



## Learning, School, and Education

Children and adults with Fragile X syndrome can benefit from education and schooling throughout their life. With appropriate support and accommodations, they can develop their cognitive and social skills and make progress in their academic pursuits. Special education programs and therapies, such as speech therapy and occupational therapy, can help them overcome their challenges and achieve their full potential.

### Your Child's Right to an Education

Your child has a right to early intervention and free appropriate public education. The [Individuals with Disabilities Education Act \(IDEA\)](#) is the federal law that makes early intervention and special education available for students with special needs. Both early intervention services and special education services fall under IDEA.

Children whose development is affected by Fragile X syndrome are eligible for special education services through IDEA. Part C of the law applies to individuals from birth to 3 years old, and Part B applies to individuals ages 3 to 21.

IDEA requires a multidisciplinary evaluation to determine if the child qualifies for special education services. This means that professionals from a variety of fields (such as medicine, psychology, occupational therapy) and the parents of the child collaborate to assess the child's strengths and needs and determine appropriate educational services.

Children in the 0-3 age range are eligible for early intervention services and an individualized family service plan (IFSP), which typically take place in the home from a variety of service providers.

Children ages 3-21 are eligible for special education and an individualized education program (IEP).

## Alphabet Soup



As you go through the evaluation process and begin to develop your IFSP or IEP, you will encounter what has been fondly termed “Special Education Alphabet Soup.” You will hear numerous acronyms such as IFSP, IEP, SLP, and OT; the list goes on.

[Making Sense of Alphabet Soup: A Special Education Glossary](#): Review this handy guide and take it to any and every meeting to help you define the acronyms throughout the conversation. This guide can also help you understand who makes up your child's team.

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## Ages 0-3: Early Intervention

When your child is between birth and 3 years old, you will be introduced to various

new terms and new services, and the importance of early intervention and treatment is emphasized. This can be daunting; the resources here help you to understand what comes next and how to help your child during early intervention best.

## **Part C: Infants and Toddlers with Disabilities**

The [Early Intervention Program for Infants and Toddlers with Disabilities](#) is the program known as Part C of IDEA. It is also known as Child Find.

Currently, every state has a Part C program, though every state is set up a little differently. The [Early Childhood Technical Assistance Center \(ECTAC\)](#) maintains a list with the contact information, websites, and more for [Part C coordinators by state](#). You can also talk to your child's doctor or call your local public school to find a program near you.

IDEA Part C is specifically designed to support any child under the age of three years who has been identified as having a disability or significant delays in development through early intervention.[1]

The human brain is most adaptable in the first three years. This is when the brain is growing at a rapid rate and, amazingly, it will double in size in the first year alone. These programs can have a profound impact on your child's ability to learn new skills now and throughout their lifetime. Early intervention programs are intended to not only support the child's development but provide support and assistance to their family.

### **Part C Summary**

- For eligible infants and toddlers (age 0–36 months) and their families.
- Families work with an [assigned service coordinator](#) during any multidisciplinary evaluations or assessments.
- Before early intervention services are put into place, a written plan detailing the early intervention services — the individualized family service plan, or IFSP — must be created and reviewed every six months (or more often if needed).
- You, as the parent or caregiver, will be a part of the team developing the IFSP.
- A transition plan must be developed as part of the IFSP (no later than 90 days prior to the child's third birthday) to ensure a smooth transition into Part B services.

How do I find out if my child is eligible for services?

Using the link below, contact your state or territory's early intervention program and tell them: "I have concerns about my child's development, and would like to have them evaluated to find out if they're eligible for early intervention services."

[Find Your State's Early Intervention Program](#)

More About IFSPs

An individualized family service plan (ISPF) is for children ages 3 and younger. An IFSP is written after the child is evaluated and found eligible for early intervention services. This plan is made by a team, including the family, Part C coordinator, and other service providers. Using their understanding of the child and the assessment results as well as the family's priorities, the plan is developed to guide everyone to achieve the desired outcomes. The IFSP is typically made up of several supports and services, and should outline those supports and services, where and how they will take place.[2]

More Early Intervention Resources

[Print the IDEA Part C statute](#)

[Wrightslaw](#) is our go-to site for anything related to special education law and advocacy

- [IDEA 2004](#)
- [Topics from A to Z](#)

[Learn the Signs. Act Early.](#) from the CDC

[Overview of Early Intervention](#) from the Center for Parent Information and Resources, includes Spanish version

[Early Intervention and Special Education Services](#) from USAGov

[Download the model IFSP form](#), published by the U.S. Department of Education

[State-Developed Outcomes Materials](#), from the Early Childhood Technical Assistance Center

[Newborn, Carrier, and Early Childhood Screening Recommendations for Fragile X](#)  
from *Pediatrics: Official Journal of the American Academy of Pediatrics*

[IDEA website](#)

Related Recommendations

*Learn more about early intervention and the IFSP process.*

### **Early Childhood Developmental and Educational Guidelines for Children with Fragile X Syndrome**

For all children within the early childhood age range of birth to 5 years and especially for young children with identified disabilities associated with a diagnosis like Fragile X syndrome (FXS), inclusive, nurturing, and developmentally appropriate environments and caregiving are essential to growth and development.

[Go to the treatment recommendation](#)

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## **Ages 3-21: Schooling & Education**

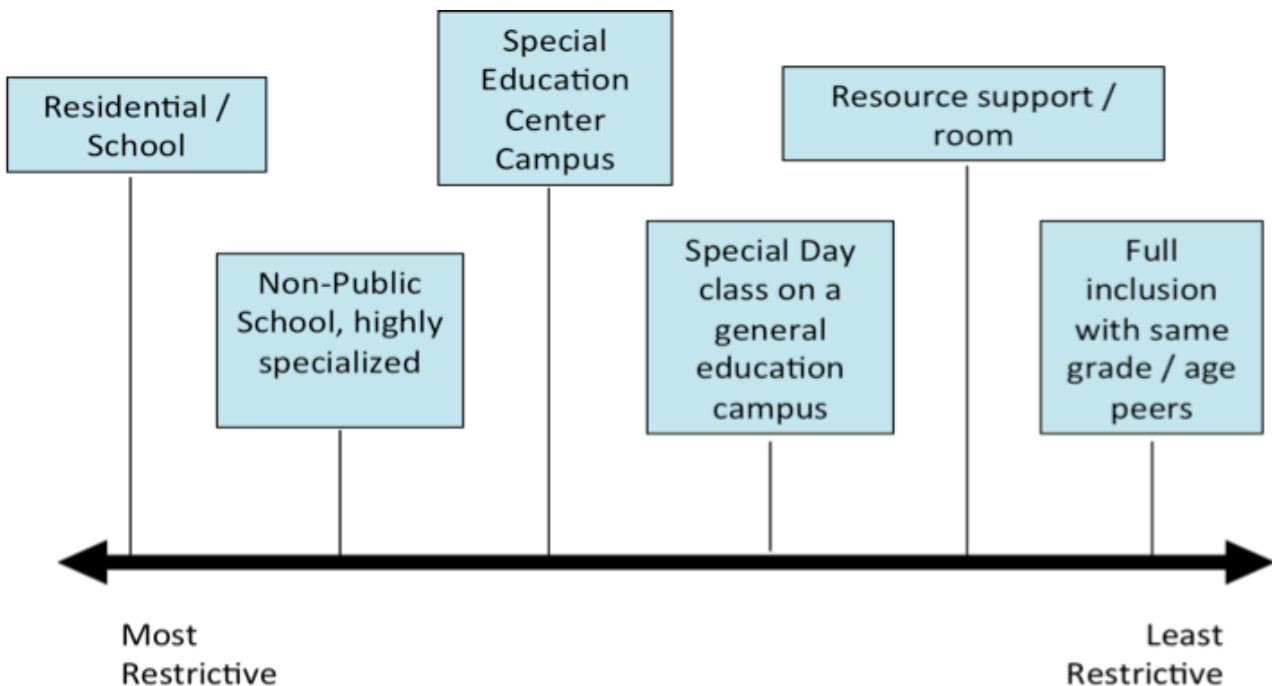
### **In This Section:**

- Free and Appropriate Public Education & Least Restrictive Environments
- Part B: Assistance for All Children with Disabilities
- Before, During, and After IEPs
- Webinar: No Tears for Fears in the School Age Years — IEPs

When your child is either transitioning to school or in school there are a wealth of resources and programs to help you and your child, but they vary by state, can be bureaucratic, and the information can be overwhelming. And then when your child enters high school, it is time to start thinking about what experiences you want for your child as well as what you're looking forward to when your child leaves school. It can be a little perplexing at times, but it can also be an exciting time. You will also want to start looking at the transition program that your school offers for the 18-21 years. The resources here help you to understand what comes next and how to best help your child through their schooling and education.

## Free and Appropriate Public Education & Least Restrictive Environments

[Free and appropriate public education \(FAPE\)](#) is central to IDEA and is a protected right of children eligible for special education. Just like all other children, students with special needs have the right to a free public education. Within this law, the school must also consider teaching a child with special needs in general education whenever possible or the least restrictive environment (LRE). There is a continuum of “restrictiveness” ranging from the most restrictive of residential placements, to special education centers where all children on the campus have special needs, to special education classrooms on general education campuses, to resource-style classes where students spend parts of a day in special education and parts of the day in general education plus full inclusion in general education settings. The graphic is a representation of “restrictiveness.”



A representation of most to least “restrictiveness.”

## Part B: Assistance for All Children with Disabilities

Part B of IDEA governs how special education and related services are provided to school-aged children (ages 3-22) with disabilities.

## Part B Summary

- For eligible children age 3–21 years, and early childhood special education (or ECSE) applies to ages 3–5 years.
- Families work with preschool programs within their local school district.
- Before early childhood special education services can be put into place, a written plan — this time called an individualized education plan, or IEP — must be created. IEPs are similar to IFSPs, but focus more on the child than the family as a whole.

## Find Your Part B Coordinator

### How to Access Your Part B Coordinator\*

1. Locate your [Part B coordinator](#) by state
2. Click on your state name.
3. Call, email, fax, or write to your state contact.
4. Set up an appointment to meet with your coordinator.

*\*Your local school district or doctor can also refer you, but their referral is not required.*

## More About IEPs

An IEP is a written document for each child with a disability. It is developed, reviewed, and revised according to the requirements of IDEA. IEPs are typically held once per year, but the timing may vary depending on the needs of your child.

### **TIP: You can call an IEP meeting any time.**

IEPs typically have a flow of how things will proceed. Each team is different, and it is important that parents and caregivers know and feel they are part of the team. Generally during the IEP meeting the team collaboratively brainstorms the following:

- Identify present levels of performance.
- Develop goals and objectives.
- Discuss and document necessary therapy supports.

## More Special Education Resources

## [Preparing for Your Child's Individual Education Program \(IEP\)](#)

From the [Center for Parent Information and Resources](#):

- [Part B Summary](#)
- [The Short-and-Sweet IEP Overview](#)

[Print the IDEA Part B statute](#)

[Wrightslaw](#) This is our go-to site for anything related to special education law and advocacy.

- [IDEA 2004](#)
- [Topics from A to Z](#)

[IDEA website](#)

## **Before, During, and After IEPs**

Preparing for an IEP can feel overwhelming. Take time to walk through before, during, and after the IEP meeting with us. Download our handy [IEP checklist](#) to help you prepare.

Related Recommendations

### **Middle and High School Educational Recommendations for Children with Fragile X Syndrome**

By using legal guidelines such as IDEA and implementing promising vocational, educational, and life skills training practices, students with FXS can be better prepared for a successful transition into adulthood.

### **[Go to the treatment recommendation](#)**

### **Elementary School Educational Recommendations for Children with Fragile X Syndrome**

Information on legal educational policies and recommendations, plus strategies and supports that have proven successful for academic and adaptive functioning.

## [Go to the treatment recommendation](#)

### **Before the IEP Meeting**

What to ask for in advance of the IEP meeting:

- An IEP agenda.
- A draft copy of the IEP, including present levels and proposed goals.
- Assessment reports.

**NOTE:** *Requests for present levels, goals, and assessments prior to the meeting may need to be in writing. This can often be done via email or by dropping off a note at the school. Be sure to find out how much advance notice is required in order to have your requests honored and to allow the school team to adequately prepare your drafts. This can vary by district (for example, 3 days, 1 week).*

Prepare your own thoughts about your child's present levels. Have strengths and areas of concern in mind. Consider bringing this information in a handy note format that is comfortable for you to share with the team.

Consider using our [About Me template](#) (similar to a positive student profile) and adapting it to fit your needs!

### **During the IEP Meeting**

**Go in as a collaborator not as an adversary.** You are the best source of information on your child, and their best advocate. Begin with your child as an individual who has strengths and gifts, and from there:

- Ask to have the IEP notes read aloud at the end of the meeting with all team members present. This helps to make sure the team is in agreement about what was discussed and will help to clarify any issues.
- Pointedly discuss collaboration during the IEP meeting.
- Put it *on* the IEP as part of the service delivery. For example:
  - Schedule team meetings monthly or quarterly.
  - Define expectations for team communication (e.g., logs in notebooks or email).
  - Many therapists and teachers have good intentions, but unless we have formal *collaboration spaces, time, and places*, it may not actually happen in the way we all want it to happen.

- You do not need to sign the IEP right away at the end of the meeting. You can take it home to review and sign and return it later.

Many families make this their regular practice, not just when things are contentious.[3]

### **Questions to Ask About Goals**

- What the goal will “look” like during the school day? (Provides context)
- How will skills be generalized?
- How and when will progress be updated?
- How will parent-school communication work?
- How will the goal will be measured?
- How will data be collected and shared?

### **Your IEP Goals**

- Interdisciplinary — not just a “speech goal” or “OT goal.”
- Functional, measurable, and data driven.
- Clear and easily understood by anyone.
- Highly individualized to your child.

### **After the IEP**

Collaborate and follow through!

Actively engage in the agreed upon team communication strategies — you are a key team member!

Don't hesitate to ask follow up questions. Remember, you can call an IEP meeting at any time, so if you want to meet again with the team, that is your prerogative.

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### **Prefer a Video?**

Check out this great presentation from Kerrie Lemons Chitwood, PhD, CCC-SLP, Laura Greiss Hess, PhD, OTR/L, and Anne Hoffmann, PhD, CCC-SLP, presented at our 18th International Fragile X Conference.

## No Tears for Fears in the School Age Years — IEPs

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## Home Schooling and Fragile X Syndrome

Whether you have decided to home school your child for a year or for an extended period, developing a curriculum can be a challenge. Start by setting goals for your child, research and experiment with ways your child learns, review various curriculums, and put together a program for your child. Here are websites to get you started:

[About Homeschool](#)

[Free Homeschooling Resources](#)

[Home School Advisor](#)

[Homeschool Central](#) (Additional resources for special needs)

[Homeschool.com](#)

[Home School Legal Defense Association](#)

[Homeschooling Today](#)

[Homeschool World](#)

[The Home School Mom](#)

[Time4Learning](#)

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## Agnes 21+: Education In Adulthood

Following high school, many individuals living with FXS 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 be discussed as a part of the transition planning process discussed above. Some post-secondary educational opportunities are available for individuals with FXS nationally, with federal support from the [Higher Education Opportunity Act of 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 not typically 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](#). Successful employment may require reduced hours, opportunities to take breaks, and social interaction with other workers. Some examples of successful employment placements for adults with FXS have included grocery stores, food preparation, janitorial work, landscaping, animal care, childcare, and working in skilled nursing facilities.

[Learn more about work and employment.](#)

Not all individuals with FXS with high support needs are able to engage in these two options and may need different types of support. For these individuals the transition should include a plan that includes meaningful activities and being a part of the community. These activities may not be academic or vocational, they 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.

## **Transition Strategies**

Parents and other caregivers must consider many factors as young people with Fragile X syndrome approach the transition from high school to adulthood. Although the concept of transition to adult services for concerns such as housing, employment, medical needs, and other general life services may seem straightforward, the process of planning and obtaining adequate care for adults with special needs can be quite complicated.

Transition is a multi-faceted and individualized process that involves securing support services that best support the individual's move to post-secondary education or employment, independent living, and community participation. These services require a significant amount of paperwork and are solidly embedded in various bureaucratic systems, which can often be overwhelming to families.

To provide crucial support to families and students prior to, during, and through the transition process, we have partnered with the University of Denver's [Morgridge](#)

[College of Education](#) to bring you these tips. This list is not exhaustive but is based on important information the Morgridge College students discovered when researching adult services for those with Fragile X syndrome. Thanks to Kirsten Brown, Christopher Hughes, Christianna Ratty, Megan Welsh, and Karen Riley for this great list!

Due to the localized nature of policies around service delivery for individuals with disabilities, the information gathered during the project focused on the state of Colorado, but the thrust of this article is on general guidelines the authors trust will be useful to families across the country.

## **1. Plan Early**

The Individuals with Disabilities Education Act (IDEA) requires that transition planning start by the time the student reaches age 16. Transition planning may start earlier than 16 if the IEP (individualized education program) team decides it's appropriate.

Parents and legal guardians have a legal right under IDEA to be a member of their child's IEP team. When beginning the transition process, the team should collaborate to formulate goals that will develop the skills necessary for living, socializing, and working in adulthood. This is the optimal time to begin this process and to initiate inquiries and applications.

Related Recommendation

*Additional IEP guidelines.*

### **General Educational Recommendations for Students with Fragile X Syndrome**

A basic framework for understanding different aspects of the educational system and an overview of the terminology. We also have resources for each level of the education system.

[Go to the treatment recommendation](#)

## **2. Remember That It's Never Too Late**

Though early planning is helpful, don't be discouraged if your child is already older than 14. It's never too late to secure appropriate services for your child.

## **3. Actively Pursue Adult Agency Services**

Unlike children's services, disability alone does not guarantee individuals will be served through adult services. Eligibility criteria may be narrower and services are not mandated, nor are they individualized. Wait lists exist in adult agencies — and are often lengthy. For these reasons, families should pursue adult agencies actively and persistently.

## **4. Appeal Initial Rejections**

Initial rejection for services is frequent, but can often be appealed. Learning to advocate for you or your loved one's needs is a valuable lesson in working through the complicated process of accessing adult services.

## **5. Practice Patience and Persistence**

It may seem like a monumental task to find all the information regarding how to access transition and adult services for your child. But time and again, persistence and patience pay off.

Many important pieces of information may only be accessed by searching a text or website thoroughly, or by clicking on multiple links. With this in mind, it can be very helpful to ask trusted family or friends to help in your search. One way to do this is to form a group and divide up responsibilities, with each of you taking a piece and reporting back to the group.

## **6. Look for Comprehensive Toolkits**

Individual states often differ in the allocation of various adult services, making universal guidelines for transitions very difficult to create. However, many U.S. states offer comprehensive toolkits as guidelines for families considering adult services for their child. These toolkits describe a range of support services and usually offer agency contact information. Typically, a Google search for “[Your State] Department of Education” will lead you to their special education information where a transition toolkit might be found. We found this toolkit, [Transitioning to](#)

[Adulthood](#), from the Colorado Department of Education.

## **7. The Internet is Your Friend, But Pick up the Phone When Needed**

Several government agencies, services, and policies listed here provide useful information. A Google search for the websites of the agency or policy within your state should supply further details (we also supply some helpful links below to help locate these by your state). Although websites can be helpful, don't hesitate to call agencies directly for answers to your questions and ongoing guidance. You'll want to tap as many sources as possible in learning how to successfully set up transition services for your child:

**Your state's Developmental Disabilities Services**, or DDS, provides information about residential services, supported living services, and family support loans. [Find your state's intellectual and developmental disabilities agency.](#)

**Your state's Division of Vocational Rehabilitation**, or DVR, is responsible for helping individuals with disabilities obtain employment. A child can apply for DVR assistance when the focus shifts from education to employment. [Find your state's vocational rehabilitation agency.](#)

**Other important agencies** — including Medicaid, [Social Security Disability Insurance \(SSDI\)](#), and [Supplemental Security Income \(SSI\)](#) — are gateways to accessing a range of services, ranging from health care to assistive technology and therapeutic support services.

Visit [Medicaid.gov's state waiver list](#) to see if your state offers Medicaid waivers that provide coverage for transition services, homemaker services, transportation, personal care, specialized medical equipment and supplies (including assistive technology), dental and vision services, supported living consultation, behavior support services, and employment services. Securing SSI is very important as it often serves as a gateway to other services.

Ask your case manager about gaining an ISSP (individualized service and support plan). The ISSP is critical for acquiring behavior supports, home-based services, and SLS (supportive living services) waivers.

## **8. Don't Forget General Life Planning**

Finally, it's important to also think about general life planning, such as legal issues

(including [trust funds, guardianships, or conservatorships](#), and [protections from abuse and neglect](#) under the Americans with Disabilities Act), the various options and how to apply for [housing](#), transportation (i.e., types, availability, locations served), and recreational activities.

Also see [Purposeful Vocational Training for Your Teen or Adult Child](#)

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## School & Education Tips from Families

Families are experts, too! Here are some helpful tips about school and education we gathered from families like yours.

### IEP Meetings

“My input as a parent is really important in the IEP. So, I always write a detailed page for the “Parent Concerns” section. All year long I add bullet points to a document I keep on my computer. When something comes to mind — a particular challenge, a great success, a dream for him — I type a bullet point. Then when it’s time to write my part of the IEP, I have my bullets to refer to. I try to do my piece well in advance of the meeting in hopes that his teacher might use some of my thoughts to form the goals.”

“I always tried to act as another part of the whole team. I did things, I volunteered to provide things, and expected others to do the same. I never went in just pounding my fist and requesting unrealistic things. It has to be cohesive!”

“It never hurts to ask for something, the worst they can say is no.”

“Trust your gut.”

“Educate the IEP team on FXS and what you as the parent know about FXS learning styles each year.”

### Food and IEPs are a Great Pairing!

“For every meeting (monthly or IEP) we bring food. Muffins, scones, cut up fruit-

yogurt and paper bowls since we usually meet in the early morning. We know their dietary needs as well and provide something healthy. It lets them know that we care about them and appreciate their help.”

“I believe it’s a nice gesture AND it’s harder to say no with a bagel in your mouth. Pete suggests bringing enough so there is extra. Then when it’s in the teachers’ lounge and someone says, “Where’s this from?” the answer shows you’re generous parents as opposed to the talk in the teachers’ lounge being about your list of demands.”

“We bring food in as well. I always come in a few minutes early and stop in the front office and make sure the secretary and principal have some as well as anyone else on the team who may not be at the meeting (like the paraprofessionals!). These small gestures have always helped not just with IEPs but also throughout the year because they all KNOW me so when we have had to be firm about a decision, they understand a little better. They are also more likely to go out of their way for us.”

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## For Educators

A great place for educators to start is by reviewing our tips below. This resource is one of our most popular. It has since been adapted into a [10 Things Everyone Should Know About Fragile X Syndrome](#) for anyone learning, working, living, and loving someone with Fragile X syndrome.

### Know Their Strengths

Common strengths associated with Fragile X syndrome include a good visual memory, a sense of humor, a desire to be helpful, an empathic nature, and a gift for mimicry.

To work with these strengths, provide opportunities to be of assistance to you and other students, for example, encouraging them to provide emotional support to their peers. Your primary teaching technique should use modeling, and it’s best to embed academics into useful and practical tasks, such as taking attendance (counting) or ordering from a menu (reading).

## Interacting with People with Fragile X Syndrome

Adapted from the PDF, [Back-to-School Resources For Families and Teachers](#).

- **Don't force eye contact.** We know that children and adults with Fragile X syndrome make wonderful eye contact when their level of arousal and anxiety are minimized, allowing them to feel comfort in the social situation. Eye contact will come naturally as the student becomes more comfortable with you.
- **Expect inconsistency.** Try to accept this to avoid frustration; your student will pick up on frustrated energy and that will exacerbate anxiety.
- **Students are “simultaneous” vs “sequential” learners.** Students with Fragile X syndrome are good sight word learners. This means that they are “gestalt” learners who need to see and understand the “whole” and not the parts that add to a whole.
- **Allow and encourage frequent breaks.** Accommodate attention difficulties by keeping tasks brief.
- **Verbal expression is cognitively taxing.** Avoid direct, open-ended questioning: prompt “The president of the United States is ...” vs. “Who is the president of the United States?”
- **Think “indirect.”** There are times when students with Fragile X syndrome enjoy attention, but most often they are averse to the limelight. Give compliments in the third person about the student to others within earshot.
- **Prepare for transitions.** Give 10- and 5-minute prompts. Allow to be at the head or back of the line. Use social stories about routine transitions. Provide a purposeful errand so the focus is on the outcome (e.g., delivering an envelope) rather than moving from one place to another.
- **They are visual learners.** Visuals function as an ongoing means of keeping hyperarousal in check. Do not fade this kind of support. The nature of the support may change — a visual picture schedule at age eight may turn into an iPhone calendar app at age 23.
- **Work with an occupational therapist knowledgeable about sensory integration.** A sensory diet consists of a carefully planned program of specific sensory-motor activities that is scheduled according to each child's individual needs. Integrate these activities throughout the day to sustain a calm, regulated nervous system: heavy work like rearranging desks, cleaning windows, or moving stacks of books; vestibular input, like going for a walk, doing wall push-ups, and swinging.

- **Notice environmental triggers.** Students with Fragile X syndrome often have sensory sensitivities to sound, light, textures, taste, and smell that provoke hyperarousal. Make adjustments to the environment as much as possible.
- **Integrate knowledge of hyperarousal into any intervention strategy.** This is critical, especially for those treatments that come from a tradition of autism intervention.

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### NFXF MasterClass: Fragile X 101 for Educators Part 1 & 2

This is a course for educators, by professionals. This two-part course discusses an overview of FXS, learning style, the relationship between FXS and autism, and strategies to support individuals throughout their lifespan.

[Learn More](#)

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