NATIONAL FRAGILE X FOUNDATION
FRAGILE X CLINICAL & RESEARCH CONSORTIUM

Consensus of the Fragile X Clinical & Research Consortium

EDUCATIONAL GUIDELINES FOR FRAGILE X SYNDROME MIDDLE SCHOOL AND HIGH SCHOOL

Introduction

The transition into middle school or high school serves as an exciting time for many families but is often accompanied with some stress and anxiety that may reignite the grieving process. This is especially difficult for some families as many cultural milestones occur within this time frame. For the individuals with FXS, the adolescent and early adult activities of driving, dating and exploring post-secondary opportunities may look very different than for their neurotypical peers. Within the educational setting, this divergence is also evident as the focus often moves from the academic to the vocational. The following document will provide information regarding legal educational policies and guidelines as well as promising practices for academic, vocational and independent living progress.

Middle School
Given that elementary school supports the basic building blocks of learning, 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/ herself independently (without fill-in assistance from peers or the teacher) helps foster confidence and appropriate risk-taking in social settings. In cases where the child is non-verbal or very low functioning he/she should be encouraged to use alternative forms of communication including but not limited to sign language and augmentative systems. 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 consider the invaluable social skills 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. Depending on the students' individual needs, many benefit from accommodations and modifications to assignments to account for learning styles and cognitive areas of improvement. Socially, it is important to foster relationships that will develop into friendships at this age. These friendships will provide good transition into High School and beyond.

High School
As the student moves into high school, 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. Academic goals change from acquiring skills to learning how to apply them in the larger world. Central to this community-based instructional emphasis are lessons on self-help, recreation, exercise, medication management, accessing public transportation, and other facets of daily living. Job experiences are particularly invaluable

for developing virtually every skill needed for post-secondary success, including social and 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 16, the emphasis shifts to the transition between school and independent adult living. It is important to note that this shift occurs at 14 in some districts across the country. A transition plan becomes a required part of the Individualized Education Program (IEP) through age 21. Transition programs are provided in high schools for those with FXS and other disabilities aged 18 to 21. Transition services under the Reauthorization of the Individuals with Disabilities Education Act (IDEA; 2004) addresses skills necessary to be successful in moving from the school into communities, colleges, and careers. The student, based on his strengths, interests, and preferences, can focus on goals related to post-secondary education, vocational education, supported employment, independent living, day programs and other forms of community participation.

Post-Secondary

Following high school, the majority of individuals have two options: engage in the work force at the appropriate level or pursue a post-secondary academic experience. The appropriateness of these opportunities should have been discussed as a part of the transition planning process discussed above. Limited post-secondary educational opportunities are available for individuals with FXS nationally, with federal support from the Higher Education Opportunity Act (HEOA; 2008). If the individual does not choose a post-secondary academic option after graduation or upon earning a certificate of attendance from high school, 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 can be supported in a work setting and services are funded through a regional center in many states, as outlined by the Workforce Innovation and Opportunity Act (WIOA; 2013). Successful employment may require reduced hours, opportunities to take breaks and social interaction with other workers. Successful employment placements for some FXS adults might include: grocery stores, food preparation, janitorial work, landscaping, animal care, child care, and working in skilled nursing facilities.

It is also important to note that not all males are able to engage in these two options and as a result will need different types of supports. For these individuals the transition should have included a plan for activities that include meaningful activities that include being a part of the community, but may not be academic or vocational in nature. These activities may be more recreational and social in nature. These activities could include things like swimming, horseback riding, bowling and going out to eat. Leaving the individual's place of residence on a regular basis is important to decrease the likelihood of a compressed social world after formal

education options have been completed. This is also important as a protective factor against agoraphobia which does occur in some males as they age.

Educational Services/Assessments List

The following is a compilation of services and assessments that are often provided to middle and high school age children with FXS. This list is simply a guideline and should not be viewed as comprehensive. The heart of the Individual Education Plan (IEP) is a determination of the student's need based on formal and informal assessment results and observations. The needs form the basis for IEP goals and objectives, services, and accommodations necessary to provide an appropriate educational program in the student's current educational placement. For further information on the IEP see the General Education Guidelines.

EDUCATIONAL SERVICES CHART (12 TO 18 YEARS AND	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	As needed	As needed
Evacuation Plan	As needed	As needed
Individualized Health Care Plan (IHP)	As needed	As needed
Health Summary	As needed	As needed
Job Coaching	As needed	As needed
Occupational Therapy (OT)	As needed	As needed
Multitiered systems of support (MTSS)	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 Language Therapy	As needed	As needed
Transition Planning (begins when student is 14)	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	As needed	As needed
Functional Behavioral Assessment	As needed	As needed
Occupational Therapy Assessment	As needed	As needed
Physical Therapy Evaluation	As needed	As needed
Psychoeducational Evaluation*	As needed	As needed
Speech/language Assessment	As needed	As needed
Vocational Assessment	As needed	As needed

    ∗ **Recommended every 3 years (the educational team, in consultation with family, may decide testing is not required);**

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

The educational services, including IEP goals and objectives must be **reviewed annually based on present levels of academic achievement and functional performance**.

Description of Service Components (alphabetized)

Physical Education (PE)/Recreation: Physical Therapists and/or adaptive PE instructors can help students develop leisure time interests and assist students who experience fatigue or mobility issues. Adaptive options may be necessary for some individuals.

Behavior Intervention Plan (BIP): This individualized plan is designed to address a behavior or set of behaviors that interfere with the student's ability to learn and/or participate in the school setting. It is based on the results of the Functional Behavior Assessment (FBA). The plan should include positive behavior supports and specific interventions that will be utilized by school personnel. These should be included in the IEP. These techniques and strategies should be evidence-based and monitored by appropriately trained personnel. The BIP, along with the IEP, can also serve as protective documents in case of a manifestation determination review.

Communication/Language: Speech and language pathologists (SLPs) can help students improve both receptive and expressive language through targeted interventions. *Augmentative and Alternative Communication (AAC)* includes all forms of communication outside of oral speech. AAC methods used for individuals with speech and language disabilities may include gestures, communication boards, pictures/symbols, or the use of an assistive technology device. *Pragmatic (social) language interventions* may be beneficial for children with FXS. For example, they may need assistance with using language for different purposes, adjusting language to meet the needs of the listener or situation, or 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. This plan should be developed in conjunction with the parents or caregivers and with the appropriate local authorities when possible.

Individualized Education Program (IEP): This is a written, legal document listing the special educational services designed to meet the student's individual needs. The IEP is developed by a team that includes the student, the parents/caregivers, and school staff (e.g., special education teacher, general education teacher, SLPs, school psychologists). An IEP is based on a psycho-education evaluation conducted by the school team generating a body of evidence to formulate annual goals, accommodations, modifications, supplementary aids, and related services. One important component of the IEP is the

Impact of Disability. This allows for the service providers and parents to describe FXS and how the neurobiology impacts a number of learning and behavioral issues described in the educational strategies section. It provides the foundation for the needs and accommodations of the student and helps guide the IEP and possibly the BIP.

Individualized Health Care Plan (IHP): This plan should combine all of the student's healthcare needs into one document for health management in the school setting. It is developed by the registered school nurse using comprehensive data, including medical information provided by 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 FXS. Typically, the IHP 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/or use of EpiPen. A *Health Summary* should be provided, which consolidates medical records, immunizations, and findings of the health plans (e.g., seizure activity or specific care for any medically fragile student, medication dosage and side effects).

Individualized Transition Plan (ITP): An emphasis on transition issues is formalized through a mandated transition plan by age 16 (IDEA, 2004). Interest inventories, adaptive behaviors, community access, living options, leisure skills, and vocational/post-secondary education skills and placements form the foundation of this plan. The transition plan, like IEPs, must be strengths focused (taking into account the student's interests and preferences) and outcomes orientated. Specific goals and objectives outlining skills, interventions, and persons responsible for monitoring progress and attainment should be explicitly outlined. Accommodations and modifications necessary for independent living, vocational placement, and/or post-secondary education participation must be considered.

Job Coaching: Job coaching can be provided to the student as they enter the world of work. In addition to vocational instruction and career assessment, coaches may provide support around issues relating to the student's disability such as need for self-regulation, environmental accommodations or modifications, and communication. Job coaches may be provided by the school district to serve as liaisons between the school and the workplace.

Multi-tiered systems of support (MTSS): This is an evidence-based framework for effectively integrating multiple systems and services to simultaneously address students' academic achievement, behavior functioning, and social-emotional well-being. MTSS allows for varying levels of support, instructional and behavioral screenings, progress-monitoring of instructional strategies, and data-driven decision making. The use of a tiered approach to academic and behavioral interventions coupled with significant data collection requirements is beneficial for children with FXS and should be explored even when an IEP is in

place. Encompassed within MTSS is _Response to Intervention (RTI)_. RTI is used to determine eligibility for specific learning disability (SLD). With the reauthorization of IDEA (2004), or Public Law 108-446, educators must now use RTI as a key indicator for SLD eligibility. Although males with FXS typically do not qualify for services via a SLD diagnosis, this change is very important for females. First, RTI allows children to receive interventions to support their learning when there is a suspicion of academic difficulties. Second, children no longer need to demonstrate an IQ-achievement discrepancy gap to qualify for SLD services. RTI has implications for assessment and diagnosis issues and intervention and behavioral applications.

Occupational Therapy (OT): This therapy may be recommended to address fine motor, handwriting, and self-help difficulties. This may serve to reduce anxiety and frustration related to academic and vocational tasks. OT may be utilized to address adaptive functioning or selfhelp skills such as dressing, grooming, or feeding. It may also be used to help determine the need for compensatory tools (e.g., use of the computer and keyboarding skills) to optimize functioning. Occupational therapy also supports self-regulation, to include coping skills to support academic and social participation. Sensory Processing: Occupational therapy may include sensory integrative and sensory processing approaches that may help address or reduce behavioral symptoms of children that experience hypersensitivity to a number of environmental stimuli. Sensory integrative interventions are often used to reduce hyperarousal and manage the biological antecedents to behavior, and are most typically paired to self-regulation strategies. Many students with FXS have hypersensitivity to smells, tastes, textures and sounds. Anecdotal observations have indicated that sensory processing issues often make it difficult for children with FXSX to participate in large group activities, eat certain foods, and tolerate certain clothing. Sensory processing issues may also be addressed through environmental accommodations in the school environment (e.g., adjusting the lighting in classrooms, reducing noise level, taking breaks, using fidgets).

Sexuality and Personal Safety: Sexual/Human Growth and Development instruction includes discussion of public and private behavior, nonverbal behaviors (e.g., staring, touching, personal space), issues around sexual maturation and safety (e.g., consent, sexually transmitted infections), and social behaviors (e.g., initiating and extending conversations, flirting). Such instruction increases the rate of successful integration in college, work and social settings. Classes on these topics are often offered by local ARC organizations, local universities and law enforcement organizations.

Social Skills Training: This training supports topics around social, communication, and nonverbal skills. Instruction may include modeling behaviors, repeated practice (e.g., turn-taking with an adult), or structured peer group activities (e.g., lunch buddies). Young adults and adults may benefit from discussions and role playing related to dealing with situations involving substances (e.g., drugs, alcohol) and relationships (e.g., platonic, sexual). In addition to improving social skills for improved social participation, it is critical to support social skills that include self-advocacy and limit setting to ensure reduced social vulnerability. Social skills require interdisciplinary supports.

Speech/Language Therapy: This therapy may aid in the development of functional communication skills and improve a child's pragmatic use of language, as well as articulation. Continued speech/language therapy in middle and high school is important to improve ongoing communication skills that facilitate the building of peer relationships and functional communication
for employment.

Transition Program: This stage of the educational process begins at age 18 after high school programming has been completed. These programs include more of a college and career readiness focus – skills related to vocational training, daily living experiences, and independent travel are emphasized. The focus is no longer academic content, but real life context and experiences.

Transportation: IDEA (2004) requires that schools provide transportation from door to school, with specialized equipment as needed, for children in special education.

Description of Assessments (alphabetized)

Adaptive Behavior Assessment (administered by licensed or certified service providers): A determination of specific aspects of functioning that includes, but is not limited to: communication, activities of daily living (e.g., community use, home living, health and safety, leisure, self-care), self-direction, social, work, and motor skills. Information is gathered from parents, caregivers, teachers, and the individual, as appropriate.

Educational Assessment (administered by special education or general education teachers; related service providers): An informal assessment that may include an observation of the child in classrooms, job sites, community settings, work study programs, and the greater school community. Interviews with parents, teachers, employers, job coaches, and private providers might also be included in the informal assessment. A review of the child's academic history
(e.g., work samples, school records, and school evaluations) can be part of this process. A formal administration of individual standardized tests of academic abilities and functioning may be provided by the school psychologist (see below) or trained special educator. 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) (administered by related service providers): A problem-solving evaluation, typically conducted by personnel trained in behavioral practices (e.g., behavioral specialist, school psychologist), designed to determine the underlying cause (function) of a specific behavior to determine the best approach for reducing or eliminating the undesired behavior(s).

Occupational Therapy (OT) Assessment (administered by licensed occupational therapists): An assessment to help determine the need for skill development or compensatory tools and strategies (e.g., use of the computer and keyboarding skills) to assist with daily living 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 (PT) Evaluation (administered by licensed physical therapists): This assessment provided by a physical therapist typically includes developmental tasks necessary to navigate the environment using gross motor skills and assessing overall physical stamina. The PT is also essential for ensuring the proper body mechanics and body alignment are appropriate given the loose connective tissue and low muscle tone issues that are prevalent in FXS. The PT evaluation can help plan an adaptive PE program.

Psychoeducational Evaluation (administered by certified/licensed school psychologists, licensed psychologists): An evaluation process utilized to ascertain the underlying cognitive and academic processes that might influence the child's educational performance. The evaluation must include more than cognitive testing (which may not be needed). For example, the school psychologist/psychologist may conduct FBAs, administer achievement tests, analyze adaptive behavior scales, interpret behavioral assessments such as checklist for ADHD, Autism Spectrum Disorders, and Mood Disorders (e.g., anxiety, depression), and initiate interviews with the parent, teacher, and student. They may review school, clinical, medical, and other private records. The evaluation must consider diversity factors. For example, 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. Social-emotional checklists are completed by teachers and parents and/or caregivers who have knowledge of the child's skills in various environments. Formal educational testing, which is a part of the psychoeducational evaluation, is typically recommended every three years; however, the educational team may decide to waive further psychoeducational testing if they feel such assessments are not required.

Speech/language Assessment (administered by licensed speech & language pathologists): An assessment typically focused on all domains of language (e.g., phonology, syntax, semantics, pragmatics, and receptive and expressive language), as well as oral motor skills and hearing. Some areas may need further assessment and might involve more in-depth testing. For example, speech intelligibility may include an assessment of individual sounds, phonological processes, and measures of prosody (e.g., intonation, stress pattern, loudness variations, pausing, and rhythm).

Vocational Assessment (administered by special education teachers; related service providers): 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. Vocational assessments should include in vivo exposure to a variety of work environments, job coaching, and natural supports. When there is a social component, it usually increases engagement and motivation.

Helpful Guidelines and Strategies

Families play a valuable role in the IEP process and are necessary partners with the school personnel to meet the needs of the student. Parents should feel comfortable providing specific information about their child to the rest of the IEP team, because they know their child best. The family voice is valued and needed during this process and working collaboratively with the school professionals is the best way to achieve positive outcomes for the child.

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

IEP Checklist

☐ The IEP team has provided a written copy of the Procedural Safeguards (Parental Rights) and have spent sufficient time making sure the parents understand their rights and the rights of their child.

☐ All special service providers are present at the IEP meeting for the entirety of the meeting (including the general education teacher) unless they are formally excused by the parent.

☐ The evaluation report or "present levels of development" report has been provided to the parents/caregivers prior to the meeting so that parents can read and digest the report in their own environment and in their own time.

☐ Work with the IEP case manager to develop an agenda for the IEP meeting and start with the strengths of the child and then address the areas of need.

☐ Eligibility may need to be determined for an initial evaluation or a triennial review. This should be a conversation with the whole IEP team, including the parents about the appropriate disability category for the student and the specified criteria for that disability category. 13 disability categories are outlined in IDEA and then implemented within each state.

☐ Least Restrictive Environment (LRE) is a concept, not a location, for how the child with a disability is educated alongside his/her same-age peers without disabilities. This discussion should always begin with the child in the general education classroom and must ensure "to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities are educated with children who are non-disabled" (34 C.F.R. 300.113).

☐ Academic and non-academic goals are SMART
　　☐ Specific - linked to functional performance and/or grade-level curriculum
　　☐ Measurable - progress monitoring methods and frequency are determined and reported
　　☐ Active (uses action words)

□ Realistic/relevant - number of goals is limited (maximum of 5 is recommended)

□ Time-limitedThe IEP team has provided a written copy of the Procedural

□ Goals and objectives incorporate the student's strengths and interests and family input.

□ All relevant services are included on service page of the IEP (e.g., speech therapy - 30 minutes per week). Services include those provided directly to the student and those provided indirectly, such as consultation with special service providers.

□ Specific accommodations and modifications are discussed and individualized based on the student's needs and next steps (see Educational Strategies below).

□ If an AAC device is provided, equipment is available for home use and necessary training is provided for parents and/or the student.

□ A draft whole IEP may be provided to the parents/caregivers 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.

□ The final IEP has been checked for errors and inconsistencies.

□ Special educators and special service providers responsible for implementing and monitoring each of the goals are specified and included, not by name, but by profession.

□ The BIP is included and outlines common and idiosyncratic behaviors related to FXS and the student.

□ There is an evacuation plan in place in case of emergencies.

□ An IHP written by the school nurse is included (and the staff are appropriately trained to implement it) If the child is on medication or has a significant medical need.

□ At the end of the meeting, parents are provided with a "Prior Written Notice" that summarizes the discussions, rationale, and decisions determined by the whole IEP team.

Educational Strategies for Students with FXS

• The basis for educational strategies should be a Universal Design for Learning (UDL) in which there are multiple ways of the presenting the information, multiple ways of the student demonstrating what they know, and multiple ways of engaging the student in learning. UDL is the "what," "why," and "how" of learning.

• Incorporate a simultaneous learning approach. Simultaneous information may also be described as being presented in a spatial arrangement or using a gestalt approach. Methodologies using spatial/visual memory are thought to be more effective rather than sequential/successive approaches.

• Include visual cues (e.g., pictures) to help children follow the daily routine in the classroom.

• Provide visual supports (e.g., individual schedule with words, photos or actual objects).

• Incorporate routine and structure in the daily classroom routine.

• Prepare the student of changes in advance, if possible through timers, visual, and verbal reminders (e.g., count down).

• Incorporate a multi-sensory approach to instruction. For example, teach math using visual and tactile strategies, using real object counters, size and shape manipulatives, and concrete examples.

• Reduce abstract instruction. Break down steps when teaching new skills and presenting ideas, preferably with visual supports.

• Focus on activities that are completion based ("closure technique"), such as matching, pattern-finding, and if-then activities. • Consider interactive visual activities (e.g., computer applications, role-plays) that allow for repeated and highly-engaging practice of skills.

• Use a scaffolded approach to instruction, such as backward chaining, in which the teacher reduces their input while the child increases their input.

• Provide a quiet space to regroup, if necessary.

• Utilize work tasks or special jobs to engage cooperation.

• Use high interest learning materials to maintain attention.

• Ensure that the child has time for observation before being required to participate.

Accommodation List

• Small group instruction.

• Preferential seating.

• Structure and predictability in daily academic routine, including scheduled breaks.

• Reduced level of environmental noise by providing headphones and decreasing unnecessary noise.

• Predictable transitions supported by visual cues (e.g., provide a transitional object to assist in the transition).

• Role playing for behavioral consequences. Practicing something is a good way to learn.

• Video modeling and social stories.

• Frequent breaks and movement.

• Picture and "low tech" schedules are very helpful especially during this time of change.

• Technology such as iPads, or iPhones to prompt adaptive behaviors. For example, schedules for breaks, toileting, and grooming can be created and implemented using technology.

• Sensory tools including weighted vests or noise cancelling headsets with a preference for age appropriate supports.

• Provide alternatives for handwritten communication. For example, in academic skill assessments consider: computer entry; multiple choice formats; rubber stamps to circle correct answers; oral responses; or written responses by proxy (i.e., peer support, caregiver).

• Adequate physical and personal space are necessary.

• Situational eye contact remains a goal. Reinforce but do not force eye contact; avoid "look at me" prompts.

• Appropriate attention for positive behavior. Adjust amount of attention based on the student's level of excitability and preferences (some student's do not like being "singled out").

EDUCATIONAL GUIDELINES FOR FRAGILE X SYNDROME
MIDDLE SCHOOL AND HIGH SCHOOL

High School Specific Considerations

All of the previous educational considerations listed above are also applicable for high school students. In light of the student's life task at this age, which is to become increasingly independent as they move toward young adulthood, educational considerations have significant importance as they relate to post-school opportunities (e.g., employment, higher education) and their social life (e.g., independent living, relationship changes). 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 educational change for high school students is supported by the IDEA mandated transition plan. As a reminder, the transition plan is aimed at assisting the student move forward into adulthood. It may include goals related to academic instruction, related services (e.g., speech therapy, occupational therapy, physical therapy), community experiences, the development of employment and other post-school adult living skills, and/or acquisition of daily living skills (IDEA, 2004). Prior to initiating the transition plan, special focus on graduation requirements and selection of diploma track (e.g., standard diploma, certification of completion) should be discussed. This will dictate the nature of the goals included in the transition plan.

Though IDEA specifies that transition planning begins at age 16, it is prudent that this process begin earlier (e.g., age 14). 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. For example, if the primary goal is employment after high school, vocational assessment/planning and community job placements will be an important aspect of the student's high school experience. If post-secondary education appears to be an option, it is important early on in the student's high school career to explore institutional resources and ensure that the student will have attained the appropriate pre-requisite skills and requirements for available programs.

Transition Strategies:

Additional Resource:
8 Tips on Transitioning Your Child to Adult Services

Transition Guidelines and Worksheet

AGE 14:

□ Discuss future educational, recreational, and vocational goals based on the child's interests and skills.

□ Hold IEP meeting with school to discuss transition issues and include transition-related goals in the most recent IEP; most children with FXS will remain in the school system through age 21.

□ Address social, sexuality, and safety issues in a developmentally appropriate manner; ask the school to focus on functional academics (e.g., budgeting, reading), vocational training, and skills of daily living.

□ Start considering estate planning and special needs trust to help the child continue government entitlements and programs in adulthood.

□ Begin formal transition planning with the development of an Individual Transition Plan (ITP); the ITP will formulate a long-term plan focused on graduation from school.

AGE 16:

□ Continue to develop daily living, vocational, and functional academic skills.

□ Identify and foster community-based employment and volunteer opportunities by job shadowing, integrated/supported employment, internships, and volunteering and doing odd jobs/household chores.

□ Develop a network of committed adults who will take responsibility for certain aspects of planning for the child's future (e.g., family friends, relatives, and school staff).

AGE 17:

□ Address guardianship issues, power of attorney, power of financial attorney, and medical directives prior to the child's 18th birthday, as they become an adult at the age of 18.

□ Check for eligibility with your region's Aging and Disability Resource Center (ADRC; www.adrc-tae.org).

AGE 18:

□ Apply for Social Security Income (SSI), Medical Assistance, and SSI-Exceptional Expense Supplement (SSI-E) are government programs for those considered disabled; applications are made through your Social Security Office www.ssa.gov.

□ Consider transitioning medical care to adult providers; ask the child's physician to contact the new physician.

□ Register to vote; males must register for selective service; obtain an identification card through the 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. The WIOA (2013) One-Stop Centers can also provide additional assistance to job seekers.

□ Assist with learning how to use public transportation.

□ Visit ThinkCollege.net for information about comprehensive transition programs (CTPs), federal aid, and the benefits afforded by HEOA (2008) if post-secondary education is a consideration.

On-line resources
www.ed.gov/
wrightslaw.com
BACB.com
ASHA.org
theARC.org
AOTA.ORG
APTA.ORG