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# **Transitioning to Adulthood Plans and Services for Adults With XXYY Syndrome**

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## **Part 5: Addressing His Medical Needs**

# Part 5: Addressing His Medical Needs

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# Transitioning to Adulthood Plans and Services for Adults

## List of all booklets in this series

Booklets in the Transition to Adulthood Series are as follows. You can click on the titles to be taken to the one you want to read. Orange indicates where you are now.

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- What to do in the years before he turns 18
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- Protect him from what?
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- What to do if he never got or lost benefits or services

# Health Insurance

## Health Insurance

In the United States, the health insurance system is fairly complicated, especially for a person with a disability. If your son will need community services, he must be on Medicaid to receive those services. If he does not work full-time, he may not have medical insurance through work. While some things have changed in the U.S. because of the Affordable Care Act, there are still steps to take in order to keep your son insured. We know that we have adults right now who do not have medical coverage, too, so we will explain how to get it.

### **About the “regular health insurance” vs. “Medicaid” issue**

Lots of parents don't apply for Medicaid for their adult sons because they already have health insurance. What you don't realize is that your son can have both and having both is very beneficial. When you have both, your primary insurance is the “first payer” but Medicaid picks up everything else. In other words, your son will never have a medical bill. The only caveats to this are that you have to use Medicaid-accepting doctors and hospitals and you have to use Medicaid-approved drugs. That isn't always easy. But you have to remember that your son is an adult now and these are his bills and his money, not yours. As we have also said, Medicaid pays for services. We will explain more in the Medicaid section.

### **Employer-based health insurance**

Under the Affordable Care Act, any of your adult children can stay on your health insurance policy until they are 26 years old. Once your son with XXYY reaches age 26, you can usually still keep him on your insurance, if you contact them. You need to provide information to your insurance company that your son is an adult disabled dependent. All you need is information from a doctor to do it.

There are also a few employers who allow part-time workers to be on their employer-based health insurance plan. So in terms of working, if your son can work for one of those companies he can have health insurance from work if he is unable to work full-time.

### **Affordable Care Act Insurance Plans**

If you do not have an insurance plan that your son can be on, it is an option for him to obtain insurance through the exchanges under the ACA. Every state is different in terms of where to go to apply. You either go to the government Web site or to your state's exchange Web site.

Here is what you need to know about this:

A person has to meet a minimum income threshold to qualify for an ACA plan through the exchange. That means if your son has no income (SSI doesn't count), he cannot get a plan of his own through the ACA. The alternative is either a private insurance option or Medicaid or both.

### **Private Insurance Plans**

Anyone can buy private insurance using an insurance broker. These plans are all governed by the ACA, which means your son can't be turned down because of a pre-existing condition. Without any subsidy or employer contribution to the plan, they are expensive and most likely out of reach for adults with XXYY but there may be some out there who need this and didn't know this was an option.

### **Medicaid (some states name their own Medicaid program, like Medi-Cal)**

Medicaid is *extremely* important to every person with a disability. It not only pays for medical care, it also pays for long-term care and community services. In other words, if your son needs to live in a supervised home or if he needs a job coach through the developmental disability service system, Medicaid is what pays for it. We will explain how that works as well.

In some states, a person automatically qualifies for Medicaid and is put on Medicaid when they are approved for SSI. In other states, you have to apply separately. If your son was on Medicaid as a child, he will most likely just stay on it as an adult. What is important for you to know if he was on Medicaid as a child is that as an adult, the assets threshold immediately applies. So make sure he still meets the asset threshold or you will lose Medicaid until his asset is paid down. This is very important if he gets a back payment from SSI.

You apply for Medicaid through your county social services office. Every state does this the same way. While you are at it, you can also apply for "Food Stamps" for him. That program is actually now called SNAP. Some social service offices might do it automatically or in just one application.

Your son must qualify for Medicaid every year. You will receive paperwork that you must return in order to keep him on it. And Medicaid is notorious for getting things mixed up and suddenly you get a letter that says he lost it out of the clear blue sky. Always call your case manager immediately when you get a letter like that. It's almost always some kind of error on their end. Sometimes, you can figure out how it happened before you call.

Your son will stay on Medicaid until the following things happen:

- He gets a job that puts him over the income/asset limit
- You or his other parent become disabled and go on SSDI (so long as you made sure that Social Security knew that he is an adult disabled dependent). Once you or the other parent are on SSDI, you will both be put on Medicare. There is a waiting period, which can be very difficult.
- You both go on Medicare at 65 (so long as you made sure that Social Security knew he is an adult disabled dependent).

He will still keep a form of Medicaid that pays for services, however.

*Health insurance (continued)*

### How Medicaid Pays for Services for People with Disabilities

This section ties into the booklets *Where Will He Live* and *Disability Services*. The systems that provide those services bill Medicaid for the services, even though they are not what you might perceive as medical services.

There are two elements to the services Medicaid Waivers pay for:

1) Intermediate Care Facilities (ICF)

ICFs are what you know of as “institutions.” All people who qualify for ICFs (we will tell you about qualifying for that in the booklet *Disability Services*) are entitled to ICF care. The word “entitlement” is an important distinction here. It means the government must pay for it through Medicaid and your son must have it if he needs it. Your son must also qualify for an ICF before he can get the “lesser” level of care:

2) Medicaid Waiver Services

Medicaid Waiver services are community-based programs. When you opt for a waiver, you are “waiving” your son’s right to the entitlement care (ICF) in favor of community-based care.

The thing is, because of a law called the Olmstead Act, all institutions are closing in the United States. In fact, many states do not have them at all anymore already. There are even some places that housed large numbers of people with disabilities in large communities that can no longer receive payments from Medicaid because they are considered to be ICF facilities. It also means that states are moving people who have severe behavioral problems out of ICFs and into community-based care (group homes, etc.) There may still be some other ICFs, such as nursing homes.

*Who cares? What does that even mean? Nobody likes institutions anyway!*

What it means is that people with disabilities are not entitled to Medicaid Waiver Services. That means that the government (state governments) are not required to have Medicaid Waiver programs (but they all do). It also means that they are not required to adequately fund them (which they don’t). So that means **waiting lists**.

The only state that is an exception that we know of is California. California has a law called the Lanterman Act, which made Medicaid waiver services entitlements in California. That means that a person must receive services when they need them, without waiting lists. It also means that the state is required to fund the program, even though California of late has NOT done that. (The legislature sets the budget and the California legislature has not adequately funded the waiver program. This was in the news in 2015).

States pay for part of the Medicaid waiver program and the federal government matches that funding. The more the state funds them, the more money they get from the federal government. This is why the services vary drastically from state to state.

*Health insurance (continued)*

*Why is any of this stuff about waivers important to know?*

It's important to know because this could be your son's only funding source for services and specifically for homes where he can receive 24 hour care, or drop-in care and other great services that he might need. When you understand how it all works, it empowers you. You know the lingo now. You know the rules.



It's also important because it means that all of your son's services are state-based and they are **not** automatically transferable to another state. If you or he has to move, you have to start all over again in another state and that means you go to the bottom of the waiting list again.

In the *Disability Services* booklet, we will go into detail about how to qualify for services through the Medicaid Waivers.

We also know that similar things are true in other countries, such as Canada, where medical and community services are all province-based and quite similar to the U.S. In the UK, we know that everything that families have access to is different from one area to another and can be different outside of England.

*What else does Medicaid do?*

Since each state's Medicaid program is determined by the state legislature, the benefits are also different. There may be other benefits in what is called your Medicaid State plan. Some of them provide services that are not included in the waiver. In some states, Medicaid also has a dental benefit for adults. Some states also have a Medicaid buy-in program for adults with disabilities who are working to buy into Medicaid.

## **Medicare**

Your son will move onto Medicare when you or his other parent does (whomever is oldest), but only if you had him tied to you both as an adult disabled dependent when you applied for SSI or when you contacted SSA later to make sure that he is.

About divorced parents and parents who aren't "involved": This is where this gets sticky. Your son should be tied to both of his legal parents. If his other biological parent is older than you are, he could miss out on getting Medicare (and Social Security) sooner if he is not tied to that parent with the SSA. Please call the SSA or make sure when you apply for SSI for him that they know who is other parent is. Medicare is much better than Medicaid alone. His Medicare premium and copays will be covered, too. Make sure you do this!

## Medical coverage in other countries

Many families in our group live in countries with socialized medicine but some countries have some different, hybrid systems. We do not know the systems in all of the countries but we invite you to tell us more about how your son is covered. The following are links to information about medical coverage in several different countries. We want to encourage our members in other countries to still read through the U.S. information and use any info that can be helpful for obtaining the medical coverage you need. This may not be much of an issue for people in some countries.

### [Health Care Systems Around the World](#) (pdf)

Covers: Canada, Denmark, France, Germany, Israel, Japan, the Netherlands, Sweden, Switzerland and the United Kingdom.

### [International Health Care Systems](#)

Covers: Japan, Turkey, the Netherlands, Australia, India, Brazil, Germany, China, United Kingdom, Canada, Sweden



# Changing Doctors

## **Changing Doctors**

Changing from pediatric doctors to doctors for adults is not that easy, we know that. Your medical insurance and Medicaid or country-specific health services will dictate where you can actually go for your son's care.

The two main areas where you have to have new doctors are for primary care and endocrinology. Finding doctors who have relevant experience to manage XYY is tough. Here are a few suggestions.

### **Primary Care doctors**

First, we will say that it's not actually *that* important for your primary care doctor to know much about XYY. Primary care doctors deal with day-to-day illness like the flu and sore throats. If you can't find a primary care doctor who has ever even heard of XYY, it's really not the end of the world, provided that you educate the doctor, know what you might be dealing with in XYY and that you visit one of our clinics, which we will talk about later. Give your primary care doctor the research info we have.

Parents have had success in finding new primary care doctors in these ways:

- Asking your pediatrician for a referral to someone they trust.
- Calling your local autism, Down Syndrome, Fragile X or other group for recommendations.
- Connecting with support groups for parents of people with disabilities and asking other parents for local recommendations.
- If you have an AXYS support group near you, join it and ask the members of that group who they would recommend locally.

If your son is on Medicaid or other government health plan, your list of doctors will get much smaller. There are some areas where there are Medicaid clinics specifically for people with disabilities.

### **Endocrinologists**

There is a shortage of endocrinologists in the U.S., making it very hard to find one that is accepting new patients, has any related experience that is helpful and accepts Medicaid. Parents have had success in finding new endocrinologists for adults in these ways:

- Through university hospitals. Just ask them if they have had any Klinefelter patients. That's usually enough experience for an endo, but not always.
- Through AXYS members and eventually through a database that AXYS is developing.
- Through some of the same methods as above for primary care doctors.

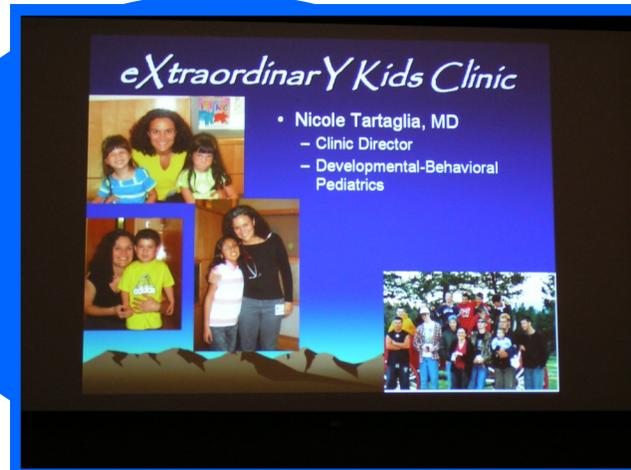
Endocrinologists also do not necessarily need specific experience with XYY. As long as they have had Klinefelter Syndrome patients, it should be OK, but you may still need to provide them with more education. Our clinic consortium, outlined later, will develop some treatment guidelines for XYY that will help with this.

## **X & Y Chromosome Variation Clinics are Key**

Now that the XXYY Project is tied closely with AXYS, we are also involved in the clinic consortium, which is working to open more X & Y chromosome variation clinics for both children and adults. Right now, these clinics are in the United States, but there is no reason that clinics cannot be opened in other countries as well. The clinic consortium will be developing standards of care for XXYY and all of the X & Y chromosome variations, too, so no matter where you live you will benefit from them.

The clinic in Denver is still the main hub for XXYY treatment and Dr. Tartaglia will see XXYY adults of any age there, even though it is at a Children's Hospital. The clinic consortium is working hard to make sure we have some clinics for adults as well.

These clinic openings are moving very quickly as this paper is being written. We will keep you informed about them and AXYS will have a special Web site where you will be able to access information for all of the clinics.



### *Why is it important to get to a clinic?*

Do whatever you have to do to get to one of the X & Y specialty clinics. They will do psychological testing as well as provide treatment plans that you can take home to your own doctors. You should go at least one time and hopefully more than that if you can but you don't have to go really often. The Denver clinic has seen XXYY families from all over the world.

### *Do you know doctors who might be willing to open a clinic?*

Parents are behind the opening of all of these clinics. In fact, we may end up recruiting you specifically to help with the effort in your area. But if you know a doctor or group of doctors at your local Children's Hospital, University Hospital or General Hospital who seem to be working with a lot of people with disabilities, tell them about the clinic consortium. Then, send us their information.

## **Mental Health**

An important part of the team for your adult is a good psychiatrist with experience with other conditions such as Fragile X, Autism or other intellectual and developmental disabilities. Those with experience with other mental health conditions and co-existing behavioral issues can be of great value as well. You may need a psychiatrist to prescribe medications or to help your son to understand his disability.

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**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>

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