



ADULTS WITH FRAGILE X SYNDROME: MAKING A BETTER TOMORROW

From the transition to adult services
to thriving in the adult world

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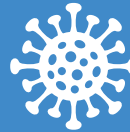
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CHAPTER 1

TRANSITION TO ADULT SERVICES

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).



Due to the ongoing response to COVID-19, some of the recommendations and guidelines contained in this book may not be currently applicable.

As the person with FXS leaves high school, and the transition services that are typically included from ages 18 – 21 (or the age in your state), and moves into adult services, it is important to realize that IDEA comes to an end. There is currently no equivalent law that guarantees services at age 21 (or the age in your state).

It is 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, seven days a week.

What do you need to do? Where do you start? Here are different aspects to think about as you make the transition to adult services.

In general, it is best to search for information on adult services in the state where the adult resides. Services can vary widely from state to state and even vary within a state, so it is up to the parents or providers to figure out what is available and to set up the daily schedule of the person with FXS. That should be an important consideration if the person and/or the family decides to move, particularly if it is to another state.

Here are suggested contacts:

- 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 NFXF Community Support Network (CSN) group. Talk with parents who have adult children. <https://fragilex.org/living-with-fragile-x/community-support/>
- 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.

Note: The use of “person”, “young adult” and “adult” refers to people who have Fragile X syndrome (FXS). The use of “parents” also includes anyone who cares for the person with FXS.

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. You may have signed up to be on the waitlists several years ago, but it is always a good idea to double check that your young adult is on the right ones.

For example, there may be a wait list for housing in your area. There could be a wait list to get the next available slot for housing and there could be a list for emergency placement or there could be others. This is a good time to start (or continue) the documentation and paper trail for adult services.

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.

Applying for SSI can take several months and involves providing various documentation, which may include a medical exam. The process can be initiated by a family member, support person, or by the individual directly at any time. For more information on SSI, visit <https://www.ssa.gov/ssi/> or call or visit the local Social Security Administration office.

The local CSN group and the local Arc may also be able to provide further guidance for obtaining SSI in your area.

Resources:

Understanding SSI

https://search.ssa.gov/search?utf8=%E2%9C%93&affiliate=ssa&sort_by=&query=ssi+training+for+parents

Help for Parents of Children with Disabilities

<https://www.eifamilies.com/app/view-resources/100008>

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.

Who is eligible? In all states, Medicaid provides health coverage for some low-income people, families and children, pregnant women, the elderly, and people with disabilities. In some states the program covers all low-income adults below a certain income level.

Research the information in your state. Contact your local disability organization and your local Arc for more information.

Resources:

Medicaid and CHIP Payment and Access Commission
<https://www.macpac.gov/subtopic/people-with-disabilities/>

Medicaid & CHIP coverage
<https://www.healthcare.gov/medicaid-chip/getting-medicaid-chip/>

How to Apply for Medicaid and CHIP
<https://www.usa.gov/medicaid>

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. In most, if not all, they are different people, and the families need the primary care provider (PCP) to also be knowledgeable about FXS, or at least, willing to learn about FXS.

Primary Care Doctor

Similar to learning about how the adult systems work, the parent will need to tap into their network to find a PCP who will see the adult with FXS.

Here are places and people to contact for referrals for a doctor who sees adults and who has experience with people with disabilities.

- Local disability organization
- Local Arc
- The current pediatrician
- Friends

Things to consider when choosing a doctor:

If the person with FXS has Medicare or Medicaid, he or she will have to go to a doctor who takes that insurance. That limits your options right off, as some doctors who do take those insurances, may not be taking new patients. The parent will need to call around.

What are your expectations for this doctor? Be available for things such as the flu, earaches, immunizations? Or do you need them to assist you with FXS concerns? And to what level?

How much does the doctor know about FXS? What should he/she know? Is he or she willing to learn about FXS, especially in how it relates to the person with FXS?

You will most likely have to spend time educating the doctor and keeping him/her up to date on the latest research.

Will you expect this doctor to do medication management?

Do you have a relationship with a FX doctor that the PCP can communicate with?

Will this doctor communicate with your pediatrician for guidance and advice?

Location? There may be a doctor down the street or he or she could be a 30-minute drive. He or she might be worth a 30-minute drive.

Are they open to have the parent visit initially? Is the office open to having the person with FXS visit the office and walk around?

Can the person meet the doctor? Does the doctor talk to the parent or to the person with FXS? Does the doctor use terms the person can understand? Does the doctor seem interested in the person? Does the doctor seem hurried or impatient?

In Covid-19 time – does the doctor do telehealth visits? Will he/she be willing and able to continue them once covid-19 has passed?

Can you often get an appointment the day you call or how far out do they schedule?

Do you see the doctor for most appointments, or do they have a physician's assistant, or a nurse practitioner take most of the appointments?

Note that depending on the type of guardianship for the person with FXS, the parent/provider may/may not be able to converse with the doctor. The parent/provider will have to provide documentation of the type of guardianship they have for the person.

Fragile X doctor who see adults

The NFXF has worked to have all the doctors in the FXCRC have referrals for doctors who see adults with FXS, if they are not able to. We understand this has been a challenge for many families and will continue to work on this in the years ahead. We also understand that the referral doctors do not always have the experience of the FX doctors. In that case, it is important – like the information given above – that the doctor be willing to learn about FX and the pediatrician be available for questions. Please know the NFXF has ongoing work on this.

Resources:

Moving from Pediatrics to Adult Services with Dr. Marcia Braden

<https://fragilex.org/webinar/moving-from-pediatrics-to-adult-services-with-dr-marcia-braden/>

Practical Steps to Help Transition Pediatric Patients to Adult Care

https://pediatrics.aappublications.org/content/144/6/e20190373?utm_source=high-wire&utm_medium=email&utm_campaign=Pediatrics_etoc

How to Prepare for a Telehealth Visit

<https://fragilex.org/blog/how-to-prepare-for-a-telehealth-visit/>

Using Telehealth to Expand Access to Essential Health Services during the COVID-19 Pandemic

https://www.cdc.gov/coronavirus/2019-ncov/hcp/telehealth.html?deliveryName=USC-DC_2067-DM30432

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 services and the wait lists vary widely from state to state, but it is important that the parents get their child on the wait list for services as early as they can. And if they decide to move to a different state once the child is an adult, they will want to ask how this will affect services and the place on the wait list.

Resources:

Medicaid Waiver

<http://medicaidwaiver.org/>

*When the young adult with FXS does begin to receive services from the state, he or she will develop an **Individual Plan (IP)**, which could go by various names in the state, such as Individual Service Plan or Individual Program Plan, etc. While not as detailed as an Individual Education Program (IEP) under IDEA, these IPs will detail the needs of the adult with FXS and services he or she will receive.*

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. The ABLE Act recognizes that there are extra costs of living with a disability and allows eligible individuals and their families to establish ABLE savings accounts that will largely not affect their eligibility for SSI, Medicaid and other public benefits.

Resources:

The ABLE National Resource Center

<https://www.ablenrc.org/>

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.

Google: “guardianship in (your state)” or “guardianship alternatives in (your state)”.

Some states require that the parents use an attorney in the process, but some don't. The local Arc is a good source of information on this topic and often offer classes where parents can learn more about this process in their state. It is important to review what guardianship means in their state and to look at all the options that may be available to the parents and their adult with FXS.

Also, be sure to review the impact that guardianship can have on voting, driving and marrying in your state. Again, it varies from state to state.

Resources:

National Guardianship Association

<https://www.guardianship.org/what-is-guardianship/>

DMV-issued Photo Identification (ID)

It is important to have a legal photo ID for the adult with FXS. 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.

If an applicant cannot appear in person at a DMV office, he or she may be able to obtain an ID card by mail.

For more information, google: “(your state) Photo Identification Card Options”

Register for Selective Service

Almost all men age 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. People with disabilities are required to register unless the person is completely home bound or in an institution full time.

Information on how to register: <https://www.sss.gov/Registration/How-to-Register>

If the adult son is over 18 when he gets his DMV-issued photo ID, he should automatically get registered at that time. Be sure to ask about that.

Resources:
Selective Service
<https://www.usa.gov/selective-service>

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. For more information: <https://www.usa.gov/voter-registration-age-requirements>

Guardianship can have an impact on the right to vote in some states. Be sure to review that if and when applying for guardianship.

If the person with FXS is over 18 years of age when the DMV issues the photo ID, he or she may be offered the option to register to vote at that time.

Resources:
How to Register to Vote
<https://www.usa.gov/register-to-vote>

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. Every family has unique needs, so the parents should consider their own situation carefully and seek advice based on their particular circumstances. As so many other aspects of adult living, seek information in the state where the person with FXS is living. This would be especially important if the person moves to another state.

Resources:
10 Steps Caregivers Can Take to Prepare for the Financial Future
<http://www.disabilityresource.org/28-10-steps-for-caregivers-to-prepare-for-the-financial-future>

Financial Planning Toolkit
<https://www.autismspeaks.org/tool-kit/financial-planning-tool-kit>

Special Needs Personal Planning Guide
<https://www.achieva.info/files/Family%20Trust%20Documents/Personal%20Planning%20Guide.pdf>

Post-Secondary Education

This topic is covered more in a future chapter, but it is mentioned here as some parents will be considering this for the person with FXS as they leave the high school environment.

As you can see, many aspects change when the person with FXS becomes an adult, starting at age 18. There are new “systems” to navigate and new acronyms to learn. The parents or providers must take a more active role in setting up the day, and it takes time and energy to find the right number and mix of activities. Depending on the waitlist for various services, the person with FXS may be living at home for a few years. The parents should take the time to draft a plan of what they would like to see happen, in what order and what kind of tentative time frame. This will keep the parents from feeling like they have to do everything at once.

Resources:

Autism Speaks – Transition Tool Kit

<https://www.autismspeaks.org/tool-kit/transition-tool-kit>

Parent Comments:

For SSI - We chose to make an in-person appointment because the online application was lengthy, and I was concerned I might do it incorrectly and result in an appeal. We called and made an in-person appointment. Glad we did.

Thank goodness for the Arc. They had classes that helped explain a lot of the adult system.

I was so overwhelmed at first, as I felt like there was so much I had to learn. I wrote down my priorities and started from there.

My son was going to pediatrician who said he would see my son until he retired. I called one day to make an appointment and they said, “You have Medicare and so you have to go to a doctor who takes Medicare.” The journey began.

The wait list in our state for out-of-home services is 10 years. It took a while to get my child’s day set up, but I am glad I took the time to set up a day she enjoys.

We decided full guardianship was best for our son. He cannot make medical or financial decisions. I had people tell me we were the worst parents for doing that and others tell me they made the same decision as us.

I was scared to take my child to the DMV to get a photo identification, not knowing how they would treat my child. I was pleasantly surprised, as they were very nice. Call ahead to make sure you bring all the right papers.

I was not sure my child would ever want to or show an interest in voting, but she did. She likes talking about the candidates. Must be the NFXF Advocacy Day!

We are actually going to look into some of the colleges. Yikes, not sure I am ready for that.

Some of the best advice I have ever received is: In case something happens to you, have a document that states what your son or daughter will need in the next year. Don’t worry so much about what they will need in ten years. Focus on the next year. What would they need tomorrow, next week, next month, through the year. Write it down now and revise it yearly.

CHAPTER 2

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. Focus on continuing to teach skills throughout the life of the person with FXS.

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. Show information on the computer or print out pictures and create a story of the transportation. Follow the lead of the person with FXS.

Note: Parent, care provider, and helper are all used interchangeably in this document.

Consider a Tracking App

Need to know the location of the person with FXS? Want to make sure he or she gets to her job? 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.

The individual with FXS and the caregiver(s) have a cell phone.

Want to know when the individual leaves the house, the route they take and when they arrive at their destination? There are a number of apps that can be downloaded to achieve this. Do your research and talk to other families. Some are free and others have a fee. It can provide independence and peace of mind at the same time.

Examples as of the writing of this document that parents are using:

- Life360 - <https://www.life360.com/>
- Zenly – Best Friends Only
<https://apps.apple.com/us/app/zenly-best-friends-only/id838848566>
- Find My Friends (Apple only) - <https://support.apple.com/en-us/HT201493>

The individual with FXS does not have a cell phone – but the parent does.

There are trackers that parents can attach to backpacks or other items and the parent can track the location of the backpack/item/person.

Examples as of the writing of this document that parents are using:

- PRIMETRACKING Personal GPS Tracker – Click [here](#).
- Jiobit Location Monitor -- <https://www.jiobit.com/product>

TRANSPORTATION OPTIONS

In general, for all the types of transportation options that follow, start with the big picture and then break it down into the different aspects. For example, the goal of the person with FXS is to go from home to work. What mode of transportation will be used? Then break it down into the different steps needed to accomplish the goal.

- Driving
- Paratransit
- Walking
- Riding a Bike
- Riding a Bus
- Uber or Lyft
- Subway/Light Rail/Amtrak/Other Mass Transit Systems
- Airplane

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.

The level of planning needed for driving to a location will be dependent on where you are going and whether or not it is a new place or some place that you have been to numerous times. Driving to a new place will take more planning and discussion and, depending on where it is and the reason for going, a social story, or views on the Internet of the location may be needed.

For extended driving trips, see Appendix 1 for more ideas and information.

The person with FXS is able to get a driver's license

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.

Like any place that people go when driving, some level of planning should take place before the person walks out the door. For example, if the person is going to the store, what is the best way to get there? Think about the time of day and whether there could be a lot of traffic, or if there is another event going in town that might make taking a different route a good idea.

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.

There may be a minimal fee involved or use of a sliding scale. The advantage is that it promotes independence for the person with FXS. The potential downsides are that the person with FXS may not know what type of vehicle is coming, there might be other people on the bus/van who the person does not know, and there could be multiple stops along the way.

Planning for the first of one of these trips will take some time, depending on how anxious the person with FXS gets over a new activity like this. After a few of these trips have occurred, the person will hopefully get more comfortable with some of the unpredictable aspects of this type of transportation.

How to find paratransit in your area. There are a few ways to determine if there is some sort of paratransit in your area, as it could go by a variety of names:

- 1) Contact your local CSN group
- 2) Google: "paratransit in (your city)"
- 3) Contact your local Arc
- 4) Contact your local disability organization

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 the people will get an opportunity to meet the individual), and to get exercise.

There are additional safety precautions that will have to be put into place, and I recommended to start with a "set" trip, such as walking back/forth to the store or to work.

Walking to Work Independently – A Systematic Way to Teach this Skill

Here is an example of how Olivia learned to walk to work.

Initial Steps

Olivia recently got a job that is within walking distance of her house. She is very interested in learning to walk to work, because she sees it as a way to stay fit.

Start with the overall trip. Olivia and her helper considered which route to take to work and reviewed the types of road signs that she may see on her way to work, as well as the safety rules that apply to walking. They walked around their neighborhood on several occasions and took pictures of the various road signs and marks, including a stop sign, a stoplight, the box showing the various walk signals, and intersections with stop signs both with and without crosswalk signs. What follows is the sequential “lesson plan” used for Olivia to master this critical skill.

Items to Teach

- 1) Walking in a neighborhood. In a neighborhood, Olivia should use the sidewalk if there is one. If there is not a sidewalk, the helper should determine whether it is safe to teach Olivia to walk “against” the traffic.
- 2) Crossing at stop sign intersections. Look for painted crosswalk marks when crossing a street that does not have a stop light, because drivers are supposed to stop for pedestrians. However, because drivers do not always stop and there are a lot of intersections that are not marked, follow these simple rules:
 - If a car is coming, wait for the driver to motion you to cross.
 - If there are no cars close, then look both ways, first left, then right, then left again, before crossing the street.
- 3) Crossing at stoplight intersections. Review the different signals Olivia will see in her area when she crosses the street at a stoplight. When it is okay to walk, she may see a figure that appears to be walking or the word, “WALK.” The caution signs may be a flashing person, a flashing hand, a flashing “DON’T WALK,” or the word, CAUTION.”

Be sure to teach Olivia that if she sees these signs when she is already in the intersection that she should hurry to cross the street.

The signs she may see when she is not to walk may be an “X” through it or a constant “DON’T WALK.” The lights for cars may or may not coincide with these lights, so she always needs to be aware of the cars, regardless of the lights.

- 4) Walking in business areas. When walking in a business area, Olivia should walk on the sidewalk, close to the buildings, and away from the street.

5) Consider whether there are other aspects that apply in your area, such as Do not cross in the middle of streets. Olivia should never cross in the middle of streets or enter the street from between parked cars, because it can be very difficult for moving cars to see her.

Safety Rules

Discuss the following safety rules as part of the Items to Teach. Review the following safety rules each day before Olivia leaves the house, until it is clear that she understands and remembers all the rules.

1) Always take her charged cell phone with her whenever she goes out. She should always let her care provider know when she is leaving the house. If she gets hurt, sick, or becomes afraid for any reason, she is to call her care provider or 911 if it is “serious.”

She should always call if her plans change in any way, so that no one worries about her. Her care provider should be “speed dialed” into Olivia’s cell so she can call easily if she gets scared, sick, or does not know what to do.

Information under “ICE” (in case of emergency) should also be stored on Olivia’s phone, in case she is unable to relate this information to another person.

Discuss which tracking app will be uploaded on both phones.

2) Do not talk to strangers. This rule applies now and will for the rest of her life.

3) Never take rides from people, even if she knows them, unless she calls her care provider first. Teach Olivia to say, “I need the exercise.”

4) Do not give out personal information to anyone (other than uniformed law enforcement, fire, or rescue personnel). That includes her name, phone number, and address.

5) With the increasing number of homeless people in many communities, discuss guidelines if/when encountering someone who appears homeless.

- Limit interactions – it is preferable not to engage the person at all.
- Do not give money or food to the person.
- Report them to the nearest business if they harass the person.

The Five Phases

Move from one phase to the next when you think Olivia has safely mastered the relevant skills.

1) Planning and Safety—Review the previous information to make sure Olivia has gained the initial knowledge and skills. Determine the best route to take to work.

2) Olivia and the Helper Walk Together—They discussed different aspects as they walked to work to make sure Olivia knows what to do at various times along the walk: at crosswalks, stop signs, stoplights, and any other types aspects encountered along the way.

3) Helper Fades Support—As Olivia becomes more confident the helper talks less. This may take a couple of walks or it could take several—it just depends on her understanding and performance. Because crossing streets can be so dangerous, you will have to use your judgment as to how quickly support is faded. You can allow Olivia to figure things out on her own as long as her safety is not an issue.

4) Helper Fades Further—Meet Olivia at about the halfway point to check in on how she is doing.

5) Independent Walk—Now, Olivia will walk to work independently but will call you when she leaves the house and after she arrives at work.

Other Considerations

1) Different people will spend varying amounts of time in each phase. Let them take the lead on when they are ready to move on.

2) Be on the lookout for special circumstances. For example, if Olivia is afraid of dogs, consider that factor as she learns to walk to work. Teach her to step into a driveway when a dog passes or move onto a lawn if she needs to. Teach her to tell the owner, “I do not like dogs.”

3) Remind Olivia that it is okay to watch emergency vehicles pass, but it is not okay to follow them.

4) Olivia was encouraged each step of the way with a reward. Coming up with a reward system or an incentive system may be a crucial component of successful walk training.

Learning how to walk the streets independently opens up a whole world of self-confidence and independence for a person. The possibilities are endless. For each new location, Olivia may require additional training, but it may not take as long as it did initially. However, the same process should be followed.

Riding a Bicycle

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 the people will get an opportunity to meet the individual), and to get exercise. The good (and what could be challenging) aspect about riding a bicycle is that an individual can go further and faster than what walking may allow.

There are additional safety precautions that will have to be put into place, and it is recommended to start with a “set” trip, such as riding the bicycle back/forth to the store or to work.

Learning to ride a bicycle? Look into the program iCanShine -- <https://icanshine.org/>

Riding a Bicycle to Work Independently

Whether riding the bicycle is a way to get to work, get some exercise, or just to have fun, it is a great tool for building self-confidence and independence. Spend time planning, like was done in walking to work, to figure out the best route. Look at the overall picture and what might be encountered along the way. Here are the strategies used with Olivia:

Safety Items

- 1) Review all of the guidelines and rules that apply to walking.
- 2) Make sure that Olivia has a helmet that fits appropriately. If there is any doubt, consult bike shop personnel.
- 3) Emphasize that Olivia should always ride her bicycle on the right side of the road—no exceptions.
- 4) Rules that apply to cars also apply to bicycle riders—meaning stopping at stop signs and stoplights, signaling turns, and all other traffic laws. You may have to teach the hand signaling to make a right turn.
- 5) If she ends up walking her bicycle for any reason, the “walking” instructions described earlier apply.
- 6) It is illegal to ride a bicycle on some sidewalks, so it is important to know what the sign looks like. It often is a picture of a person on a bike with a line through it.
- 7) It is important when passing people who are walking to slow down and ring your bell to let them know you are close. This prevents people from being surprised and suddenly jumping out in front of you. When 10-20 yards behind them, it is also good to say, “On your left” (or right) in a normal voice so they are not startled.
- 8) It will also be important to teach Olivia how to lock her bicycle up. There are many types of locks for bicycles. Visit a bicycle store together to find one that works best for Olivia.

The Five Phases

When you teach a person to ride their bicycle to work, follow the same phases as described for walking. Move from one phase to the next when you think the person has safely mastered the skills.

Review the safety material, ride with the person the first time, ride behind the next, be staged somewhere in-between, and then, when you think the person is ready, let him or her go independently.

Being able to maneuver independently and safely in the community on a bicycle is an invaluable skill, with potential carryover to many other areas of a person’s life. Encourage this healthy and liberating form of transportation whenever possible.

Riding a Public Bus Independently

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. The following is how Jack learned to take the city bus between two locations.

Initial Steps

Jack used to ride a school bus when he went to school. He had to walk to the end of his street at 7:30 each morning to meet the bus. The bus was usually on time except in inclement weather, and in those cases, the school district would often call to let his parents know. Jack got to know the bus driver, Tony, very well because Tony was always very friendly. Jack also got to know many of the other students on the bus, and they would often laugh and joke on their way to school. Jack had been apprehensive about riding the bus to school at first, but it soon became an activity he looked forward to each morning.

Now Jack is out of school, with a job that requires him to take a public bus each day from his home. There are many differences between the two buses, so as the person helping to direct Jack's new situation, you may want to begin by taking him to a central bus station so he will be able to see the public buses come and go. You may also want to go on a bus ride to some destination in your town. You could use those opportunities to discuss the differences between the school and public buses.

School Buses vs. Public Buses

Review the following with Jack:

- 1) The bus driver may or may not be the same every day—even if the bus is taken at the same time.
- 2) The bus driver may or may not be particularly friendly. Many drivers will be friendly, but you cannot count on that.
- 3) The bus could run late. No one will call you to tell you this. It is important to be prepared for this, especially in poor weather.
- 4) You have to pay to ride the bus each time you ride, though you may decide to use a bus pass. See the planning section below for ideas on this.
- 5) The bus waits for no one. Just know that, in most cases, if you miss a bus, another one will come along—you just may have to wait a while.
- 6) There are often rules on public buses:
 - No food.
 - No drinks.
 - No loud music.

You may want to impose additional rules depending on Jack’s personal profile. If you think talking on a cell phone (non-emergency) or listening to music with ear buds in would cause him not to pay attention, you may want to tell him that we are not going to use those things until he has more experience. Of course, you want to tell him that he can always use his cell phone in case of an emergency. Then again, listening to music may help Jack calm himself or offer just enough distraction for success; look at individual needs here.

7) The public bus will be much quieter. Many of the people on the bus will be going to work, so it is a much more serious environment.

8) There will be “strangers” on the bus. Most likely, everyone else on the bus will be a stranger to Jack, at least initially.

9) As with the bus driver, some of the passengers will be friendly, others will not. Saying “hi” or “good morning” could be the extent of communication with them. There is a chance that no one on the bus will say anything in response.

10) Jack will have to signal to the driver when he wants to get off, by using whatever method is on the bus—usually pulling a cord or pushing a button. Otherwise the driver will not stop. Though, if Jack misses his stop, there will be another one.

Planning

Once you have reviewed the differences between a school bus and a public bus, it is time to plan the trip. Come up with an overall plan of what is to happen – from home to work and everything in between.

1) Look at the bus routes and schedules along with Jack. Determine the best route for him to take to work. Write the bus number on an index card for him to keep in his pocket. Index cards are good because they are stiff and do not crumple easily. You might also consider laminating the cards.

2) Determine that Jack is always going to take his charged cell phone with him every time he gets on the bus. He should always let his care provider know when he is leaving the house. If he gets hurt, sick, or becomes afraid for any reason, he is to call his care provider or 911 (if it is “serious”).

He should always call if his plans change—in any way—so no one worries about him. Jack’s care provider should be “speed dialed” into Jack’s cell so he can call if he gets scared, sick, or does not know what to do. Information under “ICE” (“in case of emergency”) should also be stored on Jack’s phone, in case he is unable to relate this information to another person. Discuss which tracking app will be uploaded on both phones.

3) Figure out method of payment to be used each time. Is he going to use money or a bus pass? Whichever is chosen, he has to be ready when he gets on the bus. That means he either has to keep a lot of change at his house or keep track of where the bus pass is.

Strategies: Have him keep the pass in his billfold or put it on a neck lanyard and then put it in the same place every time at both work and home. If he is paying daily, he should keep a bag of quarters at home for the bus and use a wallet or coin purse to hold the exact amount for each day. It should be prepared the night before as part of the night-time ritual.

4) The bus could get crowded and people could bump into Jack. This could be very irritating to him, so he may want to practice his response if something like this happens. For example, he could put a thin briefcase, or a light jacket next to himself so there would at least be something between him and another rider. He may also want to practice deep breathing in case a situation like this cannot be avoided.

5) Jack may need to practice what to say to the bus driver. Set up chairs to serve as the bus, have someone role-play a bus driver, and have Jack practice what he would say in different situations. For example: "Is this bus number 2, going to Central Avenue?"

6) What if Jack misses his stop? Most likely, he will be able to get off at the next stop and either walk a little further or take a return bus back to his regular stop. You may want to practice this on one of the bus trips.

Safety

Review safety rules with Jack before he gets on the bus.

1) Do not give out personal information including last name, address, or phone number.

2) Have Jack practice saying the following when he gets on the bus: "I am going to work. I have to get off at the Taco Bell" (or wherever he needs to get off). Hopefully, if he says this when he gets on the bus, the driver will keep an eye out for him.

3) Teach Jack to talk to the bus driver if there is a problem.

4) To repeat the above - With the increasing number of homeless people in many communities, discuss guidelines if/when encountering someone who appears homeless.

- Limit interactions – it is preferable not to engage the person at all.
- Do not give money or food to the person.
- Report them to the nearest business if they harass the person.

The Five Phases

1) Planning and Safety—Review the previous information on the differences between a school bus and a public bus, and the planning and safety sections.

2) Riding the Bus—In this phase, the helper will stay at Jack's side and show him all the steps of riding the bus.

- Before Jack gets on the bus, make sure he has taken care of his hygiene, is nicely dressed, and has his cell phone.
- With Jack at the bus stop, point to the sign that shows the bus stops at this location.

- When you both see the bus you want, step up by the sign so the driver knows you want to get on. You may wave to the bus, too.
- Model saying “Good morning” to the bus driver and put your money in the box. Jack may add, “Hi, I am going to work. I have to get off by the Taco Bell.”
- Help Jack determine which seat is best for him. He should sit close to the driver, so Jack may have the choice of sitting sideways or facing front.
- You may talk to Jack about appropriate manners while he is on the bus.
- Show Jack the bell he is to ring when he wants the bus to stop. It is also good to find a landmark for Jack to watch out for that coincides with when he is to ring the bell.
- Have Jack join you in saying “Thanks” to the driver when getting off the bus.
- The only caution here is that some buses stop on a sidewalk that can be very busy with pedestrians or bikes or both. Always look both ways when getting off the bus!

3) Helper Fades Support—You may start at Jack’s side and not say anything, then adjust further by standing right behind him. As Jack becomes more confident, you can become just another person on the bus. This may take a couple of bus trips or it could take quite a few more—it just depends on how Jack does.

As you begin to fade your assistance, it is important to allow Jack to figure things out on his own and even make mistakes. You should not jump right in and fix things quickly, unless of course, Jack is in danger. Allowing this kind of problem solving will help Jack really handle the independence alone. A good example of this would be if Jack forgets to ring the bell at his stop. You may want to intervene only if a couple of stops have passed and it looks as if Jack does not intend to ring the bell.

4) Follow in a Car—In this phase, Jack will ride the bus independently and you will follow along in a car.

5) Be Available by Phone—Finally, Jack will travel independently but will call you when he is leaving and after he arrives at his destination.

Other Considerations

Different people will have to spend varying amounts of time in each phase. Let them take the lead on when they are ready to move on. Likewise, you may be able to skip some phases.

Jack was encouraged each step of the way with a reward. Coming up with a reward or incentive system may be a crucial component of successful bus training. Create a unique one for each person.

Being able to ride a bus independently is a great accomplishment. It opens a world of opportunity to Jack. He will probably want to take the bus home from work. He may want to try to take the bus to different places all over his community, such as the recreation center, a movie, or even a restaurant. The possibilities are endless. For each new location, Jack may require additional training using a similar process, though with experience, he may not take as long to achieve mastery.

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.

Note: Both Uber and Lyft have the option to share the route and estimated time of arrival (ETA) with friends or family.

It would be good to start with a set route, such as from home to work. If needed, the helper can ride with the person the first few times, then fade support, follow in another car, if needed, and then check in once the person is at work.

The person should always have a charged cell phone with him or her. He should always let his care provider know when he is leaving the house. If he gets hurt, sick, or becomes afraid for any reason, he is to call his care provider or 911 (if it is “serious”).

How does Uber work?

<https://help.uber.com/riders/section/a-guide-to-uber>

How Lyft Works: 6 Things to Know Before Your First Ride

<https://blog.lyft.com/posts/how-does-lyft-work>

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.

Use the guidelines above with regards to the safety and training.

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.

Wings for Autism/Wings for All
<https://thearc.org/our-initiatives/travel/>

From their website:

During a Wings Event: Participant Activities

- Check-in to receive boarding passes
- Pass through the TSA security checkpoint
- Wait in the boarding area
- Board an aircraft (that does not take off)

Airplane - Traveling Alone

If traveling alone, the parent can meet the person with FXS at the gate. Contact the airport and the airline and ask for information on how to obtain an Escort Pass.

See Appendix 2 for additional ideas on plane travel.

Conclusion

There are a variety of transportation options to consider for the individual with Fragile X syndrome (FXS) and knowing that there is a range of abilities in people with FXS, the goal is to make the individual as independent as possible. Continue to try different modes of transportation throughout the life of the person, and if it does not work the first time, then take a break and retry another time. Just because one method of transportation does not work now, does not mean it will not eventually work. You may just have to go slower and add more steps.

***Yes, you use transportation to get somewhere.
Learn to enjoy the journey to get there.***

- Jayne

APPENDIX 1

Extended Car Trip – Travel Ideas

- Involve the person with FXS in the planning as much as possible – let him or her help pick the route, if possible. Use the computer or a road atlas to talk about different routes.
- Read books about or find pictures of the place(s) you are going, including some of the activities you may be doing while you are there.
- Create a picture schedule of your trip. You will most likely need one for while you are at your destination, too.
- Discuss the types and amounts of clothes that will be needed. About a week before the trip, find a place to start laying out clothes that will not be needed until the trip.
- If the parent does most of the packing of the person’s bag, encourage participation by asking for assistance. Where would you like your socks?
- Encourage the person to pack his/her own bag of “fun stuff” (items he/she may want during the trip). You may throw some items in later that you think he/she may also want, such as a special pillow.
- Let your child see you get your own items ready.
- Find as many ways as possible to have the person with FXS help. Examples include carrying bags to the door, getting last minute items, asking him/her if he/she can think of anything that anyone forgot or might need.
- Have him/her help load the car.
- Say goodbye to the house.
- Have stops such as gas stations scheduled throughout the day, where the person can pick out one treat. Also consider rest areas where you can all run around and get some fresh air.
- Consider keeping a trip diary (tie some sheets of paper together with a piece of yarn), get a postcard from every stop, and keep mementoes from places you visit. Bring a glue stick for possible scrapbooking.
- Tablet devices, headphones.
- Listen to a book on tape.
- Have little wrapped surprises along the way.
- Try to eat healthy food, but have a few treats, too.
- Play games—car bingo, cards, and magnetic travel games.
- Sing songs—even if you do not have very good voices/harmony.
- Check in with your child periodically to see how he is doing—“catch him” being good!
- Consider driving part of the time at night when your child may sleep.

Incorporate unique tourist attractions

- World's Largest Ball of Twine -- <http://www.kansastravel.org/balloftwine.htm>
- Roadside America - Guide to Uniquely Odd Tourist Attractions
<https://www.roadsideamerica.com/>
- The Ultimate Road Trip Map of Things to Do In The USA
<https://handluggageonly.co.uk/2017/01/22/the-ultimate-road-trip-map-of-things-to-do-in-the-usa/>
- Google: "unique roadside attractions"

Other References:

- 5 Fun Things to Do in the Car on Road Trips
<https://babbletop.com/15-fun-things-to-do-in-the-car-on-road-trips/>
- Google: "fun things to do on road trips"

NOTE: Many of these ideas can also be used or modified for other forms of travel.

APPENDIX 2

Plane Travel Ideas

- Call the airline when making reservations and ask for bulkhead seating.
- Try to travel during low traffic times, which is usually early in the morning or late at night. Hopefully, your child will end up sleeping for at least part of the trip.
- Visit the airport ahead of time so you can take your time looking around and maybe get a snack.
- Social stories/visuals about the entire trip – traveling to the airport, going through the airport, boarding the plane, and what will happen after the plane ride.
- Allow plenty of time to travel to the airport, to park, check in, and get to the gate, so it does not turn into a frantic “we’re running late” experience.
- Go to the bathroom before boarding the plane.
- Talk to the gate attendant. Do pre-board seating if you think your child needs it, no matter how old he is.
- Hand out Fragile X cards to the people around you. <https://fragilex.org/education/raise-fragile-x-awareness-printable-cards/>
- Make sure you bring your own food for the plane and try to have a few options, especially for take-off and landing
- Depending on the length of flight, have little activities to do throughout the flight.
- Movies, music, ear buds. Make sure electronics are charged.
- If you need something during the flight, do not hesitate to ask.

Plane Travel Resources

TSA Cares

<https://www.tsa.gov/travel/passenger-support>

Guide: Air Travelers with Developmental Disabilities

https://www.transportation.gov/sites/dot.gov/files/docs/Developmental_Disabilities_Guide.pdf

TSA shares tips for travelers with disabilities, medical devices, medical conditions

<https://www.tsa.gov/news/releases/2016/11/15/tsa-shares-tips-travelers-disabilities-medical-devices-medical-conditions>

Disabilities and Medical Conditions

<https://www.tsa.gov/travel/special-procedures>

CHAPTER 3

HOUSING

The questions start coming—

When to start?

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

Where to start?

- Reach out to your local disability organization (usually in your county).
- Reach out to your local Arc (especially if you do not know the disability organization).
Google: Arc of (your state); and contact the office nearest you.
- Other parents are always a good option, especially if they are knowledgeable about the adult system in your state.

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.

Source of Funding

What will best determine your options will be your source of funding – public or private (you will pay). Let us look at each.

Public funding

Once the person with FXS qualifies for adult living services in your state/area, the parents will have to see what options are available to them.

Private funding

If you will be providing the funding for the living setting for your young adult, you will have numerous options, basically you will be able to set up whatever living situation that you think will work best for your young adult. You will be able to place the young adult in an existing facility or you can create your own. More on that below.

Combination

You pay part but you also use public funding to pay part. That may or may not be an option for the housing situation you decide upon.

Note, *if you decide to move to a different state or are thinking of moving* when your young adult turns 21 years old, you will want to check ahead to see how the adult services work in that state. You may end up at the bottom of the wait list and you may not be able to get on the wait list until you actually move to the state. Reach out to parents who live in the state if you are considering moving and call the local Arc.

Various Types of Housing Options

Following is a range of living situations that may be considered, depending upon the person's level of independence.

1. Completely independent
2. Shared living environment
3. Solo living environment with various levels of service/care provision
4. Shared living environment with various levels of service/care provision
5. Host Home – live with a family; numbers of people with disabilities who live there could vary
6. Intentional/life sharing communities, such as a “Camp Hill” environment where people with and without disabilities live and work together (they may/may not take public funding)
7. Residential educational facilities, such as Stewart Home (they may/may not take public funding).
8. Group home—numbers of people with disabilities can vary—with a responsible adult(s) always onsite
9. Residential/assisted living, usually with a larger number of residents

10. State institutions/developmental centers, only considered for individuals who are a danger to themselves or others

Note: This list is not intended to be all inclusive; parents will come up with their own ideas for what is best for the person with FXS. For example: the person with FXS:

- May live with a sibling or other family member.
- May live in their family home with or without other people with disabilities and caregivers, and the parents move out.
- May live in an Accessory Dwelling Unit (ADU) next to the parents' home, or a care provider may live in the ADU and they become care providers of the person while living in their home.

Ways to find additional housing options:

Google these terms with "for people with DD" and "state":

1. Housing options
2. Residential options
3. Residential school
4. Life Skills Programs
5. Group and Individual Homes
6. Residential Living, Special Needs Education
7. Independent Living Program
8. Community Living Options
9. Life Sharing Programs

Aspects to be aware of and consider, as you build your list of aspects that are important to you and your young adult:

- 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?
- There could be fewer options if the person with FXS has behavior issues.

Note: States or regions may have various terms for identical living situations. For example, one state might call a setting “prevocational training residence” and another state might refer to the same setting as “assisted living.” Therefore, consider the description rather than the term. There may be other variations of the situations listed above, but the most important consideration is to evaluate the individual’s needs when considering a living 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. Since housing assistance is provided on behalf of the family or individual, participants are able to find their own housing, including single-family homes, townhouses and apartments. Call your disability organization and your local Arc for more information.

https://www.hud.gov/topics/housing_choice_voucher_program_section_8

Independent Living: Summary of Guidelines for Establishing a Private Home

By Marcia Braden, PhD

1. Purchase a home in a “neighbor-friendly” community.
2. Fund it with private or trust monies.
3. Look in an area close to community access (bus lines, grocery stores and vocational opportunities).
4. Evaluate the home’s physical structure: number of bedrooms, common areas, baths, and places to recreate. Consider the neighborhood, demographics, and socio-economic status.
5. Solicit construction bids for renovation, taking into account accessibility for adults with challenges.
6. Begin the process of soliciting donations for remodeling materials. (Home Depot, Sears, Target, and local proprietors.)
7. Solicit monetary donations from local service groups, churches or associations.
8. Solicit volunteer help for smaller remodeling projects such as painting, landscaping, etc.
9. Acquire information about staffing services for the home setting, including both professional and volunteer staff.
10. Establish remodeling and staffing costs.
11. Establish a budget for utilities, food and incidental maintenance.
12. Total up the costs, divide by number of residents, and establish living costs for all residents.
13. Host open houses during the remodeling process and encourage neighbors to attend to meet the residents and their families.
14. Plan activities within the neighborhood and provide flyers about services the residents can provide (mail pick-up, plant watering, raking leaves, etc.).

Advantages of the Private Home Model

1. They are not subject to public facility requirements and restrictions.
2. Neighborhood and zoning may not be applicable, so more opportunities are available.
3. Staffing, liabilities, and agency involvement is limited.
4. You choose the location.

Disadvantages of the Private Home Model

5. The family and residents absorb all expenses.
6. Public resources are limited.
7. You must find staffing and do the background checks, etc.

Other Housing Ideas

Because of the wait list in some states for out-of-home placement (often very significant, up to 20 years) or the options they have available to them are not ideal, some families are joining together to find other options for their children. Buying a home as suggested above is just one possibility. Listed below are other ideas that parents across the country are considering. Note that in some cases, these options may start out as private pay, but as the person moves up/off on the wait list, some of the services may be publicly funded. If that is important to you, be sure to consider that if you create your own housing.

For families who are looking for a “community” that includes people both with and without disabilities living in the same area:

1. Build their own “Camp Hill” which is mostly self-contained and self-sustaining.
(See www.camphill.org for more information.)
2. Buy several condos in an existing complex that has a clubhouse and pay for support people.
3. Build a city version of Camp Hill.

The point is that many families are not waiting for their disability organizations to provide living services. They are moving forward on their own and doing what their young adults say they want.

Unfortunately, not all families can afford such a luxury. There are many parents who have their children still living with them as they age into their 60s and 70s. The children, who are now older adults, then move out only when their parents die. Imagine that transition for their “child!”

With this in mind, it is important to become active in your state, advocating for funds and services for adults with developmental disabilities. After the age of 21, your young adult no longer has the guarantee of services as he or she did under IDEA. Join with your local ARC to see what you can do!

Living Settings Checklist

| | Present and problematic | Present: Not problematic | N/A | Comments |
|---|-------------------------|--------------------------|-----|----------|
| PHYSICAL STRUCTURE | | | | |
| Security measures | | | | |
| Smoke/fire detectors; fire extinguisher | | | | |
| Carbon monoxide detectors | | | | |
| Locks on doors | | | | |
| Alarm system | | | | |
| Steps vs. ramps | | | | |
| One- vs. multi-level house | | | | |
| Number of bathrooms | | | | |
| Location/size of bedrooms | | | | |
| Deck/other places to safely "hang out" | | | | |
| Size/location of kitchen and family room | | | | |
| STAFFING | | | | |
| Ratio of staff to residents: weekday/weekday evenings | | | | |
| Ratio of staff to residents: weekends | | | | |
| Ratio of staff to residents: holidays | | | | |
| Staffing, caregiver turnover: percentage per month/year | | | | |
| Administrative turnover: percentage per month/year | | | | |
| Training of staff/ability for staff to model appropriate behaviors | | | | |
| Level of supervision | | | | |
| Staff member(s) with exceptionally punitive, intrusive, and/or rigid personality | | | | |

| | Present and problematic | Present: Not problematic | N/A | Comments |
|---|-------------------------|--------------------------|-----|----------|
| ENVIRONMENT | | | | |
| Small group of residents (less than 4) | | | | |
| Cleanliness of grounds | | | | |
| Cleanliness of living areas | | | | |
| Cleanliness of bedrooms and baths | | | | |
| Cleanliness of other residents | | | | |
| Cleanliness of staff | | | | |
| Routine maintained 7 days/week | | | | |
| Variable routine weekdays vs. weekends | | | | |
| Scheduled or encouraged "down-time" (the more down-time, the more negative behaviors often observed) | | | | |
| Routine displayed prominently with pictures and words | | | | |
| Dietary management provided | | | | |
| SOCIAL DEVELOPMENT/INTERVENTION | | | | |
| Routine activities/openness to new ideas for social activities | | | | |
| Scheduled vs. spontaneous activities | | | | |
| Required vs. optional activities | | | | |
| Opportunity for therapeutic activities (music, art, drama) | | | | |
| Opportunity for entertainment (pool, cards, etc.) | | | | |
| Opportunity for leisure skills/hobbies | | | | |
| Opportunity for shared/supervised work (yard, kitchen, etc.) | | | | |
| Opportunities for trips to community events | | | | |
| Shared bedrooms, bathrooms | | | | |

| | Present and problematic | Present: Not problematic | N/A | Comments |
|--|-------------------------|--------------------------|-----|----------|
| SENSORY ISSUES | | | | |
| AUDITORY | | | | |
| Barking dogs in neighborhood | | | | |
| Housing located close to a busy street, railroad, airport, etc. | | | | |
| Radio or TV playing throughout day | | | | |
| Whistling, singing, self-talking, frequently heard within house | | | | |
| Resident with particularly high-pitched or loud voice | | | | |
| Number of residents | | | | |
| Private bedrooms, bathrooms | | | | |
| Shared bedrooms, bathrooms | | | | |
| "Quiet area" available | | | | |
| OLFACTORY (SMELLS) | | | | |
| Scheduled vs. spontaneous activities | | | | |
| Required vs. optional activities | | | | |
| Spicy or unusual types of food often prepared or cooked in living setting | | | | |
| Scented body, bath, and hair products, perfumes, candles apparent in housing | | | | |
| MOVEMENT | | | | |
| Open-backed steps in stairways | | | | |
| Available rocking chair | | | | |
| Available outside swing | | | | |
| Numerous flights of stairs to climb | | | | |
| Stair railing available | | | | |
| Heights of decks, stairs, windows | | | | |
| Outdoor areas safe | | | | |
| Opportunity for daily exercise | | | | |

| | Present and problematic | Present: Not problematic | N/A | Comments |
|--|-------------------------|--------------------------|-----|----------|
| VISUAL PROCESSING | | | | |
| Fluorescent lighting | | | | |
| Natural lighting | | | | |
| Vertical shades in house | | | | |
| Window shades kept down during day | | | | |
| Messy environment | | | | |
| Orderly environment | | | | |
| Numerous distractions present (e.g. many residents constantly moving about, many staff changes during day, additional personnel, bright wall colors, etc.) | | | | |
| TOUCH PROCESSING | | | | |
| Enough chairs or sitting area for all residents in living setting | | | | |
| Separate sleeping quarters | | | | |
| Flooring allows for going barefoot | | | | |
| Independent food choices allowed | | | | |
| COMMENTS: | | | | |

Sample Interview Questions for a Care Provider

Employment questionnaire laws and regulations differ from state to state. The NFXF does not warrant that all of the following sample questions can be asked in your state/locality. If you have any questions about the employment interview process, please consult with your state's Department of Fair Employment or equivalent agency, or consult with an attorney familiar with employment law in your area. Note: We have used the term "child" below to include: daughter, son, young adult, adult or any other person with FXS for whom you may be interviewing a care provider.

Potential Provider's Name _____

Tell me a little about yourself.

Where did you grow up? Do you have fond memories of your childhood?
Tell me about one of them.

Where do your parents live? Can you tell me about your relationship with them?
And with siblings?

Tell me about your schooling. What or who influenced you there? What were your favorite subjects? Favorite teachers? Extra-curricular activities in which you participated?

What is your work experience? What kind of jobs did you have as a teenager?
What has been your favorite job so far? Were you ever fired? Do you have a supervisor I could call for a reference?

What is your experience with people who have developmental disabilities?

Have you ever spent time volunteering? What did you do? For how long?

What are your hobbies? Would you include our child in them or would you rather keep them as your own? What about if my child took up photography—would you feel like you had to do it, too, or would you be willing and comfortable to let him do that with other people that you helped him find?

What kind of music do you listen to? Are you willing to listen to the type of music our child likes? What if he asks you to turn your music off? What if he does not want to ever listen to music?

Do you have an exercise routine? Are you willing to make sure that our child gets daily exercise—even if you don't feel like it yourself? Would you be willing to join in the type of exercise that our child likes even if you do not care for it? Would you be willing to teach our child a new sport or activity that you know about? If our child participated in a unified sport (one that includes people both with and without disabilities) that you love, would you insist on being a part of it or would you be content to be a spectator?

Do you like to cook? Will helping our child with his dietary needs be a problem for you?

What kind of books do you like to read? Will you read to my child, even if they're books that you don't personally enjoy? Do you get a newspaper? Will you work on reading with my child? Do you have any experience with that?

What are your sleep patterns? Morning/evening person? Will you have a problem with sticking to a routine for our child?

Do you watch TV? Would you sit with our child and watch what he wants sometimes? And talk to him about it? What kind of movies do you watch? Do you have a favorite(s)? It is very important that you monitor the movies that our child sees for violence and inappropriate sexual content—how will you do that?

What do you like to do on the weekends? Are you active? Do you like to “veg?” How will you decide what to do with our child?

Do you consider yourself a people person? How much socialization do you typically do in a week? Will you have get-togethers with friends on the weekends? Would you help host get-togethers with our child's friends?

We respect your privacy rights, but how will my child be exposed to significant others in your life? If those relationships raise questions for my child, will you discuss it with him?

What types of places have you lived in before?

Are you neat or messy or something in between? Are you used to doing yard work?

How is your current health? Do you have any physical limitations that might impact your work with our child?

Do you own a car? Adequate insurance? What is your driving record?

Tell me about your sense of humor, or tell me about the last thing (or some thing) you laughed about today.

Tell me about your capacity for patience. Give an example.

What are your smoking and drinking habits? Obviously, any illegal drug use is out of the question, but do you take any prescribed medications that would impact your ability to concentrate or focus on tasks, or in caring for my child's needs? If so, what would be your action plan in caring for your own health while not compromising my child's care?

Do you have any pets? What kind(s)? Would you consider getting a pet? Would you consider getting rid of a pet if our child is allergic to it or doesn't like it?

How do you deal with disappointment? Give an example.

Tell me about your strengths.

Your weaknesses?

What qualities or habits of other people most bother you?

How do you handle daily stress? Stressful events?

Talk about your attitude toward life. Do you have a basic philosophy you try to go by?

What do you know about our child's disability? Are you willing to learn about it?

How would you go about it?

What is your experience in teaching life skills? Are you willing to discuss his needs and set a plan?

How do you feel about dealing with toileting issues (day and night)? How do you feel about private sexual behavior that our child may engage in, such as masturbation, and will you be able to respect our wishes regarding the matter? (*Note: Parents should be clear, ahead of time, what their actual wishes are and what their instructions to the caregiver would be.*)

Do you know anything about IEPs? IPs?

If our child was having a hard time doing something, e.g., cutting up some meat, how would you approach it?

I assume you are aware that you would become partners with my spouse and I in the care of our child. Do you have any feeling, anxieties, or questions about that?

Tell me about how you resolve differences with others. Can you give an example? Do you have a plan for when you will need a break? If you use other respite providers, will you allow me to meet them? What if I disapprove?

Where do you see yourself in 5 years? 10 years?

Will you ever consider having others besides our child live with you?

What is your current schedule?

Do you have any questions for me?

Last question: why should we hire you?

When Your Young Adult Moves Out

Every parent's dream?

Yes, but... You have given your young adult your best of "everything" for his whole life. You have given your utmost attention, you have figured out ways to teach him, you have created the best IEPs you possibly could, and you have planned for the future.

Now that the future is here, how do you let go? How can anyone else do what you have done for the last 20 years? They will not do it as well as you have, but your young adult must learn to depend on someone other than you.

Of course, that is easy to say, harder to see to completion. The emotions you have are the same for any parent with a young adult who moves out, whether to college or into an apartment. You want this for your young adult. That is why you have worked so hard all these years. Right?

So, what are some strategies for dealing with this momentous event?

1. Make sure you are comfortable with where your young adult will be living. For many parents, that means close enough so that either of you can visit the other without too much hardship, but with enough distance so that neither of you can visit too easily.
2. Interview your care provider carefully and thoroughly. There will always be issues that pop up that you will have to work through, so keep that in mind when choosing the person.
3. Put thought into the environment that will be best for your young adult – number of people, size of "home"; think about all the sensory issues.
4. Make sure your young adult has a daily schedule appropriate to him or her—a comfortable combination of activity, work, socialization, and down time.
5. Set up regular communication—such as daily phone calls—with your young adult, and weekly meetings with the care provider. Make sure you each have emergency numbers of the other in case either needs to get ahold of the other right away.
6. Make sure you get to see your young adult on a regular basis. Make this part of the weekly routine, knowing that you may need more visits in the beginning. Letting go is hard.
7. Make sure you have some of his "stuff" still at your house for when he comes to visit.
8. Read books about empty nesters and how others have dealt with it. Ask friends for book recommendations or search the websites of the major booksellers.
9. Know that it is an emotional time, maybe an incredibly emotional time—and that is okay.
10. Celebrate by doing something you have always wanted to do.

Every parent's dream? With the proper preparation and acceptance, "Yes."

General Resources

American Association of People with Disabilities (AAPD)

<https://www.aapd.com/advocacy/housing/>

American Association on Intellectual and Developmental Disabilities

<https://www.aaid.org/news-policy/policy/position-statements/housing>

Assisted Living Options for People with Disabilities

<https://www.assistedliving.org/assisted-living-options-for-people-with-disabilities/>

Autism Speaks – Housing and Residential Supports Tool Kit

<https://www.autismspeaks.org/tool-kit/housing-and-residential-supports-tool-kit>

<https://www.autismspeaks.org/housing-and-community-living>

Housing Options for Adults with Special Needs

<https://specialneedsanswers.com/housing-options-for-adults-with-special-needs-14975>

HUD Apartments

How to Find Yourself a Nice, Affordable HUD Apartment (for People with Disabilities)

<https://howtogeton.wordpress.com/how-to-find-yourself-a-nice-affordable-hud-apartment-for-people-with-disabilities/>

Special Needs Alliance

<https://www.specialneedsalliance.org/>

Special Needs Answers

<https://specialneedsanswers.com/housing-options-for-adults-with-special-needs-14975>

The Arc – Housing

<https://thearc.org/policy-advocacy/housing/>

USA – Government

Housing Help

<https://www.usa.gov/housing-help-audiences#item-37012>

Parent Stories

Our intention from the beginning has always been for our son with FXS to move out of our home when he was an adult. He has no siblings, and we were older parents when he was born. We felt that it was in his best interest to live with peers while we were still around to advocate for him.

When he was 25, we were approached by the agency, that was providing Supported Community Living services, about an opportunity for him to live in our community in a home they were purchasing. This was a dream come true! He could live in his hometown and get services from the same agency that we had been working with since he became an adult. I spoke with Jayne at NFXF about transitioning him to a new home. She suggested spending split time at our home and his new home and gradually increasing the time spent at his home. The agency agreed and we did this for the first 60 days. He now visits us but does not stay overnight on a regular basis. He has matured, but it has not been easy. It has been a long journey.

We have made some mistakes by not asking some of the questions below and are currently looking for a new home with different roommates and a different agency to provide services.

Things to ask your case manager and staffing agency:

- *When can you meet the others moving into/living in the home?*
- *How often can you/your loved one meet to decide if the roommates are a good fit?*
- *How long has the staff/managers that will be at the home worked for the agency?*
- *Do you have any guardians (whose adults are with the agency) that we could talk to?*
- *What is the proposed schedule for meals/chores/activities for those living in the home?*
- *How many staff will be in the home at one time?*
- *Who ensures that each roommate is transported to their job/day program at the correct time and on a regular basis?*
- *Can you provide an organizational chart with e-mails and phone numbers if there are concerns with management?*
- *What information do I need in the annual plan to ensure their goals/needs are being met?*
- *How detailed does the annual plan need to be?*
- *What information do you need from us on how to specifically encourage good choices and behavior from our loved one?*
- *Can we see daily notes concerning our loved one?*

Having that information would help immensely.

Our son is 24 years old, and besides having Fragile X, he has severe anxiety, explosive behavior and is nonverbal. Right now, he lives at home. In our state there are several adult Medicaid waivers. The waiver he is currently on does not provide funding for housing. In order to get on the waiver that does provide housing, a life changing event would need to happen, i.e. divorce, death of one of us. It has a HUGE waitlist. It literally takes an emergency to get on this housing waiver.

My husband and I have talked about housing and what it would look like for him. We think he would do well in a group or host home setting, and we hope there would be housing close by us.

Right now, he spends most of his day in his room, so a group home would hopefully help him to become part of the group. Because of his behavior he would need a place that would understand him and be educated in providing structure and positive reinforcement. He also needs help with bathing, toileting, preparing meals and laundry.

As of today, and for the foreseeable future we will keep our son in our home.

My husband and I were part of a group of families of students in a residential post-secondary program who got together to plan the next steps for living arrangements for our children. We had similar goals of creating a community in which our adult children could live independently with supports.

We looked for and found a small city that was walkable, had good public transportation, apartment housing and shopping. We found two agencies that would collaborate to administer the program, charging families an annual fee. In 2008, this became the POINT Community in White Plains, NY. About half of our individuals were eligible for funding from the NYS Office for People with Developmental Disabilities.

It took a couple of years for individuals to start receiving this funding, which includes a rent subsidy (families are responsible for finding housing). The POINT Community provides a weekly meeting in each individual's apartment with his/her POINT specialist, social activities, community habilitation, vocational internships and support and health and fitness activities.

CHAPTER 4

EMPLOYMENT, VOLUNTEERING, & DAY PROGRAMS

Introduction

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 (see Chapter 5). 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.

Be sure to also look into what services or funding will be available for the young adult. Some states have services available when IDEA ends (Part B of IDEA provides services through age 21) and some have a wait list for services. If your state is the latter, make sure your young adult is on all appropriate wait lists. Talk to your disability organization, your local Arc, and your local parent CSN group.

During High School

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

- 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 a 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?

Note: A person can volunteer at a job that others are getting paid to do – **while they are in school**, but once they leave school, they can no longer volunteer at a job where others get paid to do, even if it is okay with you.

Look into how the Transition Program works at the high school. The services can vary widely, from offering full programming to offering only a few hours of service a week.

This is also the time to look into the services that the person will have access to when they graduate. To find more information, reach out to:

- The local Arc.
- The local disability organization.
- The local parent group.

The Transition Program While Still in School

This is generally the program for those 18 through 21 years of age, though some 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.

Take advantage of whatever transition services the school district offers, such as trying out different jobs, expanding life skills, work on academic skills or functional skills.

When school services (IDEA) ends, parents/caregivers will need to set up the day for the person 24/7. In addition to looking into employment and volunteer options, check out the day programming options in the area where the individual lives.

The idea during these transition years is to set up the day of the individual with FXS – as much as you can - to what it will be like when they leave school services. Will the person work at a job, volunteer or go to a day program – or do a combination of those?

***NOTE: Work with the school district to create a resume for the individual with FXS while they are in the transition program, as many employers will ask for one. This is covered in more detail below.**

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 to used to staying at home and not want to leave. Include the individual in setting the schedule.

For example:

You might start with:

- Breakfast
- Lunch
- Downtime
- Chores
- Chores
- Dinner
- Outside Activity
- Outside Activity
- Downtime

Then you can fill in details of the chores or the activity, and hopefully, you will add in work or volunteering or a day program.

Employment:

Vocational Rehabilitation Services (Voc. Rehab)

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.

Every state has a federally funded Bureau of Rehabilitation Services that helps people who have physical or mental disabilities get or keep a job. To find out if the adult with FXS qualifies for services, contact the local Vocational Rehabilitation Services in your area for more information. The person with FXS will meet with a counselor to determine if he or she is eligible to receive services and, if they are, they will help find employment that works for the young adult.

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 and ask about:

- The hours of the program each day.
- The schedule of each day. Do they do different activities each day? They should try to visit at different times of the day, if possible, to see how the activities change throughout the day.
- Do they go into the community?
- How are the parents/providers notified of any changes to regular daily programming?
- How transportation to/from the program works.
- Use of visual schedules? Process for making transitions.
- Interest by the providers in learning about the unique aspects of the person with FXS.
- How many other people are in the program and the number of providers they have to assist the group, that is, the staff ratio.
- What has been the level of staff turnover? Is there a process for transitioning/educating new people to work with the individuals who attend the program?
- Do they offer opportunities to learn new skills? Basically, is it an environment where you think the adult will thrive? That will be important to keep in mind if you decide to go with the program.

The remainder of this chapter focuses on finding a job, which also includes a volunteer opportunity.

Even if you use your local Vocational Rehabilitation organization to help with finding a job, the parent will most likely be very involved to make sure the job is a good fit. Use the following information, as appropriate, to help ensure finding the best job(s) for the individual.

Finding a Job: Building 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. In this section, let us look at the process some parents went through to find 20-year-old Jack the “real job” he had begun to express a desire for as he entered adulthood. Using a series of interview questions, they looked at the jobs he had in high school, his overall strengths, and found out what else, if anything, he was interested in doing. This led to the development of a preliminary list of “potential” jobs. From there, it remained for them to further evaluate Jack’s needs, desires, and skill set, while beginning, with his active involvement, to explore possibilities with employers.

The first section below presents the interview questions and discussion process, followed by a summary. The second section is a blank form for readers to use in their own process. Feel free to copy this form and adapt it to the needs of the individual.

1. Tell us about some of the jobs you had in high school, and what you liked and disliked about each job.

Jack said he had done recycling at a three-story senior apartment building. The residents would put out the papers for recycling at 9 o'clock every Monday morning, Jack would go through with a cart and put the newspapers in it. When the cart was full, he had to take the elevator down to the basement to dump it into a big recycling bin. It took about an hour to do the whole building, and then Jack would go to the snack area and have a hot chocolate. Sometimes there were other people around.

Jack said the job was okay but that he did not have much opportunity to talk to people.

Jack also talked about a job he had folding boxes at a pizza place. He liked wearing the uniform, and while he could fold the small boxes, the large ones were very difficult for him. Since he only worked there once a week, he never got to know the other employees very well, and after a while, only the supervisor talked to him, and that was only to greet him and then to tell him what a good job he had done.

Jack's next job was washing buses at the city bus station. The actual job was a lot of fun, but there was not anyone to talk to and it was a real hassle to get to the location on a bus.

Another of Jack's jobs involved working at a college bookstore. He really liked this job, because he was able to do many different things—from putting on price tags to stocking items. There were always many people around and they were always very nice. In addition, he got to dress up, which he enjoys. The parents started a list of potential jobs.

Jack also helped serve lunch at a senior center. He said he liked this job because everyone was nice to him, but they only needed him two days a week, and only for a couple of hours during lunch. He said he wished he could work at this job more often. This was added to the list of potential jobs.

2. What do you like to do when you are not working? What are your interests?

Jack said he likes all sports—he had been the manager of the football team in high school and loved it. He also likes to play basketball and baseball and go bowling. He likes to watch sports on television and in person. He also likes going to the movies and cooking, but most of all, he likes being around people.

Jack asked if he could still be a manager for either the high school or local college football team. The parents did not know, but it was added to the list of potential jobs for him.

He had helped make pizzas at a restaurant one time for a fund-raiser and he had really liked that. That was also added to the list of potential jobs.

3. What are some of your strengths—what are you good at doing?

Jack is good at activities in which he knows what he is supposed to do, and which he can follow through on independently. He is good at activities that are based on a fairly consistent routine. Not only is he interested in people, but he is also good at working with them. Jack has pretty good communication skills and good work habits. He loves to get dressed up and wear uniforms.

4. Are there other jobs you are interested in pursuing?

Jack said he wanted to work at a grocery store, so it was added that to the list. He said he would like to help at a fire station. The parents thought it might only be on a volunteer basis, Jack was fine with that. It was added it to the list of potential jobs.

5. Do you want any more ideas for jobs?

When Jack said yes, we asked additional questions: “Do you like to work with animals—like at a humane society?” He answered that he was somewhat afraid of dogs. We did not put it on the list but decided to make a note of it so that later we could possibly address this fear. “Would you like to work in a library?” He shrugged his shoulders and asked what he would do. We did not really know but thought we could investigate it if he was interested. We added that to our potential job list.

6. How much do you want to work? Every day? Full-time? Part-time?

He seemed to think that just mornings would not be enough but was not sure about an entire day.

7. Would it be okay to have more than one type of job?

Jack said he was fine with that.

Potential Job List

Based on this discussion, we came up with this potential job list:

- Working at a college bookstore.
- Serving lunch at a senior center.
- Serving as a manager for a (college) football team.
- Cooking at a local pizzeria.
- Working at a grocery store.
- Volunteering at the fire station.
- Working at a library.

Then What?

Then the parents started evaluating and looking into each potential job listed. Based on conversations with Jack and other providers, they learned that he liked to have his job explained to him, to have it modeled for him, and then to do it side-by-side with a co-worker. Sometimes a visual schedule is helpful.

They also found out that while Jack generally has good communication skills, he does not always ask for help when he needs it, so they had to keep that in mind.

Environment also plays an important role in Jack's day, so it will be an important consideration in his job.

With that in mind, the parents called or emailed the appropriate person who made decisions about the job at each location.

The college bookstore was not going to be an option. They had decided to keep a position open just for students to try-out, but it was not intended to be an ongoing position for someone.

Serving lunch at a senior center was going to be an option, though they only needed someone to clean the tables and it would only be from 11am to 1pm each day. The nice thing about his job is that they would take Jack for whatever days he wanted to work. Job #1.

Being the manager of a college team was not going to work, but the local high school varsity football coach was more than happy to have Jack as a manager of the football team. It worked out great because Jack could go to the practices when he was able, he could eat with the players at the pre-game meal, he could ride the bus to the games with the team, and he could be on the field during the game. The team had several managers, so they were not totally dependent on Jack to do all the responsibilities. Job #2.

The local pizzeria did not need any help in the kitchen and at the time the parents checked, they did not need any help in the restaurant.

When the parents checked into working at the grocery store, they were told that the minimum shift was four hours. When the parents asked further, they discovered that Jack could work an hour a week and increase from there. The store managers said that Jack would have to do safety training but that the parents could help. Job #3.

The fire fighters did not use volunteers because they never knew when they were going to get calls. They did say that Jack could visit them on occasion. Kind of a job #4. (more like an activity).

Working at a library did not seem like a good fit. It was going to be a quiet place with not much interaction with others.

The parents developed a schedule that included serving lunch at a senior center, working at a grocery store, and being a manager for the local high school football team. They also included times to drop off treats at the fire station.

Over time, working at the grocery store became a favorite and the hours increased, and the days became Monday, Wednesday, and Friday. Jack worked at the senior center on Tuesdays, and Thursday became a day of sometimes working extra hours at the grocery store or at the senior center. There was an activity for Jack to do every day of the week. During football season, there was added activities for Jack to do, and while, in this case, the parents did much of the leg work, the parents thought it important that people in the community got to know Jack and for Jack to continue to be a part of community life.

Summary

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.

It is important to bear in mind that the perfect job may not be found right away, and that, actually, the individual may end up working at many jobs throughout his life. Focus on a job or jobs the individual will enjoy and thrive in—for now!

Interview Form and Checklist

1. Tell us about some of the jobs you had in high school, and what you liked and disliked about each job.

Job:

Likes:

Dislikes:

2. What kinds of things do you like to do when you are not working? What are your interests?

3. What are some of your strengths—what are you good at doing?

4. Are there other jobs you are interested in pursuing?

5. Do you want any more ideas for jobs?

A Resume

Some companies will request a resume as part of employment, but do not worry if you do not have any or only minimal job experience. Let the company see what a great person the individual is. See an example of a Resume at the end of this chapter.

Here is one format:

- Resume
- Name and Contact Information
- Objective
- Education
- Employment/employment Experiences
- Special Skills
- Activities & Interests
- Honors & Awards

Developing Appropriate Work Attributes

Work attributes differ from ones in the school and home, and it is important to realize that there is a certain “formal” air to work that is and should be different from home. This applies to volunteer jobs as well as paid ones. Cassie works at a clothing store for one of her jobs. Some of the differences between work and home are discussed below.

Dress

It is very important that Cassie be appropriately dressed at work every time, whether it is neat, clean clothes. At home, Cassie can wear a T-shirt, jeans, and sandals/tennis shoes, but when she is at work, she should wear clothes suitable for an employment setting.

Hygiene

The work setting does not accommodate poor hygiene. Cassie should arrive at work neat and clean. It is also important to help Cassie realize that when she needs a tissue, she needs to excuse herself and get one. Cassie needs to maintain her hygiene the entire time she is at work. If she eats or has a snack, she must remember to wash her face and hands afterwards.

Punctuality

It is important for Cassie to arrive at work on time, every day. She will most likely have to arrive a work a few minutes early, so she is ready to start at her designated time. She should be well rested and dressed when she walks in the door. If something causes Cassie to be late, she (or a care provider) should call work as soon as possible. Ask the work supervisor, but if an individual is going to be more than five minutes late, call. Do not let being late become a habit!

Manners

Cassie should pay close attention to her manners when she is at work. Cassie should make sure she always says “please” and “thank you.” She should clean up after herself right away when she has been in the snack room, put trash in the receptacle, and she should not chew gum or talk on her cell phone.

Speech

Using appropriate speech is another critical attribute for success in the workplace. When Cassie is at work, she should not use slang or swear words, and speak at an appropriate sound level.

Attitude

When Cassie is at work, she should have a good, positive attitude. When she is at work, she should follow the rules or instructions, do her best, work when she is “on the clock,” and take breaks when she is supposed to. She must understand that time spent at work is usually much more structured than at home.

Behavior

Cassie needs to meet work standards for her behavior. At work, if she gets frustrated, it is okay for her to take deep breaths. This might need to be practiced this at home, so Cassie does not forget when and/or how to do it.

Also, while it might be okay for Cassie to hug a friend outside of work, it is more appropriate for her to shake hands with others at work. Setting limits on the type of touching permitted in the workplace helps eliminate any ambiguity and potential awkwardness for both Cassie and her colleagues. This is another behavior that can be practiced at home.

Personal/Workspace

Cassie must learn to respect others’ personal and workspace. The fact is most people prefer a certain amount of space between themselves and others, though sometimes with good friends, that space is reduced. Standing about an arm’s length away from another person at work is a good general rule. It is also important to show Cassie where she can and should not go at work. For example, an employee does not ever go behind the employer’s desk. Do not assume that Cassie knows this.

Illness

Everyone gets sick on occasion, and Cassie must come to understand that if she gets sick, she should stay at home. She should call in as soon as she can or have someone call for her. If Cassie feels ill at work, she should tell the boss right away. This might be a skill that has to be taught. Co-workers do not like being exposed to sick people in the workplace.

Asking for Help

It is important that Cassie learn to ask for help when she needs it, so she does not persist in doing something wrong at work. At home, others may be in the habit of asking her if she needs help. At work, she needs to feel confident about who to go to and when it is appropriate to do so. This ensures the job is either done right the first time, or that mistakes are not unknowingly repeated.

Ultimately, Cassie must learn that there is a home life and a work life. Sometimes the difference is minimal—for example, it really is not appropriate to swear in either place. But usually, work and home are different spheres with different standards. These may include dress, speech, behavior, and many other factors she will have to take note of if she is to be successful at work. She must learn that she will have more choices at home than she will at work, but that is simply how work, and the larger world is. Learning this crucial lesson will benefit her throughout her life.

Behavior at Work: Modifying the Environment

By David Hessler, PhD

Problems at work often result in (or from) inappropriate behaviors. Generally, it is easy to identify the sources of problems that arise in the work environment, and often it requires only simple changes to the environment and interaction patterns to improve the situation.

Example: DAY 1

Michael has Fragile X syndrome and like many people with the condition, he easily becomes stressed or anxious. In addition, he can be very sensitive to sounds, touch, and other types of sensory stimulation. These things can make it hard for him to work and relate to others.

Michael is standing at a table, collating materials for a mailing, with several others doing similar work nearby. He is trying to focus on his task, but there is a lot going on around him. Two of his co-workers are talking loudly and joking around, and another is dancing to a nearby radio and occasionally bumping into Michael. The phones are ringing and there is the constant paging of people over the PA system.

While the others are productive in preparing materials for mailing, Michael has not completed anything, and his materials are scattered. The supervisor comes over to talk to Michael, but he looks down while his supervisor is speaking.

The supervisor, appearing annoyed, leans in towards Michael to make eye contact with him. Michael becomes very anxious and upset because he is unfamiliar with this supervisor, he feels threatened by direct eye contact, and he cannot process all the instructions. The phone conversation and loud music are over-stimulating him and adding to the overwhelming environment.

Michael turns his head away from the supervisor and starts biting his hand in an effort to cope. The supervisor becomes annoyed. The supervisor tells Michael to look at him and asks him if he understands the directions. Michael indicates that he does understand, but when the supervisor walks away, Michael just starts moving papers back and forth. Michael clearly did not understand the instructions and does not know how to ask anyone else for help.

The supervisor becomes clearly upset and walks back to where Michael is standing. He asks why Michael did not follow through with his instructions. Michael, still looking down, shrugs his shoulders.

The supervisor throws his hands up and walks away. Michael clenches his fist and angrily gestures towards his co-worker who is working nearby. The other co-workers start to back away nervously. It is hard for Michael to express his feelings easily with words, so he expresses his feelings through behaviors that are not welcome or appropriate in any work environment.

Michael gets anxious, then agitated, pounds his fist on the table, and ends up walking out of the building. He is trying to communicate that he is unhappy and that he needs help to make this work experience better.

Now, we are going to explain some changes that can be made to Michael's work environment and in his interactions with others, resulting in a more successful work experience.

DAY 2

Michael and his supervisor are sitting next to each other, eating lunch, and talking casually. The supervisor is taking steps to get to know Michael in a relaxed atmosphere. This will help to reduce Michael's anxiety about interacting with him, hopefully making Michael more motivated and less irritable at work. Lunch is a great way to do this because they do not have to maintain eye contact to have a conversation.

The radio is removed from the work area. The area is also regularly monitored for unnecessary or extraneous sounds, blinking fluorescent lights, and pervasive odors from the nearby restaurant. If any of these hinder Michael's performance, minor adjustments can be considered (e.g., replace deficient light fixtures, install a fan).

The supervisor sets up a separate workstation for Michael, with his back against the wall. He can still see his co-workers and talk with them if he wants to, but he is not in as close proximity. By sitting with his back to the wall, Michael feels more comfortable in his own space and does not have to worry about someone approaching him without any warning.

The supervisor has created a board with three pictures on it, each with a red X through it. One shows Michael threatening with a clenched fist ("No hitting or even pretending to hit."). The second shows Michael yelling angrily ("No yelling."). The third shows Michael threatening to break something ("No breaking things."). The supervisor explains each one to Michael.

The supervisor sets up a visual display showing Michael the steps necessary for completion of his task. He has the materials organized in separate boxes and there are photographs of each step mounted on a poster board on the wall, with each step numbered. The supervisor is going to watch Michael do the task, give him positive feedback on his successes, and encourage him to work carefully. He does not stand too close to Michael and he does not try to make eye contact.

A reward system is set up with reasonable expectations for Michael to manage aggressive impulses, in order, to obtain the reward of playing basketball with his co-workers at the end of each week.

Michael has identified a person that he can go to when he has any questions. The identified person's name has been shared with the supervisor.

If Michael should become upset, he should take a break and remove himself from the source of frustration. He may need help recognizing these feelings. If so, the person that Michael can go to with questions has agreed to help Michael recognize them.

You may need to identify a person who is qualified to go into the work environment and suggest changes such as these. Anyone familiar with the characteristics of FXS should be able to help explain the combination of sensory integration issues, processing issues, and anxiety, and their influence on daily work and social activities.

Professionals to consider for this are occupational therapists, special education teachers, case managers, and social workers. And, of course, parents always know their children better than anyone else does! They or other close relatives can serve important roles in smoothing the way for their child's job success.

Parent Stories

As this chapter is written towards the end (!) of the covid pandemic, these stories are a mix of what happened before and during the pandemic.

When our son was close to aging out of school at 21, we attended some meetings by DVR Division of Vocational Rehabilitation.

They basically said he was too low functioning, and they would sign off on providing us vocational services. Several years later the laws changed, and they are trying to employ more people with disabilities.

We reached out to a parent who guided us on who to call and how to go about acquiring services. We signed up with a PASA/Personal Assistance Services Agency and reapplied to DVR. Because this was during the pandemic, we were meeting virtual, and it was taking months! We felt like because our son was nonverbal and low functioning, they were just going through the motions without really having any clue as to how to support our son. Once our son was able to join a supportive, behavior-based day program, we stopped working with DVR.

Our son receives supported employment through his waiver as an adult.

He now volunteers at a local Arc Thrift store collecting hangers from the clothes racks that are left behind. He loves it and is really good at it.

As with most adult services, it is up to parents to find the best day program, employment, or volunteer opportunity. It takes time and is a slow process.

We found out in the last year of school that the school was not going to help my son find a job. We contacted our Vocational Rehabilitation and were told there was a wait list for appointments, and then there was a wait list to find jobs - but that if your child could not be fully independent at a job, not to bother. I think things have changed now, but they did not help then.

Fortunately, we were able to find a job for him at a grocery store, but we had to provide the training. It did take awhile for others to appreciate my son and some of his speech and mannerisms, and I think that, at least initially, they thought he would be able to work as fast as others, but for the most part, they have come to appreciate his friendliness and people seem to enjoy working with him.

Before the pandemic, our son had 3 different “work” situations. The common thread was co-workers with whom our son clicked and felt comfortable with.

1. **Competitively paid employment** – 10 hours per week. Cleaning toys, mats doorknobs, etc. at a center providing OT, Speech, PT for children with disabilities. Our son had started going to the center for OT, though he was the only adult attending. His OT knew he did not have a job and had a lot of time on his hands, so they hired him to volunteer at the center for a few hours on the days of his sessions. It turned into a paid position for 10 hours per week. He was employed there for about 10 years until they closed for the pandemic. He has not been offered his job back yet.
 2. **Volunteer.** Our local synagogue worked out a situation in which David would volunteer Friday mornings, working alongside the custodian to change over a room from a luncheon program to setting up for Friday night services. The office manager and David really clicked as did David and the custodian. He was there for many years until they closed the building for renovation and then the pandemic came, and the renovation is still going on so there is no building in which for him to work.
 3. **Internship.** In October 2020, our son started participating at a non-profit that assembles different types of kits, which at the time was assembling PPE kits. They subsequently closed in the winter when COVID rates started rising again but they are starting up again June 2. It is about 3 hours once a week.
-

Our daughter wanted to work at a bakery, but she really wanted to work in the kitchen. We started going to the bakery to get to know the people who worked there. Over time, I helped my daughter ask if she could help clean the tables as people left. They hired her 4 hours a week to do that. Then it went to an hour a day. They needed her most right after lunch.

We still spent time going to the bakery just to continue to get to know the people. Soon, they had her filling to-go orders and replenishing items in the case. They are having her do more and more in the kitchen all the time. It is wonderful. The owners have turned out to be the nicest people.

Do not be afraid to go after a job you really want.

Bake Ability, a Sweet & Savory Bakery opened in February 2021. This bakery serves baked goods, baked by individuals with special needs who are mentored by neurotypical peers and parents. Eventually, as we grow (possibly into a bigger space) we plan to use our bakery as a teaching facility to teach the intellectually disabled community baking cooking skills.

This bakery came to be because a group of local parents had experienced that unemployment within the intellectual disability community is significantly higher than the national average. Originally, we planned to purchase a van and create a “staffing firm” and were going to work with local small business merchants to see if we could offer them the services of our children, like a staffing firm. Since they don’t drive, the van was going to be a carpool service to drop them off and pick them up from jobs in the downtown Doylestown area.

While we were thinking about this staffing firm, one of the moms found out about a local bakery that was closing and being sold. I knew this bakery model with special employees had worked in other parts of the country, and I was consumed with the possibilities. The other moms thought I was a little crazy to do this, but I had the means to do it, and with their support, we forged ahead.

Bake Ability affords individuals opportunities to learn a trade, grow and serve the community in the baking industry. There is no bakery of this kind in the surrounding area, where individuals with special needs can have gainful employment. Bake Ability fills this void. We are still learning, and we take our lead from the employees in terms of their interest and capabilities. Some have shown a strong interest in baking, while others are super savvy with our point of sale system. Others are cleaning focused and love washing dishes.

Our employees are loyal, dedicated and hard working. This bakery gives them an opportunity to showcase how productive they can be and what an asset they are to any community. The pride they feel in earning a weekly paycheck is all the reason we need to push ourselves harder to grow this business as much as we can.

My daughter has always wanted to work with young children. I reached out to one of our local preschools to see if my daughter could volunteer, to work with the children or clean up or do whatever they needed done. She started at two hours, twice a week. Within a short time, the other children loved her and she loved them. Soon, the daycare offered to pay her and they wanted her to work for two hours every day. I don't know whether they will ever be able to increase the time but it is working well for now and she is gaining valuable experience in working at a job.

Employment Opportunities—Nationwide Companies

There are employment opportunities for people with disabilities throughout the United States. After you have considered your young adult's strengths and interests, it is time to find a job in your community. Most grocery stores, restaurants, and coffee shops have jobs available at one time or another. The service industry has long been a "buyer's market," with plentiful jobs available for reliable workers. If your young adult is interested in an office-type job, use your connections or the resources below to help him or her pursue that opportunity.

The following list is of major companies known to hire people who have developmental disabilities. Please note that it should not be viewed as a complete list, nor does it guarantee employment, because availability, of course, is subject to the company's need. Most of these companies operate in multiple sites, so you need to apply for a job at the location in which you are interested. Use this list as a starting point for your own search; you may even use it for ideas when you look at your child's strengths and interests. But please, in no way let it limit you! Do not forget to look at the "Mom & Pop shops" in your community, too!

NATIONWIDE COMPANIES

Coffee Shops

- Starbucks

Department Stores

- Macy's
- Dillard's
- Penney's
- Marshal's

Discount Stores

- Kmart
- Target
- Wal-Mart

Restaurants/Fast Food

- Burger King
- Five Guys
- McDonald's
- Noodles & Company
- Panera's
- Wendy's

Thrift Stores

- Arc stores
- Goodwill
- Savers

Grocery Stores

- Acme
- Albertsons
- Hy-Vee
- Jewel
- King Soopers
- Kroger - all Kroger stores
- Osco
- Publix
- Safeway
- ShopRite
- Whole Foods Market

Employment Opportunities—State and Local Resources

Another way to find a job for your young adult is to use state and local resources. Each will provide you with different types of information.

1. Division of Vocational Rehabilitation—Do an Internet search by that title and your state, because each state has its own office. Their goal is to help people with disabilities find employment.
2. Workforce organizations—Do an Internet search by that title and your state, because this organization operates in most states. While it is specific for people with developmental disabilities, they do have information on finding jobs.
3. DisabilityResources.org—Search by state.
4. Local ARCs—Thearc.org. See if they have a list of or any experience with companies that hire people with disabilities. They may be able to connect you with other local organizations that help find employment for people with disabilities, including supported employment.
5. Developmental Disability Council (DD Council)—Search by state.
6. Internet search—for your state and “supported employment” or “developmental disability employment.”
7. Local disability organizations—Search by phone book or Internet.
8. Personal connections—Talk to all your friends (not just parents of children with disabilities.)
9. Direct employer contact—Talk with the manager if your child is interested in a specific job.

RESUME

John Doe

5609 N. Euclid
Kansas City, Missouri, 64117
505.555.1212
john@gmail.com

Objective:

Work as a team member of a grocery store in the front- end assisting customers and packaging their grocery items. Interested to do a variety of work duties such as stocking shelves and returning carts.

Education:

High School 2016 - 2021

Employment/Employment Experiences/Volunteer Work:

- Volunteering at a pizza restaurant.
- Volunteering at a senior living facility assisting with recycling.
- Volunteering at a Meals on Wheels location, doing custodial work.
- Lawn care – mowing, general cleanup.

Special Skills

- Freshman and Varsity football manager for 10 years.

Special Skills

- Participates in Special Olympic softball, soccer, and flag football.
- Honorary fire fighter for the local fire department.

Resources

Getting and Keeping a Job

<https://fragilex.org/2016/treatment-and-intervention/getting-and-keeping-a-job/>

Making Vocational Training Purposeful

<https://fragilex.org/2017/adolescents-and-adults/making-vocational-training-purposeful/>

Teaching your Child to Ask for Something

<https://fragilex.org/2015/treatment-and-intervention/teaching-your-child-to-ask-for-something/>

Life Planning

<https://fragilex.org/treatment-intervention/adults-life-planning/>

How an Adaptive Physical Education Class Should Be “Run”

<https://fragilex.org/2015/treatment-and-intervention/how-an-adaptive-physical-education-class-should-be-run/>

Living with Fragile X Resources

<https://fragilex.org/living-with-fragile-x/life-strategies/resources/#1496345029157-d8be18b2-43e2>

CHAPTER 5

COLLEGE FOR INDIVIDUALS WITH FRAGILE X SYNDROME

More people with Fragile X syndrome (FXS) are attending college than ever before. This is partly because of increasing awareness regarding the sometimes-hidden strengths of those with FXS, and also because colleges are increasingly welcoming people who have different abilities. Sometimes, however, further education can be useful for both a degree and training in a field of employment interest as well as a next step in independence for the student.

We understand there is a wide range of abilities in those with FXS – from those who can attend a college without supports to those who will attend college with specific programs for people with intellectual disabilities (ID). The intent of this chapter is to provide you with resources to best enable you to meet the needs of the individual with FXS.

The possibility of attending college is still a new idea for many people with FXS and their families, and as the NFXF learns more about the expanding opportunities in this area, we will convey the information to you. Meanwhile, we have compiled a few resources to assist you in seeking more information.

One aspect to consider – Sometimes the right post high school continuing education can be found locally without the need to live away from home; one example is a community college. One advantage of a community college is that the individual gets used to the education demands of college, and then at some point the individual may consider attending a college and living in a dorm. This simplifies the approach, but the student still needs a high level of determination to attend college and appropriate supports in place.

Think College

<https://thinkcollege.net/>

The only directory of its kind, Think College Search features 308 colleges and universities that offer postsecondary education programs for students with intellectual disability.

Think College is a national initiative dedicated to developing, expanding, and improving research and practice in inclusive higher education for students with intellectual disability. It is based at the Institute for Community Inclusion, University of Massachusetts Boston.

When School Services End

<https://www.nccsdonline.org/>

The only federally funded national center in the U.S. for college and graduate students with any type of disability, chronic health condition, or mental or emotional illness.

Here you can:

- Access the NCCSD Clearinghouse that has information like Finding a College, Paying for College, Handling Problems at School and much more. Lots of resources for students, families, high school and college faculty and staff, researchers, and policymakers.
- Contact them to ask a question or get help with an issue
- Find stats and read about campus climate, student needs, employment and more in their Research Briefs
- Learn how to maximize your accommodations and other topics in the NCCSD Training Center.

Pacer's National Parent Center on Transition and Employment

<https://www.pacer.org/transition/>

<https://www.pacer.org/transition/learning-center/postsecondary/>

Postsecondary education is an exciting opportunity for all youth, including those with disabilities. Going to college today can mean attending a 4-year college or university, a 2-year community college, or a technical institute or trade school. It can mean studying full-time or part-time, or living at school or commuting from home. Learning and earning go hand-in-hand. The more years of schooling your youth completes, the higher his or her income is likely to be. The wide variety of postsecondary educational programs currently available for youth makes exploring options with your son or daughter an exciting process.

Although postsecondary students with disabilities are entitled to certain protections, the process for accessing accommodations is much different than in high school. Youth must take a more active role in knowing their rights and advocating for needed supports. This means they must know about their disability and the accommodations they need to be successful. Families play an important role in helping their young adults learn self-advocacy skills, as well as their rights as a person with a disability.

Inclusive Postsecondary Education for Students with Intellectual Disabilities

<https://www.pacer.org/transition/learning-center/postsecondary/college-options.asp>

In 2008, the Higher Education Opportunity Act (HEOA) for the first time provided access to financial aid to students with intellectual disability attending college programs that meet the requirements of a “Comprehensive Transition Program” (CTP). The legislation emphasizes participation in inclusive college courses and internships and requires the students to be socially and academically integrated to the maximum extent possible. CTPs are designed for postsecondary students with intellectual disabilities to continue academic, career and technical, and independent living instruction in order to prepare for employment.

The ADA, Section 504 & Postsecondary Education

<https://www.pacer.org/transition/resource-library/publications/NPC-42.pdf>

Many parents of students with disabilities have learned the basics of the Individuals with Disabilities Education Act (IDEA). However, as students and their families prepare for the transition from secondary programs to postsecondary options, they often find they are less familiar with the protections provided by the Americans with Disabilities Act.

6 Inclusive College Programs for Students with Intellectual Disabilities

<https://www.noodle.com/articles/6-inclusive-college-programs-for-students-with-intellectual-disabilities>

Historically, it has been difficult for students with intellectual disabilities to find a path to college. Fortunately, that path became more accessible with the 2008 reauthorization of the Higher Education Opportunity Act (HEOA). The legislation made it possible for students with intellectual and developmental disabilities to receive specific federal aid and grants and for universities to pilot inclusive programs.

Currently, over 270 colleges and universities open their doors to students with intellectual and developmental disabilities. Two- and four-year programs are available at a wide range of private and public universities and culminate in a certificate of completion.

Helping students with intellectual disabilities conquer college

<https://hechingerreport.org/helping-students-with-intellectual-disabilities-conquer-college/>

More colleges are opening doors to students with intellectual disabilities and giving them life skills and a ticket to employment, but federal funding for some of these programs runs out next year.

Programs for Students with Intellectual Disabilities

<https://www.affordablecollegesonline.org/college-resource-center/students-with-intellectual-disabilities/>

Even if a student with intellectual disabilities isn't yet prepared for the rigors of a full degree program, that doesn't mean there aren't countless other paths offered at college campuses to help them transition into independent adulthood. In addition to the two offerings highlighted below, students can use the map to find similar programs in their area.

Inclusive Higher Education

<https://inclusivehighered.org/about/who-we-are.html>

Inclusive higher education is an option for students with intellectual and developmental disabilities to attend college. Inclusive higher education is made for students who may need additional supports to be successful in college. Students who attend a college offering inclusive higher education do not need to meet the regular admissions criteria for college, instead they are evaluated on their unique abilities and desire to go to college.

Can students with intellectual disabilities attend college?

<https://www.washington.edu/doit/can-students-intellectual-disabilities-attend-college>

Yes, some students with intellectual disabilities attend college and other postsecondary programs. The ThinkCollege.net website is devoted to helping students with intellectual disabilities, parents, and advocates find postsecondary programs and resources that are a good match for these students. It includes a database of over one hundred programs that serve individuals with cognitive disabilities.

20 Colleges with Great Inclusion Programs for Students with Disabilities

<https://themighty.com/2019/03/college-university-disability-inclusion-programs/>

Graduating high school and entering college is often seen as a coming-of-age experience. It marks the starting point of many things: obtaining independence, developing, and harnessing various skills, making new and potentially lifelong friends and gathering new experiences. However, it can also be difficult adjusting to these new aspects of college life.

Association of University Centers on Disabilities (AUCD)

<https://www.aucd.org/template/page.cfm?id=498>

AUCD advocates for legislation and policies that increase access to postsecondary education for students with disabilities, such as the Higher Education Opportunity Act.

Evaluating a Postsecondary Education Program for Students with Intellectual Disabilities: Leveraging the Parent Perspective

<https://pubmed.ncbi.nlm.nih.gov/32926305/>

Postsecondary education (PSE) programs serving individuals with intellectual disabilities (ID) aim to improve life outcomes by increasing skills in three key areas: academics, independent living, and employment. To ensure that PSE programs are successful, ongoing evaluations are necessary. It is particularly important to gather parental perspectives given the integral role they play regarding decision making for students with ID.

Educational Options After High School for Students with Special Needs

<https://www.parentingspecialneeds.org/article/educational-options-after-high-school-for-students-with-special-needs/>

As a person with learning disabilities, or the parent of a student with LD, there are many decisions to be made about the future, post-high school. Maybe college is one option, or a different educational opportunity may be the right choice. Perhaps a career path such as an internship, apprentice program, or some entrepreneurial enterprise is more suited. Whatever direction is ultimately taken, the following information will help provide some insight and assistance as options are reviewed.

Postsecondary Education Opportunities for Students with Autism

(Includes various checklists for individuals considering college):

<https://www.autismspeaks.org/sites/default/files/2018-08/Postsecondary%20Guide.pdf>

This guide is designed to help you and your family explore the different opportunities and learning environments after leaving high school. With only about one third of youth with autism attending college in young adulthood, Autism Speaks wants to offer the best possible resources on this topic to help you explore all the various options available to you.

Financial Aid for College Students with Disabilities

<https://www.learnhowtobecome.org/career-resource-center/financial-aid-for-college-students-with-disabilities/>

College can be expensive for anyone, but it can be especially costly for those with disabilities. Some classroom accommodations are paid for out-of-pocket, medical bills tend to be much higher, and even transportation costs can be greater than what a typical student would have to pay to get to and from class. These are just a few of the reasons why it's so important for students with disabilities to have ample funding options available to them. This guide focuses on those options, with the goal of helping students with disabilities find the resources they need to pay for and succeed in college.

Scholarships for Students with Disabilities

<https://www.bestcolleges.com/financial-aid/students-with-disabilities/>

Here are many circumstances that make financing college harder for disabled students. Disabilities may prevent students from attending school full-time, which makes it harder to qualify for financial aid and scholarships reserved for those with full-time status. Disabilities may also require access to accommodations or support that are not provided by schools; require medical care that is not covered by school-sponsored insurance plans; and prevent students from working part-time jobs to offset tuition costs.

Fortunately, there are many financing options and benefits available to students with disabilities. This is our guide to the opportunities out there. We'll start with those that are available to students living with any kind of disability and then break down awards designated for students living with particular types of disabilities.

Stories from Young Ladies with FXS

How did you decide you wanted to go to college?

Well, I knew I wanted to not just better my education, but to create a social environment that wasn't just my friends from home. Also, my parents wanted me to get the experience of living on campus and being almost 2 hours away from home.

How did you pick a college?

It was tough picking a college. I applied to five colleges, got into three, and narrowed it down to two. It really came down to price but I'm happy with my decision to go to Bridgewater State University where I majored in communications with a minor in public relations.

What did you like about college?

I liked that Bridgewater wanted you to make a difference at their school by getting involved in things like sororities and different groups they had on campus. It is a commuter school so that was their main goal to get others involved. I also liked the long-lasting friendships I made there. One of my best friends was my maid of honor at my wedding.

What was hard?

Well of course for any Fragile X kid it was school that was difficult. The test, the quizzes, the homework, etc. but Bridgewater had a great academic center for kids to utilize for extra help which I used almost daily.

What advice would you give to someone considering college?

I would say don't pick a school because you don't want to live in your hometown/stay, go because it's the right place for you. College is scary for some; I know I was terrified my first month or so being away from my family, but I went to my first social gathering at the dorm, and I didn't turn back from there. I would also say don't get discouraged if you keep getting those rejection letters, there is a school for everyone out there and the right one will come your way.

How did you decide you wanted to go to college?

I was interested in childcare. I wanted to earn an Associate degree to be better prepared for this field of work and present myself as a qualified candidate.

How did you pick a college?

I enrolled in a two-year community college and obtained my degree.

What did you like about college?

I was very happy about earning a degree, loved the experience of living independently on campus in a dorm room, and very pride about the accomplishment and the feeling of being prepared for work in the field of childcare. I have been successful as a teacher's assistant in a day care for many years.

What was hard?

Living in a dorm with a roommate has its rewards and challenges. Sharing the room with her roommate was complicated by things such as the roommate having a boyfriend or different schedules for studying, eating, and sleeping.

College cafeterias have a tempting and abundant offering of food choices for any student and this family's experience was difficult as the daughter gained a lot of weight without the level of nutrition supervision that one has while living at home.

What advice would you give to someone considering college?

The parents said:

- Make sure the individual really wants to experience higher education and is prepared for the new environment with the determination to succeed.
- Find a school with a good fit, with the right curriculum, and an environment that has adequate supports for the additional tutoring or learning needs of the student.
- Monitor success and challenges, particularly in a situation where the student will be living away from home, arrange frequent contact to make sure everything stays on track.
- Be prepared for the unexpected.

Some wonderful friendships with fellow students were made. Many students and education staff “looked out for” the daughter.

After the first semester of college in the CarolinaLIFE program at The University of South Carolina.

How did you decide you wanted to go to college?

I wanted to know what it was like. I just always wanted to go.

How did you pick a college?

I visited some colleges and picked the best program for me.

What have you liked so far in college?

Going to football games, meeting new people, and seeing a whole different place. I also have liked the book club I joined.

How do you like living in the dorm?

It's ok.

Have you been homesick?

A little in the beginning.

What is something you have learned living on your own?

I've learned how to get places using google maps. I've learned that I get lazy with the dishes.

Do you think learning to live on your own at college has been hard?

Yes.

Are you proud of yourself for what you have learned?

Yes.

What advice would you give to someone going to college?

Don't drop out, it's totally worth it, be brave.

Advice from the parents:

Parents must be brave too! There is a thing called dignity of risk and people with special needs should be given the freedom, the dignity, to face the same risks as everyone else (within their capabilities of course). Sometimes we shelter them because it makes us feel better, and we are trying not to do that for our daughter. It's hard and scary sometimes. But we are so proud of CB and all that she has learned and accomplished this first semester in the CarolinaLIFE program.

It's really been amazing how she has learned how to get to her classes, how to walk to the CVS and pick up her prescriptions, get groceries, go to football games, join the book club, communicate with her professors, take flights home and back independently, and the list goes on. We look forward to continuing this journey and watching her live her best life!

At first, picking a college as a senior was quite difficult. At the time I didn't know who I wanted to be. At one point, I wanted to be an archeologist and looked at a program at Fort Lewis in Durango, Colorado. That quickly faded because being in that field requires being good at math. I then switched to wanting to be in culinary school. Ever since I was three, I wanted to be a chef. There was a program I was set on at the Broadmoor Culinary Institute where I could be paid to go to class and have a chef job at the same time.

I was so ready to make that decision until one day. My mom received a brochure for a college in Denver called CCU. She then made an appointment for a tour without telling me and made me go. I thought to myself I'm going to hate this; it will be stupid and a waste of time. Again, I was only a senior in high school and at that point, everyone should be okay with not knowing where to go.

The following weekend my mom and I drove up to Denver to the campus. I still had that skepticism about the whole thing. I got out of the car and was immediately greeted by the nicest people, and they had a whole luncheon prepared for the tour. I remember walking around the campus at the tall stylish dorms and academic buildings. The campus was small, but it had a rustic charm that made me feel at home.

I think what drew me the most was the fact they had a student help center where they gave you a chance to take a test to determine what your major could be. They, as well, had on-call tutors for struggling students and I felt a sense of community.

Also, the brother and sister dorms would gather once a month and do crazy activities like go to Elitch Gardens (an amusement park), a movie, or dress up in costume and go to Boondocks (an amusement park). They often bragged how there were moments of Voodoo Donut runs in the middle of the night. After that tour, I was convinced I wanted to go there. I even heard they had an excellent psychology program to which I will get to.

I applied the fall of my senior year and wrote my essays all on my own because let's face it, my mom wasn't going to be there when I was in college to correct my grammar. I will admit after hitting submit on those essays I was nervous. The reason being is on the application I had to mention I had Fragile X. Don't get me wrong there's nothing wrong with having it. It is just I always kept it a secret from everyone just so I would be treated "normal."

I was really nervous about them seeing my grades and thinking I wasn't what they were looking for and my math grade would speak for itself. I had to take the ACTs multiple times and finally got a 19 the cut-off was 21. I thought I wouldn't get in because I was two points off. I waited and waited for the letter in the mail and in April of 2013 I got accepted to CCU. I remember being over the moon and thinking I conquered the biggest obstacle.

Over the summer they gave us a questionnaire about ourselves. For the first two years of college, you had to live in on-campus housing. I went to the weekend of welcome feeling super nervous about being on my own. I couldn't believe that I was now a full-fledged adult coming into the world.

The first day I was there I remember pulling up my van to the dorms and twenty people came around my car and took all my stuff up to my room. They told me to check it out while they unloaded. The dorms were apartment-style, so it had a fully furnished living room a bathroom and two bedrooms, and it housed three other roommates. This is how it was the rest of the years I was there. I lived with roommates and majored in psychology.

My major was probably the greatest decision I ever made. The program academically was challenging at points but the most difficult was figuring out study strategies and test-taking. Every student at my campus had a counselor who was with you till you graduated. They basically helped you with your academics and testing.

The first thing I asked my counselor for was for my books to be in audio format. I got a software called Learning Ally which had every textbook I ever had till I graduated. It definitely helped a lot, plus with the program they gave me permission to record lectures as I took notes.

When it came to tests, I had a hard time taking them. I had the extra time on my 504 but it didn't seem like enough. I was failing some tests even though I studied hard the whole week. Nothing seemed to be working and I was getting burnt out and frustrated. I decided to have a meeting with my counselor to discuss strategies that could help me in the long run. I told her, "I know I have books on audio and extra time but maybe we could try this idea I have." She nodded and I said, "How about someone reads my test to me out loud." Apparently, this was the first time she heard about this said, "Well, let us try it with your next couple of tests and see how it goes."

One of my grades that was in a history class went from an F to a B in just a few months because of my idea to have a reader. They ended up having a computer set up for me to read my tests to me. Low and behold I found out they added this accommodation to the program. A lot of students apparently use it to help them with tests. I felt so proud of myself. Thinking I just helped a lot of people.

Further down the road, I got involved in clubs such as a publication for the school. I spent three years in that club and eventually became editor-in-chief. I edited and laid out 500 plus copies of the books we made. In my psychology degree I made a growing research project that to this day people are still using. In the end, I graduated with a 3.59 GPA and had the best experiences. I met the greatest of friends, and it truly was one of the best decisions of my life.

To those who are, considering college all I have to say is take that leap of faith. You never know who you're going to inspire just because of something you need in your learning. It may help others in the long run. You just got to go for it.

Stories from the Parents of Young Men with FXS

LIFE AFTER THE CLIFF

A life full of hours of Xbox, working parents out of the house, and nowhere to go with no transportation is, sadly, the only option for many young adults with Fragile X Syndrome once high school or transitional programs are complete. It's "The Cliff" we all hear about when the structure and socialization of school comes to an end.

College life-skills programs for students with intellectual disabilities were just gaining recognition when we started exploring "next steps" for our son in 2017. The transition program at our public school was an option for us but he was very aware that his peers were going to college, and he wanted to go too.

Most importantly, we believed that our son would be a good candidate to try such an endeavor given that he does transition well and was very familiar with time away from home due to years of sleep away camp. These curriculums are VERY supported both socially and academically in the dormitory, the classroom and throughout campus life.

DIFFERENT TYPES OF COLLEGE LIFE SKILLS PROGRAMS

We applied to programs at colleges within a few hours from home. Since most were new, they were small and without a residential component so that meant that I needed to rent an apartment and find support.

Essentially, many start (and remain) more of a commuter program which is just perfect for many. You get dropped off in the morning and picked up in the afternoon. Similar to a "day" program only it's college so truly, much different. This setting offers much comfort to candidates and families, where sleeping away from home in a dorm on a college campus is not the right fit... just yet. While interviewing at various programs, repeatedly I'd hear that many were trying to emulate the ClemsonLIFE program at Clemson University in South Carolina. We applied and interviewed. We had such low expectations that my husband and I rehearsed how we would break the bad news. When the notice came in the mail, I'm embarrassed to admit that we opened it without him so as to have the opportunity to hide the bad news... only to discover that he was accepted. I'll always regret that choice and the raw, genuine excitement we had, without him, that we had to re-enact! (We performed well).

Our son attended the non-degree seeking 2-year basic program at ClemsonLIFE and it was a tremendous experience for the whole family. We are so glad we pursued this. Sadly, he did not qualify for what is called the “Advanced Program” which is years three and four. That program requires much more independence and while it is still supported, the support is minimal, requiring students to live off campus. While we saw the writing on the wall, we were devastated.

PLAN B

Our son wasn’t done with college yet, but truth be told, while referring back to our original application process, he wasn’t a candidate for most programs as many required at least a third-grade math level and a fifth grade reading level, which our son did not and does not possess. So don’t be misled into thinking only high functioning students qualify. In the end, programs do look at the whole student as our son has much to offer socially.

We next applied to the only program that would accept him which was MasonLIFE at George Mason University in Fairfax, Virginia. This was similar to ClemsonLIFE, a bit more academic and not as much fun. No football team and if you know anything about Clemson football, you understand the disappointment. We tried to make this work, then COVID struck, he transitioned home for online continuation (which actually was quite good) but when it was time to return for year three, we reassessed and felt it was time to consider a residential setting.

We could have chosen to keep our son home, but I felt like such a failure to have sent to him to four years of independence “training” only to end up at home with Mom as his only friend.

HOW TO PREPARE FOR COLLEGE

Again, I realize that not all individuals with FXS will be candidates for a college or residential setting away from home but for those of you with school-aged kids, if you think there’s a glimmer of a chance that you might consider this, start creating opportunities now for your child to experience time away from home. Maybe sleep away camp... doesn’t have to be long... A weekend? A week? Sleep overs at a relative’s home? Even family travel to experience “away”. I truly believe our son’s early start at sleep away camp set the stage for success away from home, allowing us the chance to even consider these programs.

All these programs have open houses and strict timelines for applying so start your research during junior year of high school to prepare for those timelines during senior year. Contrary to what you might think, just about every program recommended NOT keeping your young adult home for that first year out of high school or making use of the transition program if you’re certain you plan to pursue a college program. They all said there is too much regression from the structured setting of school that takes place if a “gap year” of sorts is planned before the college program.

That being said, many do choose not to go directly to college for a variety of reasons and therefore, the entry age for these programs does vary.

WHAT TO LOOK FOR WHILE RESEARCHING COLLEGE PROGRAMS

I was shocked at the varying degree of support at different programs and that matters. Not just how much support but by whom. Some programs strictly make use of volunteer students. That is necessary to truly offer that inclusive, peer experience but you want special education teachers, special education majors and graduate students instructing your young adult. Find out what, if any, support exists on weekends. Not all offer that.

Find out how much parental input is expected and/or not wanted. ClemonLIFE and MasonLIFE were VERY different in this regard, and it was a bit problematic for us at MasonLIFE. You'll need to find balance between offering beneficial insight regarding how your young adult functions versus micro-managing, of which I did too much of and made myself crazy.

MasonLIFE pretty much cut off communication from parents with the exception of tuition (of course) and health issues. I would go visit and spent my entire weekend "working" assisting with laundry and cleaning because the support appeared inadequate. This could have been a workable situation if administration at the program would have been more amenable to parental input and support design. Prices for these programs are all over the board. It seemed many students were attending with some sort of aid and/or scholarship. These are public universities so in many cases, financial aid is an option so don't think only those with means attend. Once you choose a program and you find yourself at "move-in," get the name and contact information of a direct peer that will be working with your child as it was helpful to have someone, outside of administration, to reach out to for a quick question. Maybe consider a holiday gift for them as well!

There's a chance you're overwhelmed. The link below is amazing. Simply put in your filters (commuter, residential, what state(s), 2-year, 4-year, and so on) and a multitude of choices and tons of details will populate.

www.thinkcollege.net

One last bit of advice. Don't assume that your child will never be a candidate for these programs. Have high expectations. Be willing to try challenging things, bit by bit as the years go by. I'm not saying that your kid will always surprise you and it will be successful, but you'll likely get SOMETHING positive out of just trying. You know your kid best.

I don't want to sound like a know-it-all. I didn't do it all right during the younger years. It took me a while to admit but I over-sold our son to the Clemson program. I wanted it bad. I knew he was the weak link there and I ask myself if I set myself and him up for the eventual disappointment of not qualifying for the advanced program and his on-going obsession with Clemson. Having said that, I don't regret sending him to Clemson and it contributed to his development with coping skills. I'm still working on differentiating between what I want and what is truly best and finding common ground. We've since moved on to a residential placement and I think I got it right. Stay tuned. Life sure is a journey, isn't it?

As parents, we had never given a thought about our son going anywhere else after he graduated from high school. We just assumed that would be the end of his formal education, and he would just continue working part-time.

All of that changed when they had college day during his senior year, and he came home with a bag and said: "This is where I'm going to college!" With excitement revealed in a big smile, he pulled out material from a nearby Community College. We thought that his reaction was sweet but didn't give it a lot of thought. However, along with our son's Fragile X syndrome comes a healthy dose of "you might as well figure out how I'm going to go to college because I will never stop bringing it up every day until you do!"

We tried to ignore it for a few weeks but decided to call a teacher at the local Community College who had actually been a student teacher for me when I was in high school! Mrs. Long said he absolutely could go, and she suggested he start with 2 classes per semester and see how he did. She set it up for him to be in one of her classes and one with another teacher she thought would be good for him. Our son did very well taking 2 classes a semester for 2 years.

By then, Mississippi State University had started a program called the ACCESS Program for students with intellectual disabilities, and our son was already a big Bulldog fan and had been going to football games on campus for years. He applied and was thrilled to be accepted into the program. Our son loved having new friends and living in the dorm. He attended sporting events frequently, enjoyed his classes and learned to navigate the campus well. It was a huge confidence booster for him as he improved his level of independence. We were thankful for the support the program gave each of the students.

There are hundreds of post-secondary education programs and opportunities for students with intellectual disabilities all over the country, and I would encourage families to look at those possibilities as a way for that child to grow and learn how to be more independent.

CHAPTER 6

DAILY LIVING

As the individual with FXS becomes an adult, thought and care should be given to making their life as fulfilling as it can be. It is also important to help them be as independent as they can. It is never too late to start and with time and a thoughtful process, skills can continue to be learned. In this chapter, the following is discussed:

Daily Schedule

- The hours of the program each day.
- The schedule of each day. Do they do different activities each day? They should try to visit at different times of the day, if possible, to see how the activities change throughout the day.
- Do they go into the community?

Staying Healthy

- Exercise
- Meal and Snack Time

Hygiene

- Make it a daily activity

Doctor Visits

- Finding a doctor who sees adults
 - Primary care
 - FXS doctor
- Regular checkups
- Illness visits
- Dental
- Vision

Social Life

- Strategies for Common Activities
- Talking on the Phone
- Sensory Processing issues

- Anxiety
- Making Outings Safe
- Handling Social Media
- Sexuality/Relationships/Marriage

Behavior

Medication

Daily Schedule

- Daily Schedule - Make and keep a daily schedule
- Get out of the house everyday
- Chores - Have an expectation that everyone will do chores

Daily Schedule - Make and keep a daily schedule

It is important to have a schedule for every day. It not only helps the individual with FXS, but it is important for the care provide and everyone else in the house or living situation. As much as you can, instill routine and predictability into the schedule for the whole week.

Keep in mind:

- The needs of the individual – their anxiety, the environment, and everything else is going on in their life.
- Anxiety – Check in each day to see what the individual is “thinking” about; have access to calming activities – swing, music, therapy ball, or whatever they need.
- The environment – calm, quiet, predictable, non-stimulating.
- What else is going on in the individual’s life – work/day program, personal, other activities. Find strategies to help with the other activities – write things down for the individual, i.e., bring worries to a “close” as much as possible.
- Each day should have a combination of gross and fine motor activities all day long. Here are some ideas: The Sensory Diet – <https://fragilex.org/living-with-fragile-x/treatment-intervention/sensory-diet/>
- It is also important to ensure that the daily schedule include time for the individual to take care of one’s personal hygiene, covered later.
- Every activity should also include time for prep and time for cleanup or time to get ready and time to put items away, whatever the activity is.
- Watch the type and amount of television/video games.
- Instill a sense of pride in whatever you and they do.

Aspects to consider for the daily schedule:

- Make the schedule visual – in whatever way works best for the individual. Examples include: using actual photos, icons, or words.
- Review the schedule the day before.
- Review the schedule the morning of and throughout the day, as needed.
- Plan for how changes to the schedule will be communicated.
- Allow adequate time between transitions.
- Also consider a visual schedule where the individual can see the week, the month and even the year, as appropriate.
- As schedules are developed, listen to what the individual is asking, which will help determine the level of detail needed for the schedule.

Get out of the house everyday

This is an important enough aspect that it is pulled out on its own.

- Leave the house every day and make it part of the daily schedule.
- Ask the individual what they would like to do.
- Mix it up with what you do – errands, grocery shopping, walk in the neighborhood, go to a park, go out for a meal.
- Make the activity fun – you do not have to spend money every time – so that the individual looks forward to it every day.

Chores - Have an expectation that everyone will do chores

Having expectations for the individual to help around the house are important for the continued development of the person, and it is also important for the individual to be a contributing member of the household, as should everyone. Accommodations will need to be made on the number and type of chores but add them to the daily schedule, so they are expected and predictable. Depending on what is currently being done, consider adding one chore at a time. Everyone in the house should have chores to do.

Possible types of chores:

- Make the bed
- Clean up their room
- Do laundry - Separate clothes, put into washer, put into dryer, fold, put away
- Wash dishes – load/unload dishwasher; wash by hand
- Clean the floor – vacuum or mop

- Take out the trash – take out to bin, take bin out on trash days
- Wash windows
- Do yardwork – mow, rake leaves

Strategies for doing chores:

- Incorporate them into the daily schedule
- Use a visual when teaching the chore
- Model the chore, do it together, slowly fade away
- Make sure the individual can do the chore and “knows” when it is “finished.”
- If there is a need to have a chore done a certain specific way, make sure it is doable and taught that way. Try not to give the individual a chore and then go through afterwards and do it “your” way.

Example - Putting drinking glasses away

Here are options to consider:

- Make it simple – the small glasses go on the bottom shelf, the large glasses on the top shelf.
- Use a photo on the inside door of the cabinet– that shows which items go on which shelf.
- If it does not matter – the individual can put the glasses on whatever shelf they want.

Staying Healthy

- Exercise
- Meal and Snack Time

Exercise

It is important to keep the person with FXS active. This cannot be emphasized enough. Exercise helps to maintain or lose weight, is good for building bone and muscle, and among the many other benefits, it can be a wonderful social activity, and it makes people happier.

Many individuals with FXS find it difficult to engage in physical activities without support and encouragement. Sometimes the aspects such as low muscle tone, challenges with hand-eye coordination, and difficulties understanding the rules of games may affect the likelihood of consistent exercising. Some adults have found success hiring a personal trainer or finding a friend to help maintain an exercise routine or participation in a group activity.

To access activities for your adult child, reach out to:

- The local city recreation center. See if they have activities for people with disabilities (ask about unified sports), knowing that some individuals will be able to participate in many of the regular programs. In some cases, the parks and recreation programs will provide volunteers that will enable the person with FXS to participate in regular activities.
- Special Olympics. Google: “Special Olympics in (your state)”. Many individuals with FXS enjoy participating in Special Olympics sports.
- Best Buddies. Though the focus of this organization is more than exercise, it is a social group that can add multiple benefits to the life of the individual.

<https://www.bestbuddies.org/>

Utilize the occupational therapist (OT) on your team to consult and problem solve to ensure successful participation. There may be college programs near you with students who are studying Physical Therapy, Occupational Therapy or Sports Medicine who would be interested in working with the individual.

The bottom line - It is good to include a daily exercise activity into the living situation wherever it is. Making a physical activity fun, with social contacts and support, will ensure better success and promote long term positive effects.

Meal and Snack Time

One often hears: eat healthy, eat healthy. So, how do you do that? Let’s explore a few ways.

Aspects to consider:

- Plan meals ahead of time and involve the individual(s) and everyone in the household.
- Keep in mind that some individuals with FXS will have sensory issues with regards to eating – things such as the smell, the texture, and the taste of the food.
- Depending on where you are, start slow and make changes that individuals can live with for the long-term – such as eating some kind of salad or vegetable every night.
- Create a visual for the options for snacks that are healthy.
- Look for meals and snacks that the individual can learn to make on their own. Create a visual for it.
- It is okay to have a “treat” every now and then.

For more information:

- The CDC (Centers for Disease Control & Prevention) has some guidelines for healthy eating: https://www.cdc.gov/healthyweight/healthy_eating/index.html
- Disability Support Guide
<https://www.disabilitysupportguide.com.au/information/article/top-healthy-eating-tips-for-people-with-disability>

Hygiene

Make it a Daily Activity

Hygiene is sometimes challenging for some individuals due to a myriad of issues often related to sensory sensitivities. Brushing hair and teeth can result in resistance due to sensory overload created by touching the head or inside of the mouth. It is okay to accommodate the person and their sensitivities if the hygiene is addressed.

It is important, none the less, to set up a routine to address hygiene on a daily basis.

Brushing Teeth

The routine for teeth brushing is not always habituated early and can result in major dental problems that may require dental maintenance using anesthesia to clean, repair and remove decayed teeth. If there are issues, consider using a very soft toothbrush (that you might have to change out more frequently) and use of toothpaste that has a mild taste.

Using Deodorant

Find a style the individual is willing to use and consider stating that deodorant should be applied each time the individual puts on a clean shirt.

Showering/Bathing

Parents report difficulty with showering and bathing, again, due to the sensory overload of water hitting the body or face of the person with FXS. Motor planning to use soap and a washcloth over the entire body to ensure cleanliness and good hygiene can be problematic. Getting water on the head and then following up with hair washing is hard and the person with FXS may try to avoid prolonged exposure to showers and hair washing. One parent developed a visual schedule heavily laminated and posted in the shower that directed her son to wash all areas of his body before ending his shower. Other parents suggest using liquid soap, low volume shower heads and music to promote tolerance and eventual acceptance.

However, at the other end, there are some who report significant resistance to getting in the shower, but once in, the individual stays in until the hot water runs out. A timer may be needed to end the shower in a timely fashion.

Either way, making it part of the routine and schedule, as well as creating a visual for cleaning, can be very helpful.

Toileting

Independent toileting can be delayed especially with males. This can cause hygiene concerns when going in public, and so it is prudent to go to the bathroom before leaving the house and find the bathroom in the location being visited.

There can be issues with wiping completely. A diet low in fiber can cause constipation which may become problematic when trying to encourage consistent bowel training and hygiene. Loose stools can also be an issue for some. It is important to consult professionals who are familiar with FXS to find strategies to develop independence in this area.

Haircuts

Tolerating haircuts is also difficult and needs to be instilled over time by using behavioral strategies such as systematic desensitization. It is also important to find someone who will take the time to get to know the individual and who is able to “tolerate” some movement. With some time, the individual may learn to love getting their hair cut. (Who doesn’t love having someone else wash their hair?)

Clean Clothes

One other area to keep in mind – wearing clean clothes. While there can also be excessive clothes-changing, walking past someone with body or clothes odor is offensive to many in the community. It is also important to remember to wash jackets and other outer clothing. Some parents have reported that they almost go to extremes to make sure the individual has on clean clothes whenever they go into the community.

In Summary

Having good hygiene is important for social acceptance. Grooming and hygiene play an integral part in the school, community, volunteer, and work settings. The overall presentation of one who is well groomed increases the likelihood that others will offer a positive response, which can be far reaching in thriving in the community.

As the old saying goes: “Your friends will never remember the day your clothes smelled good, but they will always remember the day they didn’t. “

Doctor Visits

- Finding a doctor who sees adults
 - Primary care
 - FXS doctor
- Regular checkups
- Illness visits
- Dental
- Vision

Finding a doctor who sees adults

As the individual moves into adulthood, it is important to find doctors who specialize in adults. This includes finding a primary care doctor and a FX doctor who sees adults.

- Primary Care Physician (PCP)

As the individual moves into adulthood, it is important to find doctors who specialize in adults. This includes finding a primary care doctor and a FX doctor who sees adults.

Finding a primary care physician (PCP) who sees a adults can be challenging. Not all physicians are comfortable treating individuals with a developmental disability or an intellectual disability (ID), so it is critical to talk with other parent groups as well as local disability organizations to get names of those physicians who might work out. Many physicians do not feel comfortable treating psychiatric symptoms so it may also be important to find a psychiatrist who treats adults with ID.

- FX doctors

There are more and more FX doctors who see adults or who have referrals to doctors who see adults with FXS. Start with the NFXF website, and you can always contact the NFXF for guidance:

<https://fragilex.org/our-research/fragile-x-clinics/>

During this process, it is important to guide the adult into a new environment by following the several strategies used when supporting any transition, for example, the use of visuals. The environmental changes may be familiarized by photos of the new office building, waiting room, examination rooms and staff. In addition, bringing cookies or other treats to the staff by the adult with FXS before the initial appointment can be helpful to both the staff and the individual.

Regular checkups

Regular checkups are most likely done yearly because they are required when the individual receives public funding. As for everyone, they are needed as the person ages, to monitor changes, maybe FX related, maybe not. Things like hypertension can run in the non-FX side of the family and yet, show up in the individual with FXS.

Illness visits

These visits can be tricky because the individual may not be feeling or may have gotten hurt. If the visit is to a known doctor such as the PCP, it is one thing, but if you have to go to the emergency room or to an urgent care, it can be challenging because you probably do not know the doctor and the location is going to be new too. See what you can find ahead of time, call them if you think it will help and allow plenty of time to make transitions.

When you get into a room, ask the doctor if he or she will tell the individual what is going to happen right before it happens, e.g. I am going to take your temperature by putting this on your forehead. Now, I am going to take your blood pressure; this is a cuff, and it will squeeze your arm.

Dental visits

Finding a dentist who sees adults and meets the needs of the adults can sometimes be a challenge. Maybe the current doctor can continue to see the individual. If not, ask the current dentist, reach out to your local Arc, and talk to other parents. One must also be aware of the funding for dental appointments, that is, the source of your funding and whether that will work with the dentist.

Vision checkups

Like other physicians, it can time to find a doctor who is willing to work with the individual, but when it comes to vision checkups, you can often stay with the doctor from when the individual is a child, well into adulthood.

Social Development

- Strategies for common activities
 - Talking on the Phone
 - Sensory Processing Issues
 - Anxiety
- Making Outings Safe
- Handling Social Media
- Opportunities for Socialization
- Relationships/Marriage
- Sexuality

While many people with FXS are included, at least partially, with their peers in school, once they reach adolescence, they face a new set of challenges in maintaining these friendships. Most males continue to want interaction and friendships as they grow older, but the gap widens when those peers go on to explore the world of work, college, and start their own families.

What often happens is that many of the friendships—those that offer opportunities to enjoy recreation, camaraderie, and true reciprocity—more often include peers who also have developmental delays of their own. Thus, it is important to have a broad array of friendships and may include involvement with common opportunities such as Special Olympics, local ARC activities, the local parks and recreation facilities, and faith-based groups.

Strategies for Common Activities

Talking on the Phone

Because of the anxiety associated with FXS, some individuals will have difficulty with simple phone conversations. It is important to help individuals learn strategies to overcome this anxiety. In this example, Claire and her helper will examine ways to become more successful in this important everyday skill.

The phone rings.

Helper: Hey Claire, it's for you; I think it's your friend Ann from school.

Claire: I don't want to talk now.

Helper: Claire is busy right now; can she call you back later? Okay, bye.

A little later:

Helper: Hey Claire, remember Ann called earlier—you should call her back.

Claire: I don't want to.

It can be hard for Claire to use the phone even when the caller is a friend. She may not know what to say, so help her out by giving her a way to start the conversation.

Helper: How about if I dial the number for you? When she answers, I'll say hi and then give you the phone, is that okay? I know you can do it!

Claire: I'll try.

When Claire is on the phone, help facilitate the conversation with specific statements. You may need to take it sentence by sentence at first.

Helper (to Claire): You can start by telling her what you did today.

Claire: I went to the gym. And I went to work.

Helper: Then ask her what she did today.

Claire: Okay.

Helper: Ask her if she'd like to come over to watch TV.

If Claire is still resistant to talking on the phone, you can model the flow of a phone conversation.

Helper: I'll dial the number—you pick up the extension and listen while your friend and I talk.

Will you try that for me?

Claire: Don't tell her I'm on the phone.

Helper: All right. You talk when you're ready.

Claire: Okay.

Another approach is to set up a call in which the other person is aware of Claire's anxiety and this person will ask questions for Claire to answer so that she doesn't have to initiate conversation herself. Over time and with practice, Claire should become more comfortable talking on the phone.

Sensory Processing Issues

Many individuals who have FXS can become overwhelmed by sensory stimuli. It is critical to help them learn techniques to deal with sensory issues, which will affect them for their entire lives.

Nick and his helper are having dinner in a restaurant. The noise level is high, the area is crowded, and people keep bumping into Nick. To a person who has fragile X syndrome, an accidental bump can feel like someone rubbing sandpaper on him. It can make him want to run away, yell, or hit something.

Helper: It is crowded in here. People keep bumping into me.

Nick: Me too—I don't like it. I've got to get out of here.

Nick may not know how to ask for or secure his own space.

Helper: Here are two things you can do: Tell the person, "Please don't bump into me."

Or ask to sit at the end of the table.

Nick: Okay, good idea. Thanks.

To help the individual with FXS, pre-plan social activities so you select restaurants that are not too small or too noisy.

Anxiety

Individuals who have FXS can sometimes become anxious and nervous in social situations. It is important to help them learn to interact in appropriate ways, especially as they get older. One technique to address nervousness is deep breathing.

Helper: Jack, is everything all right? You look upset.

Jack: [Grunts]

Large groups of people make Jack nervous, and he may not know how to ask to leave. In fact, he may be able to communicate in such situations only with a grunt or even by yelling.

Helper: You know what? Large groups of people can make me a little nervous. Sometimes I feel confined and I want to yell. But usually all I need to do is take a few deep breaths—it really helps to calm me down. Do you want to try it?

Jack: [Taking deep breaths] That feels better.

Helper: If you need to, you can tell me, “There are too many people around. I want to leave for a while.” We can go outside for a bit, or even go for a short walk.

Jack: I’ll try it. Thanks!

Jack may need to practice these skills with his helper when he is at home. His helper may need to prompt him the first few times he is in a large group. Eventually, Jack will do it on his own. This is a great skill for him to develop and is important in developing his independence.

Other daily strategies might include:

- Using visual schedules
- Doing visit(s) ahead of time to get the layout of the place
- Meeting some of the people who work at the location of the activity
- Talking about “what is expected” in these situations ahead of time when it is calm
- Modeling appropriate behavior
- Providing opportunities to practice appropriate behavior
- Explaining “inappropriate behavior” and what could happen as a result
- Using verbal cues and prompts
- Using non-verbal cues and prompts
- Participating in social skills program/therapy
- Consistency in as many areas as possible is key
- Young adults prefer to be “observers” at social occasions
- Keep exposing them to new things
- Exposure in community helps the community as well as the individual with FXS.

Tips for Making Social Outings Safe

These tips are the same as you would discuss with any young adult, but when the person has a disability, you need to repeat the tips more often and maybe even do some role playing to make the point clearer.

The parent or care provider should know these things about the outing:

- Who exactly is going?
- Where specifically are they going?
- Are there others whom they will be meeting?
- What are the activity plans?
- What is the length of the planned outing?
- What is the expected time of return?
- What means of transportation will they be using?

Additional points to clarify:

- How much money is being taken and how is it being carried?
- Is the individual's attire appropriate?
- Is the individual's hygiene appropriate?
- Is the young adult comfortable with all the plans for the outing?
- Is the young adult's cell phone charged? Make sure that they take their cell phone and that I.C.E. (in case of emergency) is programmed into the phone.

Reminders for the young adults:

- Make sure to follow the reported plans. If any of the plans change, or you are going to be later than expected, make sure to call a designated person and update your whereabouts.
- Make sure to order your own drink and never let it out of your sight, including soft drinks and water.
- Stay with your group—never go out/leave on your own. Always stay with a buddy.
- Don't hesitate to call if you become concerned or afraid.

Have a good, safe time!

Handling Social Media

This is an aspect where the parents or caregivers may have to take a more active role when it comes to social media, due to the many options and changing aspects of those options. See what the individual is interested in – is it just sports or the weather, or is it searching and perusing websites? The parent may have to talk about what is appropriate and set boundaries, or they may have to set controls on the device. the point clearer.

Sexuality/Relationships/Marriage

Young adults with FXS may become interested in the opposite sex just like many human beings. If the parent is not comfortable discussing the topic with the individual, contact the local ARC – they may have classes for the person or know of an organization that does. The parent may want to review the curriculum to make sure it is appropriate for the individual.

Adults with FXS do marry and can procreate. It is most likely that more females with FXS will marry and have children because they are often less affected and have more opportunities to interact with others to build relationships. Sometimes, adults with FXS will opt not to have children due to the amount of care children require. Some adults who have married report a platonic relationship more typical of roommates or good friends with less sexual or romantic qualities. Nevertheless, the relationships can be extremely strong and healthy with support and care for the person with FXS.

Behavior

As a Consensus of the Fragile X Clinical & Research Consortium, the best guidance on behaviors in FXS can be found in the Treatment Recommendation:

Behavior Challenges in Fragile X Syndrome

<https://fragilex.org/wp-content/uploads/2018/12/Behavior-Challenges-in-Fragile-X-Treatment-Guidelines.pdf>

Medication

As a Consensus of the Fragile X Clinical & Research Consortium, the most current and up-to-date guidance can be in the Treatment Recommendation:

Medications for Individuals with Fragile X Syndrome

<https://fragilex.org/wp-content/uploads/Medications-Treatment-Recommendation.pdf>

Parent Comments

- It took a lot of time to come up with a daily schedule, but it was sure worth it in the long run.
- Sometimes I get lazy when it comes to the daily schedule, and when I don't do one, the perseverative questions start up right away. I do a schedule right away.
- We tend to encourage a lot of walks in the neighborhood. We are lucky to have a safe place for our son to walk any time he wants. Walking is also a calming activity for him.
- I know it is important to do chores, but it takes a lot of time to teach our daughter, and then to allow time for her to complete it. But I know it is best in the long run.
- For taking a shower, it was best for us to have a single handle to turn the shower on and off. You approach buying appliances completely differently when you think about making your son or daughter independent in using them.
- My son hates taking a shower, but when he finally gets in, he stays for about a half hour. We may have to start using a timer or he uses all the hot water.
- I really stressed having clean clothes and good hygiene when going out in public. I think that is so important for our children. Well, I am also big on “please” and “thank you.”
- We had a friend who was a pediatrician who said he would see my son forever. But one day when we called to make his annual appointment, they said that since our son has Medicare, that he HAS to go to an office that takes Medicare (which they didn't). The search began. I reached out to my friends and talked to lots of different people. A friend's son had just become a Physician's Assistant (PA) and had just started working in a local family practice office. And this PA knew my son. We lucked out.
- It is one thing to find a doctor but getting my son to actually go to the appointment is another story. Even a short appointment takes hours of planning ahead of time, to make sure things go smoothly.
- I am sure liking the telemedicine option for seeing the doctor. My daughter is much more receptive to that than an in-person visit.
- My son likes to take a can of sparkling water to the doctor when we go – it helps my son go right into the office. It is his favorite type of transition object.
- Finding a dentist or a dental hygienist who would take the time needed to work with my son took a lot of time and energy, but once I found someone, wow, she was wonderful, and the doctor ended up being amazing too.
- My son still needs to have anesthesia to have his teeth cleaned. As an adult it is almost impossible to find someone to do it, much less be able to afford it.
- We have found that eye doctors have been trickier to find. They think your young adult can read an eye chart correctly and that when they say, “1 or 2?” (showing different options for seeing) – that your child will be consistent.

- Anxiety is my daughter's biggest issue. Seems to worry about everything, all day long. It helps if I can get an issue resolved (like what we are having for dinner), but then she just moves on to the next thing (like what we are having for dinner the next night).
- I wished my son could enjoy the moment. It might be something he has been looking forward to for weeks, but when it happens, he is worried about the next thing coming up. I try to tell him – but I am having fun right now. Let's enjoy this. Then it is – sure mom, but what about...
- Wow, sensory processing issues. We have tried many of the de-sensitizing techniques, but nothing really seems to help. That is top of mind for us - for every place we go.
- My daughter just got married. She met the most wonderful guy. She is so happy.
- Some things about my son's behavior have improved with age, some things have not. It seems like he has good behavior most of the time, but 3 or 4 times a year we have a major outburst. I just worry about this for when I am gone.
- My daughter has so much anxiety. I try all the different strategies, but it is always there.
- I suppose my son will be on medications for his whole life – unless we get treatments for the missing protein of FX. That is what I am hoping for.

Resources:

Transition to Adult Services for Individuals with Fragile X Syndrome

<https://fragilex.org/wp-content/uploads/Adult-Services-Consensus-Document.pdf>

Treatment and Intervention Recommendations for Fragile X

<https://fragilex.org/our-research/treatment-recommendations/>

Webinar: Adults and FXS

<https://fragilex.org/webinar/aging-in-fragile-x-syndrome/>