

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

EDUCATIONAL GUIDELINES FOR FRAGILE X SYNDROME: GENERAL



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Introduction

The Individuals with Disabilities Education Act (IDEA) provides for a free, appropriate, individualized education in the least restrictive environment (that is, as much as possible with children in regular education classes) for children birth through age 21 (or older if they are still attending high school). For individuals with fragile X syndrome (FXS), a variety of services and programs should be available. A broad review of school services issues follows, with checklists in other Consensus Documents specific to preschool through elementary and middle school through high school years.

Response to Intervention (RTI)

One of the most significant shifts in education policy of the past several decades has been the implementation of response to intervention (RTI). The reauthorization of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA; P.L. 108-446) allows educators to use RTI as a substitute for, or supplement to, IQ achievement discrepancy to identify students with learning disabilities (LD) (Fuchs and Fuchs, 2005). Although there is no single, absolute definition of RTI, a quick and descriptive summary comes from the National Center on RTI and reads: with RTI, schools identify students at risk for poor learning outcomes, monitor student progress, provide evidence-based interventions and adjust the intensity and nature of those interventions depending on a student's responsiveness, and identify students with learning disabilities or other disabilities ([NCRTI](#), 2010). RTI is seen as a positive step in serving children with special needs, however it is not uniformly applied across states and even within districts. Many feel RTI is a general education issue while others feel it has only special education applications. The debate illuminates a significant concern regarding students with delays of known or genetic etiology and has direct implications for this proposed framework. Current applications of tiered approaches often immediately place children with genetic disorders generally, and FXS specifically, in tier three at the top of the RTI pyramid or even worse outside of the pyramid entirely. Although this practice is theoretically correct, and these children do not need to qualify for services, it limits the utility of the approach. Unilaterally placing any student at the top of the pyramid due to his/her diagnosis operationally assumes that he/she is unable to benefit from the interventions and approaches afforded to other students in the lower tiers. This concept is pivotal to effective inclusion practices. Inclusive practices, for preschoolers as well as their school age peers, extol the benefit of best practices for children with special needs. As a result it is important for children with FXS to be included in the RTI process whenever possible. This serves many purposes: it operationalizes the idea that children with FXS can and do benefit from universal practices, it provides a structure for them to engage in tier 2 practices that might not otherwise be considered for these children, and it provides the progress monitoring structure necessary to document effective educational interventions.

Inclusion (Braden, 2011)

The momentum to include students with FXS in the general education mainstream grew out of the Individuals with Disabilities Education Act (IDEA). The assertion that children with disabilities had a civil right to attend school in their home school setting grew out of Civil Rights

litigation. The emphasis to include students with FXS in general education classrooms has been noted throughout the literature. Perhaps the impetus for this movement comes from the fact that children with FXS have a considerable interest in people—one of the hallmarks of this population is a strong desire to interact socially. This often makes inclusion more viable and increases the success rate.

It is important to remember, however, that levels of affectedness vary from one individual to another, and placement options must include enough flexibility to meet individual needs. There are occasions when inclusion can wind up being restrictive to children with severe needs. Successful inclusion cannot be accomplished without a systematic, sequential process. Just placing the student with FXS in a general education classroom with a para-professional close by does not necessarily constitute success

Students with FXS may require different levels of inclusion during their school development. In addition, the outcome for the each grade level may also change. For example, during the early elementary years the outcome may be to engage in classroom routines, participate in social activities and to engage in academic tasks. As the student enters middle school and high school, the outcome may again vary. The student may at this point gain access to social skills, vocational experiences and extracurricular activities by being included.

Educational Strategies for Individuals with Fragile X Syndrome

People with FXS represent a broad spectrum of intellectual development - generalities must always give way to the specific person. Nevertheless, we know that most individuals with FXS exhibit deficits in cognitive development ranging from mild to severe. While females can demonstrate the same deficits, they tend not to be affected as widely or severely as males. Both genders tend to show weaknesses in auditory processing and what are called “executive functioning” skills. These skills include planning, attending, sustaining effort, generating problem solving strategies, using feedback, and self-monitoring.

Males with FXS may exhibit strengths in verbal labeling, simultaneous learning, receptive vocabulary (which is often higher than expressive), “gestalt” learning, visual perceptual tasks, mimicry, and adaptive functioning for life skills. Their weaknesses typically lie in higher level thinking and reasoning, complex problem solving, sequential tasks (because males with FXS tend to perceive the “whole” rather than individual parts), quantitative skills, motor planning, socialization and communication.

Strengths of females with FXS include vocabulary and comprehension, short-term visual memory, reading, writing, and spelling. Their deficiencies tend to include abstract thinking, understanding spatial relationships, quantitative and conversational processing, short-term auditory memory, maintaining attention, and impulsive behavior.

Part of an educational plan should involve the integration of technologies including personal computers, digital devices, entertainment systems, audiovisual equipment, and games that can assist in every facet of learning. The assistive technology plan should involve programs and

applications designed to enhanced learning based on the specific cognitive and learning profile of the individual with FXS. Since this technology is used by typically developing children there is reduced stigma attached to these devices. Modified mice/keyboards and touch screens can also be used to interface with technologies for educational purposes and to reduce motor demands, reducing limitations from motor dyspraxia and allowing responses more reflective of the ability of the individual with FXS. Games and educational Apps that involve touch, as well as physical manipulation of the instrument, including a wide variety of movements (e.g. shaking, tilting), help children learn through a variety of modalities to support skill development. These technologies often allow concepts to be delivered through visual learning and visual memory strategies, an area of cognitive strength in FXS, thus enhancing learning.

Key developmental challenges in the range of school age individuals have been identified and, along with a detailed lesson planning guide, are available online at:

www.fragilex.org/treatment-intervention/education/lesson-planning-guide/

Strategies for teachers that have been found to be most useful when educating children with FXS include (but are not limited to):

- To the degree possible, provide a calm, quiet classroom environment, with built-in breaks e.g. a job in the school delivering mail to the office
- Teach student to request a break and provide a “safe” refuge area (be cautious not to confuse this with timeout area)
- Consider distractibility and anxiety issues when arranging seating for student e.g. avoid the middle of a group, seat the student away from doorways and a/c or heating
- Use small-group or one-to-one instruction when teaching novel tasks.
- Explore use of calming strategies in concert with an occupational therapist trained in sensory integration. Have an occupational therapist prescribe a sensory diet to be used proactively through the day
- Give ample time for processing and alternative methods of responding.
- Simplify visually presented materials to eliminate a cluttered or excessively stimulating format.
- Use high and low technological adaptations, such as word tiles, sticky notes and the computer, for writing assignments.
- Provide a visual schedule and/or transitional object or task to prompt transitions.
- Use manipulatives, visual material paired with auditory input, videos, and models.
- Provide social skills lessons and social stories, and have typical peers model appropriate behaviors.
- Provide completion or closure for activities and lessons.
- Capitalize on strengths in modeling, memory, simultaneous and associative learning.
- Use indirect questioning in a triad format to include a child with FXS, a typical peer, and teacher, rather than direct questioning to the child with FXS.
- Utilize “Cloze” techniques (fill-in blanks) to help facilitate executive function skills.
- Use backward chaining—ask the student to finish the task after you begin it.

- Provide visual cues—such as visual icons, color coding, numbering, and arrows—to help organize tasks.
- Use reinforcements, such as “high fives”, rather than hugs or pats on the back (close physical contact tends to over-stimulate children with FXS).
- Introduce novel tasks interspersed with familiar tasks to hold attention and reduce anxiety
- Avoid forcing eye contact or giving “look at me” prompts; reinforce eye contact by pairing yourself with positive interactions; many students with FXS increase and initiate eye contact when they are comfortable with staff

Many of these strategies are suitable for the Specially Designed Instruction (SDI) and Accommodations section in the IEP.

Early Intervention

Early intervention is the process of identifying, assessing, and providing intensive, multimodal services and support for children with developmental disabilities from birth through age three. The portal for these services is Child Find. Each community has a Child Find agency. Some are housed in school districts while those in rural areas use a BOCES structure. This is a free service to all families. The process typically begins with the Child Find team completing a multidisciplinary team evaluation in order to determine the child’s eligibility as well as the needs for the child and his or her family. Once a child with FXS undergoes a multidisciplinary assessment and is determined to be eligible, an Individualized Family Service Plan (IFSP) must be created within 45 days. An IFSP is a legal document that provides family based intervention services that may include: speech-language pathology (SLP) services, occupational therapy, physical therapy, audiology, family training, health services, respite care, service coordination, nutrition, vision services, and in some cases transportation. These services are appropriate and beneficial for children with FXS. Individual developmental trajectories are common within FXS. However, speech-language and occupational therapy services are particularly important during this developmental stage. Intervention services are provided in the child’s natural environment, usually the child’s home.

Although there has been a great deal of research on intervention strategies, there continues to be a paucity of evidence based practices that are targeted to the birth to 3 age group. It is clear that infants and toddlers with FXS typically demonstrate developmental delays. It is also clear that they respond to early intervention services. When selecting these services it is important to utilize a family-centered approach that focuses on educating, training, and involving the child’s parents, as this is necessary to ensure positive outcomes. Goals, therapeutic targets, and implementation plans should be established with a multidisciplinary team and the family. A routines-based approach to these services is optimal because it increases the likelihood the child’s family will be able to follow the established therapeutic interventions.

Early Childhood

Children with FXS may receive services from special education team members in a preschool (often called an integrated preschool) designed for children without such needs, or they may

attend special early childhood programs designed specifically for children with developmental delays. For children with FXS, a structured, calm atmosphere, with a predictable routine is vital. Visual cues and calming spaces (e.g., corners with bean bag chairs and CDs) are helpful for many children with FXS. Children with FXS benefit from modeling other children, so a setting that includes children at a variety of levels, including some at a higher functioning level, may be most appropriate. Related services such as speech/language, occupational therapy, physical therapy, and psychological or counseling services can be provided through the IFSP (Individual Family Service Plan (from birth to age three) and IEP (Individual Education Plan (from three to 21 years). The IFSP involves the family and can include goals for the family and the child. The delivery of services can also be provided at home, in the community and in preschools. As is the case with typically developing preschoolers it is important to have the child in a program that employs a best practices approach. This should include an evidence-based curriculum, appropriate student teacher ratios, a highly qualified staff, a licensed physical space including a variety of materials that are safe and well organized, and family centered practices. A routines based approach to inclusive interventions is often optimal for young children with FXS; it is important to remember that often additional individual or small group therapy is warranted.

Elementary School Years

The elementary school years require more focus on attending behaviors. Relative mastery of these behaviors achieves two key goals: the obvious and universal one of allowing for learning to take place and greater acceptance by peers.

Even children who are minimally impaired will likely exhibit speech and language deficits. It is critical that this area receive maximum emphasis in the elementary school years. Teachers should always consult a speech/language therapist for assistance. Speech/language goals should also be an integral component of an IEP at this stage. Teachers can achieve the most success by using measured introduction of new material, closely observing the student's response, then sustaining clear expectations while encouraging the student's effort and supporting the outcome. Parents and educators must explore the appropriate balance between functional and traditional academics, always bearing in mind such students' general preference for hands-on, experiential learning with an emphasis on content area instruction. If evaluation reveals that fine motor deficits exceed 1-2 years' chronological age, teachers should access the services of an occupational therapist familiar with motor planning deficits. This area can present persistent and pervasive frustration to many with FXS even for those who are less affected. Being unable to write, take notes, and complete written language assignments sets one with FXS apart from peers, which can build feelings of incompetence. Mastery of dressing and hygiene skills are particularly critical for social acceptance. General acceptance at this developmental level may pave the way for the student with FXS to experience spontaneous interaction with typically developing peers. Social activities, such as scouts, music, and sports, provide invaluable exposure to socially appropriate behavior by peers.

Some children, especially girls, who may not meet criteria for an IEP, could be eligible for in-class accommodations through a "504 plan". This plan refers to Section 504 of the

Rehabilitation Act

(specialchildren.about.com/od/504s/504_Plans_for_Students_with_Disabilities.htm) and the [Americans with Disabilities Act](#), and specifies that no one with a disability can be excluded from participating in federally funded programs or activities, including schooling.

The Middle School Years

With elementary school having put the basic building blocks in place, middle school teachers can focus on helping students with FXS achieve greater clarity and precision in oral and social communication. Encouraging the student to express himself independently (without fill-in assistance from peers or the teacher) helps foster confidence and appropriate risk-taking in social settings. All academic instruction should reflect a practical, functional base, equipping students with tools they can call upon in their interactions with the larger world. These functional modalities range from consumer math skills to following written instructions for tests. Questions regarding inclusion in regular classroom settings should take into account the invaluable social skill set gained there, as well as each student's unique—and often highly motivated—interest in a particular subject area such as science, history, and music. As always, students do better when assignments are modified to account for learning style and cognitive deficits. Transitional planning (as described on the next page) also begins to play a role as mandated by the IDEA at age 16. As with other students, open discussion of sex education topics helps destigmatize normal sexual feelings. Students with FXS also respond well to rules and clear delineations of what is expected in “mature” behavior, so inappropriate actions can often be curtailed. Including students with FXS in social skills groups at this level will more often include peers with disabilities because the gap between those with FXS and typical peers is widening at this age. It is important to foster relationships that will transcend into friendships at this age. These friendships will provide good transition into High School and beyond.

High School Years and Beyond

The curricular focus shifts to more practical concerns of employability, social adaptability, and ultimately, the capacity of the student with FXS to achieve self-satisfaction and happiness in life. The specific method of service delivery tends to be less critical at this age, as long as the IEP addresses the student's general needs. The most critical of these is to continue skill building for the community beyond the school walls. Allowing them to apply their own logic to problem solving is critical to the student's intellectual and emotional development— however unformed that logic may be. The academic focus shifts from acquisition of skills to learning how to apply them in the larger world. Central to the community-based instructional emphasis are lessons on self-help, recreation, exercise, medication management, accessing mass transit, and other resources of daily living. Job experiences are invaluable for developing virtually every skill in the repertoire of students with FXS, including emotional maturity and the confidence that accompanies it. Whenever possible, school programs should provide a rotation of job placements so interest and competence levels can be assessed. Work Experience Studies (WES) can provide academic credit while the student gets to practice appropriate work behaviors. When the student turns 18 and has an IEP in place through age 21, the emphasis shifts to the transition between school and independent adult living. Transition Programs are provided in high schools for those with FXS and other disabilities. Transition services under the Reauthorization of IDEA (2004) addresses skills necessary to be successful in moving from the

school into the community and into the world of work. The student can access post-secondary education, vocational education, supported employment, independent living and community participation. Developing appropriate social/sexual behaviors is critical in the high school years, because young people with FXS must experience a degree of peer acceptance in order to build their self-confidence and credibility for work. With guidance and patience, it is possible to instruct students with FXS in how to respond to sexuality issues e.g. privacy, exploitation, and sexual expression.

After graduation or earning a certificate of attendance, the person with FXS enters a new stage in personal development. Although resources from public schools are no longer available after age 21, if the transition has been properly provided, the person with FXS is usually supported in a work setting and services are funded through a regional center in many states. Anecdotal reports of successful vocational placements include social contact, movement, and work environments that provide a variety of tasks. Successful employment may require reduced hours and opportunities to take breaks. Some have reported success working in skilled nursing facilities delivering drinks and visiting with clients, working in child care and animal care, providing food preparation, doing janitorial work, serving food in a slow paced cafeteria, and working in landscaping.

School Services

Some related services that are or that should be made available to school age children with FXS can include but are not limited to the following:

- **Assistive technology and Augmentative and Alternative Communication:** Assistive technology (AT) is defined as equipment that helps the child improve his or her functional capabilities. For a child with low muscle tone, the assistive technology could be a special chair to help with positioning and posture. Augmentative and Alternative Communication (AAC) refers to methods of communication that enhance or replace conventional forms of expression. For children with FXS who are not yet speaking, the AAC might be picture exchange communication system, manual language, a language board, or a computerized, talking device. The decision and selection of the technology devices should be a team decision and reviewed periodically. The school is responsible for both the purchase of the appropriate devices and the training of personnel to use them when the device is identified as a need and a related service. The goals of learning to use and generalize language use with AT devices should be included in the IEP.
- **Audiology:** For children with FXS syndrome, audiologists might also provide advice regarding amplification. Aphonic ear, although uncommon, may improve attention and concentration for children with normal hearing and can be helpful on occasion.
- **Counseling services:** School counselors work with students to improve their behavioral adjustment and self-control. Many times the counseling or psychological services include social skills development by creating opportunities for children with FXS to be included in small groups at lunch, recess or during the school day

- **Occupational therapy:** Occupational therapists are vital components of the team for children with FXS (Scharfenaker and Stackhouse, 2012)
- **Orientation and mobility services:** This may include assessment, instruction, technical assistance and materials for safe travel in home and community e.g. public transportation
- **Parent counseling and training:** Counselors provide information about the child's disability and provide referrals for support groups, financial assistance, and professionals outside the school system. This service does not provide direct service (therapy) to the parents but rather support for services provided to the child
- **Physical therapy:** Physical therapists generally focus on gross motor functioning, postural control, sitting, standing, and walking
- **Psychological services:** School psychologists are part of the multidisciplinary team and often administer the individual IQ test and other measures. They also consult regarding placement, academic interventions, social emotional skill development, and learning profiles. They may also provide psychological counseling for children and parents as well as provide Functional Behavior Assessments (FBAs).
- **Recreation:** Some children require adapted physical education or recreational therapy to teach the necessary skills to engage in leisure and play, such as golf or taking a hike. For younger children, the adaptive PE may help them develop prerequisite skills to enable them to participate in group sports, such as tag and kickball.
- **Rehabilitative counseling services:** For older children and adolescents, rehabilitative counselors provide assessments and advice regarding career development, vocational choices, achievement of independence, and integration into the workplace and community
- **School health services:** School nurses provide services such as the administration of medication, supervision of hearing and vision screenings
- **School social work services:** School social workers may work with problems in the child's living situation, and coordinate community services for the child. School social workers may also work with classmates to help them understand the disability of the child in special education (this service can also be provided by psychological and counseling services depending on the school district). Social workers often serve as "service brokers"; connecting children and families with community services.
- **Speech Pathology:** Speech Pathologists assess receptive and expressive speech and language, refer for medical assessment when necessary, and provide therapeutic services
- **Transportation:** IDEA requires that the schools provide transportation from door to school, with specialized equipment as needed, for children in special education



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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)*