



Transitioning to Adulthood Plans and Services for Adults With XXYY Syndrome

Part 10: Older Adults: Now What do We Do?

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Older Adults, Now What do we do?

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**Older adults with XXYY
whose needs are
not being met**

About older adults with XXY who are struggling

When the XXY Project conducted the survey outlined in Part 1 of this series, *Laying the Groundwork*, we were so sad to read that some of our adults are just not getting the supports they need in many areas. We are very concerned about you parents who have been struggling so much. So we wrote this booklet to at least begin the process of gathering information that we hope can help you. We do not have a lot of answers but we do have a few ideas. We strongly encourage anyone reading these booklets to send us more ideas that can help our parents to help their sons.

What follows is a list of recommendations we have for you now, by categories of issues.

We do suggest that if you are in this situation it will be useful to you to read this entire series of booklets to see if you can find resources you did not know about. We are so sorry that you have struggled so much and we truly hope this information helps you.

We know you've "been there, done that"

Nobody knows better than the XXY Project does that you have "been there, done that." There is nothing more frustrating than having naïve, well-meaning people hand us lists of futile referrals. However, we can tell you with certainty that we have had parents of older adults who have successfully obtained resources they did not know about before. It is possible, in other words, to change the course of your son's life. We are writing these things because of what we know is true, because we have more information about XXY than we had before, because we know how errors occur in applying for resources and because every once in a while, parents actually do find resources they did not know existed.

Your son is older now. You have more history now to use in your favor. Your prior attempts may have failed for reasons that are known mistakes that are made and can possibly be corrected. We just can't give up on you, so we give you this information.

For some, we know there may be "no going back," for many reasons. Even for you, we will attempt here to give you some idea of what to do now.

All adults with XXY who are unable to work full time to support themselves completely *should* be receiving government disability income and community services!

Never applied for government disability income? Do it!

If your son is unable to work full time to support himself completely, you definitely should apply for government disability income to ensure that he has a safety net to support him. No matter how old he is, please look into this. Read our booklet in this series entitled, *First, He Needs an Income*.

Denied government disability income? Start over!

A few parents reported that their sons were denied government disability income, such as SSI, years ago. We need you to know that the vast majority of our families who have applied for government disability income have qualified. While each case is different, we believe that something must have gone wrong in your original application for benefits and we strongly suggest that you try again. Your sons' histories of being unable to stay employed is data you can use for trying again, plus new information on his health and issues. Please read our whole section about applying for disability income in the *First, He Needs an Income* booklet.

We do not know how it works in other countries, but we will tell you that you can reopen your son's SSI case in the United States. If you live in another country, please look into how to reapply. (Let us know what you find out!)

There are rules that apply to reopening SSI cases, but there is a great benefit to doing it if you win. Your son will get back payment back to your original application. We know for some of you, that could be a boat load of money to help him.

You definitely should hire an attorney to reopen your son's case. Make sure you tie him to you as an adult disabled dependent. The attorney will be paid by the back payment if you are successful. Contact other groups in your local area for a recommended attorney. There is also a link within the Disability Secrets link below for finding one. We know one in Colorado, so contact us if you live in Colorado.

These web sites explain the rules for reopening a SSI case. BUT, do NOT rule yourself (your son) out just because you think you don't meet the requirements! Talk to an attorney first!

[Disability Secrets, published by NOLO](#)

From the Social Security Administration
[Reopening SSI determinations](#)



Is your son completely unable to work now? Apply for benefits!

If your son has worked but cannot work now, he may qualify for disability income that comes from disability insurance. We know several countries have this. In the U.S., it is SSDI. Read our booklet, *First, He Needs an Income*. He may still qualify for other disability income programs as well.

Lost disability income? Talk to an attorney!

There are a number of reasons why a person can lose disability income that they had before. Please read the booklet, *First, He Needs an Income* for details. If you did not appeal a decision that ended your son's disability income, please contact an attorney for information about how to get it back, especially if his circumstances have changed since he lost his disability income.

Need ideas for work?

Go back to the *First, He Needs an Income* booklet for ideas.

Denied disability services? Try again!

Because of the number of people with Autism who need services, many places have changed their eligibility for developmental disability services. If you applied for services for your son eons ago, the determination may have been based solely on his IQ, which has changed in some places to include adaptive functioning. Please read the *Disability Services* booklet in this series. Go back and apply again. Read about how to qualify for services. In the U.S., your son needs to be on SSI (or SSDI) and Medicaid to obtain these services so you may need to retrace those steps first.

Does your son now have a diagnosed mental health issue? Apply for services through the mental health system!

Please go back and read the *Disability Services* booklet in this series and the *Addressing his Medical Needs* booklet.

When was the last time your son was assessed?

We have had adults who received an Autism diagnosis as an adult. We've also had adults who had never had a neuropsychological assessment or haven't had one since they were children. Your son needs to be assessed for mental health conditions, learning disabilities, IQ and adaptive functioning. This testing will be valuable for obtaining services. If you can go to one of our clinics (more are opening), that would be great. If not, find a psychiatrist who does these assessments for adults. Contact your local Autism organization to find out who they would recommend.

Try to figure out what went wrong

Read through the previous booklets in this series. Try to figure out why your son did not qualify for benefits and services in the past or why he lost his benefits so you know how to proceed and make your case again. Here are some reasons we can think of, but there may be more:

- He may have had assets that counted against him.
- The documentation for how XXYY affects his ability to work full time to support himself may have been incomplete. You have to show how his disabilities impact his ability to work.
- They may have based his eligibility for services strictly on his IQ (and that criteria may have changed since you last applied).
- His work income may not have been reported correctly.
- He could have lost his disability income for a number of documented reasons people lose disability income as outlined in the *First, He Needs an Income* booklet.

What else you can do

If everything else has failed, please read the booklets *Where Will He Live* and *Disability Services*. Those booklets provide some alternatives. Remember that since your son is a low-income person, he can qualify for programs for low-income people. This includes housing options and medical insurance. In the U.S., your son can't use disability services unless he qualifies for Medicaid and the Medicaid Waiver program (which is based on the eligibility for disability services). But if he has a mental health condition, he may qualify for those services. In the UK, go back to your social worker even if you have been denied services in the past.



Please read the Disability Rights section of the *Protecting Your Son* booklet. We would suggest that you call an advocate.

Make sure that you talk to an attorney about other long-term plans to provide an income for your son for the rest of his life.

You will find more info about job resources in the *First, He Needs an Income* booklet.

Put together a plan that utilizes several resources to help him fill his time, improve his employment skills, provide housing and other things that are necessary for a long-term plan.

Please let us know what happens

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>
