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

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## **Part 3: Protecting your son from trouble: victimization, fraud, & *himself***

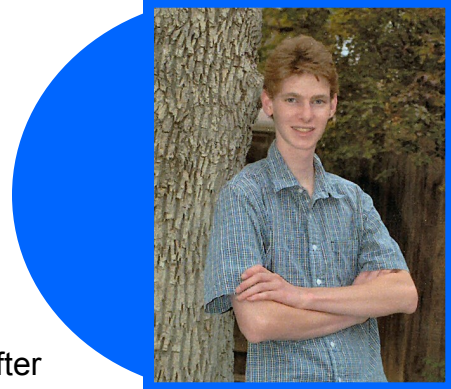
# Part 3: Protecting your son

## From victimization, fraud, trouble & *himself*

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## Protect him from what?

The photo to the right is of a teenager named Jason Holly. Jason had Klinefelter Syndrome, but his issues were extremely similar to our teens and adults with XYY.



Jason was murdered in 2009 for his video game system. His mother, Jan, told us that Jason had been acting very strangely before he disappeared. He had made some comments about some people who were after him. He had been hanging out with the wrong crowd, who threatened to hurt his family if he didn't do what they said. So he brought them his video game system and they killed him. He was missing for some time.

Jason had extremely poor judgment, which is one of the greatest hallmarks of boys and men with XYY—something we have in common with Jason and how KS affected him.

Jason's story is only the most extreme story we can tell you because he was murdered. Other than that, everything about his life overlapped with our lives and with the issues faced by teens and men with XYY. They will do anything for a friend. They cannot tell if someone is a threat to them. They hang out with the wrong crowds. They will take off in the car and head to California to meet some girl they met online.

Whatever you can think of can happen. Whoever you might think could take advantage of them, they will. **They need protection.** Your son needs protection from *himself*, basically.

## Are we trying to scare you?

We are trying to make sure that you are as proactive as humanly possible to help you to avoid massive problems and heartache. We have no other goal.

## But you need to know this:

We know things about the circumstances of many of our adults with XYY that you do not know. Things that parents of adults come to us with that you don't know about. We can't go through all of their personal situations in this booklet for many reasons. So, on the following pages, we are going to ask you to follow as many of those instructions as you can, to help prevent some situations that our adult guys have gotten into. Their parents had no idea that they would face the situations they have had to face. But now you do. Even if you think your son doesn't need "that," do it anyway.

The way we will know if we have been successful with preventing disaster is by the number of problems our guys have in the future compared to today.

## Please take our word for it

As one mom said in our survey about adults with XXY, her best advice for future planning was this: “Imagine the worst as vividly as possible.” And then do your level best to protect your son from that. Here, we are going to tell you what to do but not why. You are going to have to take our word for it and read between the lines.

### Have a good attorney

Find one you can trust who can help guide you if you have a problem and refer you to another attorney if your son gets into trouble.

### Batten down the Internet

- Tight as a drum. This is especially true for adults.
- Make SURE your son knows that just because something is ON the Internet, that does NOT make it legal. And just because “other” adults access certain things on the Internet, that does NOT mean he can.
- Tell him every story you can think of about bad people who are on the Internet, especially “love interests.” Tell him he must NEVER believe anyone who tries to entice him on the Internet. Tell him he can ask YOU any time he wonders if someone is being forthright on the Internet. Make it safe for him to tell you.
- Don’t forget his phone access to the Internet.
- NEVER encourage online relationships. Tell him people lie about their age.
- Make sure he knows that nothing is ever permanently erased from a computer.
- Explain to him how the police, FBI, CIA, Scotland Yard and other law enforcement and government are also scanning the Internet and can watch anyone, any time.

### Find a way to make certain you know who his “friends” are

- Ask frequent questions about who he hangs out with.
- Ask him where he met each friend. Write down all of their *real* names.
- Tell him you must meet his friends in person.
- Ask him *often* where his friend lives and where his friend’s parents are.
- If he is living on his own, drop in at his place.
- Know where he goes with his friends.
- Ask him *often* the age of each of his friends, especially females.
- Teach him how to “card” his friends to ensure that they are over 18.
- Make certain that he knows that he cannot hang out with people who are under 18 under any circumstances.
- Find out all you can about the pasts of these friends.

### Pay close attention to money and valuables

- Keep track of his belongings and medications that have financial value.
- Give him things that he wants, rather than money to buy things that he wants. Give him enough money to satisfy him, but not too much.
- Make sure you know where he is spending his money.
- Prevent him from spending money on “vices” as much as possible, especially gambling if he has very little impulse control.
- Keep track of YOUR money, medication and belongings.

## Please take our word for it (continued)

### Watch his behavior carefully

- Keep a journal of his behavior. If he starts behaving differently, take him to a therapist or doctor.
- Keep track of the “stories” he tells you, especially when it comes to where he was and who he was with.
- If he tells you things along the lines of secrets he can’t tell you or he seems to censor himself a lot, take him to a therapist quickly.

### Teach him everything he needs to know about interacting with police

- Teach him his rights—when he can talk and when he should not talk. Do some role play. Teach him how to say “I want to talk to my attorney” and “My legal guardian should be here.” Give him a card that he can hand to police.
- Teach him how to approach the police (we are talking about physical demeanor).
- Make sure he understands what can happen if he runs from the police or has a meltdown with the police.
- Tell him that if he does not know if a story he is about to tell the police is absolutely true, he should keep his mouth shut.
- Get to know your local police officers. Make sure they know he has a disability.

### About cars & driving

- We have a separate booklet about deciding if he should drive at all. Just because he might be able to operate a vehicle, it doesn’t necessarily mean he should drive.
- Check the mileage on his/your car after he goes out with his “friends” or if he is gone for a long time. Match the mileage up with where he told you he went.
- Check the inside of the car for bottles, receipts, and other telling trash.
- Ask him if he gives rides to people. Ask him who they are. (See friends list).

### About weapons

Because of the intensely political nature of firearms ownership in the United States, we won’t say anything about whether or not it is safe for him to know how to use or to own firearms. But we will say this:

- Since firearms are easy to get in the U.S., you need a plan for dealing with them.
- Make sure he knows what’s legal to carry and how (concealed, open).
- Don’t forget about knives, ninja stars, crossbows and other types of weapons. Several of these (or types of them) are illegal to have in public.
- Make sure he knows that paint guns are only for limited use at paint gun facilities.
- Inform him about “Make My Day” laws in your state/city, especially if he lives on his own. Lots of people think that they have Make My Day laws when they don’t. Ask a police officer about it.

### Teach him the proper use of 911 (calling ambulances and police)

- When to call, when NOT to call (and what happens with false alarms).

# **Guardianship/Conservatorship**

## **What is guardianship/conservatorship?**

We cannot give you legal advice of any kind so we will first refer you to some great Web sites that explain guardianship.

### [Guardianship Alliance of Colorado](#)

Although they are in Colorado, and guardianship/conservatorship is different in each state, they have a lot of great materials. If you live in Colorado, they can help you with guardianship as well. Check to see if there is a similar organization in your state.

### [When Your Child Turns 18: A Guide to Special Needs Guardianship](#)

### [Legal Guardianship booklet by Family Connections South Carolina](#)

Guardianship helps you to protect your son from many things. It says, basically, that someone else is in charge of making decisions for him because he is unable to make those decisions. That means, for example, that if he signs a contract, you can get that contract rescinded because he was not mentally capable of signing it. If a person has a guardian, medical professionals have to talk to the guardian as well. Otherwise, they do not have to talk to anyone other than the patient.

## **How is that different than power of attorney?**

There are many Web sites that explain the difference between power of attorney and guardianship. Here is one basic one from an attorney:

### [Power of Attorney vs. Legal Guardianship: What's the Difference?](#)

Power of attorney can be helpful, but it does not have the kind of "clout" that guardianship has.

## **State differences**

There are differences in guardianship/conservatorship state by state. We have learned from parents that some attorneys strongly discourage guardianship in certain states because the state is very restrictive. If you cannot get guardianship or conservatorship in your state, talk to an attorney about what else you can do. Unfortunately, nothing else is as strong as guardianship when it comes to protecting your son from himself.

## How do I know if my son needs a guardian/conservator or power of attorney?

**Best answer:**

**It is *always* best to err on the side of caution.**

None of these decisions about guardianship/conservatorship or medical and financial power of attorney has to be permanent.

We can tell you that if you do not have any of these, there are many professionals who do not have to talk to you or consult you about decisions concerning your son if you do not have legal authority to do so. This includes the police, medical professionals, psychiatrists and others. It also means that your son can sign contracts that you cannot reverse if you have no legal standing. This includes credit cards, cell phone contracts, time shares, bank accounts and virtually anything that someone might try to sell to him.

That said, 33.3% of our adults whose parents answered our survey do not have a guardian/conservator or any other such protection outlined. In many of these cases, it is because they are able to make their own decisions and they do consult with their parents. In others, it is simply because the water is over the dam already. But this approach can be risky.

Factors involved in making these decisions:

- How apt is your son to be taken advantage of by others? Could someone convince him to sign a contract for something he cannot afford? What if someone moved into his house without his permission?
- Can he fully manage his own money without anyone taking it away from him? Would he remember to pay all of his bills? Would he use his rent money to buy some other frivolous item?
- How likely is he to get in trouble with the police? If he were arrested and interrogated, how much would he incriminate himself? What if he were taken by the police to a psychiatric facility? What behaviors does he have that could get him arrested?
- Is he able to manage his medical appointments and decisions about his health and treatment? If he were taken to a hospital, could he give the doctors accurate and complete information about XXYY and any of his other conditions, related or not?
- Can he be trusted to manage his own medications, especially those which are controlled substances?
- Would he run off and get married?

You can reverse the protections you have in place. But you can't reverse the harm that could be caused to him if something happens that could have been prevented by having the right legal authority to make decisions and to protect him.





## **Other Ways to Protect Him**

## What are some other ways to protect him?

There are other things that can protect your son and *you* from disaster. Some of them apply only in particular situations, but they can be helpful anyway.

### Co-sign on his leases

If your son is going to live on his own in an apartment or home, it's really important to be able to protect him from squatters. Squatters are people who will move into his place and stay there without paying rent or buying food. Believe it or not, you have no authority to throw someone out if they are squatting if your son invited them and wants them to be there. So you need to plan for this before he moves into any rental. The way to protect him and you is to make sure you are on his lease agreement. (Yes, it is also a risk to be on his lease). But when you are on the lease, you can throw the bums out. :-)



The second way to prevent squatters is to own the property yourself. If you own the property, you can call the police to have them removed for not paying rent—to YOU. Yes, sometimes squatters will pay your son to live in your property and of course your son will happily take their money and never give it to you. That doesn't count. Make sure you have a lease agreement with your son to show that nobody else is on the lease.

### Security freeze to protect from identity theft

Protecting your son from identity theft is something people sometimes don't think about because they have so few assets sometimes, who would want to steal his identity? Well it turns out, lots of people do. Some states have what is called a "security freeze" that can be placed on his credit report. It prevents anyone from pulling a credit history, which means if he or someone else tries to open a credit account in his name, they won't be able to do it.

### Representative payee to manage his money

Becoming his representative payee is very important. Provide him with some cash after his bills are paid, but keep it to small amounts. As he becomes more responsible, you can adjust as needed.

### Never give him large amounts of cash

Meter out his money according to the budget for food and spending money. Pay his bills for him and then give him what he needs for his essentials. Some parents use pre-paid credit cards with limits to do this when they live independently. Grocery store gift cards are great to ensure that he spends his food money at the grocery store.

### **Hold all his important documents**

To prevent identity theft and loss of important documents like social security cards, hold on to his documents for him.

### **Netnanny**

The Internet poses some serious threats to some of our adults who lack judgment. Once your son turns 18, anything he does on the Internet out of “curiosity” or to connect with “friends” could pose a serious threat to him. We recommend that you have software on his computer that will prevent him from going to certain places on the Internet.

### **Personal Safety**

The XXYY Project has worked with the Kidpower program in the past. It is a great program that teaches personal safety. They now have a book that you can buy: [\*The Kidpower Book for Caring Adults: Personal Safety, Self-Protection, Confidence, & Advocacy For Young People\*](#)

KidPower also does workshops. You can also sometimes find workshops through an Arc in your area.

### **Food safety**

Food safety is really important if your son is going to live independently. We found the following comprehensive curriculum for food safety that can help you to make sure that he knows the most important things to prevent him from food-borne illnesses. Sometimes they learn these things in school and in transitions program but this is just to make sure.

[\*\*Food Safety Smart \(pdf file\)\*\*](#)

### **Landlines are still important**

If your son will be living independently, it is still important that he have a landline in his home for 911 calls. You can use VOIP and register the number, but the most important thing here is that you do not just count on his cell phone, which can run out of battery charge.

### **Cell phone GPS locator devices**

There are apps on cell phones that enable you to track the phone. This is useful if your son were to get lost or if he was out of contact for a while and you needed to find him.

### **Emergency evacuation, fire safety, etc.**

Make sure he knows how and when to evacuate his place in the case of emergency or fire.

# **Disability Rights & Resources**

## Where to go if you need help

There are many circumstances in which you may need help to fight for your son's rights. There are probably more examples than we can even think about. We want to provide you with some excellent resources for those times when you need an advocate. We have tried to cover the countries where the majority of our members live if we could find them but there are also listings for international resources.

### **International Resources**

#### **[International Center for Disability Resources on the Internet](#)**

This site has a wealth of information for our members across the world.

#### **[Independent Living Centers, listing of disability groups around the world](#)**

Not all of the listings are disability rights groups, but you will find them here.

#### **[Self Advocacy.net](#)**

Lists self-advocacy groups for people with disabilities in many countries

### **Australia**

#### **[Disability Advocacy Network Australia](#)**

This site lists disability advocacy organizations in every state or territory in Australia. They would be a central resource for you to find an advocate.

#### **[People with Disability Australia](#)**

Among other things, this organization provides rights-related information, advice and referral services for people with disability and their associates.

### **Canada**

#### **[Council of Canadians with Disabilities](#)**

This is a national Canadian disability rights group with affiliated organizations. Go to "Member organizations" on the left side to find the one near you. These organizations provide 1:1 assistance if you need help to apply for and appeal the denial of provincial and federal (Canada Pension Plan [CPP-D]) disability benefits. They should be a go-to source for you for referrals if you have any other disability rights questions.

#### **[ARCH \(Ontario\)](#)**

ARCH is the disability law center for Ontario. They also have a list of other disability organizations all over Canada on their site. We were not able to find a similar organization in other provinces nor a connection to any national network but we would encourage you to contact them no matter where you live in Canada to get a local referral.

#### **[Disability Policy Alliance of Canada](#)**

Here, you will find information on disability rights in Canada for your reference.

*Where to go if you need help (continued)*

## **United Kingdom**

### **[Disability Rights UK](#)**

This organization has a wealth of information on personal budgets in the UK disability system and so much more. They operate help lines for each aspect of your son's needs and services including information on independent living. They also list organizations all over the UK. This would be a go-to organization when you need 1:1 advice and referrals.

### **[United Kingdom Disabled People's Council](#)**

This organization is a broader type of advocacy group, working on the rights of people with disabilities on a national level. Therefore, they probably do not offer much in the way of individual help. However, their site has a lot of information about rights.

## **United States**

### **[National Disability Rights Network](#)**

Disability Rights Network organizations exist in every state in the U.S. They all have different names but they are all affiliated with the national group. This website will link you to the one in your state. Even if your situation does not exactly match what they do, they may be able to refer you to who can. This organization can help you if your son was denied a service that he has a right to have and situations where there is a problem with state-run services such as Vocational Rehabilitation, Medicaid Waiver problems, problems with services providers paid by the state who have abused your son or who have not accommodated him like they should. This resource is extremely valuable and has been successfully used by other XXYY parents.

### **[The Arc](#)**

The Arc is probably the most well-known disability rights advocate in the U.S. This site will lead you to the one near you. Contact the Arc when you need an advocate and ask them for referrals for basically anything that you need to find locally. The Arc will often help you 1:1 when you need an advocate.

### **[Department of Justice, Guide to Disability Rights Laws](#)**

This guide gives you information on your son's rights as a disabled person. Of particular interest to the XXYY community is the section on employment rights.

## Protecting your son at work

There are two areas we want to cover when it comes to protecting your son at work.

### Accommodations

Several parents commented in our survey that employers often did not accommodate their sons very well. Keeping in mind that an employer cannot and will not make disability accommodations they don't know about, it is important that the employer know that your son has disabilities. Keep the information provided to the employer on that limited to things that impact work. For example, if your son has a learning disability, tell that to the employer. If he has health issues that may cause him to spend a lot of time in the restroom, you need to somehow tell them that. If your son cannot stand for long periods of time because of joint and back problems, tell them that. You don't necessarily have to tell them that he has XXYY. But trouble may come if you do not tell them anything at all. We believe that more of our adults would be able to maintain employment if their employers knew they have issues.

### Bullying and harassment

Even in the world of adults, bullying and harassment are issues that everyone faces but in particular our men with XXYY. We were so sad to read the stories of parents who told us their sons were in these situations at work. Men with XXYY have a very difficult time navigating these situations. So it is important to prepare them for how to deal with it. Here are a few suggestions:

- If he has a job coach, ask the job coach to do some role play with him on workplace problems like bullying.
- Provide your son with information about how companies are supposed to handle bullying and harassment. Get a copy of the employment manual from his company. Go over the procedures for reporting bullying and harassment by coworkers. Who should he tell? How should he tell them?
- Work with your son on knowing when to report someone and when not to report someone. Some of our guys tend to be "tattle tales." You don't want them to be in the bosses' office every day reporting every little incident.
- Work with your son on various scenarios of bullying and harassment to help him have examples he can remember. You could even make it into a game called "bullying or just a rude person?" where you give him scenarios and he tells you which one it is.
- Work on his emotional reactions in these situations. What is the proper way to respond? What are ways that you could get in trouble if you responded that way?

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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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