

FRAGILE X INFO SERIES: ADULT LIVING - HOUSING

Overview

The Individuals with Disabilities Education Act (IDEA) is legislation that ensures students with a disability are provided with Free Appropriate Public Education that 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 the transition services that are typically included from 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:

- The 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 he or she will need.
- The 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.
- The 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: Housing.

Thinking of moving your young adult out of your home? The questions start coming—

When to start?

- When your young adult is in high school.
- But it is never too late.

Where to start?

- See the suggested contacts above.

What do I ask?

- How does the housing system work in our state and county?
- Is there/how much of a wait list is there? How do I get on the wait list?
- What are the housing options?
- What do I have to do to move this process forward?

Why is there not just a list of housing options in my area?

- The options vary widely from state to state, and often even from county to county.
- The needs of people with FXS vary widely.
- The “wants” of parents vary widely.
- Create a list of what is important to you and your young adult.
- The goal is for you to create a list of housing options that will meet you and your young adult's needs.



Having your young adult move out of your home is a big step and consideration and care should be taken every step of the way.

Aspects to be aware of and consider.

- Location. There may not be an option near you if that is important to you. The options near you may not be best for the person with FXS.
- Roommates. In receiving public funding, parents cannot usually pick the roommates, that is, there is little control over the people who live with the person with FXS. The roommates could also change, and this could happen without your knowledge.
- Staff turnover. There can be frequent staff turnover.
- Educational/life skill component. Do you want to have a situation that is more educationally based, not really a college, but somewhere in between?

Various Types of Housing Options

There are a range of living situations that may be considered, depending upon the person's level of independence and the source of funding, among other aspects – everything from a more segregated setting to an independent setting.

Section 8 Vouchers

This is a Housing and Urban Development (HUD) program that is the federal government's major program for assisting very low-income families, the elderly, and the disabled to afford decent, safe, and sanitary housing in the private market.

Living Settings Checklist

Review potential locations for your young adult carefully. A full checklist can be found at the link below.

Sample Interview Questions for a Care Provider

We have a list of questions you might consider asking a potential care provider for your young adult. Employment questionnaire laws and regulations differ from state to state. The NFXF does not warrant that all the sample questions can be asked in your state/locality. See the link below to view the complete list.

When Your Young Adult Moves Out

This is life changing for everyone in the family. Preparation is key! Strategies for dealing with this momentous event can be found in the eBook chapter on Housing.

For more information about Housing 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.

