

FRAGILE X INFO SERIES:

ADULT LIVING – TRANSPORTATION



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: Transportation

There are a variety of transportation options to consider for the individual with Fragile X syndrome (FXS), and hopefully, some will be a continuation of what was started during the high school years. Knowing that there is a range of abilities in people with FXS, the goal is to make the individual as independent as possible. A second goal is to get the individual out of the home or living setting every day, as agoraphobia (fear of leaving the home) can happen to people with FXS as they age.

Thoughts to consider

- While the goal is to teach skills and independence, care should be taken to minimize potential unsafe conditions, such as traveling alone at night or to places that may be unsafe or if there is the potential to have inclement weather. Some individuals with FXS will not be deterred from situations that other people with FXS would not even attempt.
- The person with FXS should always carry a government-issued ID with them. Call your local Department of Motor Vehicle (DMV) for more information in your area.
- Consider teaching a variety of transportation options, or at least, exposing the individual to various options.
- Depending on the person with FXS, the use of visuals and social stories may assist in facilitating the ability to use one of the transportation options.

Consider a Tracking App

Need to know the location of the person with FXS? There are a variety of ways to do that with today's technology. Many of us do it with our family members, as it is a good way to watch out for each other.

TRANSPORTATION OPTIONS

Driving

Driving the person with FXS. Whether the individual is living at home or outside the home, driving the individual will be used for many activities, particularly if the person has difficulties using other modes of transportation or when it is important that the parent or care provider attend the activity, such as a doctor appointment.

Many people with FXS will be able to get a driver's license. Check with your local Division of Motor Vehicles (DMV) for information regarding special accommodations that the person may need, such as extra time to take the test.

Paratransit

Paratransit is the term used to describe transportation services for people with disabilities that are designed to be more individualized; they may provide services along a set-route, or they may provide door-to-door services for the person with FXS. They may also provide bus training for individuals.

Walking

Depending on where the individual lives, walking might be a great option. It will be situation and location dependent, but walking is a great way for the individual to get to know the area where they live, to get a chance to meet people who live nearby, and to get exercise.

Riding a Bike

Depending on where the individual lives, riding a bicycle might be a great option for getting around town. It will be situation and location dependent, but like walking, riding a bicycle is a great way for the individual to get to know the area where he or she lives, to get a chance to meet people who live nearby, and to get exercise.

Riding a Bus

Another option for transportation around town, and even beyond, is taking the public bus. It does have its own set of challenges, but once a person begins to understand the nature of public busing, it opens the geographic area of travel even wider.



Uber or Lyft

This is another transportation mode to consider for the individual with FXS. The person with FXS may be able to set up a ride by him/herself or the parent may do it. Research both sites and talk to people who have used both services to see if either is right for the person with FXS.

Subway/Light Rail/Amtrak/Other Mass Transit Systems

These modes of travel will be similar to, but more complicated than, the public bus. Individuals may be fine traveling during the day, but evening and nighttime travel should be limited. It is also wise to travel in pairs or a small group.

Airplane

Airplane travel is usually used for cross-country or out-of-county travel. While airport travel is often with families or other groups, individual travel may be needed in some cases. Like other modes of travel, discuss what to expect, create a social story, show pictures on the Internet, if possible, do a practice run at the airport, and allow for plenty of time.

If the person with FXS needs or wants practice in going through the airport experience, call your airport to see if they have special days set aside for people with disabilities to go through an airport. Also check with your local Arc, as they have set up a special program at many of the airports across the country.

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 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.

