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

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## **Part 2: Teens & Young Adults**

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**What you need to do in the years  
before he turns 18**

## When to begin planning for adulthood

Planning for adulthood obviously begins when boys with XYY are very small. It starts with the right educational settings and having proper treatment and therapy. There are other pieces to planning for adulthood, however, and those are known to us now that we have been around for some time and have been able to gather information.

The information about the needs of our adults with XYY are documented in Part 1 of this series, called *Laying the Groundwork*. That document outlines the data we have on what our adults with XYY are doing now. It is the foundation of your roadmap. Everything written for this Transition to Adulthood series is based on what we know we need to make plans for when our young men with XYY become adults.

Even though we do not know the whereabouts or fate of the possible 200,000 boys and men living with XYY in the world today, the information we do have is extremely compelling and important and it should be considered the best information available at this point. Using the information we are providing to you will be a foundation that can be built upon for greater success for your son. **Every piece of it can be ditched for something better, when that something better comes along. We are advocating for your safety net.**

Continue to expect him to surprise you with his gains. Continue to be optimistic. Continue to treat him just like any other boy. But plan for a solid safety net.

When he is young, you can actually ruin his potential for having a safety net. If you work hard to compensate for his difficulties by adapting too much to suit him or if you are overly anxious to make his life appear “normal,” it can and actually will keep him from getting the services and supports he needs for his safety net. Listen to us, follow our directions and know that you will know later why we advocate so strongly for this.

Your parent-peers give you the following advice:

- ✓ Start early
- ✓ Know what will be available to you in advance
- ✓ Follow the XYY Project’s advice
- ✓ Expect the unexpected
- ✓ Keep them in high school as long as possible
- ✓ Be patient

## Potential adjustments

Some of what will be available to you when your son turns 18 will depend on what happened prior to adulthood. We thought it was important to mention these things for parents who have a few years before their sons turn 18. You may need to make some major adjustments while there is still time to do so.



## Homeschooled boys

While homeschooling has been an extremely important option for some of our boys, it also brings with it some limitations on the services and supports your son can receive when he turns 18. If your son is homeschooled and not on an IEP, you may not have access to the free transition services through the public school system. Transition services extend his schooling from age 18 to age 21 and they are very important. You may want to consider putting him back in public school in high school and make sure he is on an IEP.

## Boys currently in private school

Private schools may offer some great educational resources, especially if they are schools for kids with disabilities. However, if your son is not in a school that provides transition services, you may want to consider moving him to a public school and getting him on an IEP. You cannot access transition services if he is not on an IEP and those services are extremely valuable (and FREE). You cannot get those services anywhere else.

## Boys who are not on an IEP (Individualized Education Plan)

We can't express to you enough how important an IEP is. An IEP establishes his needs, and while in school (in the U.S. at least) it protects him from being expelled for anything that is a "manifestation of his disability." That includes behavior issues. Having an IEP will help you to obtain adult services because there is a record of his needs. An IEP also provides you with access to the transitions program in the U.S. and Canada described above. In the UK, being statemented and having an IEP are the keys to further educational supports. Some countries do not have an IEP system. In those cases, boys are often in special schools for people with disabilities.

That said, if your son is not on an IEP, your planning for adult transition needs to start earlier than those who can count on a transitions program through the public school system. It may be very valuable for you to obtain an educational assessment outside of the school system, to learn about your son's potential learning disabilities that could interfere with his ability to work. Boys who are not on an IEP in school may therefore be deemed as "normal," which means that accessing services for people with disabilities could be very difficult and maybe even impossible for you. You will need to explore other avenues and we have provided information on those in this series.

Prior to adulthood (continued)

### **Boys in the UK who do not have a SEN (Special Education Needs Plan (prior to September 2014)).**

A child in the UK can obtain a SEN to support his educational needs in school. The SEN will provide speech therapy and other supports. The UK now has a new process called an Education and Healthcare Plan (EHC) for children and adults up to age 25 who have more complex needs. Make sure you apply for EHC. [Contact your SEN coordinator.](#)



### **Boys who ARE on an IEP**

While he is in high school, be sure to speak at length with the special education director and teacher involved with your son. Make sure they know that you want information about transitions. Join local parent groups to ask others about programs.

### **Boys with bank accounts in their names**

In the U.S. and in some other countries, a person cannot access some services if they have more than \$2,000 in resources in their names. This is a bit different in Canada and the UK but there are probably still limits. The best thing to do now is make sure your son does not have significant assets in his name. Make sure your relatives know that they should not give him large sums of money directly or find out what the rules are for savings in your country. The U.S. has a new law called the ABLE Act, which we will explain later in the *Long-term Planning* booklet. Canada has a savings program for people with disabilities as well. Make sure you know all of the rules for all available programs now, so that you can make adjustments. If you have a 529 college savings plan in place for your son, you may need to talk to an attorney about what to do with that. As the ABLE Act is rolled out in the U.S., it “may” be possible to change the account to an ABLE account because they are both 529 plans but you need to find out.

### **Boys who are working before age 18 or before they apply for government income**

If your son is working, that is fantastic! There’s also a catch. We have had adults who have not qualified for government disability income because they had too many assets from paid work. This can happen especially if your son is working in what we would call an “artificial” employment environment such as working in the family business where everyone is accommodating him at work. While you might think that his working means that you won’t need that resource, we are telling you that he needs that resource for the long-term. Scale back his work, for his long-term benefit. Later, you can scale up again, when you know how it all works with government benefits. There are even some programs that can help him to achieve his employment goals if he is on SSI, for example. (See the booklet *First, He Needs an Income* for details).

Prior to adulthood (continued)

### Boys Ages 14-16

- Get on the waiting list for DD Services

In some states in the U.S., you must apply and get on the waiting list for adult developmental disability services when your son is 14 years old. Even at that, your son may not receive a “slot” for services when he is 21. The waiting lists for these extremely important services can be decades-long. Please review the booklet about *Disability Services* for more information.

- Apply for disability income (check your country’s rules now)

In some countries like Australia and the UK, your son will need to apply for disability income at age 16, not age 18. Make sure you know the rules now.

- Find out if you have access to a vocational school through your school district. Some school districts have great programs like culinary arts, computer tech and other vocational programs available for kids in this age group.
- Ask about dual enrollment in community college courses.
- Official IEP transition planning starts

At age 14 or 15, your IEP team should already be talking about your son’s transition plan. However, by the time he is 16, the plan must be written into his IEP. Make sure your team does start talking about transition planning early. His transition plan includes a decision about whether or not to keep him in school until he is 21. The period of time between when he would be scheduled to graduate and age 21 is called the transition program.

### Say yes to the transition program!

(more details on the next page)

There are two other decisions that you may need to make at this point. Every school district is different on this, but some may offer your son a choice between a “track” in a life skills program or an “academic” program. **We recommend that you choose life skills if that is the case.** We say this as an “across the board” recommendation and we have good reason to recommend it.

The other decision is related to the transition program. In some states (and provinces in Canada), a person in special education does not receive a “full diploma” if they utilize the transition program. Instead, they receive a certificate of completion or it may be called something else. No matter what it is called, it is not a full diploma, and sometimes parents get hung up on this because they are worried about limiting their sons. We recommend you say yes to the transition program even if it means he will not receive a full diploma. He can still access more education without the full diploma (see the booklet on *Continuing Education*) and the transition program is much more valuable. Some states defer the full diploma until they complete transitions but they still receive a full diploma with their actual date they were scheduled to graduate, if they complete transitions.

## Transitions Program Details

Parents have repeatedly told us that the transitions program was one of the most important programs in their son's lives.

These are some things to know about it:

### **It is NOT the same as going to "regular" high school every day.**

Every state/province and school district delivers their transition program differently. Some are better than others, for sure. In some districts, the program is not provided every day, so you will need to plan for that. It sometimes is not provided on high school grounds, either. So the stigma of still being in high school is eliminated. Ask your special ed teacher to tell you the details of how transitions works, where it is and how often they meet.

### **There are no academic demands**

The environment and expectations in the transitions program are very different than the academic setting your son was in before. He will be learning life skills, exploring his skills and learning how to advocate for himself. Take him to visit the transitions program before you let him talk you out of it. (And you know how great our guys are at talking us out of things.)

### **It provides services that you would be hard pressed to get otherwise**

Although the transitions program provides some services that the adult developmental disability service system provides, transitions is immediate and easy to access. The adult DD system has waiting lists for these services that can be decades-long. The transitions program provides some social skills training, life-skills training to manage money and things like community safety, work-behavior expectations training, job coaching, resume writing and assistance in finding a job. It is all done with your son's peers, many of whom have been in his class for some time plus others he may not know from other schools in the district. It is a social connection as well, helping to cement relationships.

The other service that provides some (but nowhere near all) of the services that transitions provides is Vocational Rehabilitation. We have explained more about Vocational Rehab in other booklets in this series. But truly, transition services are irreplaceable. Parents who skipped it have regretted it, because they found out that there is a cliff-effect. The cliff-effect means that services are hard to get and that their sons had few productive things to do once they left school.





**What to do between  
ages 18-21**

## The Early Adulthood Years

Early adulthood (18-21) is a pivotal time when you learn about how your son's skills might translate into work. It is safe to assume from our survey that it is important to do the following things as soon as your son turns 18:



- Consider guardianship/conservatorship or power of attorney over some of his affairs to protect him and to make medical and services and financial decisions.
- Contact your local developmental disability service providers, social services (UK and other countries) or any other agency (such as mental health) that provides services for people with disabilities.
- Apply for government disability pension, Supplemental Security Income (SSI in the United States) or in some cases in the United States, your son may qualify for SSDI if either of his parents are on SSDI.
- Talk to an attorney about special needs trusts and in the U.S., look into the Able Act Accounts (see the section describing services).
- Check with your public school system and ask if they have a dual community college enrollment option.
- Look into technical schools, certification programs and college programs for people with disabilities. Also consider having your son audit some classes at a community college or other educational institution.
- Contact government service providers such as Vocational Rehabilitation in the United States to find out what they offer.
- In places like Australia, most services are privatized. Begin searching for those programs. Connect with other support groups for parents of kids with disabilities to find resources.
- Conduct trainings with your son on important issues such as how people might take advantage of him, how to interact with the police, how to ride the bus, how to get help if he is in trouble and alone, how to interact with women, how to use a condom, how to budget his money. Use these trainings to help you to know what kinds of protections he may need.
- If your son has had any evaluations/diagnoses that are not in his medical records, make sure you send those to his primary care doctor. This will be important when applying for SSI.
- Driving is a subject of its own. We have written another paper about driving.

## Tips for collecting and documenting his needs

### **Easy documentation system**

When you apply for any services for your son when he turns 18, you are going to need a large amount of records. This includes documentation and proof of his disability, all of his medical records contact information and more. Fortunately, you do not necessarily need all of his paper medical records since most of that is done electronically now. However, it can be extremely helpful to obtain his records yourself and read through them. Document every diagnosis he has ever had. Find all of the assessments that have ever been done on him. Document important items of interest. Using a simple excel spreadsheet, put these important findings in an order that makes sense. Make sure that you also include a spreadsheet for his work history while in school. It helps to do this as you go along, so you are not relying on memory when you are under pressure. You'll be surprised at how valuable a simple spreadsheet can be. Below are some examples of how and what to put in a record by category:

Category	Date	Item of note	Related Contact
<b>Medical</b>			
	11/2/2002	Diagnosed with Mitral Valve Pro-lapse	Dr. Heart Address/phone
<b>Educational</b>			
	3/17/1999	IQ testing at school—Overall score: 68 (refer to paper copy)	Davis Elementary school Address/phone
<b>Work History</b>			
	9/15/2010	Part-time job at Arby's from 9/15/2010-10/27/2010 (Fired for yelling at a customer)	Arby's name/address/contact
<b>Programs</b>			
	6/25/2012	Vocational Rehab work adjustment program. Determined unable to work. See related paper reports.	David Cotton, Voc Rehab Address/phone
<b>Neuro/Psych</b>			
	2/15/1998	Diagnosed on Autism Spectrum	Dr. Smith, Children's Hospital of Austin Address/phone
	6/13/2005	Psych Eval, diagnoses: ADHD, ODD, anxiety	Susan Stone, Ph.D.

Check out the Social Security section of the *First, He Needs an Income* booklet for information on conditions recognized by Social Security as disabling to see what is important.

Tips for collecting and documenting his needs (continued)

### **Getting needed evaluations**

There are evaluations that are important to have in -hand if you have not had them done in the past. They are valuable for applying for services and disability income. They can also help you to dispute other testing that may be contrary to what your testing showed, especially if he is denied services or disability income:



### **IQ Testing**

If your son has never had independent IQ testing outside of school, it is a good idea to get that testing done to help prove his needs. Visit one of our clinics and you will get all three of the tests outlined in this section. However, if you cannot go to a clinic, find an independent evaluator to do the testing.

### **Adaptive Functioning Testing**

Adaptive functioning means how well a person handles common demands in life and how independent they are compared to others of a similar age and background. This is probably “**the**” area of the greatest struggles for guys with XYYY, even when they have an IQ that is above 70. Adaptive function is one of the most important keys to obtaining services for your son. (Please see the booklet on *Disability Services* for more information about how these scores are used). [This Web site](#) explains the tests that are used for adaptive functioning really well.

### **Other psychological evaluations**

The above two tests are part of the broader category of psychological testing but there are others. Psychologists can use the DSM-5, for example, to test for mental disorders that you may not know your son has. Again, the purpose of this is to make sure your bases are covered and that you have all of the information you need to qualify him for services.

If you get this testing before he is 18, you can most likely get them done at your local Children’s Hospital. Also check into a University Psych department. If you need other referrals for these tests, contact your local Autism group or support groups for parents of children with disabilities. They often give the best recommendations.

## Other items of note

Many of the things you need to do at this age are outlined in specific sections of this series. For example, guardianship, continuing education, getting services and applying for disability benefits. Please refer to those parts of our series for complete details.

There are a few other items of note that we wanted to highlight to bring your attention to them while you are here:

- **Boys who were on Medicaid as children**—some states allow all children who have disabilities to be on Medicaid as children. Other children are on Medicaid because their parents qualified for it. What is extremely important for you to know, so that you do not lose Medicaid, is that as soon as your son turns 18, he is an independent adult as far as Medicaid is concerned. That means that **asset limits apply to him**. If he gets on SSI and receives a back payment or if he is working and putting money in savings, you must deal with that immediately or he will lose Medicaid, which is necessary for services. Receiving a back payment with no plan for managing it can lead to a complicated and expensive problem.
- **Social skills issues**—Parents of adults reported that social skills problems are one of their son's greatest barriers to adult success. This is everything from saying inappropriate things to not understanding appropriate behavior in certain circumstances, especially at work. Social skills development, therefore, is one of the most important keys to success for all boys and men with XXYY. There are many ways to develop social skills through programs such as sports, social groups, at church and more. Be sure that social skills development are part of his IEP. Do a lot of role-playing at home.
- **Transportation issues**—We wrote a whole paper (not part of this series) about assessing your son's ability to drive and there are special driving schools that can do that. Many men with XXYY are not able to drive or they experience so much anxiety that they may only want to drive in a very limited area. Transportation barriers are very difficult, especially if you live in a rural area. This is something you are going to need to plan for, since accessing services and finding jobs relies on transportation. For those living in areas where there is public transportation, make it part of your plan to learn that system and teach your son how to use it. "Normalize" the use of public transportation as much as possible in your home. Show your son how to call a cab (but make sure he can pay for it). Teach him what to do if he gets lost in a strange part of the city. Cell phone apps are available for virtually all of these things, like locating the nearest police station using GPS.
- **Safety training**—You may be able to find a program that teaches personal safety to people with disabilities in your area. Some parents have found these through the Arc. Self-defense classes are great, too, but they may not address for your son how to identify when someone might be a threat, which is difficult for adults with XXYY to do.
- **[Contact the Parent Training Information Center](#)** —they have tons of information and presentations on transitions.

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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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