal in boys with fragile X syndrome. Developmental Psychobiology.

Roberts, Jane E., Hatton, D. D., & Bailey, D.B. (in press). Development and behavior of male toddlers with fragile X syndrome. Journal of Early Intervention.

Roberts, Joanne E., Mirrett, P., Anderson, K., Burchinal, M., & Neebe, E. (in press). Early communication profiles of young males with fragile X syndrome. American Journal of Speech-Language Pathology.

Roberts, Joanne E., Mirrett, P., & Burchinal, M. (2001). Receptive and expressive communication development of young males with fragile X syndrome. American Journal on Mental Retardation, 106, 216-230.

Symons, F.J., Clark, R.D., Roberts, J.P., & Bailey, D.B. (2001). Classroom behavior and academic engagement of elementary school-aged boys with fragile X syndrome. Journal of Special Education, 34, 194-202.

Four additional manuscripts are in various stages of preparation for publication in peer-reviewed journals:

Baranek, G.T., Chin, Y.H., Greiss, L.M., Yankee, J.G., Hatton, D.D., & Hooper, S.R. (under review). Sensory processing correlates of occupational performance in children with fragile X syndrome.

Clark, R.D., Erba, H. W., Symons, F.J., & Wolery, M. (under revision). Observational learning for students with and without fragile X syndrome.

Symons, F.J., Clark, R.D., Hatton, D.D., Skinner, M., & Bailey, D.B. (under review). Self-injurious behavior in young boys with fragile X syndrome.

Symons, F.J., Clark, R.D., Erba, H.W., & Wolery, M. (in preparation). Attending cues to support acquisition of sight words.

Presentations

Since this project was funded, we have presented these data and information about fragile X syndrome to a wide variety of audiences, ranging from scientific groups, to practitioners, to parents. A great many presentations have been made. They are listed in Appendix B.

Internet Dissemination

In 1999, using funds from the Ronald McDonald House Charities, we created an Internet site to provide information to a broader audience about the project's work (http://www.fpg.unc.edu/~fx/). The site provides a description of FXS, overviews of our research and publications, case studies of children at various ages in our project, and personnel affiliated with the study. This year we received additional funding from the Ronald McDonald House Charities to expand this resource into an international website, providing state of the art research information on FXS from around the world, as well as practical resources and intervention information for families, researchers, and practicing professionals.

Future Directions

As this grant to study boys in their elementary years came to an end in June, 2001, we had been following a large cohort of approximately 75 families with children with FXS since 1993 when our initial grant tracking the development of preschool children with FXS was initiated. This fall, we received additional funding to continue following this group of children and their families through late elementary and early middle school years. We also received a grant from NIH to focus very specifically on the nature and development of attention, memory, and executive functioning in boys 8 to 12 years of age. In addition, we are in the final year of a three-year grant that began in 1999 and focuses on the development and behavior of infants with FXS and ways to promote early identification. Our long-term goal is to complete a study of development in FXS that extends from infancy through the early adult years and to continue to disseminate the most up to date and useful information about fragile X syndrome to parents, practicing professionals, and researchers throughout the world.

Acknowledgments

We appreciate very much the funding we have received from OSEP. Without this core funding and the funding for the seminal work with these children as preschoolers, this project would not have been possible. We would also like to express our sincere appreciation to the families who have participated in this study. Their support has been invaluable, constant, and reassuring, and we hope that the information and support we have given back to them in some small way serves as repayment for their participation. Finally, we would like to acknowledge and express our appreciation to the colleagues and students who have worked with us in various phases of this project. They include:

Grace Baranek
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Renee Clark
Laura Courtney
Dawn Edgerton
Melissa Hargett-Beck
Steve Hooper
Eli Jerchower
Ave Lachiewicz
Lisa Mayhew
Gary Mesibov
Penny Mirrett
David Nelson
Jane Roberts
Jennifer Roberts
Joanne Roberts
Debra Skinner
Martie Skinner
Kelly Sullivan
Frank Symons
Flora Tassone
Annette Taylor
Elizabeth Waring
Anne Wheeler
Mark Wolery

Budget Information

Because the activities and goals of this project blended with those of our supplemental funding from the Charles A Dana Foundation, the National Fragile X Foundation, the FRAXA Research Foundation, the Ronald McDonald House Charities, and OSEP; we were able to extend our work and carry on project activities with minimal interruption during the period of our no-cost extension. Although some line items were overspent by a very small margin compared to original budgeted amounts, savings were realized in staff benefits and other current services, resulting in a balanced budget relative to total expenditures. The final account summary supplied by the account manager for this project follows:

Account Budget Report

ELEMENTARY SCHOOL BOYS WITH FRAGILE X SYNDROME
Current Budget Period **PI Name - Donald B. Bailey** **9/1/95-6/30/01**

Budget Code	**Description**	**$ Budget**	**$ Est Spent**	**$ Balance**
1000	Personnel	275,479.00	276,218.70	(739.70)
1800	Staff Benefits	51,442.00	50,825.68	616.32
1900	Contracted Services	200.00	200.00	0.00
2000	Supplies & Materials	6,845.00	6,893.73	(48.73)
3100	Travel	20,091.00	20,451.57	(360.57)
3200	Communication	4,630.00	4,994.26	(364.26)
3400	Printing & Binding	1,425.00	2,203.05	(778.05)
3900	Other Current Services	28,332.00	26,657.01	1,674.99
4900	Other Fixed Charges	132.00	132.00	0.00
6577	Graduate Asst Tuition	229.00	229.00	0.00
8983	Indirect Cost-On Campus	172,870.00	172,870.00	0.00
Total for Account:		**561,675.00**	**561,675.00**	**0.00**

Appendix A

Survey of Teachers and Therapists Who Worked with Elementary Age Boys with FXS

Services Update Interview Form

Appendix B

Presentations

Presentations
Carolina Fragile X Project

Bailey, D.B. (May 31, 2001). The nature and consequences of fragile X syndrome. Invited plenary presentation, American Association on Mental Retardation Annual Meeting, Denver, CO.

Mirrett, P.L. (April 27, 2001). Cephalometric assessment of the craniofacial morphology of boys with fragile X syndrome. American Cleft Palate-Craniofacial Association, Minneapolis, MN.

Hatton, D. D. (April 20, 2001). Fragile X syndrome: Lining gene expression, development, behavior, and physiology. Symposium Chair and Presenter. Biennial Conference of the Society for Research in Child Development, Minneapolis, MN.

Bailey, D.B. (March 5, 2001). Opportunities for integrative biobehavioral research in fragile X syndrome. Understanding the Neural Basis of fragile X syndrome, Cold Spring Harbor Laboratory, NY.

Mirrett, P.L. (November 18, 2000). Speech and craniofacial development of young boys with fragile X syndrome. Paper. American Speech-Language and Hearing Association, Washington, D.C.

Bailey, D.B. (November 17, 2000). Update on research on fragile X syndrome. Invited presentation, Southeastern Regional American Association on Mental Retardation 46th Annual Conference, Research Triangle Park, NC

Roberts, J.E. & Mirrett, P.L. (November 16, 2000). Communication skill development of young males with fragile X syndrome. Seminar. American Speech-Language and Hearing Association, Washington, D.C.

Hatton, D. D., Roberts, J.E. (October, 31, 2000). Behavior in boys with fragile X syndrome. Paper presented at the Neurodevelopmental Disorders Research Center Symposium, Chapel Hill, NC.

Hatton, D. D., & Roberts, J.E. (July 22, 2000). Behavior and physiology in boys with fragile X syndrome. Paper presented at the 7th International Fragile X Conference, Los Angeles.

Mirrett, P.L., & Roberts, J.E. (July 22, 2000). Speech and craniofacial characteristics of young males with fragile X syndrome. Paper presented at the 7th International Fragile X Conference, Los Angeles.

Roberts, J.E., Mirrett, P.L., Anderson, K., & Burchinal, M. (July 22, 2000). Early communication profiles of young males with fragile X syndrome. Paper presented at the 7th International Fragile X Conference, Los Angeles.

Roberts, J.E., Mirrett, P.L., Anderson, K., Burchinal, M. (July 22, 2000). Receptive and expressive communication development of young males with fragile X syndrome. Paper presented at the 7th International Fragile X Conference, Los Angeles.

Bailey, D.B. (July 19, 2000). Longitudinal studies in fragile X syndrome. Invited plenary lecture, 7th International Fragile X Conference, Los Angeles, CA.

Bailey, D.B. (March 3, 2000). Research on early development in fragile X syndrome. Invited research colloquium, Waisman Center, University of Wisconsin, Madison, WI.

Mirrett, P.L. & Roberts, J.E. (November 19, 1999). Speech characteristics of young males with fragile X syndrome. Poster. American Speech-Language and Hearing Association, San Francisco, CA.

Roberts, J.E. & Mirrett, P.L. (November 19, 1999). Speech and language development of young males with fragile X syndrome. Seminar. American Speech-Language and Hearing Association, San Francisco, CA.

Hatton, D.D. Roberts, J.E., Boccia, M.L., & Bailey, D.B. (August 24, 1999). Temperament and physiology in boys with fragile X syndrome. Paper presented at the 9th International Workshop on Fragile X Syndrome and X Linked Mental Retardation, Strasbourg, France.

Hatton, D.D. (July, 2, 1999). Fragile X syndrome and autism. Paper presented at the North Carolina-Israel Autism Project, Workshop for teachers and parents, Kibbutz Ma'ale Hachamisha, Israel.

Hatton, D.D. (June 29, 1999). Fragile X syndrome and autism in young males: Exploratory studies. Paper presented at the North Carolina-Israel Autism Project Cooperative Scientific Workshop. Research Frontiers in Autism: Genetics, Behavior, and Intervention., Jerusalem, Israel.

Bailey, D.B. (June 10, 1999). Longitudinal studies of early development in fragile X syndrome. MRDDRC Directors Meeting, University of Alabama at Birmingham, Birmingham, AL.

Bailey, D. B., & Hatton, D.D. (March 19, 1999). Factors associated with variability in fragile X syndrome. Paper presented at the 32nd Annual Gatlinburg Conference on Research and Theory in MR/DD, Charleston, South Carolina.

Bailey, D.B. (February 22, 1999). Early identification of children with fragile X syndrome. Invited presentation, Centers for Disease Control, Atlanta, GA.

Bailey, D.B. (December 3, 1998). Understanding variability in developmental outcomes in fragile X. Invited presentation at NICHD-sponsored Workshop on Fragile X: Future Research Directions, Bethesda, MD.

Roberts, J.E., Mirrett, P.L., & Mayo, R. (November 20, 1998). Development of communication in young males with fragile X syndrome. Seminar. American Speech-Language and Hearing Association, San Antonio, TX.

Bailey, D.B. (September 30, 1998). Fragile X syndrome: Early identification and early development. Invited presentation, 1998 North Carolina AAMR Conference, Greensboro, NC.

Bailey, D.B. (July 28, 1998). Early identification and child development in young children with fragile X syndrome. Sixth International Fragile X conference, Asheville, NC.

Mirrett, P.L. & Roberts, J.E. (July 27, 1998). Survey of current practices among speech-language pathologists working with children with fragile X syndrome. Sixth International Fragile X Conference: Asheville, NC.

Roberts, J.E. & Mirrett, P.L. (July 27, 1998). Development of receptive and expressive communication in young males with fragile X syndrome. Sixth International Fragile X Conference: Asheville, NC.

Roberts, J.E. & Mirrett, P.L. (July 27, 1998). Speech characteristics of young males with fragile X syndrome. Sixth International Fragile X Conference: Asheville, NC.

Bailey, D.B. (May 20, 1998). Fragile X syndrome: What is it and what are the implications for treatment? Invited keynote presentation, Fifth Annual Richard P. Brinker Memorial Symposium on Early Intervention, Chicago, IL.

Bailey, D.B. (March 6, 1998). Fragile X syndrome, genetics, and early intervention: Challenges and opportunities in joining forces for a brighter future. Invited keynote presentation, 1998 Kansas Division for Early Childhood State Conference, Wichita, KS.

Bailey, D. B., Hatton, D.D., & Roberts, J. (November 20, 1997). Early intervention and fragile X syndrome. Pre-Conference Training Workshop. International Early Childhood Conference on Children with Special Needs, New Orleans, LA.

Roberts, J.E. & Mirrett, P.L. (November 20, 1997). Communication skills of preschool males with fragile X syndrome. Seminar, American Speech-Language and Hearing Association, Boston, MA.

Bailey, D.B. (September 21, 1997). Challenges for families of children with fragile X syndrome. H.A. Chapman Institute of Medical Genetics, Tulsa, OK.

Bailey, D. B., & Hatton, D.D. (August 18, 1997). Developmental trajectories of young males with fragile X syndrome. Paper presented at the 8th International Workshop on Fragile X Syndrome and X-linked Mental Retardation, Picton, Ontario, Canada.

Hatton, D.D., & Bailey, D. (August 18, 1997). Temperament and fragile X syndrome during early childhood. Paper presented at the 8th International Workshop on Fragile X Syndrome and X-linked Mental Retardation, Picton, Ontario, Canada.

Hatton, D.D., Clark, R., & Bailey, D.B. (August 18, 1997). A longitudinal study of infant and preschool girls with fragile X syndrome. Paper presented at the 8th International Workshop on Fragile X Syndrome and X-linked Mental Retardation, Picton, Ontario, Canada.

Bailey, D.B. (August 17-22, 1997). Autistic behavior in young boys with fragile X syndrome. Eighth International Workshop on Fragile X Syndrome and X-Linked Mental Retardation, Picton, Ontario, Canada.

Bailey, D.B. (August 17-22, 1997). Developmental trajectories of young males with fragile X syndrome. Eighth International Workshop on Fragile X Syndrome and X-Linked Mental Retardation, Picton, Ontario, Canada.

Hatton, D.D., Buckley, E., Lachiewicz, A., & Roberts, J. (August 18, 1997). Ocular status of young boys with fragile X syndrome: A prospective study. Paper presented at the 8th International Workshop on Fragile X Syndrome and X-linked Mental Retardation, Picton, Ontario, Canada.

Bailey, D. B., & Hatton, D.D. (July 13, 1997). The Carolina fragile X project: Longitudinal studies of children and the factors that influence developmental outcome (Poster Presentation). Paper presented at the International Conference on Mental Retardation: Genes, Brain & Behavior, Staten Island, New York.

Hatton, D.D. (July 13, 1997). Social emotional development of boys with fragile X syndrome. Paper presented at the International Conference on Mental Retardation: Genes, Brain & Behavior, Staten Island, New York.

Hatton, D.D. (December 2, 1996). Fragile X syndrome: Early intervention and assessment issues. Paper presented at the Eighth Annual Leo M. Croghan Conference of Developmental Disabilities, Raleigh, North Carolina

Hatton, D.D. (September 20, 1996). Young boys with fragile X syndrome: educational/developmental issues. Paper presented at the N.C. Association for Education of Young Children, Annual Study Conference, Greensboro, North Carolina.

Bailey, D. B., Hatton, D.D., & Clark, R. (August 7, 1996). Early recognition of fragile X syndrome. Paper presented at the Fifth International Fragile X Conference, Portland, Oregon.

Hatton, D.D. (August 6, 1996). A study of the educational status of young boys with fragile X syndrome. Paper presented at the Fifth International Fragile X Conference, Portland, Oregon.

Hatton, D.D., Buckley, E., Lachiewicz, A., Roberts, J., & Burgess, D. (August 5-10, 1996). Visual acuity and ocular status of boys with fragile X syndrome (Poster Presentation). Paper presented at the Fifth International Fragile X Conference, Portland, Oregon.

Hatton, D.D. (March 23, 1996). Early educational, therapeutic, and medical interventions: Parent and clinical perspectives. Paper presented at the Symposium on Young Boys with Fragile X Syndrome chaired by Don Bailey. Gatlinburg Conference on Research and Theory in MR/DD, Gatlinburg, Tennessee.

Bailey, D.B. (February 26, 1996). Fragile X syndrome. TEACCH Winter In-service program, Durham, NC.

Hatton, D.D. (February 13, 1996). The Carolina Fragile X Project. Paper presented to Genetics Staff, Eastern Virginia Medical School, Norfolk, VA.

Bailey, D. B., & Hatton, D.D. (December 4, 1995). Fragile X syndrome: An overview. Paper presented at the Leo M. Croghan Conference on Developmental Disabilities, Raleigh, NC.

Development of Children with Fragile X Syndrome

Teacher/Early Interventionist Survey

Directions: Please answer the following questions and return the completed form to Deborah Hatton in the stamped, self addressed envelope that is enclosed. All responses are confidential. Telephone Deborah Hatton at 1-800-351-4603 if you have any questions regarding this form.

Child ________________________________ Date ___________________
Teacher/Early Interventionist________________________ Student/Teacher Ratio ______
Type of Class __________________________ Total # in Class __________

Teacher's Credentials:
Degrees in:____
Certification/Licensure:_____________________________________
Years of teaching experience:_________________________________

How many months have you worked with this child?

How many times per week do you work with this child? How long does each of these sessions last?

Have you had experience with other children with fragile X syndrome? Yes____ No____
If yes, please describe.

What were your initial impressions of this child? Have your impressions changed? If so, how?

What concerns do you have about working with this child?

What strengths have you noticed in this child?

How would you describe this child's learning style?

Have you had to make any environmental adaptations to accommodate this child? Yes____ No____
If yes, what were they?

What seems to motivate this child? Describe any reinforcement that is used.

What activities does this child enjoy most?

What activities does this child enjoy least?

Does this child seem to have specialized needs that are different from other children with special needs that you have taught? Yes____ No____ If yes, what is different?

If another teacher called you and said that she had just been told she would be working with a child with fragile X syndrome, what would you tell her she needs in order to be successful? (special knowledge, assistance, strategies)

Describe inclusive settings that this child participates in on a regular basis.

How would you rate this child's capability to function in an integrated setting? What factors would inhibit this child's functioning? What factors would enhance this child's functioning?

Does this child show any atypical sensory responses to auditory, visual, or tactile experiences (under reaction/over-reaction)? Yes____ No____ If yes, please explain.

Compared to other children with disabilities, how would you rate this child's:

	Far Below Average	Below Average	Average	Above Average	Not applicable
Developmental Skills					
Pre-reading					
Pre-writing/fine motor					
Pre-math					
Computer					

Gross motor					
Self-care					
Behavioral Skills					
Attention					
Activity					
Impulsivity					
Repetitious behavior/stereotypies (hand-flapping, biting)					
Amount of peer interaction					
Play skills					
Anxiety					
Aggression					
Transition skills					

Listed below are several general developmental and behavioral domains. Considering this child's abilities, please rank the domain in order of greatest need for specialized intervention. Put a 1 beside the area most in need of specialized early intervention service, a 2 beside the next item, etc.

_____ Cognitive Skills
_____ Expressive Communication
_____ Receptive Communication
_____ Gross Motor
_____ Fine Motor
_____ Self-Help (feeding, dressing, toileting, personal care, adaptive)
_____ Peer Socialization
_____ Inappropriate Behavior
_____ Attending/Task Orientation
_____ Following schedule and routine

Below are several dimensions of classroom planning for children. Considering this child, rate the extent to which special modification would be needed for successful participation in a well-run, developmentally appropriate preschool for typical children.

	No Modification	Minimal Modification	Moderate Modification	Substantial Modification
Physical Environment	_____	_____	_____	_____
Schedule of Activities	_____	_____	_____	_____
Teaching Strategies	_____	_____	_____	_____
Transition Times	_____	_____	_____	_____
Group Activities	_____	_____	_____	_____
Center Activities	_____	_____	_____	_____
Outdoor Play	_____	_____	_____	_____
Meals and Snacks	_____	_____	_____	_____
Reinforcing Appropriate Behavior	_____	_____	_____	_____
Dealing with Inappropriate Behavior	_____	_____	_____	_____

10. Please rate the extent to which your student with fragile X syndrome displays the following characteristics.

Characteristic	**Very True**	**True**	**Not True**

High activity level			
Poor attention			
Affectionate/loving			
Sociable/friendly			
Poor expressive language			
Anxious			
Aggressive			
Noncompliant			
Injures self			
Hypervigilant			
Autistic-like			
Avoids eye contact			
Tactile defensive			
Auditory defensive			
Transitions are difficult.			
Flaps hands			
Bites hand			
Tantrums			

10. What are your primary goals for this child?

11. Listed below are several general developmental and behavioral domains. Considering this child's abilities, please rank the domain in order of greatest need for specialized intervention. Put a 1 beside the area most in need of specialized early intervention service, a 2 beside the next item, etc.

____ Cognitive Skills
____ Expressive Communication
____ Receptive Communication
____ Gross Motor
____ Fine Motor
____ Self-Help (feeding, dressing, toileting, personal care, adaptive)
____ Peer Socialization
____ Inappropriate Behavior
____ Attending/Task Orientation
____ Following schedule and routine

12. Below are several dimensions of classroom planning for children. Considering this child, rate the extent to which special modification would be needed for successful participation in a well-run class for typical children.

	No Modification	Minimal Modification	Moderate Modification	Substantial Modification
Physical Environment	____	____	____	____

Schedule of Activities	_____	_____	_____	_____
Teaching Strategies	_____	_____	_____	_____
Transition Times	_____	_____	_____	_____
Group Activities	_____	_____	_____	_____
Center Activities	_____	_____	_____	_____
Outdoor Play	_____	_____	_____	_____
Meals and Snacks	_____	_____	_____	_____
Reinforcing Appropriate Behavior	_____	_____	_____	_____
Dealing with Inappropriate Behavior	_____	_____	_____	_____

13. Please rate the usefulness of the following strategies/suggestions for working with children with fragile X syndrome by placing an X in the column that best describes your response.

Strategy/Suggestion	Not That Helpful	Helpful	Very Helpful	Please rank order the five strategies you have found MOST helpful by placing a 1, 2, 3, etc. in this column, with 1 representing most important strategy. Only identify top five.
a. Be firm; use stern voice/affect to convey displeasure.				
b. Provide consistent and structured routine.				
c. Consider similarities to autism and incorporate appropriate strategies.				
d. Use behavior management plan consistently.				
e. Provide one-on-one instruction.				
f. Do not require direct responses.				
g. Do not let frustration escalate; allow break for regrouping and calming.				
h. Limit distractions; facilitate increased attention.				
i. Use lots of repetition.				
j. Provide structured, hands-on activities involving multiple senses.				
k. Seat child away from peers.				
l. Consider child's unique characteristics.				
m. Work with the child's family.				
n. Work with child's therapists.				
o. Provide choices and be flexible.				
p. Use music as motivator/reward.				
q. Use computer as motivator/reward.				
r. Medication				
s. Read as much as possible about FXS.				
t. Ease transitions from one activity to another.				
u. Anticipate needs and prepare for them.				

v. Provide personal workspace and area for regrouping.				
w. Use visual cues, modeling, picture schedules.				
x. Work with occupational therapist with sensory integration training to meet sensory needs.				
y. Work up to desired skill through successive approximations.				
z. Stress functional and social skills				
Please add other specific strategies/suggestions you have found helpful and rate them. Continue on back.				

Child______________ID_______ Assess. # ___Completed by_____Date___________

CAROLINA FRAGILE X PROJECT
Service Interview with Family

I. CLASSROOM INFORMATION

1. School Name ______________________________

2. How many teachers/assistants? _______________

3. Teacher name _____________________________

4. Teacher's training/experience ______________________________________

____

5. Aide assigned individually to this child? Yes No
If yes: Name of aide _________________________________

6. What grade is the child in? ________________

7. What type of classroom? *Circle one.*
Inclusion Self-contained Resource Other ___________________

8. How many students in the class?

9. Type of students (age, diagnosis)?

10. Were new assessments conducted? Yes No

11. Is your child being served under the same eligibility label? If not, what has changed?

12. What opportunities does your child have for inclusion at school? Describe.

13. Is your child involved in any inclusive activities outside of school? If yes, describe.

14. How do you feel about your child's inclusion opportunities?

II. SERVICES

1. What type of services does the child receive? (Verify with teacher)

Occupational Therapy: Yes No
Format: Individual Group
Session Length? ________________ Times per week _______________

Speech/Language: Yes No
Format: Individual Group
Session Length? ________________ Times per week _______________

Physical Therapy: Yes No
Format: Individual Group
Session Length? ________________ Times per week _______________

Other _______________________ Yes No
Format: Individual Group
Session Length? ________________ Times per week _______________

2. Are you pleased with your child's current early intervention/school experience?

3. Would you change anything about intervention/school services?
If yes, what would you change?

II. TRANSITION

1. Did the child experience a transition this year? YES NO
If yes, answer the questions below.

Circle one: Part C to B E1 to K Triennial New class
Specify Transition: From ___________________ to _________________

2. What has the transition process been like for you and your child? When did it start and how did it progress?

3. What was the IFSP/IEP process like?

4. Which came first--classroom assignment or IEP?