



Transitioning to Adulthood Checklist

Transitioning into adulthood can be an overwhelming task. We're here to help! Here is a helpful checklist of things to consider as your loved one with Fragile X syndrome ages.

Before AGE 12:

- ☐ **Understand the Fragile X diagnosis:** Get connected with a [Fragile X Clinical & Research Consortium Clinic](#) to receive specialized care from a group of medical professionals that understand Fragile X.
- ☐ **Connect with the [National Fragile X Foundation](#):** We're here to help! Browse our website for helpful tools, resources, and strategies to support your day-to-day life with Fragile X.
- ☐ **Connect with a local rare disease/advocacy group:** This group will know even more about your state's offerings and provide a local level of support. Check to see if a **NFXF Community Leader** is in your state. Another good place to start is your [local ARC](#) or [state's Department of Developmental Disabilities](#).
- ☐ **Start planning for the future:** Begin your estate planning process by speaking with an attorney and/or group familiar with special needs financial asset management, trusts, and/or ABLE Accounts.

AGE 12-14:

- ☐ **Discuss future educational, recreational, and vocational goals** based on the individual's interests and skills. Begin looking into vocational and/or recreational opportunities.
- ☐ **Discuss transition planning and include transition-related goals in this year's IEP meeting.**

Other things you may want to cover/consider including:

- The formal development of an **Individual Transition Plan (ITP)**. The ITP will formulate a long-term plan focused on graduation from school.

Federal Guidelines are to have a written transition plan that includes the student strengths and preferences by the age of 16, some states are age 14. The student is invited to the IEP/Transition Planning Meeting. The Transition plan compliments the IEP, not replaces it. Note, most individuals with FXS will remain in the school system through age 21.

- **A behavior plan**—Start by having a Functional Behavior Assessment by a board-certified behavior analyst for tracking purposes.
- **A vocational assessment**— [Functional vocational assessments](#) assess a student’s interests and skills when completing job tasks within the natural environment. These assessments can help identify what skills and supports might be needed in a future job, helping the individual and their team plan actionable strategies to help you reach your occupational goals and measure student interests and skills when completing job tasks within the natural environment. These assessments can help identify what skills and supports might be needed in a future job, helping the individual and their team plan actionable strategies to help them reach their occupational goals.
- ❑ **Address sexuality, social and safety issues in a developmentally appropriate manner:**
Consider asking school to include functional academics (e.g., budgeting, reading), vocational training, and skills of daily living and consider how you approach these topics at home.
- ❑ **Continue future planning** by considering estate planning and/or special needs financial asset management to help the individual continue government entitlements and programs in adulthood. Resources that might help include—
 - [10 Basic Financial Steps for Special Needs Caregivers | Webinar](#)
 - [Special Needs Planning Workbook - ABLE National Resource Center](#)
 - [Free Disability Financial Planning Resources | The Arc](#)
- ❑ **Understand the Medicaid waiver and learn about Long Term Care options** in your state. Resources that might help include—
 - [Find government and local disability programs](#) through USA.gov, or search on your own for your location (try searching for: “[your state] disability programs”)
 - Contact your **statewide independent living council (SILC)**
 - Review [Medicaid waiver](#) services
 - [Home & Community Based Services \(HCBS\) waiver program](#)
 - [Self-Directed Services](#)

AGE 16:

- ❑ **Apply for a [Non-driver ID Card](#):** This will provide the individual with a convenient form of government ID. This becomes much harder once the individual turns 18.
- ❑ If you have not done so already, **create an extensive Individual Transition Plan** in the IEP. Include things like pre-vocational skills, pre-community living skills, and interest survey.
- ❑ **Continue to develop daily living, vocational, and functional academic skills.**

- ❑ **Identify and foster community-based employment and volunteer opportunities** by job shadowing, integrated/supported employment, internships, and volunteering and doing odd jobs/household chores.
- ❑ **Consider legal protective arrangements:** Examples of arrangements include guardianship, conservatorship, durable/financial/medical power of attorney, naming a representative payee, and others. Resources that might help include—
 - [Guardianship for Special Needs Individuals and Caregivers](#)
 - [Alternatives to Guardianship | ACL Administration for Community Living](#)
 - [Alternatives to guardianship: Decision-making support for young adults with disabilities | Exceptional Lives](#)
- ❑ **Develop a network** of committed adults who will take responsibility for certain aspects of planning for the individual's future (e.g., family friends, relatives, and school staff).
 - **BONUS:** Begin to build a comprehensive care binder that can be used now and in the future. Include important details like medications/doctors, routines and activities, insurance, legal, and financial information, and be sure the individual with FXS shares what is important to them too. Template coming soon!

AGE 17:

- ❑ **If not already completed, apply for a [Non-driver ID Card](#):** This will provide the individual with a convenient form of government ID. This becomes much harder once the individual turns 18.
- ❑ **Address legal protection arrangements,** guardianship, conservatorship, durable power of attorney, power of attorney for healthcare, and medical directives **prior to the individual's 18th birthday**, as they become an adult at the age of 18.
 - You will possibly need legal aid for this process. *At a minimum, you will need guardian ad litem to represent your loved one.*
- ❑ **Begin to prepare and gather required information for [applying to SSI](#) once the individual is age 18:** This may include Social Security Income (SSI), Medical Assistance, and SSI-Exceptional Expense Supplement (SSI-E) are government programs for those considered disabled; applications are made through your Social Security Office [ssa.gov](https://www.ssa.gov).
 - *This is what will qualify the individual with FXS for Medicaid when they turn 18. Make sure the applicant does not have more than \$2,000 in assets (excluding primary residence). This benefit may be available to some individuals before the age of 18 if his or her family is low income, or they live in an out-of-home residential setting.*

- You can also apply for Adult Services with the supporting Federal Agency (DDS, Rehab, DMH).
- If the individual is a **male**, [register for the Selective Service](#) (the Draft): This is required by the government, though it does not mean that the individual would actually be drafted, and failure to register can affect eligibility for services.
- **Write a Letter of Intent:** It is important that you write a letter of intent, which explains your loved one's abilities, support needs, services, current and future benefits. As well as your wishes for their future and who will support them either legally and/or as natural supports.
 - Utilize [the Arc's free Letter of Intent template](#) or [Mass Mutual's free Letter of Intent template](#) to get you started.
 - Check for eligibility with your region's Aging and Disability Resource Center (ADRC).

AGE 18:

- Consider transitioning medical care to adult providers: Ask the individual's physician to contact the new physician. Note some but not all [Fragile X Clinical and Research Consortium clinics](#) can see individuals into adulthood. Transition medicine clinic(s) may be available in your area as well.
- **Register the individual to [vote](#).**
- Carefully **track any income, SSI, and related expenses**. While there may not be reporting requirements in place, you could be requested to provide records related to income and expenses.
- **Consider applying for Section 8 Housing:** Learn more about [HUD Housing Choice Vouchers](#) and why they may be helpful.
- **Consider applying for local and regional housing lists.** Ask if there are any portable vouchers for the disabled population. There may be a 10-year waiting period, but it can be worth the wait.

AGE 19:

- **A referral to the Division of Vocational Rehabilitation (DVR) should be made at least 18 months before graduation:** This should be a part of the Individual Transition plan. DVR will help in vocational training, job training and support; to help prepare for vocational services

after graduation maximize amount of paid employment in the community. The [Counsel of State Administrations of Vocational Rehabilitation](#) can help you locate local resources.

- ☐ Explore and assist with learning how to use public transportation options.
- ☐ Visit [ThinkCollege.net](#) for information about comprehensive transition programs (CTPs), federal aid, and the benefits afforded by HEOA (2008) if post-secondary education is a consideration.

AGE 21:

- ☐ The day after the 21st birthday should look exactly like the day before. Placements and funding should be in place.
- ☐ **Apply for the Medicaid waiver program in your state:** Application age varies by state.

As the individual approaches AGE 26 —

Determine whether the individual can continue to remain on your primary insurance plan if they are currently on it. This varies based on the state, the agency, and the policy. Research the following:

- ☐ Can the individual remain on my primary insurance after age 26 since they have a disability?
- ☐ If so, what documentation/forms are needed to continue the coverage?

As the parent(s) approach AGE 62 —

- ☐ Make a decision regarding the best age for the parent to begin receiving social security benefits. Consider the pros and cons for the parent/caregiver and the individual with FXS. It is very important for the parent to review his/her social security statement. Information can be found on the [Social Security website](#).