



Transitioning to Adulthood Plans and Services for Adults With XXYY Syndrome

Part 7: Where Will He Live?

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Living at Home

What is there to know about living at home?

As you could see if you read Part 1 of this series, a large number of adults with XXYY are living at home with their parents. You might think that there is nothing to know about having your son live at home, but there are actually a few things you should know:

1. If you apply for SSI for your son at 18 (or at any age for that matter), and he will be living at home, you need to charge him rent. If you do not put that on your SSI application, his SSI check will be reduced significantly. (See the Social Security Section for info on calculating rent). You might say that it's "six of one, half a dozen of another" if his SSI is reduced compared to him paying you rent. But it is not. It is possible that something could change for you and you might not be able to support even that share that he is paying you for rent one day. It is also important because he is an adult, not a child, and for him to establish his own income and expenses and report that on every form you have to fill out to obtain help for him, having a rent expense is important.
2. If he is not going to be on SSI for some reason (and as we said previously, we really do recommend that you apply), then consider having him pay you rent as a way to help him to learn life skills. He needs to learn to budget and it's probably not a good idea to start him out thinking that you will take care of everything when he is an adult.
3. Even when he lives with you, he is an adult and considered to be his own "household." Your income has nothing to do with anything anymore. He is an adult.

Living at home is not a permanent solution

First of all, of course living at home can be a great option, at least for a period of time. Ultimately, though, it will not be an option for him to live with you permanently. Because of that, you need to prepare both him and you.

As we are sure you know, it takes some time for guys with XXYY to adapt to new situations and learn new skills. For some, the transition to living outside of your home could take him years of adaptation. It's not just about moving him from one house to another. Even if your plan is for him to move in with a sibling, there has to be some planning involved with that. That planning is about getting him accustomed to living elsewhere, no matter where that is. So part of your planning for transition to adulthood needs to include how to help him get used to living elsewhere, even while he is living at home. This means many things like having him stay with a sibling for a couple of weeks each year or having someone come in and stay with him at your house while you are away. In other words, help him get used to life without his parents. He needs that. You are not immortal and life can change on a dime. You need to know where he will go if there is an emergency, too. If you are hospitalized for a long period, for example, where will he be?

What to teach him while he is living with you

While your son lives with you, there are some things you can teach him that he will need to know if he is going to live independently. These are things that people don't think much about with their typical children. For some reason, our typical kids just figure these things out. Maybe they learn it by observation, who knows. They just do. But guys with XXYY don't learn that much by observation, so here are some great things you can teach him, day-to-day:

- How to turn the pilot light back on if you have gas and safety issues around gas heat and cooking. Many apartments have gas heaters and stoves. He needs to know about safety with gas.
- How and WHEN to call 911.
- How to use the security alarm system in your home.
- What to do if the smoke alarm goes off. How do you make it stop? Also, he needs to know that taking the batteries out is only a temporary solution!
- How to remember to turn off the stove!
- Home maintenance and repair.
- The laws about shoveling side walks and driveways.
- How to use the local bus system and how to call a cab (be sure he knows he needs money to call a cab!)
- Local geography. Where is your town, relative to the capitol city, what the counties are, etc.
- Door safety issues. (Not letting strangers into the house).
- How to deal with the police. What to say if they want to come into the house, what to say if they are questioning him, etc.
- Using the washer and dryer!
- What and what not to put into the garbage disposal.
- Where the police stations are located.
- What to do if he gets lost.
- The laws about riding a bicycle or motorized vehicle if he is going to have one.
- If he will drive, keep emphasizing driving laws.
- Where the nearest hospital is located.

There are probably hundreds of other things but just think about the things you need to know if you were to live alone and make sure he knows them. Don't assume that he does.

Living in a Supported Environment

What is a supported environment?

A supported environment is just a general term for a living arrangement for your son where he receives some level of supervision, help with activities of daily living like taking his medication and cooking and activities that keep him busy.

There are many different types of supported environments all over the world. They have names like host homes, group homes, shared living, assisted apartments, assisted living, domiciliary care, clustered living and so many more. Agencies tend to name their programs their own way. These types of environments have various levels of support and they look something like this:

- People come to his home to provide some care but it is not 24 hour care.
- Someone lives in his home with him and provides 24 hour care.
- An apartment community with other people with disabilities that has on-site, 24 hour staff.
- A family home that cares for only one or two people with a disability 24 hours a day.
- A home for a group of people with disabilities with 24 hour supervision.
- Another type of group residential community such as a ranch, farm or even a large home where only people with disabilities live and have 24 hour care.
- Institutional care. (Not really available in the U.S. except for temporary mental health facilities in emergencies.)

How do we get supported living services?

There are two ways to get and pay for these services:

- 1) Private pay, meaning you finance it all out of pocket and you find the providers. Some parents have even built these communities themselves with other parents.
- 2) You apply for and receive services through the social services, mental health or developmental disability service systems which are paid for through government social services programs. In the U.S., that means the Medicaid Waiver program. (Please refer to the Medicaid section of this series in the *Addressing his Medical Needs* booklet for an explanation of Medicaid waivers and the *Disability Services* booklet). In the UK and Germany, you access them through Social Services. Once you qualify your son for disability services, you are typically given access to a list of providers of these services in your area.

These services are very expensive and usually out of reach for typical families without government programs. They can cost as much as nursing home care, for example. That is why you need to apply for disability services if you or your son can't pay for them out of pocket. Please refer to the *Disability Services* booklet in this series for information about applying. You will also be restricted under government programs to the area in which your son lives because services are not portable between areas.

This is a great link that provides info for mental health supported living services in several countries:

Schizophrenia.com



Private-pay alternatives

There are actually many places that provide long-term supported living environments that you can pay for out of pocket. They provide 24 hour care in a nice environment. They vary in cost and some are very expensive, but we have also heard of a few that accept basically only your son's disability income and they raise the money for the rest.

Most providers of these services who accept Medicaid Waiver payments in the U.S. also accept private pay clients. But not all of these types of places accept Medicaid Waiver payments. You are not allowed to do both Medicaid Waiver and private pay together because your contribution is considered income, which would cause him to lose government support.

Here is a list of some of examples. The best thing to do is to search your own area and ask other local parents for some referrals.

[Devereaux](#)

Devereaux has residential facilities in CA, NY, PA and TX. They also provide community services for adults in CA, MA, NJ, NY, PA and TX

[Hattie Larlham Residential Services, Mantua, OH](#)

[NHS Human Services, Lafayette Hill, PA](#)

[Seven Hills Foundation, MA and RI](#)

[Foundation for Independent Living, Coconut Creek, Florida](#) One of our XXYY families helped to create this community.

[Supported Living, NSW, Australia](#)

[Community Living Options, Victoria, Australia](#)

[Center for Independent Futures, Evanston, IL](#)

[People, Inc., Buffalo, NY](#)

[Buckalew Services, Northern California](#)

Camp Hill has communities around the world:

[Camp Hill Communities in England and Wales](#)

[Camp Hill Communities of North America](#)

[Camp Hill Communities World Wide](#) (Africa, Asia, Europe, North America, UK and Ireland)

We are providing this information to give you ideas. We cannot endorse any of these places because we do not know them. Listing them does not imply endorsement, even if an XXYY family is involved with it. We have not talked to any of these organizations.

Unique approaches and settings

There are a lot of people in the world trying to solve the problem of long-term living for people with disabilities. They envision ranches, sustainable communities, religion-based communities and more. Here are a few of them so you know what we are talking about. There's a chance that some of these will be working with Medicaid Waiver payments but if your son doesn't qualify for that, then most likely you would be able to pay out of pocket.

[Tall Tales Ranch, Centennial, CO](#) (Not open yet)

[Triangle Cross Ranch, Colorado Springs, CO](#)

[Sunflower Hill, Pleasanton, CA](#) (Not open yet)

One of our XXY mom is on the board of directors for this new organization. It will serve people with Autism.

[Community Living Project, South Australia](#)

[New England Village, Pembroke, MA](#)

[15 Farms and Ranches for People with Disabilities](#)

There are also religious organizations that have communities for people with disabilities. You will find similar services to these examples in virtually every state:

[Jewish Family Services, Milwaukee, WI](#)

[Lutheran Family Services, of Virginia](#)

Shared Living

Shared living is a concept we've heard a lot about and there are a lot of resources on it as well. Here are some links about Shared Living:

[Shared Lives Plus, United Kingdom](#)

[Shared Living Advocates, Framingham, MA](#)

[National Shared Housing Resource Center \(All US States\)](#)

[Community Bridges Shared Housing Program, Concord, NH](#)

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Living Independently

What do we mean by independent living?

The answer to that question isn't as obvious as you may think. We have guys with XXYY who live outside of their parent's homes who are receiving government disability income and receiving some services to help them to be able to live on their own. We also have some guys who are living completely independently without services. (Basically, they are living fairly typical lives and a booklet like this isn't really needed for them). But we need to tell you that the number of adults with XXYY that we know who are living completely independently is small. Even many who answered our survey who stated that their sons are living independently are often receiving services.

In order to achieve the most independence possible for your son with XXYY, there are many steps outlined in this entire series of booklets because he has to have an income, medical coverage and possibly services to live independently.

Financing an independent living situation

The second greatest hurdle to independent living (besides whether or not your son needs some level of help or supervision) is how to pay for it. If your son is receiving government disability benefits and that is his only income or if he is only able to work part-time, it can be a huge hurdle, in fact. But it is not impossible and finding a permanent solution is also possible. Remember that if he is on government benefits you cannot contribute any cash to help him or he will lose his benefit as well as his medical benefit. Any money you contribute is considered income. So we are going to give you as many resources and ideas that we know about to help you figure out how to accomplish independent living, by finding the ways to pay for it with the money he has.

Keeping in mind that your son not only has a disability, but he is technically a low-income person, he qualifies for programs for low-income people as well.

Renting an apartment/room/property by himself with little assistance

In some places, it is possible to pay for an apartment or other property with only a government disability income like SSI or part-time employment income. It all depends on the cost of rent in your area vs. what he is receiving in income. This is all simple math, really. Sometimes, applying for other government assistance, such as Food Stamps (now called SNAP) and energy assistance payments (which help pay for utilities in the winter), can be enough to make everything balance. We have had parents who have done this. It is not easy, but it is do-able in some places.

You may also be able to find a room that he can rent. This is probably best done through people you know pretty well.

Roommates and roommate programs

Connecting with local parents of adults with disabilities through support groups is a way to find a roommate to share the cost of housing with your son. If your son can live with a roommate, it is a great option for both parties. Some communities also have programs like this one in Colorado:

[Personal Affordable Living, Inc.](#)

The above program has some serious limitations, however. If your son has behavioral problems, this type of program won't work.

[National Shared Housing Resource Center](#) may be another resource for roommates.

If your son receives other services through the developmental disability service system, tell your case manager that you are looking for a roommate. They will tell their other clients about it.

Government subsidized housing

There are housing programs for low-income people that your son can qualify for. These programs are accessed through your county social services agency. Through social services, he can receive two types of housing:

- 1) Project-based housing—is an apartment community for low-income people. One of the problems with this housing is that there are quite a lot of rules your son must follow in order keep his apartment there. This has posed problems for some of our adults with XXYY.
- 2) Housing Voucher—Housing vouchers can be used to rent any home or apartment where the landlord accepts a voucher.

What these two programs do is the government pays the landlord a share of the rent and the rest is paid by the tenant. It reduces his rent by a lot, making his money go farther.

There are waiting lists for this housing and they typically only open up for applications at very specific times. You have to get the application in during the window when they are open for applications, which can be hard if you don't know when that is! It is also sometimes very difficult to find out which landlords will take a housing voucher.

We have found similar programs in the UK, called [Council Housing](#).

If you do not live in the U.S., google subsidized housing and your location to find it.

[Housing Justice](#) has some great information on their site about finding housing

[Independent Living Centers](#) (world-wide) has resources:

[Mencap](#) booklet on Housing (UK, pdf file)

Purchasing a property

There are three types of programs that will give you the opportunity to purchase property where your son can live. These are pretty exciting programs and not many people know about them:

- 1) Housing and Finance authority—each state has a Housing and Finance Authority. Some, if not most of them have a special program for people with disabilities to purchase a home (even if they are on SSI). They provide down payment assistance for the purchase and your son would qualify for the loan on his own. The down payment assistance they provide typically doesn't have to be paid back until/unless the home is sold. The property also does not count against him as an asset for Medicaid.
- 2) Section 8 voucher home purchase program—This is a program that utilizes the section 8 voucher to help a person to buy a home. It is available through your local Housing and Finance Authority. Your son has to have a Section 8 voucher to qualify for this program, however.
- 3) Family Opportunity Loan Program—This is a mortgage loan program for parents of adults with disabilities that is available through regular lenders. It's a U.S. government program from Fannie Mae (although it is hard to tell that when you do this). This program allows the parent to purchase a property as an "owner occupied" property, rather than an investment property. This distinction makes a huge difference in how much you have to put down on the property and what properties are available to purchase. The down payment can be really manageable for parents. Then you rent the property to your son. The link below describes the program but please know we are not endorsing the company that posted it. It's just a good description of the program and its requirements:

[Family Opportunity Loan Program](#)

There are some nonprofits that help people with disabilities and their parents to find the right program to purchase a property. Here are some links to some of them:

[HERO Alliance, Colorado](#)

Habitat for Humanity may also have a program that helps people with disabilities. Contact your local Habitat for info.

This is a great link all about home ownership for people with disabilities

[Disabled World, house purchase info](#)

You can also consider downsizing your own home, with a plan for your son to continue living there after you leave to enter assisted living of your own or after you pass away. This way, your son can continue to live with you but you have a plan for where he will live when you are gone. You can access disability services for him while he lives in your home which could be increased when you are gone.

Transitioning to Adulthood is a series of booklets prepared by Renee Beauregard of the XXYY Project. This is an excellent summary of steps that parents/guardians of young adults with developmental disabilities must consider in preparing for their entry into the adult world of employment and independent living.

The recommendations are focused on young men with 48 chromosomes, rather than the 47 that describe the trisomy X/Y variations (Klinefelter syndrome, Trisomy X and 47,XYY.) For this reason, not all of the assumptions regarding functioning level will apply to all young people with X and Y chromosome variations. Take this into consideration when reading through the sections.

For more information on AXYS and on the XXYY Project, a project of AXYS, please visit <http://www.genetic.org> and <http://www.xxyysyndrome.org>
