

FRAGILE X INFO SERIES:

ADULT LIVING – TRANSITION TO ADULT SERVICES

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: Transition to Adult Services

Here are items to explore when the person with FXS moves into adult services:

Waitlists

Is the young adult on all appropriate waitlists? Check with your local disability organization to find the different types of waitlists in your area.

Supplemental Security Income (SSI)

Supplemental Security Income is a federal program designed to help people who have disabilities (among others) who have little or no income, receive cash to meet basic needs for food, clothing, and shelter.

Health Insurance

One of the key changes as the person with FXS turns 18 is that they often qualify for Medicaid. At age 18 the income of the person is considered, not the parents' income.

Transition to a Doctor Who Sees Adults

One of the biggest changes that happens when the young adult turns 21 is the need to change to a doctor who sees adults. This is true for both for primary care and, sometimes, for the FX doctor.

Medicaid Waivers

Medicaid waivers help provide services so people can stay in their homes and in their community. Contact the local disability organization to find the types of waivers that may apply to the person with FXS and find the wait list for the various waivers.

The ABLE Act

The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to create tax-advantaged savings programs for eligible people with disabilities.

Guardianship and other Alternatives

Because the rules around guardianship and alternatives for decision-making vary from state to state, and there are numerous websites on guardianship, we recommend the parents research the laws and options in the state where they reside.

DMV-issued Photo Identification (ID)

Contact the local Division of Motor Vehicles (DMV) to find what legal papers are needed in order to get this DMV-issued ID. As an adult, it is important to have this legal ID for everything from airplane travel to going to the doctor's office.

Register for Selective Service

Almost all men ages 18-25 who are U.S. citizens or are immigrants living in the U.S. are required to be registered with Selective Service. U.S. law calls for citizens to register within 30 days of turning 18.

Register to Vote

Many people with FXS enjoy learning about politics and exercising their right to vote. While the legal voting age in the U.S. is 18, voter registration rules are different in every state.

Financial Planning

When the person with FXS turn 21, it is a good time to revisit the financial plans you have in place or need to put in place.

Post-Secondary Education

This topic is covered more in its own chapter of the eBook.

For more information about transportation ideas and other aspects of adult living, including housing and employment:

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 issues. The organization offers help for today and hope for tomorrow with personalized support, community, education, awareness, advocacy, and research. Get your free Fragile X 101 e-book, connect with your local chapter, learn about the upcoming conference, and more at <https://fragilex.org/welcome>.

If you have specific questions about what to expect, treatments, clinics, well, just about anything, please email treatment@fragilex.org or call (800) 688-8765.

