Consensus of the Fragile X Clinical & Research Consortium on Clinical Practices

EDUCATIONAL GUIDELINES FOR FRAGILE X SYNDROME: PRESCHOOL THROUGH ELEMENTARY STUDENTS

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Educational Services/Assessments List

The following is a compilation of services and assessments that are often provided to preschool and younger school age children with fragile X syndrome (FXS). This list is simply a guideline and should not be viewed as all-inclusive. The heart of the IEP is a determination of need based on formal and informal assessment results as well as observations. The needs form the basis for goals and objectives as well as services necessary to meet the needs.

Can be reviewed annually based on present levels of academic achievement and functional performance

EDUCATIONAL SERVICES CHART (3 TO 12 YEARS OLD)

	Recommendations	
Service Components (Each component is described in more detail following the chart)	**3 to 5 years old**	**6 to 12 years old**
Adaptive PE/Recreation	As needed	As needed
Behavior Intervention Plan	As needed	As needed
Communication/Language (including augmentative communication and pragmatic language)	Recommended	As needed
Early Intervention Services	Recommended	NA
Evacuation Plan	As needed	As needed
Health Care Plan	As needed	As needed
Individualized Education Plan (IEP)	Annually	Annually
Occupational Therapy (OT) (including handwriting, adaptive functioning, personal care, and compensatory strategies)	As needed; This is typically necessary for children within this age group	As needed
Physical Therapy	As needed	As needed
Response to Intervention	As appropriate	As appropriate
Sensory Integration Therapy	As needed	As needed
Social Skills Training	As needed	As needed
Speech Therapy	Recommended	As needed
Transportation	Required	Required
Assessments (Each assessment is described in more detail following the chart)		
Developmental/Multidisciplinary Assessment	Recommended	As needed
Early Intervention Evaluation	Recommended	NA
Functional Behavioral Assessment	As needed	As needed
Psychoeducational Assessment	Recommended; Appropriate methods must be employed.	Recommended at entry to school; As needed thereafter

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

Description of Service Components:

Adaptive Physical Education (PE)/Recreation: Adaptive PE instructors can help students develop leisure time interests and assist students who experience fatigue or mobility issues.

Behavior Intervention Plan (BIP): An individualized plan designed to address a behavior or behaviors based on the results of the FBA. The plan should include specific techniques and strategies and it should be included in the IEP. An important component of the BIP is the progress monitoring and crisis intervention. There is an accountability factor built- in so that a BIP does not continue to be implemented if it is ineffective.

Communication/ Language: *Augmentative Communication*-Alternative method of communication used for individuals with speech and language disabilities. It may include gestures, communication boards, pictures, symbols, drawings or the use of an assistive technology device. *Pragmatic language*-Children with FXS may benefit from explicit instruction in social language. For example, they may need assistance with using language for different purposes, adjusting language to meet the needs of the listener or situation, or for following the rules of conversation.

Early Intervention Services: The Early Intervention Program for Infants and Toddlers with Disabilities is the program known as Part C of the Individuals with Disabilities Education Act (IDEA). It is also known as Child Find. These services include services such as, occupational therapy, speech therapy, and behavioral intervention. They can occur in the home and/or in a structured program.

Evacuation Plan: This is a plan written for staff to follow in times of emergency such as weather related disasters, school fires, and acts of violence. Each staff member is directed by this plan to use procedures to evacuate as quickly as possible individuals who are non-ambulatory, nonverbal, hearing and vision impaired and/or emotionally stressed by the process.

Health Care Plan: This plan is usually developed by the school nurse who uses medical information provided by outside medical providers. Typically the Health care Plan includes medication names, dosages and side effects. In addition, treatment strategies for specific medical conditions are listed such as how to deal with a seizure, blood disorders, serious allergies and use of EpiPen.

Individualized Education Plan (IEP): Legal document that guides the child's educational program and services. The IEP is developed by a multidisciplinary team including teachers, parents, the student (if applicable), and other professionals. Based on the regulations set forth in the Individuals with Disabilities Education Act (IDEA), the plan must be revised annually (parent or school personnel may request an IEP review meeting at any time). [See IEP checklist at the end of this document].

Occupational Therapy (OT): Occupational therapy may be recommended to address fine motor difficulties related to handwriting. This may serve to reduce anxiety and frustration related to academic tasks. Programs such as "Handwriting Without Tears" may be incorporated at home and at school. For more information see http://www.hwtears.com. Occupational therapy may be utilized to address adaptive functioning or self-help skills such as dressing, grooming, or feeding. It may also be used to help determine the need for compensatory tools and strategies (e.g., use of the computer and keyboarding skills) to optimize functioning. Often, the occupational therapist will address sensory integration through testing and sensory profiling. Students with FXS often exhibit sensory dysfunction which can interfere with their ability to access the curriculum and learn.

Physical Therapy (PT): PT's can help students develop leisure time interests and assist students who experience fatigue or mobility issues.

Response to Intervention (RTI): One of the most significant shifts in education policy of the past several decades has been the implementation of RTI or Response to Intervention. The reauthorization of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA; P.L. 108-446) allows educators to use responsiveness-to-intervention (RTI) as a substitute for, or supplement to, IQ achievement discrepancy to identify students with learning disabilities (LD) (Fuchs and Fuchs, 2005). Although males with FXS typically do not qualify for services via a LD diagnosis, this law is very important for females. This law does not require children to fail prior to receiving an intervention(s) to support their learning. RTI is applied in a variety of forms across the country. Although initially developed as a solution for assessment and diagnosis issues it also has intervention and behavioral applications. The use of a tiered approach to academic interventions coupled with the significant data collection requirements of this approach are a benefit for children with FXS and should be explored even when an IEP is in place.

Sensory Integration Therapy: Sensory integration therapy may reduce the behavioral symptoms of children that experience hypersensitivity to light, touch, sound, and movement. Sensory issues may also be addressed through environmental support at school (e.g., adjusting the lighting in the classroom, reducing noise level).

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 quite effective. In addition, using video modeling strategies has also proven effective.

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

Transportation: IDEA requires that the schools provide transportation from door to school, with specialized equipment as needed, for children in special education.

<u>Description of Assessments:</u>

Developmental/Multidisciplinary Assessment: An assessment of developmental progress in the following areas: cognitive, motor, language, 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 a developmental history, observational checklists, and specific tests.

Early Intervention Evaluation: In order to determine the child's eligibility for services, a multidisciplinary evaluation takes place by a team that may include speech-language pathologists, audiologists, occupational therapists, physical therapists, psychologists, social workers, and early intervention specialists. A variety of procedures are used to determine if the child is eligible for services. They include observations, tests, interviews, play-based assessments, checklists, and other items. A diagnosis of fragile X syndrome may enable the child to receive services without an evaluation.

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 in order to determine the best approach for reducing or eliminating the undesired behavior(s).

Psychoeducational Assessment: Utilized to analyze the underlying cognitive processes that may impact your child's educational performance. As children with Fragile X are often better at simultaneous processing than sequential processing, instruments which assess both types of processing will provide helpful information regarding the student's strengths and weaknesses. Educational testing is typically recommended every three years; however the educational team may decide that further testing is not required.

The following checklist and strategies may be useful to consider when planning the educational future for the child:

IEP Checklist

- Include academic and non-academic goals (if needed). These goals are based on the needs defined in the narrative of the IEP.
- Limit the number of goals (maximum of 5 is recommended)
- Utilize strengths
- If an augmentative communication device is provided, indicate that the equipment will be available for home use (training should be provided for parents)
- Request that all service providers be present at the IEP meeting. The attendance of a general education teacher is mandated by IDEA (including general education teacher if inclusion services are provided)
- All provided services must be included on the IEP (e.g., speech therapy 30 minutes per week)
- Ask for a draft prior to the meeting
- Double check for inconsistencies
- Make sure to document who is responsible for both implementing the interventions as well as who will be responsible for the progress monitoring
- Procedural safeguards are required to be offered to parents at the time of the staffing

Educational strategies for students with Fragile X

- Incorporate a holistic or simultaneous learning approach (use a whole word technique rather than a phonics method)
- Include visual cues to help children follow the daily routine in the classroom
- Teach math using visual and tactile strategies, using real object counters, size and shape manipulatives, and concrete examples. Computerized intervention programs can be effective
- Indirect instruction-use a triad to teach the student with FXS through another peer
- Incorporate high interest materials into all areas of the curriculum as needed
- Provide an alternative math curriculum
- Use Cloze or “fill ins” for assessments. These consist of a portion of text with certain words removed and where the participant is asked to replace the missing words.
- Visually Based Instruction
- Experiential Learning
- Utilize evidence based academic interventions within an RTI framework. These interventions should be based on the phenotypic profile of children with FXS as well as the individual profile of the child. This should include visually based interventions with limited language.
- Use a routines based approach especially for the preschool population
- Utilize a family centered approach
- Avoid forcing eye contact or giving “look at me” prompts

Author note: This guideline was authored by Marcia Braden, PhD, Karen Riley, PhD, Jessica Zoladz, MS, CGC, Susan Howell, MS, CGC, and Elizabeth Berry-Kravis, MD, PhD. It was reviewed and edited by consortium members both within and external to its Clinical Practices Committee. It has been approved by and represents the current consensus of the members of the Fragile X Clinical & Research Consortium.

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The Fragile X Clinical & Research Consortium *was founded in 2006 and exists to improve the delivery of clinical services to families impacted by any fragile X-associated Disorder 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 www.fragilex.org)*