NATIONAL **FRAGILE X** FOUNDATION

FRAGILE X CLINICAL & RESEARCH CONSORTIUM

Consensus of the Fragile X Clinical & Research Consortium

EDUCATIONAL RECOMMENDATIONS FOR FRAGILE X SYNDROME - ELEMENTARY SCHOOL

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Introduction

Attending elementary school may be the child's first encounter with school. This experience can be difficult especially when separating from a parent for the first time. If the child was identified with special needs early, the child may have already learned a number of classroom behaviors necessary to access instruction. Others will be learning a variety of skills necessary to be successful at school. The emphasis at the elementary level is learning academic skills, which can be particularly frustrating if best practices are not incorporated into the process. This document lists a number of strategies and supports that have proven to be successful.

Much of the child's day will be in a classroom with other students. The placement and interaction with neurotypical peers will be determined by the team at the staffing. Because children with FXS are often social and enjoy being included if only on the periphery, this time can be especially meaningful. For the individuals with fragile X syndrome (FXS), that can include placement in a center-based program, resource program or in a general education classroom with support staff (paraprofessional, SLP, OT, PT or psychologist). The following document will provide information regarding legal educational policies and guidelines as well as promising practices for academic and adaptive functioning. It is important to note that school districts across the country vary in their interpretation and application of federal guidelines and policies. As such, it is important to use this document as a guideline.

Educational Services/Assessments List

The following is a compilation of services and assessments that are often provided to school age children with fragile X syndrome (FXS). This list is a guideline and should not be viewed as exhaustive. The Independent Educational Program (IEP) is a determination of need based on formal and informal assessments and observations. The needs of the child will form the basis for his goals and objectives along with the services that he will receive in schools.

The IEP must be reviewed annually (annual review) and should be modified based on the student's present levels of academic achievement and functional performance. A full evaluation must take place every three years (triennial review) to determine if the student continues to be eligible for special education services due to their identified disability.

EDUCATIONAL SERVICES CHART
(6 TO 12 YEARS OLD)

Service Components **(Each component is described in more detail following the chart)**	
Response to Intervention (RTI)	As appropriate
Multi-Tiered Systems of Support-MTSS (includes Response to Intervention-RTI & Positive Behavior Intervention & Supports-PBIS)	As appropriate
Individualized Education Program (IEP)	Annually
Behavior Intervention Plan (BIP)	As needed
Speech & Language Therapy (i.e., communication and pragmatic language and possible augmentative and a system)	As needed
Psychological services (i.e. counseling, behavior management)	As needed
Evacuation Plan	As needed
Health Care Plan	As needed
Applied Behavior Analysis (ABA) Therapy	As needed
Occupational Therapy (OT) (including handwriting, adaptive functioning, personal care and compensatory strategies); sensory integration within OT	As needed
Adaptive PE/Recreation	As needed
Physical Therapy (PT)	As needed
- put in OT	As needed
Social Skills Training	As needed
Transportation	Required
Assessments (Each assessment is described in more detail following the chart)	
Developmental/Multidisciplinary Assessment * that includes SLP, OT	As needed
Functional Behavioral Assessment (FBA)	As needed
Psychoeducational Assessment	Recommended at the time of eligibility and every three years for the triennial review

Additional educational information is available through the National Fragile X Foundation: fragilex.org/treatment-intervention/education/

Description of Service Components:

Individualized Education Program (IEP): An IEP is a legal document that guides a child's specially designed educational program and services. The IEP is developed by a multidisciplinary team, which includes teachers, parents, and the student (if appropriate based on age). Based on the regulations set forth in the Individuals with Disabilities Education Act (IDEA), the plan must be reviewed and revised annually. However, parents or school personnel may request an IEP review meeting at any time [See IEP checklist at the end of this document]. The primary principles and components of an IEP are:

- Involvement of parents and meeting at a mutually agreed upon time.
- Parents receiving and understanding their Procedural Safeguards (parental rights).
- Providing children with disabilities a free and appropriate public education (FAPE).
- Collaborating with a multidisciplinary team that includes families.
- Determining a child's individual strengths and needs through assessment and evaluation.
- Determining the child's eligibility for special education based on one or more of the 13 disability categories from IDEA 2004 and individual state criteria (Autism Spectrum Disorder (ASD); Deaf-Blindness; Developmental Delay; Hearing Impairment; including Deafness; Infant/Toddler with a Disability; Intellectual Disability; Multiple Disabilities; Orthopedic Disability; Other Health Impaired (OHI); Serious Emotional Disability (SED); Specific Learning Disability (SLD); Speech or Language Disability; Traumatic Brain Injury (TBI); Visual Impairment, including Blindness).
- Establishing goals and objectives to meet the child's individual needs.
- Identifying individualized accommodations and modifications so that the child can meet their goals and objective.
- Placing and educating the child in the least restrictive environment (LRE) with their same-age, neuro-typical peers to the greatest extent possible.
- Identifying special factors of the child that may include communication and language-based interventions for children who are emergent bilingual learners; children with visual impairments, including blindness, who may need braille instruction; and/or the communication needs of the child who has hearing impairments, including deafness. Additionally, the child may need an assessment to determine if they require assistive technology (AT) services.

- Outlining the specific services that the child will receive that includes the type of service, service provider, start and end dates, and frequency of services.
- Prior Written Notice is a summary of the decisions made at the IEP meeting and given to the parents at the end of the meeting. It is the school district's responsibility to ensure that parents understand the child's special education and related services.

Behavior Intervention Plan (BIP): A Behavior Intervention Plan (BIP) is an individualized plan designed to address behavior(s) based on the results of a Functional Behavior Analysis (FBA) [see below]. The plan should include specific techniques and strategies that should be included in the IEP. Various components of these interventions may include changing the environment or setting events, increasing predictability and routines within the classroom, providing the child with choices, providing positive reinforcement for desired behaviors, and the use of social stories and visual schedules (Moskowitz, Car, & Durand, 2011). Progress monitoring, data collection, and crisis intervention plans are important components of the BIP. Ongoing data analysis by a psychologist or behavior analyst should be conducted to evaluate if there is progress towards an increase in positive target behaviors and/or a decrease in challenging behaviors and to ensure that an ineffective plan does not continue.

Description of Assessments:

Developmental/Multidisciplinary Assessment: This refers to the assessment of developmental progress in the following areas: cognitive, physical and sensory motor, communication and language, adaptive, and social emotional skills. Information may be obtained from parents, teachers, and other professionals (e.g., speech therapists, occupational therapists, physical therapists). The assessment may include developmental history, observational checklists, and individual standardized assessments.

Functional Behavioral Assessment (FBA): A problem-solving evaluation, typically conducted by a behavior specialist or school psychologist, designed to determine the underlying cause or function of a specific behavior as well as maintaining consequences. An FBA can be used to determine the best approach for reducing or eliminating undesirable behavior(s) and to increase prosocial desirable behaviors. A PBIS (Positive Behavioral Interventions and Supports) plan or BIP (behavior intervention plan) may be developed utilizing the results of the FBA.

Psychoeducational Assessment (administered by certified/licensed school psychologists, licensed psychologists): Used to analyze the underlying cognitive processes that may influence a child's educational performance. Children with FXS are often better at simultaneous processing than sequential processing; thus, instruments that assess both types of processing will provide helpful information regarding the student's strengths and weaknesses. Educational testing is required every three years; however, the educational team may decide that further testing is not required. Using accommodations will enhance the validity of standardized measures by decreasing anxiety and hypersensitivity while simultaneously increasing engagement. Please see the work of Thompson and colleagues (2018) for an in-depth discussion of using accommodations during standardized assessments for children with intellectual disabilities.

School Services:

A**daptive Physical Education (PE):** Adaptive Physical Education (P.E.) can assist students who experience fatigue or mobility issues and can help them develop leisure time interests. This may be in additional to physical education classes.

Counseling services: School psychologists and counselors, and in some cases social workers, work with students to improve their behavioral adjustment and self-control. Counseling or psychological services often includes social skills development by creating opportunities for children with FXS to be included in with their neurotypical peers during small group lessons, lunch, recess, or other times during the school day.

Evacuation Plan: This is a written plan for staff to follow in times of emergency such as weather-related disasters, fires, and acts of violence. This plan directs each staff member to use procedures to evacuate individuals who are non-ambulatory, nonverbal, hearing and vision impaired, and/or emotionally stressed by the process. The plan should include procedures for people with intellectual disabilities who may respond in unpredictable ways during an emergency. Individuals should have an opportunity to practice the evacuation plan during a calm time.

Extended School Year (ESY): ESY or summer school is intended for students with disabilities who have shown a significant regression of skills over school breaks and have not regained or recouped those skills after an extensive period of time. The providers must collect data over school breaks to determine if the child is eligible for ESY. ESY programs are typically implemented over a 4-6-week period of time over the summer school break.

The child's goals and objectives are addressed during the ESY program, but the teachers may not be the same teacher that they had the previous year or the teacher that they will have the next year.

Health Care Plan: The school nurse usually develops this plan by incorporating medical information provided by outside medical providers. Typically, the Health Care Plan includes medication names, dosages and side effects. In addition, the plan usually lists treatment strategies for specific medical conditions such as seizures, blood disorders, or allergic reactions.

Occupational Therapy (OT): Occupational therapy can be utilized to address adaptive functioning or self-help skills such as dressing, grooming, or feeding. Occupational therapy may be recommended to address fine motor difficulties related to handwriting. The occupational therapist will often consult to the team to help determine the need for compensatory tools and strategies (e.g., use of the computer and keyboarding skills) to optimize functioning. Students with FXS may have sensory seeking and/or sensory avoidance behaviors, which can interfere with their ability to access the curriculum and learn in the environment. The OT will evaluate and may provide sensory processing intervention to address the symptoms of children experiencing hyperarousal and hypersensitivity to light, touch, sound, and movement. Sensory issues may also be addressed through environmental supports at school (e.g., adjusting the lighting in the classroom, reducing noise level).

Physical Therapy (PT): Physical therapists generally focus on gross motor functioning, postural control, sitting, standing, and walking.

Social Skills Training: Social skills training and support may be incorporated into the curriculum through modeling and turn taking with an adult or through structured peer group activities such as lunch buddies. Using a triad to contrive conversational exchange can be effective. In addition, using video modeling strategies has also been proven effective.

Speech/Language Therapy: Speech therapy may aid in the development of functional communication skills in order to improve a child's pragmatic (functional) use of language. Communication skills may facilitate the building of improved peer relationships. Sometimes, students with FXS have oral motor delays, which can affect their ability to produce certain sounds and sequences of sounds. This can interfere with their speech production and intelligibility or articulation.

Augmentative and Alternative Communication (AAC): Alternative method of communication used for individuals with speech and language disabilities. AAC refers to all tools and strategies that are used to supplement or replace speech when it is not sufficient for the child's needs. AAC includes high tech tools, such as tablet technology and low-tech strategies, such as picture communication, gestures, and sign language. Assistive technology (AT) refers to the technology tools, e.g., voice generated communication devices.

Pragmatic language-Children with FXS may benefit from explicit instruction in social language. For example, they may need assistance using language for different purposes, adjusting language to meet the needs of the listener or situation, or following the rules of conversation.

Transportation: IDEA requires schools to provide transportation to and from school for children eligible for special education. Children are eligible for this related service if it is determined that the child's disability affects their capacity to get to school or the child is placed in a school other than their home school.

Applied Behavior Analysis (ABA) Therapy: ABA is not a specific program but rather a behavioral framework from which specific therapeutic interventions (e.g., Lovaas therapy, verbal behavior, discrete trial, etc.) have been developed. As such, there may be wide variability from one ABA program to another. It is important to keep in mind that systematic instruction, careful ongoing assessment, positive reinforcement, and attention to the ABCs (antecedents, behaviors, and consequences) of behavior are essential aspects of any successful therapeutic program, regardless of whether or not it is designated as "ABA." Decisions about the appropriateness of ABA services for a child with FXS should be made after careful evaluation of the individual. Discrete trial training (DTT) and intensive table teaching (ITT) procedures may need to be less direct and may include another student to utilize peer modeling or turn taking. Staff working with these students should continue to glean ideas and potential strategies from well-established programs while keeping in mind the syndrome-specific characteristics associated with FXS. (See "Educational Strategies" below.)

The following checklist and strategies may be useful to consider when planning a child's educational future:

IEP Checklist

- Request that the meeting be held at a time that is mutually agreed upon by the parents and the school personnel.
- Ask for a draft of the evaluation report prior to the meeting. Teams are not able to give parents a full draft of the IEP document before the meeting because that would mean they would pre-determine parts of the IEP without the parents' input.
- Double check for inconsistencies related to the child's skills, services, and accommodations.
- It is required that Procedural Safeguards are offered and explained to parents at every meeting.
- IEP goals should be revised as the child grows and develops. If the same goals are presented every year, then the team and the family need to question if the goals are appropriate for the child.
- Include academic and non-academic goals (if needed). These goals are based on the needs defined in the narrative (evaluation report) of the IEP.
- Prioritize the number of goals (maximum of five is recommended). Having too many goals creates a hardship for the IEP team and often goals are not addressed adequately.
- Build upon the child's academic and non-academic strengths.
- Extended School Year (ESY or summer school) eligibility should be discussed at every IEP meeting.
- If an augmentative communication device is provided at school, indicate that the equipment should be available for home use as well (training should be provided for the parents).
- All of the services must be included on the IEP and individualized for the child based on their needs (e.g., speech therapy 30 minutes per week). Document who is responsible for implementing the interventions, who is responsible for progress monitoring, and the location of where the services will be delivered (e.g., in the classroom, resource room).

Educational strategies for students with Fragile X

- To the degree possible, provide a calm and quiet classroom environment with built-in breaks and a predictable daily routine.
- Incorporate a holistic or simultaneous learning approach (e.g.: use a whole word technique rather than a phonics method, present a model of a final product for the student rather than step-by-step instructions).
- Consider distractibility and anxiety issues when arranging seating for a student (e.g. avoid the middle of a group, seat the student away from doorways).
- Explore use of calming strategies in concert with an occupational therapist trained

in sensory processing and hyperarousal. Have an occupational therapist prescribe a sensory diet to be used proactively through the day.

- Use visually based instruction. Provide visual schedules to prompt transitions. Using transitional objects to help guide the transition gives a purpose and shifts the attention from the change in scheduling or environment.
- Provide social skills lessons and social stories. Encourage typical peers to model appropriate behaviors.
- Teach math using visual and tactile strategies. Instruction should include the use of real object counters, size and shape manipulatives, and concrete examples. Computerized intervention programs may also be effective.
- Incorporate indirect instruction whenever possible. Use a triad to teach the student with FXS through another peer.
- Incorporate high interest materials into all areas of the curriculum.
- Utilize a family-centered approach. Use “Cloze” or “fill-ins” for assessments to help facilitate executive function skills. This is where certain words from the text are removed and the participant is asked to replace the missing words. Utilize evidence based academic interventions within an RTI or MTSS framework. These interventions should be based on the phenotypic profile of children with FXS as well as the individual profile of the child. These interventions should be visually based with limited language.
- Use small group or direct one-on-one instruction when introducing new material.
- Avoid forcing eye contact or giving “look at me” prompts. Many students with FXS increase and initiate eye contact when they are comfortable with staff, so instead reinforce eye contact by pairing yourself with positive interactions.

Alphabet Soup (Important Terms)

ABA Applied Behavioral Analysis
ABC Chart Antecedent, Behavior, Consequence Chart
ASD Autism Spectrum Disorder
BCBA Board Certified Behavior Analyst
BOCES Board of Cooperative Education Services
BIP Behavior Intervention Plan
ESA Educational Service Agency
FAPE Free and Appropriate Public Education
FBA Functional Behavioral Assessment
IDEA Individuals with Disabilities Education Act Of 2004
IEP Individualized Education Program
LEA Lead Education Agency

LRE Least Restrictive Environment, A Continuum of Placements Considered, Beginning With The General Education Classroom With Neuro-Typical Peers
MTSS Multi-Tiered System of Supports
Part B Federal Grant to States Under Idea for Children Aged 3 To 21 Years
Part C Federal Grant to States Under Idea for Children Aged Birth To 3 Years
PBIS Positive Behavioral Interventions & Supports
Procedural Safeguards Parental and Child Rights
RTI Response to Intervention
UDL Universal Design for Learning

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* See also: Assessment of Fragile X Syndrome, a treatment recommendation document from the National Fragile X Foundation (NFXF) at https://fragilex.org/our-research/nfxf/treatment-guidelines/

Author note: 2019 revisions were completed by Jeanine Coleman, PhD, Karen Riley, PhD, Marcia Braden, PhD, Barbara Haas-Givler, MEd, BCBA, and Paige Landau, MA, University of Denver (Doctoral student at University of North Carolina, Chapel Hill). Marcia Braden, PhD, Karen Riley, PhD, Jessica Zoladz, MS, CGC, Susan Howell, MS, CGC, and Elizabeth Berry-Kravis, MD, PhD initially authored this guideline. It was reviewed and edited by consortium members. It has been approved by and represents the current consensus of the members of the Fragile X Clinical & Research Consortium.

*The **Fragile X Clinical & Research Consortium** was founded in 2006 and exists to improve the delivery of clinical services to families impacted by Fragile X and to develop a research infrastructure for advancing the development and implementation of new and improved treatments. Please contact the **National Fragile X Foundation** for more information.*
(800-688-8765 or fragilex.org)