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

EDUCATIONAL GUIDELINES FOR FRAGILE X SYNDROME: MIDDLE AND HIGH SCHOOL STUDENTS

First Issued: August 2012
Last Updated: September 2013

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EDUCATIONAL GUIDELINES FOR FRAGILE X STUDENTS: MIDDLE AND HIGH SCHOOL STUDENTS

Educational Services/Assessments List

The following is a compilation of services and assessments that are often provided to older school age children with 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 (12 TO 18 YEARS AND OLDER)

	Recommendations	
Service Components (Each component is described in more detail following chart)	**12 to 17 years old**	**18 years and older**
Adaptive Physical Education (PE)/Recreation	As needed	As needed
Behavioral Intervention Plan	As needed	As needed
Communication/Language (including augmentative communication and pragmatic language)	As needed	As needed
Evacuation Plan	As needed	As needed
Health Care Plan	As needed	As needed
Health Summary	As needed	As needed
Job Coaching	As needed	As needed
Occupational Therapy (OT) (including sensory integration, handwriting, adaptive functioning, personal care, self- regulation and compensatory strategies)	As needed	As needed
Response to Intervention	As appropriate	As appropriate
Sensory Integration Therapy	As needed	As needed
Sexuality and Personal Safety	As needed	As needed
Social Skills Training	As needed	As needed
Speech Therapy	As needed	As needed
Transition Plan	Required at age 16	
Transition Program	Not applicable	Begins at age 18
Transportation	Required	Required
Updated medical status usually provided by a registered school nurse	As needed	As needed
Assessments (Each assessment is described in more detail following chart)		
Adaptive Behavior Assessment	As needed	As needed
Educational Assessment (special education teacher, general education teacher or consultant)	As needed	As needed
Functional Behavioral Assessment	As needed	As needed
Occupational Therapy (OT) Assessment	As needed	As needed
Physical Therapy Evaluation	As needed	As needed
Psychoeducational Assessment*	As needed	As needed
Speech/language Assessment	As needed	As needed
Vocational Assessment	As needed	As needed

***Recommended every 3 years if necessary (educational team in consult with family may decide testing is not required)**

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: Physical Therapists and/or adaptive physical education instructors can help students develop leisure time interests and assist students who experience fatigue or mobility issues.

Behavior Intervention Plan (BIP): An individualized plan design 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.

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 Fragile X 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.

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.

Health Summary: A registered school nurse assigned to the child's school will review medical records, immunizations, health plans (seizure activity or specific care for any medically fragile student), medication dosage and side effects. The nurse will also interview parents regarding medical status and update records accordingly. Whenever possible, the parent should ascertain a comprehensive medical evaluation to be performed by a pediatrician experienced with children with developmental disabilities, specifically fragile X syndrome (FXS).

Job Coaching: Job coaching can be provided to the student as they enter the world of work. These coaches are provided by the school district provide liaison between the school and the employer. In addition, issues relating to the student's disability such as need for self-regulation, environmental accommodations and communication support are provided by the coach.

Occupational Therapy (OT): Occupational therapy may be recommended to address fine motor difficulties, handwriting and self-help. This may serve to reduce anxiety and frustration related to academic and vocational tasks. 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.

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 is 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).
Sexuality and Personal Safety: Sexual/Human Growth and Development instruction includes discussion of public and private behavior, staring, touching, issues around sexual maturation, personal space, and appropriate conversation. Such instruction will increase the rate of successful integration in school, at work and in social settings.
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. Higher functioning young adults and adults may benefit by some drug and alcohol education.
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.
Transition Plan: An emphasis on transition issues is formalized through a mandated transition plan by age 16. Interest inventories, adaptive behaviors, community access, living options, leisure skills and vocational skills and placements form the basic foundation of this assessment.
Transition Program: Begins at age 18 after high school program has been complete. This stage of the educational process includes more vocational and daily living experiences and independent travel training. The focus at school shifts from academic content to real life context and experiences.
Transportation: IDEA requires that the schools provide transportation from door to school, with specialized equipment as needed, for children in special education.

Description of Assessments:
Adaptive Behavior Assessment: A determination of specific aspects of functioning to include but not be limited to: communication, community use, functional activities, home living, health and safety, leisure, self-care, self-direction, social, work, and motor skills (for children). Information is gathered from parents, caregivers, teachers, and the individual when appropriate.
Educational Assessment (special education or general education teacher or consultant): An informal assessment may include an observation of the child in class, at the job, in the community, in work study programs, and the school community. Interviews with parents, teachers, employers, job coaches and private providers might also be included in the informal assessment. A review of your child's work samples, school records, school and private evaluations and medical records can be part of this process. The formal administration of individual standardized tests of academic abilities and functioning may be provided. A written or verbal report summarizing the findings with recommendations for programming strategies, further intervention or for referral is shared by the teacher with the staffing team.
Functional Behavioral Assessment (FBA): A problem-solving evaluation, typically conducted by a behavior specialist, designed to determine the underlying cause of a specific behavior in order to determine the best approach for reducing or eliminating the undesired behavior(s).
Occupational Therapy (OT) Assessment: An occupational therapy assessment may be recommended to help determine the need for compensatory tools and strategies (e.g., use of the computer and keyboarding skills) to assist with functioning. This assessment may also determine what settings are optimal and what alterations can be made in the environment to achieve the best performance by the child.
Physical Therapy Evaluation: This is an assessment provided by a licensed physical therapist. Typically the assessment includes developmental tasks necessary to navigate the environment using gross motor skills and assessing overall physical stamina. The PT evaluation can help plan the adaptive PE program.

Psychoeducational Assessment: (School Psychologist, Licensed Psychologist) Utilized to ascertain the underlying cognitive processes that may impact your child's educational performance. As children with FXS are often better at simultaneous processing than sequential processing, instruments which assess both will provide helpful information regarding the student's strengths and weaknesses. The psychological assessment is conducted by a certified school psychologist. The evaluation must include more than cognitive testing, if even appropriate. For example, the school psychologist often analyzes adaptive behavior scales, behavioral assessments such as checklist for ADHD, Autism and/or Asperger's Disorder. Most checklists are completed by teachers and parents and/or caregivers who have knowledge of skills in various environments. Formal educational testing which is a part of the psychoeducational assessment is typically recommended every three years; however the educational team may decide that further psychoeducational testing is not required.

Speech/language Assessment: An assessment should focus on all domains of language (i.e., phonology, syntax, semantics, and pragmatics), as well as oral motor skills and hearing. Some areas may need further assessment and would involve more in-depth testing. For example, speech intelligibility may include an assessment of individual sounds, phonological simplification processes, and measures of prosody, such as rate of speech.

Vocational Assessment: A determination, in collaboration with the student, whereby appropriate placement and training for adult work can be arranged that aligns the student's aspirations with their capabilities.

The following guidelines 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)
- Limit the number of goals (maximum of 5 is recommended)
- Goals and objectives should be linked to functional performance and or grade level curriculum if applicable
- Goals and or objectives must be measurable
- Decide how frequently progress will be reported
- Objectives should be designed to incorporate the student's strengths and interests
- If an augmentative communication device is provided, indicate that the equipment will be available for home use (training should be provided for parents)
- All service providers are required to be present at the IEP meeting (including general education teacher if inclusion services are provided)unless they are formally excused by the parent
- All provided services must be included on service page of the IEP (e.g., speech therapy 30 minutes per week). These services include those provided directly to the student and those provided indirectly such as consultation with staff.
- Request a draft IEP prior to the meeting. Although this is not required by law, it is a courtesy which affords the parent to be better prepared for the IEP meeting
- Double check for inconsistencies
- Make sure to include who is responsible for implementing and monitoring each of the goals.
- Be sure there is an evacuation plan in place in case of emergencies
- If your child is on medication or has a significant medical need, be sure a health plan written by the school nurse is included and the staff appropriately trained to implement it

Educational strategies for students with FXS

- Incorporate a multi-sensory or simultaneous learning approach (use a whole word technique rather than a phonics method) Methodologies using spatial memory are more effective at this time than sequential approaches
- 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.

Accommodation List

- Small group instruction
- Allow seating near exit
- Provide structure and predictability
- Reduce level of environmental noise
- Avoid crowded areas
- Predictable transitions supported by visual cues
- Role play behavioral consequences
- Provide video modeling and social stories
- Encourage and allow frequent breaks and movement
- Provide picture and "low tech" schedules
- Utilize technology such as iPads, or iPhones to prompt adaptive behaviors
- Avoid forcing eye contact or giving "look at me" prompts

High School Students with FXS: Educational Considerations

All of the previous considerations listed for middle school are applicable for high school students. In light of the student's life task at this age, which is to become even more independent as they move toward young adulthood, the considerations have significant importance as they relate to job opportunities and their social life. Parents and school staff should be attuned to a student's needs for supportive counseling as they face increased challenges during the high school years: desiring more freedom and independence; wanting to drive and engage in certain activities their parents might not feel they are ready for; drugs and alcohol issues; and, dating and sexuality.

This major change in focus for high school students is called transition planning, aimed at assisting the student move forward into adulthood. Special focus on graduation requirements and selection of diploma track (e.g., standard diploma, certification of completion) should be discussed with parents.

Though IDEA specifies that transition planning begins at age 16, it is prudent that this should begin at age 14. Vocational assessment/planning and community job placements are often an important aspect of a student's high school experience. This is a time when the student, family, and those involved with the student at school can discuss how much of the educational focus should be on academic skills versus functional living skills. If post secondary education appears to be an option, it is important early on in the student's high school career to explore resources and ensure that the student will have attained the appropriate pre-requisite skills and requirements for the programs.

Transition strategies

Please look for a link on fragilex.org (under development) to view document on transition strategies put together by
Dr. Karen Riley and her students.

Transition Guidelines and Worksheet

AGE 14:

___Discuss future educational and vocational goals based on the child's interests and skills
___Hold IEP meeting with school to discuss transition issues and include goals in the most recent IEP; most children with FXS will remain in the school system until age 22
___Address social, sexuality and safety issues in a developmentally appropriate manner; ask the school to focus on vocational training and skills of daily living
___Time to start considering estate planning and special needs trust to help your child continue government entitlements and programs in adulthood

AGE 16:

___The IDEA law requires that schools formally begin transition planning at age 16; an Individual Transition Plan (ITP) is developed; the ITP will formulate a long term plan focused on graduation from school
___Continue to develop daily living, vocational and domestic skills
___Identify and foster community based employment and volunteer opportunities by job shadowing, volunteering, and doing odd jobs/household chores
___Develop a network of committed adults who will take responsibility for certain aspects of planning for your child's future (ie. family friends, relatives and school staff)

AGE 17:

___At age 18 your child will legally become an adult; address guardianship issues, power of attorney, power of financial attorney and medical directives prior to your child's 18th birthday
___If your child has long term support needs, check for eligibility with your region's Aging and Disability Resource Center (ADRC) www.adrc-tae.org

AGE 18:

___Social Security Income (SSI), Medical Assistance, and SSI-Exceptional Expense Supplement (SSI-E) are government programs for those considered disabled; apply through your Social Security Office www.ssa.gov
___Consider transitioning medical care to adult providers; ask your child's physician to contact the new physician
___Register to vote; males must register for selective service; obtain an identification card through your state department of motor vehicles (DMV)

AGE 19:

___A referral to the Division of Vocational Rehabilitation (DVR) should be made at least 18 months before graduation; DVR will help in vocational training, job training and support; to help prepare for vocational services after graduation maximize amount of paid employment in the community
___Assist with learning how to use public transportation

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.

Funding: This project was made possible by Cooperative Agreement U01DD000231 from the Centers for Disease Control and Prevention to the Association of University Centers on Disabilities (AUCD) and RTOI 2008-999-03 from AUCD to W.T. Brown in support of the National Fragile X Clinical and Research Consortium. The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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)*