



Transitioning to Adulthood

Plans and Services for Adults

With XXYY Syndrome

Part 4:

First, he needs an income

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First, he needs an income

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Transitioning to Adulthood

Plans and Services for Adults

With XXYY Syndrome

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 if he never got or lost benefits or services

Government Disability Income

How do I know if my son will need government disability income as opposed to supporting himself?

Best answer:

This is his only safety net. It's basically a must-have if you are not 100% certain that he can work full-time to support himself for life.

If you refer back to Part 1 in our adult transition series, *Laying the Groundwork*, you will see that the data is clear.

Most of our adults with XXYY have needed disability income. And not only do they need it, but most of them have qualified for it.

Applying for government disability income does not mean that your son will never work. It does not mean that you are throwing in the towel. It only means that you recognize that he may not be able to hold a full-time job for the rest of his life to support all of his needs. If he does end up working full-time to support himself, supply his own medical insurance, etc., then he will lose his government income. That's fine!

We have had a few cases of adults with XXYY who have 1) Not qualified for SSI or other government disability income or 2) Had it at one time and then lost it because he worked full time at some point. However, usually, once he has qualified, he should not lose it as long as you monitor it and make sure that all reports are sent that are requested. Make sure that you are his representative payee. These reports include annual spending reports and reports of his income if he is working at all, which must be sent monthly.

Every state in the U.S. runs its own Social Security Office and makes its own decisions about SSI and SSDI. Some states are much more strict and hard on people than others. You have to work harder in these places to make your case and if he is denied, you should definitely hire an attorney immediately to appeal.

MAKE CERTAIN that you apply for SSI when he is 18 and when you do so, also make CERTAIN that he is tied to your social security as "an adult disabled dependent." When you apply when he is 18, this may be done automatically but if he applies later, it may not happen and you need to fix that. See the section about Social Security for more information.

In some countries, you need to apply for government disability income at age 16, not 18. Be sure to find out when you should apply.



What does it take to support an adult for life?

It is very important for you to realize what it takes to support an adult for the rest of his life. (Not the rest of *your* life, the rest of *his* life). If you do not have sufficient savings to leave to him in a trust to ensure that he has housing, food, clothing, medical and dental care and supervision if he needs it, then he needs to have disability income available. If you really want to know if he needs disability income, do some calculations. Add up the estimated annual costs of the following. Realize that these costs will increase with time:

Housing	_____
Out-of-pocket dental and medical care	_____
Supervision	_____
Food	_____
Clothing	_____
Entertainment	_____
Furniture	_____
Transportation	_____
Other	_____
Total	_____
Total x the number of years he may live beyond your ability to pay for all of the above	_____

If you thought that there would be some kind of place for him to live that you could pay for out-of-pocket, think about that as well. Those types of places typically cost about the same as nursing home care, which can run over \$5,000 per month.

In the United States, SSI and Medicaid are necessary to access services such as host homes, group homes, community services, etc.

Other countries handle those things differently for people with disabilities. But applying for disability income is part of a whole package of things to be done.

All about Social Security programs in the U.S.

The Social Security Administration puts out a very detailed booklet on each of their programs. Links are provided in the titles of the programs below. Here, we are distilling what is extremely important for you to understand.

There are three Social Security programs that apply to adults with disabilities and each of them carries with it different income levels.

Supplemental Security Income (SSI) (pdf)

SSI is a public benefit (paid for by taxpayer funds) for adults with disabilities who meet the income cap limits. Typically, this means that they have little or no other income from work, or that income is less than the maximum amount allowed (which changes). Applying for SSI at 18 and making certain that your son is tied to his legal parents as an “adult disabled dependent” impacts all of the other social security benefits he may benefit from receiving over his lifetime. To make sure that he is tied to his parents, TELL/verify with the Social Security administration that he is an adult disabled dependent!

Social Security Disability Income (SSDI)

SSDI is not a public benefit. Funds are paid into this program from working. There is no asset limit to qualify for this program but there is an income limit. Your son qualifies for SSDI if: 1) He has worked in the past and can no longer work because of disability or 2) You worked and became disabled and are drawing SSDI AND your son is tied to you as an “adult disabled dependent.” If you go on SSDI, your son will automatically be put into the SSDI program if he was on SSI. Depending on the amount of his benefit, he may be taken off SSI OR he may receive checks from both programs that total the amount of SSI. If SSDI is higher, he will receive the full SSDI amount. SSDI can be higher than SSI income, depending on how much the worker paid into the program.

Social Security (disabled dependent)

Regular Social Security is not a public benefit. Funds are paid into this program from working. There is no income cap limit for this program. Your son qualifies for Social Security if 1) He worked all his life and reaches retirement age or 2) His oldest legal parent reaches retirement age AND he is tied to that person as “an adult disabled dependent.” If he has been on SSI and/or SSDI, he will automatically go on regular Social Security when his oldest parent does. Social Security is often higher than SSI income and can be higher than SSDI as well.

Note: An adult loses his “adult disabled dependent” designation if he gets married.



Make certain that your son is tied to both of his legal parents as “an adult disabled dependent.”

SSI Application tips

People do not qualify for SSI simply because they have a medical condition or disability. There is a [list of conditions that will automatically qualify a person for SSI](#) but XXYY Syndrome is not one of them. There is also a [list of conditions recognized as disabling](#) by the SSA.

The above list of recognized conditions does not mean that the SSA automatically qualifies someone for SSI if they have these conditions. It just means that they are recognized as opposed to some conditions that are not listed there-like sensory integration dysfunction, for example.

Otherwise, a person qualifies for SSI if the condition(s) they do have limit their ability to perform substantial gainful activity (basically, that means whether or not he can work enough to support himself according to a formula that is different for each state) and he meets the asset limits. This means that everything on the application or subsequent forms or interviews for SSI needs to relate to why it limits his ability to work enough to support himself. The more you “qualify” the answer to each question they ask, the better you can make your case.

The initial application asks you many questions about assets because your son has to qualify financially for SSI. Make sure he has no assets! From there, you may need to have an in-person interview or you may receive paperwork that asks in-depth questions about his disability.

Tips:

- In order to receive his full SSI benefit, you should charge him rent if he is living at home. Be sure to include that in his list of bills. Write up a lease agreement that he has signed as proof. To come up with his rent amount, calculate your household expenses (rent/mortgage + food + utilities) and divide that by the number of people living in your home. Or, you can also calculate 30% or somewhat less of what a typical social security payment is plus food. As of this writing, that amount would be \$244 per month for rent alone. If you are going to do room and board, add food to that. (Current average for an adult male is \$224 for a “thrifty” food plan.)
- Any time they ask a question that starts with “since you became disabled,” answer “disabled from birth, genetic” and then answer the question.
- Make a list of all the ways your son’s condition(s) interfere with his ability to be successful at work. We have listed many examples on the following pages.
- Be sure to check the list of conditions recognized as disabling (link above) and include the ones for which your son has a diagnosis in your application (or in your interview).
- Have your list of doctors addresses ready to give to the SSA. They now request electronic medical records so you need to give them the right information.
- Make sure your son is tied to BOTH parents, even if you are divorced.

List of ways that XXYY traits can interfere with work-related tasks.

These may not ALL apply to your son and this isn't all of them. Use the ones that do, which you are able to justify or document in other ways:

Low muscle tone limits:

- Lifting heavy objects
- Standing for long periods of time

Joint problems limit:

- Standing for long periods
- Some physical tasks (explain elbow issues and other things)
- Ability to perform repetitive tasks because of joint pain, which is aggravated by these tasks

Attention deficit disorder, autism, executive function problems limit his ability to:

- Understand and follow more than one-step directions
- Focus on a task or focus on the safety issues surrounding a task
- Organize or plan
- Gauge time
- Get to work on time
- Get back on time to work after a break or lunchtime
- Understand complex questions asked of him
- Find places he needs to find or find his way back (getting lost).
- Keep track of things. (He loses things a lot).
- Remember things. He may not remember to turn off the gas, for example.

Low math level limits:

- Counting
- Using a cash register, providing change to a customer
- Measuring or planning to put things in a space based on sizes

Low reading level limits:

- Ability to read instructions, read labels, use email, etc.
- Ability to understand when there may be danger (as posted on a sign)

Scoliosis and back problems can limit:

- Ability to stand or sit for long periods
- Lifting heavy objects
- Ability to walk or climb stairs

Asthma can:

- Cause absences
- Limit ability to do strenuous work activity

Speech problems (including lingering word retrieval problems) can:

- Make it difficult for customers/coworkers to understand him
- Make it very hard for him to provide accurate instructions or tell someone something important. He may get angry when interrupted by people who won't wait for him to find the right words.

Tremors impact his ability to:

- Do work that requires fine detailed work with his hands
- Pick up and hold some things
- Write (i.e. taking written orders)

Intellectual disability/low social age can:

- Make it difficult to interact appropriately with adult coworkers
- Cause a severe lack of judgment

Mental health diagnoses/behavior

- Relate each of his diagnoses to how it might impact him at work.
- Think about his behaviors in the work place. How might it be difficult for an employer to tolerate his behaviors?

Other medical problems: Such as seizures, heart problems, diabetes requiring insulin, severe digestive problems. These can also relate to his ability to work. He may have many doctor appointments. He may spend long periods of time in the bathroom (more than an employer might allow). He may need monitoring if his medical problems are severe.

Check the list of conditions that are recognized as disabling conditions by the SSA on the previous page. Write down all that apply to your son.

About Social Security (continued)

Psychologist Evaluation

Social Security often (but not always) sends people who apply to see a psychologist who will conduct an evaluation. You do not get to choose the psychologist. You will receive a letter in the mail telling you where and when to report for the evaluation. Sometimes they do full psychological testing and sometimes they don't. It may depend on what they were able to obtain from his medical records.

Do everything you can do to sit in on this evaluation if it is a type of interview as opposed to psychological testing. You can tell the psychologist that your son has trouble explaining things sometimes because of his speech problems, understanding questions, etc. Add to or correct the conversation when you are in there if at all possible. Many of the guys with XXYY over-estimate their abilities. You may need to contradict your son.

Denial Letters

The first letter you usually receive after applying for SSI will be a denial letter (unless your son has worked and qualifies for SSDI). The letter is VERY confusing. That letter actually refers to SSDI, not SSI. What they are telling you is that he has not worked enough to qualify for SSDI. The letter also states something like they are working on seeing if he qualifies for any other programs. That means SSI. If you are worried about that first letter, call Social Security to confirm because you only have a short time to appeal.

If you do receive a denial for SSI, **contact an attorney immediately**. You only have a short time to appeal a denial. There are attorneys who specialize in this. They receive payment from the back payment your son will receive if he gets approved.

Back Payments

Once your son is approved for SSI, SSDI (or regular social security if you had to apply for that because you retired and he was not tied to you as an adult disabled dependent) he will receive back payment to the date when you applied. This can be thousands of dollars and you get very little warning that it is coming. They will deposit it directly into the bank account you provided to them. This can be highly problematic if he is on Medicaid because he can't have more than a certain amount in assets if he is on Medicaid. You have until the end of the month when you received that money to move it to a special needs trust or possibly an ABLE account to protect his Medicaid benefit. Talk to an attorney about what to do.

Typically, if you apply for SSI at 18, the back payment does not cause a problem for Medicaid because they give you a certain amount of time to pay it down before it impacts Medicaid. But if he was already on Medicaid, it is a huge problem. The worst thing that can happen is that he loses Medicaid until his asset is paid down. You can get Medicaid back. Losing Medicaid, however, means he also loses his services which are paid under Medicaid. (See Medicaid section).

About Social Security (continued)

Periodic Reviews

Social Security may do periodic reviews of your son's continued eligibility. You will receive a random letter in the mail that tells you that he needs to report to a specific psychologist on a specific date for testing. You must respond immediately to the letter as indicated. He cannot miss this appointment. As scary as this letter is, parents who have gone through this report that it is not as bad as it sounds. The psychologists who do these evaluations do seem to know what they are doing and can recognize a disability, even if they know nothing about XXYY. There's nothing you can do about it anyway, so just do it. If he loses his benefit, go through the appeals process.

Ways Your Son Can Lose SSI

A person can lose SSI, but it is sometimes for a preventable reason. These are some of the ways your son could lose SSI:

- You didn't send in the reports. As his representative payee, you are required to send the annual reports.
- You didn't send the SSA his check stubs from work and they found out.
- When he does work, SSI uses a formula to determine how much his benefit is cut as a result. At a certain level, he no longer receives SSI. However, if he stops working, all you need to do is tell them and they will go back to sending him his full amount.
- He suddenly has assets that put him over the limit for SSI.
- Social Security can deem his condition as "better," as if XXYY could be "cured" or "better"! But this problem can originate from when you applied in the first place and what you put on his application as his disabling conditions and if you listed him as an adult disabled dependent or not. They could look at his work history and decide that he is "able" to work full time, based on his work history. This may happen more often to those who applied after the man turned 18. You need an attorney to fight this.
- A felony conviction can cause a person to lose his benefit permanently.
- Free food or shelter are considered in-kind income. If, for example, your son was living on his own and then moved back home and you didn't report that he is paying rent to you for living at home, he could lose SSI.
- A spouse's income counts. A person can lose SSI if he gets married. He can also lose SSDI if he is on that because he is an adult disabled dependent and then gets married, losing his dependent status.
- He moved and you didn't notify the SSA.

Don't let your son manage his own SSI money or make direct contact with the SSA. Become his representative payee to make sure that the important things are covered. If you cannot be his representative payee, you can ask for one as part of his Medicaid services if you are connected to the developmental disability service system.

XXYY Case studies on SSI/SSDI/Social Security

These stories, as they say in the movies, are “based on true stories” but they are pulled together from several different stories and the names are all fictitious.

Case #1: Marvin

When Marvin turned 18, his parents did not apply for SSI because they wanted to give him the chance to live a completely normal life. They didn’t want him to think of himself as disabled and they didn’t want him to use XXYY as a “crutch” or to label him. His parents also did not want to take money from public benefits if it wasn’t necessary. Marvin had done OK in school and he graduated with a full diploma. He had many skills and interests as well. From the age of 18 until he was 24, Marvin had many different jobs. It seemed that Marv “could” do a lot of things, but he was always getting fired from his jobs because of poor judgment and sometimes behavior issues or he quit. He also had a job where he had to stand all day and he was so exhausted that he often called in sick. His employer often yelled at him for not following directions or paying attention. Once, he got hurt on the job because he wasn’t paying attention.

Marvin’s parents came to realize that full-time employment might not be in the cards for him and they began to worry about how he would get his income over his lifetime. They tried several programs to help him as well. All along the way, his parents kept documentation of what happened at his job due to things related to Marvin having XXYY. They began to see a picture of Marvin’s disabling conditions and they wrote them all down. For example, inability to follow directions was related to his severe ADHD. Getting tired from standing for long periods was related to XXYY and his joint problems, and so on.

With these details in front of them, Marvin’s parents applied for SSI for Marvin. The process was more difficult because letters kept coming asking strange questions that started with “when you became disabled...” That was confusing, but his parents answered that he had a genetic condition and he was disabled from birth. Marvin was ultimately approved for SSI.

Marvin continued to look for part-time work and his parents dutifully reported his monthly income to Social Security when he was working so he wouldn’t lose his SSI. While his SSI check was reduced when he was working, it always went back up to the normal amount when he wasn’t.

XXYY Case studies on SSI/SSDI/Social Security

Case #2: Zed

Whenever Zed was tested, his IQ was below 70, which means that he is intellectually disabled. In school, he was on an IEP almost the entire time. He struggled in many academic areas and although he had volunteered a few times, his parents could see that Zed would not be able to support himself.

When Zed turned 18, his parents applied for SSI. They used many of the items from his IEP to help make the case that Zed's condition impacts his ability to work full-time to support himself. They noted all of his other comorbid diagnoses in addition to XXYY and made certain to mention explicitly that Zed has a genetic disorder, which means that he has been disabled from birth. They noted his reading level was at 3rd grade and his math level was at 2nd grade level.

Zed was approved for SSI. His parents made certain that his record showed that he is an adult disabled dependent. Over time, when Zed's dad reached retirement age, Zed's SSI was changed to Social Security, which meant that his income increased and his mom was able to obtain more and more services for him. He also went on Medicare, which was a huge help.

Case #3: Dimitri

Dimitri's parents were pretty convinced that there was some way for him to work full-time. They were on a slow path with him to start out working part-time and then to keep at it until he had enough experience to land full-time employment. They sought out every program they could find to help him, too. But they did not apply for SSI when he was 18. While Dimitri did have a few decent part-time jobs, it became clear after many job losses that it was not in the cards for Dimitri to support himself. So his parents applied for SSI and he was approved when he was 25.

For many years, Dimitri's parents made his SSI income work. Dimitri even moved out of their home, into an apartment of his own and he received some services to support his activities of daily living.

Then Dimitri's dad suffered a debilitating illness, which caused him to have to go on SSDI himself. Dimitri's mom was waiting for Social Security to send a letter saying that Dimitri would be switched over to SSDI, because she knew that was supposed to happen. But that never happened. So she called Social Security and asked if Dimitri was documented as an adult disabled dependent. They looked and discovered that because Dimitri qualified for SSI when he was 25, instead of 18, the fact that he was an adult disabled dependent was never documented in their records. Social Security made an appointment with Dimitri's mom and together they applied for SSDI and fixed the problem. Dimitri's monthly income from SSDI was quite a bit higher than SSI and he got to be on Medicare in addition to Medicaid as a result.

XXYY Case studies on SSI/SSDI/Social Security

Case #4: Gaige

Gaige has had great moments of long-term employment in his life, which has always been very encouraging to his parents. Except when he quit or lost his job. By the time Gaige turned 30 years old, he had lost many jobs. Oftentimes, his parents didn't know what happened at his job because Gaige really didn't talk about it and he had sort of a history of not telling the whole truth anyway.

Gaige's parents decided it was time to apply for SSI. They told the Social Security administration that Gaige has XXYY and believed that they made their case because he has a diagnosed medical condition. But Gaige was denied SSI.

Gaige's parents were extremely surprised by the denial of SSI so they hired an attorney to appeal the decision. After working with the attorney, Gaige's parents realized that the main case that needs to be made to be approved for SSI is that Gaige is unable to work full-time to support himself, due to his disability. They learned that people do not automatically receive SSI simply because they have a diagnosed medical condition. To receive SSI, you have to prove that the condition prevents the person from supporting himself. The attorney pulled together all of the aspects of XXYY and the comorbid conditions that Gaige has, and showed the Social Security Administration that XXYY impacts Gaige's ability to work full-time to support himself. They had plenty of documentation, due to Gaige's past employment issues. They asked Gaige more questions about what happened at the jobs he did have. He told them that the boss yelled a lot, which upset and confused him. He also said that he was required to operate a cash register, but he didn't understand how to count change. He got angry at work sometimes because they asked him to do things he didn't understand.

Upon appeal, Gaige was approved for SSI. In his state, they also approve people on SSI for Medicaid automatically. Having Medicaid made a world of difference in Gaige's medical and dental care as well. Later, when Gaige's dad reached retirement age, Gaige went on Social Security, too. Gaige continued to work sometimes, but his SSI remained his safety net.

Important SSI tip:

There are only a certain number of conditions on the "automatic approval" list for SSI and XXYY Syndrome is not one of them. In order to qualify for SSI, you must prove that your son is unable to work full-time to support himself, as a result of having XXYY and any other conditions he has. Go back through his medical and other records and find every condition for which he has a documented diagnosis for your application. Use his past work problems to document how his condition got him fired from jobs or made him unable to keep a job.

If your son was denied SSI in the past, TRY AGAIN. Contact an attorney this time.

About Disability Income in other Countries

As a U.S. based organization, our expertise on how to obtain income to support your sons in other countries is much more limited. We rely on parents in our group to learn about their systems and to tell us how it works. However, thanks to many parents who responded to our survey, we do have some great information about some other countries. If you know more to add to this booklet, please tell us about it so we can update it. Information that is in the U.S. Social Security Section of this booklet can also be helpful to those in other countries when applying for benefits. We wish we could provide such details for every country!

The U.S. Social Security Administration has a fantastic page on their Web site that provides information on the [Social Security Programs Throughout World](#). (Go to the bottom of the page to see the reports for 170 countries!)

Australia

Disability pension in Australia is accessed through the [Department of Human Services](#). You can apply for this pension between age 16 and “age of pension” (we don’t know what that means). There are income and asset limit requirements and you must prove that your son cannot work more than 15 hours per week within the next two years.

From a parent's experience:

“Our son was assessed by government appointed doctors, psychologists etc when he was 16 years old for a Disability Pension. Before he left school we were advised to register him with a Disability Employment Service in order to coordinate and help with his post-school options, however we tried several but didn't find a service that we were happy with. We found him a job with a Disability Enterprise which was advertised in the local paper. They are regulated by the government so that they pay a reduced wage based on an assessment of our son's productivity at work - This is reassessed each year and it is still much below our minimum wage, however it is topped up by his Disability Pension.”



Canada

Canada's disability income support safety net is provided through **provincial Disability Support Programs**. In the provinces that have these programs, they can have different names. In British Columbia, the program is called Persons With Disabilities benefits but in Ontario it is called the Disability Support Program.

The Canadian Down Syndrome Society has created [this booklet](#), which lists all of the programs in each province, which includes information on disability income systems in Canada.

Through these programs, a person receives disability income. Your son qualifies for the program through an assessment of his disability and means testing (needs-based). [This web site has valuable information about applying for the PWD program in BC](#)

[**Canada Pension Plan or Quebec Pension Plan disability benefits**](#) is for those who have worked at least the [minimum amount of time](#) specified.

[Employment and Social Development of Canada](#)

Has information about disability income and savings program

Europe

We do not have direct information from parents for all countries in Europe. The U.S. Social Security Administration has a Web page devoted to explaining [Social Security benefits in European countries](#)

Germany

[The Pension and Benefits office](#) (*Versorgungsamt*) in the disabled person's place of residence will assess the degree of disability. It provides a person with basic security income (Grundsicherung)

The Netherlands

The Netherlands provides disability support pensions to permanently disabled people and those who have been documented as disabled from birth.

United Kingdom

England and Wales have two different programs that provide income for people with disabilities. The Disability Living Allowance (DLA) is a program that is ending for adults born after 8 April 1948 and are 16 or over. But you can make a DLA claim for a person under 16 years old.

The newer program for adults is called the [Personal Independence Payment \(PIP\)](#). To qualify, your son must be assessed by the appointed professional who looks at his ability to perform activities of daily living outlined on this site.

From what we have learned from parents, social workers from the Local Education Authority (LEA) are the center of receiving all services and supports in the UK including being recommended to apply for DLA or PIP.

Parents have provided us with information for services in the UK, which also may include a disability pension as part of a “package” of services and supports. Please refer to the *Disability Services* booklet in this series for more information.

Comment from a parent, specifically related to disability income:

In UK social services assesses need. Payments (benefits) are awarded on that basis. These may be for housing, general disability allowance, unemployment. Health is covered by the National Health Service.

If you have information about how to obtain disability income in your country, please send us that information. We are especially interested in the “ins and outs” of systems and how to successfully navigate them.

The best path to success is by learning from the experiences of others. Our information on Social Security in the U.S. comes from real experience on the ground. That’s what we want for all of our families!

Employment Income

Where do we begin?

Well, that is a good question! We didn't even know where to begin to write about it!

So, all we can do is start!

Employment for adults with XXYY can be extremely challenging. Here, we are going to try to give you every idea we think can be useful and worth pursuing. There are a lot of avenues to pursue employment. Some of them start with the *Continuing Education* booklet in this series, some of them start with making sure your son receives transition services, some of them start with the *Disability Services* booklet in this series and some of them start with plain old creativity on the part of the parents.

The Foundation for Success

There are some important basic things that need to be in place in order for your son to have successful employment, according to our survey data. They are:

- On-the-job support and understanding of his disability
- Flexible work hours
- Low physical demands
- Job protection (such as a union or making sure the employer knows he has a disability)
- The right environment (low noise levels, less interaction with people, etc.)
- Work that is interesting to him
- The right fit for his skills (or lack of skills as the case may be)
- Social support on the job—people who care and will watch for bullying
- Transportation
- Jobs that do not require many steps that he has to remember
- Jobs with consistent duties

What does not (usually) work:

- Placing him in any-old-job just because that's all that a particular job coach could do for him
- Expecting him to have immediate "work ethic"
- Expecting him to handle complicated social interactions at work, especially a mean boss or demanding coworker
- Jobs where the supervisor has very low skills of their own—such as teenagers and low-skilled workers in charge
- For some, jobs that involve handling money
- Jobs with a lot of rules involved
- Jobs with odd hours that will interfere with his sleep
- For some, jobs that involve customer service
- Jobs with a lot of distractions
- Jobs with a lot of standing involved
- Jobs which have many changing duties
- Jobs that require him to keep close track of time

Why is it so hard for our guys?

No matter if your son is the sweet guy with XXYY who rarely has an outburst or the explosive guy with XXYY who says everything that comes into his mind, or something in between, employment problems exist for nearly all of them. While we do have some who have done really well, their success has literally nothing to do with how they were raised, how much education they got, the private school they may have attended or when they were diagnosed. Instead, it has everything to do with how much they are affected by having XXYY and in what ways. Because there are so many ways that they are affected by having XXYY, they struggle with many things that relate to being employed.

These are their main issues on the job:

- Interactions with peers and being bullied
- Anger and frustration
- Anxiety
- Inability to follow rules or conversely, being hyper-vigilant about rules with coworkers
- Following multi-step directions
- Everything to do with executive functioning (planning, organizing, memory, keeping track of time, staying on task)
- Education gaps (math, reading, geography)
- Too much flirting, not much work
- Accidents
- Lying, stealing
- Not showing up for work
- Personal hygiene problems
- Health problems
- Customers who didn't understand

Before you go down the employment road, it will be helpful for all concerned if you make a list of your son's most difficult issues and then compare the jobs that could be available against his list to see if there can possibly be a fit.

A great example: We have many men with XXYY who had culinary arts training. They love to cook! However, jobs in that field require them to mostly work in restaurants, which are actually very stressful work environments where everything is done in a hurry. Their personal hygiene problems can be a serious factor there as well. A better fit may be a bakery, so long as he doesn't have to interact with the public much.

Teens and Young Adults

If you read the earlier booklet in this series for teens and young adults, you know now that the transitions program is actually the place to start for pursuing employment if you live in the U.S. In other countries, connecting with your social worker or disability service agency is the only path.

We do want to tell you about some other ideas and programs that are available that could be very useful during this time period. Since every state and province and every school district is different, it is very difficult to tell you everything. If you like any of these, search your local area to see if they exist near you.



School to Work Alliance Program (SWAP)/BOCES

Before your son leaves high school, make sure you ask about these programs. They may go by different names or they may be tied to one another. The SWAP program provides job coaching and on the job support to teens with disabilities. Sometimes the program is run through BOCES, if it exists in your area. BOCES is a great program that does many different things. Here are a couple of links that tell you about these programs in different places:

[SWAP Program, Denver Public Schools](#)

[BOCES of New York State](#)

Summer youth employment programs through cities

Some cities actually have organized summer youth employment programs. Sometimes they are for “at-risk” youth and sometimes they are for everyone. Either way, Google “summer youth employment program” with your city name or go to your city Web site to see if they have one. Here’s an example of one:

[Denver Summer Youth Employment Program](#)

Other job programs for youth with disabilities

[Canada, Services for Youth](#)

[National Collaborative on Workforce and Disability \(U.S.\)](#)

This Web site has a lot of programs listed in various states!

[Partners for Youth with Disabilities \(Boston, MA\)](#)

Teens and young adults (continued)

Job Corps

Job Corps is a **free** education and training program that helps young people learn skills for a career, earn a high school diploma or GED, and find and keep a good job. For eligible young people at least 16 years of age that qualify as low income, Job Corps provides the all-around skills needed to succeed in a career and in life.

Apprenticeships

Some of the previously mentioned links had information on some apprenticeships and internships. We also want to help you to think outside of the box here. If your son has a specific interest, go to a place that does that and ask if they would take on an apprentice. Offer to pay the employer to do it. Don't forget to talk to some small businesses and find them on the Chamber of Commerce Web site.

Here are just a few ideas, based on some unique interests of some of our guys with XXYY:

Train lovers—Do you have a train museum in your city? What about a railroad? Is there an active local union in your town for railroad workers?

Dinosaur enthusiasts—What about the Natural History Museum or a small, local museum?

Animé lovers and card collectors—There are many small businesses that sell these things.

Bakers—Talk to a local bakery or contact your local grocery store chain to find out where their bakery is and if they consider apprenticeships.

Car enthusiasts—What about a local body shop? Or, for the racing enthusiasts, contact a local shop that builds race cars.

Consider joining one of your local service clubs, like Kiwanis or Rotary so you can network with some people in various businesses. Let them get to know you and later, approach them about apprenticeship.

The U.S. Government has an entire program dedicated to apprenticeship. While some of these opportunities may be beyond reach, there really is a wide variety of apprenticeships available.

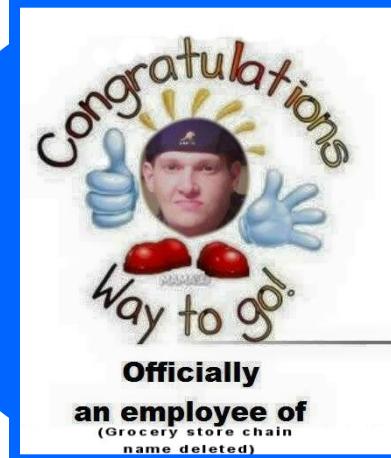
[US Department of Labor](#)

Adults of all ages

Here, we provide a mix of ideas and links to various programs. Again, what we want you to take away from this is to go search for similar opportunities where you live, no matter where that is.

Airport jobs

We wanted to make sure to mention that airports hire a lot of people with disabilities. This is something you may not have thought about. There are many jobs at airports and many job coaches for people with disabilities are placing them at airports.



Union jobs

In the U.S., union jobs can be a great fit for boys and men with XXYY, if you can get them. Unions provide a whole other level of job protection that can come in handy. Not all union jobs are in trades. Start to investigate industries in your area where there are a lot of union jobs.

Local and Federal Government employment

Be sure to check out both your local and federal governments for job opportunities. There are too many to mention but just for an example, city governments have jobs in parks and recreation.

[U.S. Federal government Jobs for people with disabilities:](#)

[U.S. Office of Disability Employment](#)

[Disability.gov Guide to Employment](#)

U.S. Military base employment for people with disabilities

We have an adult with XXYY who has had great success working on a Naval Base. We learned through his parents that the U.S. military (and basically all federal agencies) hire many people with disabilities (see links above). To find employment on a military base, go to the employment opportunities section of the military base near you. [Here is one](#) that talks about how people with intellectual disabilities can get jobs on base, but they would all provide the same basic information.

Other agencies that help people with disabilities to find jobs and supported employment

All U.S. states and cities have disability employment programs like these through the Department of Labor and other agencies. These are a few of them, to help you get on the right track for finding them where you live:

[Minnesota Employment Resources for People with Disabilities](#)

[Texas Department of Aging and Disabilities \(DADS\) Employment Guide \(pdf\)](#)

[Maine Department of Labor Career Centers](#)

[California Employment Development Department, Service for People with Disabilities](#)

[New York Mayor's Office for People with Disabilities](#)

Adults of all ages (continued)

Ticket to Work program through Social Security

The Ticket to Work program is for SSI and SSDI beneficiaries. We will be honest; this program looks much better on paper than it is in practice but we do think it varies a lot from state to state. The pros of Ticket to Work are that they will pay for a job coach to work with your son 1:1 and that, while on the program, the ratio of money your son can keep from his SSI or SSDI benefit is higher. The cons of this program are that there are few qualified providers, there are onerous reporting requirements and that the ultimate goal of this program is to get a person off of SSI and SSDI permanently. While that sounds like a great idea, there is a lot of room in this program to cause hardship for males with XXYY who may be able to work sometimes but who may not ever be able to get off SSI or SSDI permanently. We have had XXYY parents who have used this program for their sons, to no avail. It is a resource but we don't hold much hope for this program being of great value to our families, with exceptions. This program could be a great resource for some of our higher functioning guys with XXYY who could, in fact, work full time if he were in the right situation. We would recommend this program to our adults who have been able to hold long-term jobs but who are now having trouble finding a job. We do not recommend this program for our adults who have severe behavioral problems. They are just not equipped for this.

Vocational Rehabilitation (Voc Rehab)

State Voc Rehab programs can also be a very valuable resource OR they can be a bust. Many of our parents have used Voc Rehab programs for their sons with mixed results. Voc Rehab can pay for a job coach, which is really important. They also pay for some certification courses that can help your son to get a specific job such as fork lift operator. However, parents who have used Voc Rehab programs have found that they are not equipped to deal with people whose main barrier to employment is behavior problems. If your son does not have significant behavior problems, it could be a good resource and several parents recommended some of these programs. Here are some that our parents named:

[VESID, NY state](#)
[Access-VR, Rochester, NY](#)

[List of all state Vocational Rehabilitation agencies \(pdf\)](#)

Other Governments' Resources

[Disability Rights UK \(Careers and work for disabled people\)](#)

Adults of all ages (continued)

Other job resources:

[Disability job exchange U.S.](#)

[WORKink Canada](#)

Each state and province should also have organizations that help people with disabilities to find employment, like the ones listed below

[Works for Me, Pennsylvania](#)

[4 Organizations in San Luis Obispo, CA](#)

[Ontario \(Canada\) Disability Employment Network](#)

[Looking for Work if you are disabled \(info from the UK government\)](#)

[Australian Government Social Services—Employment for People with Disabilities](#)

Local nonprofits that provide job assistance to people with disabilities

[Project Search at Bryn Mawr Rehab Hospital, Malvern, PA](#)

[Ken's Krew, NY, NY](#)

[The Center for Parent information and Resources has lists of resources](#)

Supported employment through the disability services system

Once your son qualifies for services through the developmental disability services system, you will also have access to supported employment resources. Please refer to the *Disability Services* booklet.

Starting a Business

Starting a Business

We believe that some of our most successful guys with XXYY have been successful because of a small business that their parents have helped them to start. There are resources to help people to start businesses.

[Small Business Administration](#)

[SCORE](#)

Score partners retired business people with people who want to start businesses

Microloan programs for small businesses

There are a number of nonprofit organizations that help low-income people to start businesses. They even provide micro-loans to do it. Your son does need to be able to attend their education programs to qualify but it is worthwhile to find out if a program like this could help him. Here are some examples of these organizations

[Rocky Mountain Microfinance Institute](#)

[8 Microfinance Lenders in the U.S.](#)

[Info from the SBA for people with disabilities starting businesses](#)

[Service Canada](#)

[SCOPE About Disability UK](#)



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>
