

FRAGILE X INFO SERIES:

ADULT LIVING – VOLUNTEERING, DAY PROGRAMS & EMPLOYMENT

Overview

The Individuals with Disabilities Education Act (IDEA) is legislation ensuring disabled students are provided with what's called Free Appropriate Public Education, which is tailored to their individual needs through age 21 (there are some variations in each state).

As the person with FXS leaves high school and attends transition services typically included for ages 18–21 (or the age in your state), the next move is into adult services. It is important to realize that the services under IDEA come to an end. There is currently no equivalent law that guarantees adult services after IDEA.

It is also important to note that after the young adult leaves high school, it is up to the parents/care providers to set up the person's day – 24/7, that is, 24 hours a day, seven days a week.

Here are suggested contacts to find more information in your state about adult services:

- Your local disability organization. Hopefully, people from this organization have been coming to the IEP meetings the last few years at the high school. Check in with them to see how long the wait lists are, and make sure the young adult is on the correct wait list for the services that they will need.
- Your local Arc is also a good source of local and state information. The Arc is a national organization, with state and local chapters, who advocate for people with disabilities. Google “Arc of (your state)” to find the chapter nearest the family. If there is not a chapter near them, contact the state office.
- Your local NFXF Community Support Network (CSN) group. Talk with parents who have adult children.
<https://fragilex.org/living-with-fragile-x/community-support/>
- Other parents in your community especially if they have adults already in the system, regardless of the disability.

Topic: Volunteering, Day Programs & Employment

When looking into life after high school for the young adult, it is important to include a regular daily activity, whether it is working at a paying job, volunteering with a local organization, participating in a day program, or attending post-secondary education. The young adult might even like or prefer a combination of those activities.

Whatever is decided, it is important to keep the individual engaged, interested and active in the community every day.

During High School

Questions to ask when the person is in high school or preferable before:

- What job/volunteer experiences do you offer while the person is in high school?
- Are they only job experiences or do you help the person actually find job for when they leave high school?
- How does the program work? For example, as a 9th grader, do they work/volunteer one day a week, as a 10th grader – two days a week, and so on.
- Who provides transportation?
- Does a para go with the person?
- Is it individual programming or it is group work – how big are the groups?
- How long does each job experience last?
- What if the person does not like the job – can it be changed earlier?
- What are some of the job experiences that are currently provided?



The Transition Program While Still in School

This is generally the program for those 18 through 21 years of age, though some states/school districts offer services for longer. These programs vary widely on what they offer, so be sure to look into how your school district functions.

When School Services End

Set a Daily Schedule

Regardless of what you are able to set up when school services end, set a daily schedule for the person right away, even if it is a general one. You can always add to it or revise it later. A visual schedule will help both of you – it sets expectations, and it gives the individual structure, routine, and knowledge of what will happen each day. As much as possible, be sure to include – leaving the house- every day, as many individuals can get used to staying at home and not want to leave. Include the individual in setting the schedule.

Volunteering

Volunteer jobs can offer the type of work that is not found anywhere else. Working at the Humane Society? In a senior center? These can be very rewarding jobs. Volunteers are an important part of many organizations, and in many cases, they are invaluable! Companies/people who hire volunteers count on them just as in a paying job. Volunteering is a commitment, and it is important for the individual to look at it that way.

Day Programs

To find the options in the area where the family lives, reach out to the local disability organization, the local Arc, or other parents who live in the area. It is important that parents visit any programs they are considering.

Employment

Seek employment for the person with FXS if he or she is able to work part or full time. It is not unusual for parents to find the job for their adult child, but there are also resources to help find the job - and a job coach, if needed.

Finding a Job: Build on Strengths and Interests

Finding a job for your adolescent or young adult is similar to the process that everyone goes through to find a job. Look at the jobs the person had in high school, their overall strengths, and find out what they are interested in doing. This will lead to the development of a list of “potential” jobs.

Basic Guidelines to Consider in Determining a Person’s Ideal Work Environment Include:

- His or her personal talents and preferences, learning style, and tolerance levels for various stimuli such as noise level and social interaction.
- The job location as it impacts transportation needs and the level of supervision required are also important.
- The individual’s learning styles.
- Whether sensory processing an issue and how it might relate to the job.
- Considering each of the potential jobs and evaluate them in light of the individual’s skill set—including those skills they might still develop.
- The support the individual might need—both initially and in the long term.

Developing Appropriate Work Attributes

Areas to include dress, hygiene, punctuality, manners speech attitude, behavior, personal/workspace, illness, and asking for help.

For more information about employment, volunteering and day programs and other aspects of adult living:

Get your Free eBook: Adults with Fragile X Syndrome: Making a Better Tomorrow

<https://fragilex.org/living-with-fragile-x/adults-with-fragile-x-syndrome-book/>

About the NFXF

The National Fragile X Foundation (NFXF) was founded in 1984 to support individuals with Fragile X syndrome (FXS), their families, and the professionals who work with them. Today, it is a comprehensive resource not only for FXS, but also for the conditions of Fragile X-associated tremor/ataxia syndrome (FXTAS), Fragile X-associated primary ovarian insufficiency (FXPOI), and other premutation carrier conditions and disorders. The NFXF is dedicated to serving the entire Fragile X community to live their best lives by providing the knowledge, resources, and tools, until, and even after more effective treatments and a cure are achieved. Learn more at <https://fragilex.org/welcome>

If you have questions please reach out to us at treatment@fragilex.org or call (800) 688-8765.

