



Transitioning to Adulthood Plans and Services for Adults With XXYY Syndrome

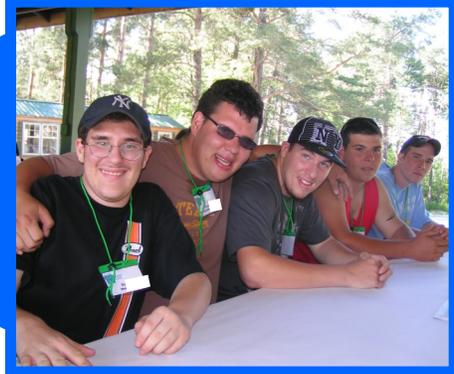
Part 1: Laying the Groundwork

Part 1: Laying the Groundwork

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Introduction

When our children grow up, there is an expectation that the plan for their future is usually built to carve out a life that includes good wages, health insurance and a means to provide housing for themselves and their family. That's what we call "Plan A."



There are certainly some men with XYY syndrome for whom "Plan A" will work. This booklet series was written to provide you with a way to begin with an alternative "Plan B" so that your son has a safety net first in order to secure him for years to come.

We gathered information from parents and caregivers of adults with XYY for this booklet series. The XYY Project has 188 families in our database with an adult son representing 48% of our membership. Of those, 41.14% (84) responded to the survey. However, as we all know, there are thousands of men with XYY in the world that are still unknown to us or still undiagnosed. What we will tell you is that the insights of the parents of adults represented in this booklet are extremely valuable and should be considered the best advice we have right now, especially if your son is having any difficulties at all.

There are ten parts to this booklet series. We have listed all of the topics in this series on the next page.

This booklet, *Laying the Groundwork*, provides you with the information from our experts—parents who have been there already. This part of the series is important for you to understand what is ahead and what you might expect.

We've worked hard to obtain information globally in order to give a rounded view for this booklet series. We strongly encourage all families to read every section, even sections about how things work in the U.S. because we know that what we have said in many areas applies everywhere. We are working to broaden our knowledge about resources in other countries. If you have additions that you think should be included in this booklet series, please contact us. We will update the booklets.

"Three grand essentials to happiness in this life are something to do, something to love, and something to hope for." -- Joseph Addison

Transitioning to Adulthood Plans and Services for Adults With XYY 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.

Part 1: [Laying the Groundwork](#)

- Managing expectations
- What we know about adults with XYY now
- The Best Path to Success

Part 2: [Teens and Young Adults](#)

- What to do in the years before he turns 18
- The 18-21 checklist
- Tips for collecting and documenting his needs
- Other items of note

Part 3: [Protecting your son from trouble: victimization, fraud and himself](#)

- Protect him from what?
- Guardianship, Conservatorship and Power of Attorney
- Other ways to protect him
- Disability Rights & Resources

Part 4: [First, he needs an income](#)

- Applying for disability income (SSI, disability pension, etc)
- Employment resources
- Starting a business

Part 5: [Addressing his medical needs](#)

- Health Insurance
- Medicaid
- Medicare
- Medical coverage in other countries
- Changing doctors
- X & Y Chromosome variation clinics are the key

Part 6: [Continuing education options](#)

- The challenges and reasons to still do it
- Ideas for continuing education
- Overcoming his resistance

Part 7: [Where will he live?](#)

- Living at home
- Living in a supported environment
- Living independently

Part 8: [Disability services](#)

- Why you need government disability services & what is available
- How to Access Government Disability Services
- Qualifying for Services
- Other Services & Resources

Part 9: [Long-term planning](#)

- Special Needs Trusts
- Pooled Trusts
- ABLE Accounts
- Wills
- Letter of intent

Part 10 [Older Adults: What do we do now?](#)

- What to do if he never got or lost benefits or services

Managing Expectations

It is always interesting to us to see the types of expectations that parents of males with XYY have. We thought we would outline a few of the ones we hear about often:



“There are no services for guys with XYY where I live.”

No parent should expect to find any XYY specific services where they live. They do not exist and will probably never exist. XYY is rare. Even parents of kids with autism are having trouble finding appropriate services! It's just not realistic to expect you will find anyone, anywhere who knows much of anything about XYY. It is up to you to educate them, as sad as that is. There are those who have seen Klinefelter Syndrome but in the world of services, there may not be many who have seen Klinefelter's either because those adults often don't use those services.

However, there are many services that do apply to guys with XYY and they are virtually everywhere. Services for people with developmental disabilities apply to XYY. Mental health services apply to XYY. Autism services can often apply to XYY. You have to make your case, yes, but they do apply and are very useful.

No government entity will recognize XYY as a disability, either. Never fill out an application expecting to receive assistance with just an XYY diagnosis. You will need to make your case.

“Nobody knows anything about XYY.”

Again, you will most likely find this to be true everywhere. Just because there are doctors in the U.S. who know everything about XYY, it doesn't mean they exist in other places. We developed that relationship. We made that happen. We are working to replicate that. But it takes time. Educating your doctors is the best way to do it. There are also doctors who have other experience that relates well enough to XYY to get decent care. There are doctors who treat patients with Fragile X, Autism, Down Syndrome and other disorders. If you need a psychologist, find one that has worked with adults with Fragile X or autism. Sometimes you will find professionals that have worked with Klinefelter patients. That is often useful, particularly for endocrinology.

“My son just needs to take some initiative”

Initiative is definitely not a strong suit of guys with XYY. In fact, we could say that “lack of initiative” is one of the most disabling aspects of having XYY. You might be waiting a very long time for your son to have initiative. Don't wait for this to happen. There is actually a medical reason for this which is about the executive functioning of their brains. You will have to be his advocate, while teaching him to be his own advocate.

Managing Expectations (continued)

“He just needs to (fill in the blank).”

Inside that blank are usually things like “control his temper,” or “learn his lesson,” or it can be as simple as “try.” Most of the time, these statements are coming from outsiders who just walked into your life and think they can solve all of your problems as if you’ve never thought of that. (Magic wand, please!) However, sometimes even parents think these things because these men are confounding on so many levels. They get in their own way, too.

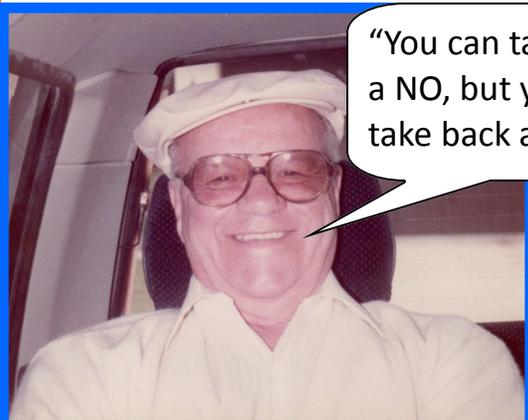
The real truth is that everyone needs to face that it is unlikely that he will “just do it.” He will mature over time and may be more able than he was before. But he has a life-long disability that keeps him from “just doing it.” This is a fact that **must be faced**.

“If we have him designated as disabled, he will give up trying”

Actually, the opposite is true. Time and time again, we have seen our precious guys try really hard to do what everyone else can do and not succeed. It wears on them, deeply, to keep being forced to be something they can’t be. It’s better to start with the solid foundation and then every success he has can be built on top of that.

“These boys are all so different...”

Boys and men with XYY have mostly the same issues that get in the way of their own success. They are not as different as you think, as you will read in this paper.



Normand O. Beauregard, Renée’s dad

When asked why he always said NO when asked for permission to do anything.

“It can’t hurt to try”

Unfortunately, it can hurt to try some things. Be methodical. Analyze the potential danger/disaster that could come of a decision. Put some things off until you are as certain as you can be that the outcome will be positive. There are many decisions that fall into this category, such as learning to drive, giving them complete control of their finances, allowing unmonitored Internet access and more.

**What do we know now about
adults with XXYY?**

What do we know about adults with XXYY Syndrome now?

In order to provide you with the best information on what to expect, the XXYY Project surveyed all of the parents of adults in our database that we could reach.

This is the summary of their responses. Their actual responses follow this page.



- The impact of having XXYY on a man's ability to live independently and work full-time to support himself completely, ranges from mild to significant. While we do have a few adults who are supporting themselves completely, the majority of those we know are not.
- Adults with XXYY were in several educational settings, but the majority of those we know who answered the survey received some kind of special ed services.
- 66.96% of adults either graduated from high school or received a GED.
- 36.14% of adults with XXYY received some type of post-secondary education. Of those, 32.14% completed their certification or degree program.
- 13.10% are living completely independently.
- 63.85% of adults we know with XXYY are unemployed.
- 75.9% of adults are receiving government income and 33.13% are supported by parents or a trust.
- 29.76% of adults have a full, legal guardian but 66.67% of adults have someone who has control of at least some of their affairs.
- Lack of social skills is cited as the most major barrier to success for adults

Adult Survey Results

All parents of adults with XXYY were asked to complete this survey. We received responses from 83 of the 188 adults (48% of our entire membership) we have registered with the XXYY Project. There were also 38 families (22.21%) that could not be reached because of bad email addresses.

We conducted this survey so you would have the best possible information about what we know right now of the living situations of adults with XXYY. This information gives you a clear picture of what you might need to plan to do moving forward.

How much control does he have over his affairs?

He is legally a fully independent adult with no guardian/conservator of any kind	33.33%
Someone has power of attorney for medical purposes only	7.14%
He has a conservator or guardian for some of his affairs	13.10%
Working on guardianship and/or Power of attorney, etc. now	4.76%
Power of Attorney or equivalent over some of his other affairs	5.95%
He has a representative payee	2.38%
He has a full legal guardian/conservator	29.76%
Other	3.57%

Notes: The original survey did not ask if he has a representative payee. There are probably many more adults who have a representative payee than shown because of the way the question was asked. Some adults may be fully legally independent but may have a representative payee as well. Our main point of this question was to ask about his legal level of independence.

Final number: 66.67% of adults we know whose parents/caregivers completed the survey have someone else in control of at least some of their affairs.

Why is this information important to you?

It is important because if you take a “wait and see” approach, your son could be in jeopardy. Once he is an adult, he is 100% responsible for all of his actions. If your son had issues with judgment as a teenager, expect that to continue until he or if he becomes more mature. If your son:

- tended to hook up with the wrong “friends”
- liked to challenge authority
- spent all of his money very quickly and unwisely (or gave it away)
- was easily taken advantage of
- got into any kind of trouble
- has had drug problems
- cannot understand contracts
- would do anything for a love interest

.....and others....then it is very important for you to protect him.

Where does he live?

All adults (N=84)

Completely independently in his own home or apartment (also some w/girlfriend or roommate)	13.10%
In college/university in a dorm (higher education beyond 12th grade)	0%
At another school, away from home (Special schools for people with disabilities, etc.)	1.19%
At home with his parent(s)	57.14%
Living with another relative (grandparent, sibling, etc.)	1.19%
In a supported living, semi-independent environment (i.e.supported apartment or a supported apartment with 24/7 care)	17.86%
In a group home with 24 hour supervision	1.19%
In a host home (with one family or couple who live with him or similar)	3.57%
In an institution with 24 hour supervision	3.57%
Homeless	0%
Other	1.19%

Final number: 86.9% of all adults are living in some kind of supported environment but only 57.14% are living with parents.

18-21 year olds (N=22)	% of all adults	% of 18-21 year olds
Completely independently in his own home or apartment (also some w/girlfriend or roommate)	0%	0%
In college/university in a dorm (higher education beyond 12th grade)	0%	0%
At another school, away from home (Special schools for people with disabilities, etc.)	1.19%	4.55%
At home with his parent(s)	20.24%	77.27%
Living with another relative (grandparent, sibling, etc.)	0%	0%
In a supported living, semi-independent environment (i.e.supported apartment or a supported apartment with 24/7 care)	0%	0%
In a group home with 24 hour supervision	1.19%	4.55%
In a host home (with one family or couple who live with him or similar)	0%	0%
In an institution with 24 hour supervision	1.19%	4.55%
Homeless	0%	0%
Other	0%	0%

Final number: 100% of 18-21 year olds are living in a supported environment, but only 77.27% are living with parents.

22-29 year olds (N=31)	% of all adults	% of 22-29 year olds
Completely independently in his own home or apartment (also some w/girlfriend or roommate)	2.38%	9.68%
In college/university in a dorm (higher education beyond 12th grade)	0%	0%
At another school, away from home (Special schools for people with disabilities, etc.)	0%	0%
At home with his parent(s)	23.8%	64.52%
Living with another relative (grandparent, sibling, etc.)	0%	0%
In a supported living, semi-independent environment (i.e.supported apartment or a supported apartment with 24/7 care)	8.33%	19.35%
In a group home with 24 hour supervision	1.19%	3.23%
In a host home (with one family or couple who live with him or similar)	0%	0%
In an institution with 24 hour supervision	1.19%	3.23%
Homeless	0%	0%
Other	0%	0%

Final number: 90.32% of 22-29 year olds are living in some kind of supported environment, but only 64.52% are living with parents.

30-39 year olds (N=20)	% of all adults	% of 30-39 year olds
Completely independently in his own home or apartment (also some w/girlfriend or roommate)	5.95%	25%
In college/university in a dorm (higher education beyond 12th grade)	0%	0%
At another school, away from home (Special schools for people with disabilities, etc.)	0%	0%
At home with his parent(s)	10.71%	45%
Living with another relative (grandparent, sibling, etc.)	1.19%	12.5%
In a supported living, semi-independent environment (i.e.supported apartment or a supported apartment with 24/7 care)	2.38%	25%
In a group home with 24 hour supervision	0%	0%
In a host home (with one family or couple who live with him or similar)	1.19%	12.5%
In an institution with 24 hour supervision	0%	3.23%
Homeless	0%	0%
Other	1.19%	12.5%

Final number: 75% of 30-39 year olds are living in some kind of supported environment, but only 45% are living with parents.

40-49 year olds (N=8)	% of all adults	% of 40-49 year olds
Completely independently in his own home or apartment (also some w/girlfriend or roommate)	0%	0%
In college/university in a dorm (higher education beyond 12th grade)	0%	0%
At another school, away from home (Special schools for people with disabilities, etc.)	0%	0%
At home with his parent(s)	0%	0%
Living with another relative (grandparent, sibling, etc.)	1.19%	12.5%
In a supported living, semi-independent environment (i.e.supported apartment or a supported apartment with 24/7 care)	2.38%	25%
In a group home with 24 hour supervision	0%	0%
In a host home (with one family or couple who live with him or similar)	1.19%	12.5%
In an institution with 24 hour supervision	0%	0%
Homeless	0%	0%
Other	1.19%	12.5%

Final number: 100% of 40-49 year olds are living in some kind of supported environment, but none are living with parents.

Over 49 years old (N=2)	% of all adults	% of 49+ year olds
Completely independently in his own home or apartment (also some w/girlfriend or roommate)	0%	0%
In college/university in a dorm (higher education beyond 12th grade)	0%	0%
At another school, away from home (Special schools for people with disabilities, etc.)	0%	0%
At home with his parent(s)	1.19%	50%
Living with another relative (grandparent, sibling, etc.)	0%	0%
In a supported living, semi-independent environment (i.e.supported apartment or a supported apartment with 24/7 care)	0%	0%
In a group home with 24 hour supervision	0%	0%
In a host home (with one family or couple who live with him or similar)	0%	0%
In an institution with 24 hour supervision	1.19%	50%
Homeless	0%	0%
Other	0%	0%

Because we have only 2 adults in this age bracket, the numbers speak for themselves. More on this to follow.

What does the data on where guys with XXYY are living mean?

There have been major changes in society to include people with disabilities into the community. Our data reflects that as our adults age, they are becoming more independent. However, when you reach the 40-49+ categories, you also need to consider the age of their parents. They are less likely to live with their parents for that reason alone.



You can see, in the data for 30-39 year olds (many of whom have been in our group for some time), that parents are moving much more toward independent living and supported living environments, which is a reflection of the change in society. This also means to us that they are finding these resources, which is very exciting!

Remember when the doctors told us that “all” men with XXYY should be automatically institutionalized? Well the data speaks for itself. That is not what is happening. Of course, it is true that institutions in many countries are now a thing of the past. But that is not true in all countries. And furthermore, it may not be a good thing that there are no more institutions. We have known families who have needed them—desperately, for so many understandable reasons. Our comments on institutions should not be viewed as any kind of judgment of parents who have been in this situation. While we agree with the move toward community inclusion, we know that there are often not enough supports to make that a reality for some males with XXYY and people with disabilities in general. One thing we know for sure is that if your son needed an institution, you would know it.

We do think there is a major conclusion to be drawn from the data, however. That is that **most adults we know with XXYY need some kind of supported living arrangement.** When you look at our data on employment, you will see why. The sooner and the more you plan for this outcome, the better.

Education of guys with XYY

We asked several questions about educational background in our survey. The main purpose as far as adults with XYY is concerned is to show what types of continuing education our men have received. But we also asked some background questions so you could understand the data better.

What type of school was he in from grades 9-12?

Public	60.24%
Private	16.87%
Homeschool	2.41%
Other:	22.19% (total)
Special Education BOCES	1.2%
Combination private & public	2.41%
Special School for people with special needs	14.46%
Answered "never finished" but did not say type of school	2.41%

What was his high school situation up to grade 12 (and beyond for special education students?)

Graduated with a full diploma	28.92%
Received his GED	3.61%
Graduated with a special education type of diploma	33.73%
Currently in high school "transitions" program	4.82%
Is currently in "secondary," "college" or other equivalent in countries outside of the US referring to grades 9-12.	0%
He dropped out of school (or was asked to leave school) and did not receive an equivalent diploma (GED in the U.S.)	12.05%
When he finished up to a certain level of school, he did not move forward to the next level.	9.64%
Still in school, will receive full diploma	2.41%
Uncategorized (other)	4.82%

Please select all that apply to the educational supports that he received while in school, if any. We are mainly interested in grades 9-12 here.

He was/is in a regular education program	13.25%
He was/is on an IEP	69.88%
He was/is "statemented" (UK)	7.23%
He was/is on a "504" plan (US)	3.61%
He was/is receiving other educational supports	14.46%
He received private tutoring	8.43%
He was/is homeschooled	3.61%
Other	28.92%

Note: Because this was a “choose all that apply” category, there are many who chose several categories. In the “other” category, we received a number of responses about individual situations, speech and language therapy received, types of programs they were in and more. There were too many to list.

Has he received any continuing education beyond 12th grade?

Yes	36.14%
No	63.86%

What type of school did he attend beyond 12th grade? (Choose all that apply if more than one applies). (N=30 Yes responses from previous question)

Certification program in a specific field	10%
Two-year trade school, community college or other type of school	30%
Four-year college/university	6.67%
Special college program for people with disabilities	30%
Other	36.67%

Notes: In the “other” category, there were several explanations. Most of them talk about the type of program they were in such as computers and IT, certification programs for culinary arts, horticulture and others and some talk about taking courses.

Did he complete the program?

Yes	32.14%
No	67.86%

Did he receive a certification or degree and if so, what is his certification/degree in? (Open Ended answers)

4 people answered no

5 people answered that he is still enrolled and working on it.

Certifications received:

- I.T. B tech level 2
- Culinary Arts
- Agriculture
- Basic trade level from the National Qualifications Authority
- No degree but did something called ASDAN (UK program)

Employment

What is his current employment situation? (All adults)

Employed full-time	10.84%
Employed part-time	25.30%
Unemployed temporarily	25.30%
Permanently unemployed	38.55%

By age group:

	18-21	22-29	30-39	40-49	Over 49
Employed full-time	4.55%	16.13%	5.26%	12.50%	0%
Employed part-time	13.64%	41.94%	26.32%	0%	0%
Unemployed temporarily	36.36%	25.81%	10.53%	37.50%	0%
Permanently unemployed	45.45%	16.13%	57.89%	50%	100%

The following section is difficult because it was an open-ended question with a lot of varied responses. Therefore, we tried to categorize them as much as we could.

Please tell us more about his employment situation. If he worked in the past but does not now, please tell us about that. What happened?

Successful employment situations

Supported employment

A large number (16) of the comments related to various supported employment situations. Here are a few of the comments related to supported employment. We have deleted details that may identify the individual.

"He works in an institution called (deleted) where he is fully employed and can stay all his working life. He has just started a new job. "(Deleted) has so-called "out-groups" which means people working at a firm like "normal" workers but accompanied by a professional from (agency). My son is working at (deleted store) where he puts the parts of furniture together (wardrobes, tables, sideboards,...). He is really good at it. I am very proud of him and very happy, because it is a sort of integration in the "normal" world."

"He works as a "truck driver assistant" for a document destruction group through the local developmental disabilities workshop."

"He is employed by (deleted) and he works 4 days a week, 7 hours a day. His employment is provided for him as a client of (developmental disability service provider). They also provide his transportation to and from his job. He does a variety of different tasks at his job. He also receives behavioral support as part of his placement at (deleted). We meet once a year to go review his goals."

"He works in a sheltered workshop part time and just recently hired for a part time community job working as a monster in a haunted house."

"He works 1 day at a restaurant as a dish washer. 3 Hours. He is in a program thru (developmental disability service provider), where he goes the other 4 days and does piece work."

Successful, typical and/or creative employment

A smaller number of parents commented on successful employment.

"Has been full time employee for over 15 years. Works midnight to 8 shift in convenience store. Responsible for check out, ordering products, stocking shelves. Works independently and is well respected and trusted by employer. He is often working on his own, totally responsible for the shift."

"He is a heavy equipment operator with several operator licenses including a CDL for tractor trailer trucks. He is currently employed with a garden design company which means he is busy in the summer and unemployed during the winter. He does snow plowing and clearing. Last winter he was working for a company that clears large scale parking lots; this coming season is unclear. He is brilliant with heavy machinery and thoroughly understands the machines and how to handle them. He needs clear instructions to work effectively and a relaxed environment as he gets easily tense and overwhelmed. He has had jobs in the past such as a (deleted) truck driver for a construction and building material company. The work environment was stressful as he had to negotiate several managers and supervisors. He had a hard time being diplomatic and unruffled."

Successful employment situations (continued)

Successful, typical and/or creative employment (continued)

“He has been working for at least ten years doing yard work and has done well. Several things have made this workable - flexibility, limited contact with people, no supervisor beyond homeowner, clear cut duties, immediate pay, working only a couple of days a week for a few hours a day, and others.”

“He worked at a grocery store straight out of high school for 4 1/2 yrs.”

“He has two part time jobs. He works at a grocery store stocking shelves 8 hours a week for the past year and a half. He also just started working two mornings a week at the preschool I teach at doing maintenance work around the church with an older gentleman.”

Works within the family business, for a friend or where parent works

Five of the comments related to guys with XYY who work in their family business, where their parent works or for a friend of the family. Here are some of their comments.

“He works two eight hour shifts, two days a week at the auto repair shop where his dad works. He does oil changes, tire repairs, helps with brake jobs, cleans up around the shop, restocks shelves with parts. All are done under supervision of dad.”

“He works part time at his father’s company. If this was not his fathers company he would have been terminated by now. He requires constant reminders and repetition is key plus an environment of trust. If he has someone who he feels safe with and that has patience with him he can do well.”

“We are fortunate to have our son be able to work with my husband in the lumber industry. He works in the warehouse pulling orders. My husband is the operations manager and is able to be onsite for training and all other issues. Our son does a good job there because he has to read the order then fill it, his visual memory is extraordinary so he rarely makes mistakes on the orders, however, he is not the fastest worker and he has been known to get distracted and mess around at times (especially if the other guys are (modeling the behaviors)).”

Other successes that were not in the survey

Before you delve into the next section which tells you about the many difficulties our adults with XYY have had with employment, we do want to tell you that there are some other cases we know about but did not capture in the survey. These are individuals we know who are working.

1. We know of one adult with XYY who is working on a military base and doing quite well. He was hired through the disability employment program. More on that in the employment booklet.
2. We know of an adult with XYY who works as a quality control inspector at a factory.
3. We have another adult with XYY who has his own landscaping business.



Employment barriers & struggles

The survey data speaks for itself and should not be a surprise to you. Our adults with XXYY struggle ***mightily*** with employment. There are reasons for it. Here, we have structured parent comments about employment problems into categories of difficulties that came up often in the same open-ended question from the previous section.

Medical issues

“He works as a kitchen porter (mainly pot washing) in a (deleted name) restaurant in our local town. We know the chef. He has been there nearly 4 years but is leaving due to long hours and standing having an impact on his health. At present he has no job to go to and it will not be easy for him.”

“Did work in the past but was let go from his job over 10 years ago and has some health issues that prevent him from working,”

“He has some health issues that would make it difficult for him to work. He also lacks the motivation to work and as a parent I am worn out and I do not have the energy to push him like is necessary to get him to work. I don't think he has the ability to or motivation necessary to keep a job.”

“He does not work. He receives Disability Support Payments on a monthly basis. I believe he is not employable due to an erratic sleep pattern and ongoing health issues related to various medical conditions including chronic fatigue, anxiety, cystic fibrosis.” (Cystic fibrosis is not related to XXYY)

Emotional/behavioral/mental health/judgment issues

“He has worked with the support of vocational rehab. providing a support coach. He worked as support staff in a restaurant, however the pace and noise lead to a melt down and he was let go. He also has worked at (deleted store) stocking the freezer. He struggled to stay on task, and had difficulty with a boss who constantly changed his duties. He quit that job at the advice of the job coach. He now is doing volunteer work to build up tolerance for what typical jobs may require of him.”

“When he was eight, he worked delivering newspapers. When he was 17 he tried construction and found it too hard. Lasted 2 days. He wants so much to work but his anxiety won't let him. and if he could work it would have to be maybe half days or 2 to 3 hour a day job just a few times a week.”

“He has had supportive jobs, but behavioral problems in previous jobs led to discharge.”

“He worked for many years in a full time capacity. He was a very diligent and dedicated worker, until the mental disorder hit him.”

“He is deemed unfit for work due to inappropriate speech and behaviour.”

“Multiple pizza delivery jobs until a couple accidents alerted insurance company that he needed expensive commercial insurance. He was fired from (deleted) when customers supposedly complained about his speeding in neighborhood. Then, we made him quit from (deleted pizza shop) when we learned he was doing delivery instead of food prep as he claimed. Then, he started to meet with state rehabilitation services again but with no follow-up from their end. :(Recently started job at (deleted department store) (3 weeks in so far) in their electronics/photo department which seems to be capturing his interest since he is still so addicted to TV/video/games.”

“Worked several jobs. Mostly part time but not for very long. Early after high school worked for 3 years at document shredding company. Worked 2 years at car wash detailing cars. Worked 7 months full time at car dealership. Anger management issues. Lying and not showing up for work.”

Employment barriers & struggles (continued)

Emotional/behavioral/mental health/judgment issues (continued)

“Socialization issues have created problems at several jobs, particularly regarding his extreme religious views.”

“He had various jobs in high school during school, but never was able to get along with people, and would generally get kicked out.”

“He found it difficult to sustain jobs therefore he had several between the ages of 18 and 32. These ranged between kitchen portering and gardening. He suffered a lot of bullying. At this stage I was able , after great effort, to get support from social services. This meant he went on to government benefits which he would lose if he was in paid employment. Given that employment was unsustainable, losing benefits and having to go through the lengthy procedure of regaining them, was not an option. Also at this age (of 32) he had began with mental and physical health problems: paranoia, and ulceration of the leg which eventually needed major surgery. He has lost the work ethos but desperately needs occupation.”

“He briefly worked in a sheltered workshop for the disabled but was unable to handle the stress of a structured schedule. He also had difficulty coping with the other workers. Some were blind, had seizures, drooled, etc.”

“He works and enjoys being a security guard. Although, he has been fired twice, for poor decision making. He has a part-time job and is currently on unemployment.”

Lack of supports at work

“He has had two unsuccessful attempts at working-without any one knowing about any of his disabilities. The first attempt he received barely any training before being left alone and was responsible for the cash register. The second attempt involved preparing raw chicken and that didn't work out because it made him gag. :) “

“Has held many part time jobs unsuccessfully. The job he held for almost two years was delivering flowers. His boss understood his needs and was wonderful with him. However, eventually she had to let him go because her business was suffering because everyone else didn't understand his issues. He has done some landscaping work. His dad helped him, but he got the money. That went pretty well. However it was quite stressful at times for his dad (not there on time, wanting to do things his way, impulsive decisions instead of waiting for direction from homeowner, long breaks, on his phone). And then he made very poor decisions on how to spend the money, and never had any money.”

“He is presently looking for a part time job. He has had many jobs in the past. Usually he ends up quitting or walking out, if he feels people are "picking" on him or talking about him or not treating him fairly. He likes to work and does a really good job when he is employed.

“He found a job for himself working with a company that designed computer games. He was paid fairly well. This was before we had diagnosed him. He worked with them quite faithfully for five months but gradually became irregular and was then laid off. He now works when he is needed with a company that makes documentary films. This is about three to six days a month.”

Transportation issues

“He had 2 summer jobs in kitchens. Didn't care for it. We live out in the country and he is too nervous to get a driver's licence. Plan is for him to volunteer at a local Veterinary Clinic and possibly go to college to become a certified Veterinary Assistant.”

Employment barriers & struggles (continued)

XXYY related issues

"Sent him away for course in butchery. People was nice and keep him longer to help him get his certificate. Was working as butcher for 20 months. At first it went well. But..he was working slow. Talk to much. Smoke to much and have no fear losing his job. Then there were started a new boss. It was very hard for him...no respect for each other and they interrupted him all the time. Many conflict. One week after the 3 boss started working there he was fired. He was devastated. He applied for another job at butchery and was appointed the day after his interview. In his 2 month there. On probation for 3 months. Still going well. No shouting. He get more respect but also tried to talk less and work more. He get up on his own but 2 early and use public transport...sit hours waiting for the shop to open. Tired in the evening. Sleep when he get home and cant sleep when its time to go to bed. When he is tired at work he will swear at people. He get used to a salary and he really tried to keep his job but dont know to use his money wisely."

"He works at a company that makes construction equipment, he is paid by the school system until May when he is done with school.. The company has said they won't hire him after that because he declines to do some tasks he is told to do. I am looking for another job, hopefully one he likes."

"He has had a variety of jobs that never lasted very long. He was a dishwasher at a restaurant chain. He had a job coach with him at all times. He did the job well but he didn't like being in the back of the restaurant and preferred to be out in the front where all the people were. He often felt tired and distracted. He was let go about 9 months after he began. His next job was at (deleted) Video store. He liked this better. I think he stocked the shelves at this job. Having no concept of time and having no job coach led to him taking long, long breaks. He was at this job for a few months until he took a bottle of water that wasn't his from the common refrigerator. He should have put a dollar in the bucket beside the refrigerator but didn't. Being fired for this was, in my opinion, only an excuse to get rid of him. He was then placed at (fast food restaurant) but, rather than do his work, he was much more interested in attaining his co-workers' phone numbers; especially the girls'. He called one of the young ladies too many times. She complained to the manager and He was let go. After this experience, the agency that was supporting him (he lived in a group home at the time) decided that they should hold off on any more jobs because they didn't want to burn all their bridges in the community. This was at least 10 years ago. Now he, who is 35 years old, is receiving general job training. In other words, he is being taught how to do an interview, how to dress and behave in a job, what might be expected of him while at work. They are assisting him with job applications. I am hopeful that this will lead to a more permanent job for him; one he will enjoy and where he will recognize his value in the work place. A very important detail about his lack of employment has everything to do with the fact that he had been, until recently, attending a day program for handicapped people. The vast majority of those clients are more mentally and physically handicapped than is he and I don't think this placement was of great benefit to him. Even though it was almost his entire social network I think He went backwards in his development rather than forward. He had a long-time girlfriend who also attended the program and when they broke up everyone decided it was in everyone's interest that He no longer attend the program. The same agency still supports him and he has a high enough level of funding to warrant a support staff for 6 hours per day. He just doesn't hang around the day program and the same people anymore. Now they are much more vigilant about looking for employment for him and finding more appropriate activities for him. He is currently working at a government building serving lunches from the lunch wagon that he rolls from office to office. He likes it because he is very social. He makes a pitiful hourly wage but he also earns tips. He only does this twice a week. He also gets paid by the agency to wash their vehicles and to landscape the group home properties. These jobs are all through the support agency and are not regular employment. It is my hope that he will be able to hold a "real" job soon. Until now He did not seem to see much value in working or making money...no matter how little money he has had. He is still maturing, though at glacial speed. I have always seen that he can continue to learn and change for the better and this is what keeps me hopeful for his future."

These were not all of the comments on employment but are a fair representation.

Sources of Income

(choose all that apply)

Government income (such as SSI, SSDI or any other type applicable to any country that provides income for people who are not able to work.)	75.9%
Other government support	6.02%
Unemployment compensation	3.61%
Supported by family or trust	31.33%
Full-time Employment	9.64%
Part-time Employment	25.30%
None of the above	0%
In process of applying for government support	3.61%
Self-employment	1.20%

Services & Supports Received

Medical (i.e. government healthcare)	54.55%
Medicaid Waiver Services (United States)	24.68%
Vocational Rehabilitation	18.18%
Community Services from a Developmental Disability Service Provider	29.87%
Mental Health Services from a community or government provider	22.08%
Job services & job coaching	25.97%
Services from an Autism organization	6.49%
Did not qualify for any services	3.90%
No services have been needed	5.19%
Does not receive services for some other reason	9.09%
In process of applying	2.60%
On the waiting list	1.30%
Lost his services	5.19%
He refused to accept or quit services	3.90%
No services in our country	1.3%
Receives other services not listed	2.60%

Greatest Barriers in Adult Life

We asked parents an open-ended question concerning their son's greatest barriers in adult life. Here, we have categorized their answers to the best of our ability. We think if we had provided a list of choices that the percentages would be much higher in certain categories but this gives you a good picture that can help shape your plan.

Social Skills	28.57%
ADHD/Executive function related	15.58%
Lack of motivation	15.58%
Poor judgment/reasoning	14.29%
Behavior	12.99%
Does not understand his limitations/what's good for him	9.09%
Handling Finances	9.09%
Transportation barrier	9.09%
His size	7.79%
Impulsivity	7.79%
Lack of training, inadequate support on the part of service providers	7.79%
Other people's unrealistic expectations of him; "he looks normal"	7.79%
Getting into trouble with the law	6.49%
Mental health issues	6.49%
Speech/communication related	6.49%
Dating issues	5.19%
Health Problems	5.19%
Immaturity	5.19%
Low IQ	5.19%
Decision making	3.90%
Dishonesty (including telling tall tales, stealing, etc)	3.90%
Will not accept guidance/help	3.90%
Alcohol/drug abuse	2.60%
Exhaustion (sleep problems & tires easily)	2.60%
Learning disabilities	2.60%
Failure of the education system	1.30%
No barriers	1.30%
"Himself"	1.30%

What is the best path to success?

What is the best path to success?

The very best path to success starts with a solid foundation that supports your “building.” That foundation looks like this:

Solid, reliable income. (SSI or Disability Pension or whatever it is called in your country.)

Medical Insurance. This is an issue in the U.S. Apply for Medicaid, even if he has other health insurance. This is important because Medicaid pays everything your insurance does not pay and is also necessary to pay for services in the developmental disability service system (DD System). DD System services are paid by Medicaid Waivers. The waivers pay for supported living environments.



Every adult with XYY should have the above two things in place when he turns 18. (In some countries, the age is 16). The only exceptions are families with enough means to fully support their son for the rest of *his* life, not *yours* OR if you are nearly 100% certain he can work full-time to fully support himself.

We have good reason for saying this and here's why:

- Your son needs a strong safety net. Come what may, if he has the above two things in place, most of his needs are covered no matter what.
- SSI and Medicaid must be in place to receive other services to help him move to the next step.
- He typically won't lose the above two things completely if he begins working. There are provisions for him to keep both of these while working. It does happen, though.
- If your son establishes a work record first, the likelihood that he will get disability income becomes *much less likely*. You know that phrase “you can't go back again?” That applies here.
- If you wait until he is older to try to get these two things, it is more difficult to get approved. Establishing his disability at 18 is continuation of what you established while he was on an IEP in school. It provides a long-standing record of his need for supports.
- In the U.S., medical insurance is mainly employer-based. Keeping employer-based medical insurance for him could be a challenge if he can't work full time, or if you can't.

In addition to the above two things, you should also have:

- **Control of his money** (representative payee, financial power of attorney or full guardianship.)

These are all the foundation for success moving forward. From here, he can get more education, explore jobs, become more independent and more. Each success builds on your foundation, but your foundation will **save him from himself**.

Best advice from your parent-peers

We asked parents of adults to give you their best advice. They are the experts and their advice is priceless. Here are some of them, in their own words.

Try to instill independence in everyday living. (Not my strong point, but I am learning) set up a plan of action for the inevitable (you will not be around forever) use services offered to you, they can be very helpful.

You have to be the best advocate for your son, because no one else can or will do it. It all starts with the school system, making sure he gets anything provided to him. Make sure he is signed up thru your local developmental disability service program. Keep records of everything, no matter what it is, this will help you when you need to file for SSI benefits in the future.

Foster the strengths, speak to potential employers about xxyy. Offer to subsidize the income if possible. I believe it is important to have a first positive experience from which to build self esteem.

Counseling. have someone with authority that will be a voice and advocate to get things done. Find out what his strengths are and what makes them happy and base a job around that. Make sure any future goals are realistic

If they will be attending college, I feel being a part time student is best. To keep the work load light. Also start out with a part time job. Our son has been at his job over 2 years now and can do every job in the store. He also is very accommodating with his days and hours.

Push for as much help in school as you can. Check out Community Mental Health Services as soon as possible. Make sure you keep good records of school and doctors appointments. Get counseling for them anytime you can. We found out the hard way in counseling. Do it right away when there become problems with behavior that are getting out of control fast. It has helped tremendously. Apply for SSI as soon as possible.

Find out if their high school offers a transition program.....my son learned many life skills. They also found him a job. They helped us, the parents with any questions and concerns. My son loved school

They are all so different, the boy will need to find a niche, parents can only hope the boy will succeed, try many different endeavours

If we were doing it over again, I would put my son in a different high school program, one where he would learn more life skills. The school he attended has about 90% of graduates going on to college, and it was probably not the best choice for him. But we didn't get his XXYY diagnosis until after he was already registered there, and his older brothers went there and he doesn't like change. Look for developmental disability agencies.

The best advice i can give from experience is to be relaxed with them. Don't make a drama out of a crisis, explain things in a way they understand.

From personal experience this ride has been a lonely, solitary one. Nobody can put our son into a category. His psychiatrist is stumped. A cocktail of disabilities is how he has been described.

My first advice would be to seek good mental health counselor or personal trainer.

Best advice from your parent-peers (continued)



Be patient. Be very very patient.

Be prepared WELL IN ADVANCE. Health insurance, wills, trusts, social security, employment or job coaching, anything that makes them feel more independent. Be involved at school and with local disability groups.

Keep them in high school as long as possible. Apply for disability benefit at 18. Apply for services but be flexible. My son can only handle one thing a day in terms of plans and we've accepted that's how it is. He's quite unmotivated and it causes more stress and anxiety if we pressure him to do anything that requires commitment. We just let him plan his days and his life unless the commitment is extremely critical (dr. appt). We ensure he gets his meds. He won't take them unless we put them out. He stays out of trouble, he's honest and he's happy.

Always ask yourself: Is he unwilling or **unable** to do something? The answer makes a huge difference in what you need to focus on in terms of supports. We learned that most of the time he is unable and he needs help with that. Also, focus on the big stuff and let go of the small stuff—you may have to learn how to “redefine” what big stuff really is. Big stuff is life-threatening or when he could get into serious trouble. **EVERYTHING** else is small stuff. Go from there.

Try and develop a support network outside of family when you can.

DUAL ENROLLMENT (in high school with community college). If child has UTMA assets make sure to set up special needs trust by 18. His own assets must go in self-funded trust. Other assets can be in 3rd party trust. GET DOCUMENTATION of disabilities from doctors including psychiatrists documenting his disabilities in DSMIV terms. Accept that there is probably not a good group home situation for most of our boys (too much focus on severe intellectual disabilities) and you are probably going to have to “build a home” yourself. That is what I am trying to figure out now! Ask me again in five years. :-) I definitely do not have this figured out yet!

1. Get full guardianship well before your son turns 18.* You can always lighten it up later.
2. Make a exit school plan with your child starting in elementary school.
3. Document everything, and check up on every one. Be a micro-manager. It will be needed.
4. Be realistic with yourself. There will come a time when your child maxes out what they can do. Until then help your child continue to grow mentally, academically, and physically
- 4b. Put together a “once you have gone” plan. Ask the tough questions: how will your child care on? Put together a plan now...don't wait.
5. Never forget your son is a gift. He wasn't an accident...and don't let ANYONE working with your child think otherwise.
6. Your budding adult needs an advocate to help him biodegradable a future HE see"s for himself, not what WE see for our child. Give your budding adult as much control over his future. It's his life, not ours.
7. Lastly, give yourself a pat on the back once in a while. We're all on a journey together. Remember your more than your son"s care taker and parent. Don't burn out during the journey. Take breaks without your child. Stop, laugh, and enjoy being just “you”.

*To our knowledge, you cannot seek guardianship before the age of 18. Guardianship happens when he becomes a legal adult. Parents are legal guardians of children under 18 automatically. Check with an attorney.

Best advice from your parent-peers (continued)

We made the mistake of not knowing what was available for him as support. His IQ was just officially tested in 2014 to get him government support which we are still waiting for. Our family physician was not really aware of what was possible and until we had his IQ checked with professional psychologists we then got more supportive info. Check first with their family physicians for support groups and agencies. Ensure they qualify for support financially. I believe a life coach would be important for my son, someone outside the family as the frustration can mount at times with him and important they gave someone to talk to about this syndrome and social behaviours. Learn as much as possible about what is available for your child for support. It scares us to death what will happen to our son if something happens to us. Daily concern for his well being.

If you will be seeking SSI, start early in collecting copies of medical records and psychological testing. Collect everything that shows any kind of disability. Go to one of the x&y clinics and have as much testing as possible- speech and language, psychological evaluation, occupational therapy evaluation, adaptive behavior/functioning assessment. I can't offer any other advice because I feel like I've done very poorly in seeking out services so far for him.

Start any and all applications before they turn 18 because the wait lists are phenomenal and they have no services or drop in centers or groups until they have been through the processes of adult services.

Try and prepare as early as you can Work out with your son what you all want and try and achieve that. Talk to everyone and find out where to go for advice Get advice from school, and then look outside the box and see what there is in the adult world. We were told a lot of things could not happen, but they could. Nothing is impossible Talk to other parents, esp on the Xxyy website

-Find friends with teenagers that also have special needs. You will need each other. -Find out what your state's local services are and apply. -Be involved with your son's teachers and schools. Offer help, praise them for the work they do, feed them at IEP meetings - it's amazing how much help you can get if the school teachers and admin simply like to work with you and your son. Being nice, generous, and grateful goes a long way!

Oh gosh, the best thing I can say is what has been said so well before ... hope for the best, but plan for the worst. And imagine that worst as vividly as possible.

Is he ready to be an adult, society will hold him accountable for his actions, does he need guardianship? I think DD services should be a priority, as situations can change and do change. I also think residential placement is crucial for those guys not able to live on their own, if let out there alone so much can happen to them. I also think the guys should be involved in support groups, see a psychologist or psychiatrist on a regular basis. It is hard for them living in a world where they realize they are not like other guys. They have the same dreams, but due to limitations can't fulfill them. I think parents have to know their son's limitations and accept he may need help the rest of his life, so start early.

Find out what services are available after high school. We asked questions about this while he was still in high school and we were directed to the (Developmental disability service system). Our state has a good system in place and we are fortunate to have had good supports while he was in school that directed us to what we would need to do after high school.

Only just expect the unexpected.

Prepare them for the stigmas of those who refuse and or do not understand the XXYY.

Best advice from your parent-peers (continued)

Keep loving them. Arrange a trusted guardian if anything should happen to you. Learn to balance encouragement with realistic expectations. Push for the best academic help possible. Keep up to date with medical information and care. Be prepared for achievement surprises when previously undiscovered skills emerge. Social development is continual.

Oh man, to let yourself off the hook. It's not your fault that your child is different. Fully embrace his uniqueness and celebrate the wonderful, special person he is. Let him know you couldn't be more proud of him and nothing about who he is is a let down to you. Then work like mad to get him supportive services so that when you're gone, he won't become homeless. Check with local and governmental agencies to see which services he'll qualify for. Be patient because these things don't happen or move fast. Expect it to take a year or longer but do the work to get him approved. The peace of mind it brings is so worth the long wait. Surround yourself with supportive people who fully understand your son's unique diagnosis and its corresponding limitations to his life and society's perceived successes. For our sons, success may just be getting up and showering that day. Your son needs to be around those who understand and will acknowledge these successes and never bully or berate him for not "measuring up" to other boys his age. Get rid of negative people quickly and insulate your son as much as possible from negative, unreasonable people. Set your son up for success by getting him in a positive environment. But most of all just love him exactly as he is with no expectations. My son brings me so much joy, I can't imagine my life without him

Put yourself squarely between him and anyone who is supposed to serve him in any way. Don't let him do it on his own until he has learned from you how to self-advocate.

See if there are any programs available to them to help transition to live after high school. See if there is a "buddy" program so the young man can go out and learn to be independent. (without parent supervision if possible). We took our son to church and talked to the pastor and was given a name of a college student who needed credit for "caregiving" class - sort of like Big Brother. Now my son has a someone who is not family for a friend.

Find things your son is interested in and really help him to pursue these interests, e.g. my husband 'coached' my son's soccer team. Especially in regards to career directions, expose him to work experience (even with family, neighbours), volunteer work (if it was just for adults we signed up for the volunteer work and took him along, e.g. bushcare and wildlife rescue groups), information and practical exposure to work in that area. Make daily self care and chores a regular fixture - get professionals to explain to him the importance of these, e.g. dentist to reinforce twice daily teeth brushing, endocrinologist to reinforce his need for testosterone. They need everything to be very consistent and concrete, and then on a regular basis to be reassured and reminded why these things are necessary.

Start early, don't let the school district just get by with the minimum. Put strong vocational goals in your IEP and contact your state residential provides to make sure your kept fully informed of current services available as well as new initiatives being tested. Find out the person who signs off on the supports and build a positive relationship with them. I volunteered to sit on an adult advocacy board. It helped me learn what services were available and how to fill out the forms. My biggest advice is don't give up. No one can advocate harder than the parent. For every tear I've shed I've smiled a million times more because I learned how to navigate an ongoing never ending storm. Surround yourself with people who know and who have traveled before you.

They are more likely to finish a short course as opposed to a degree course that takes several years.

Patience- lots and lots of patience. Love them, because its not their fault. Push him to be the best them. Don't give or do things for them that they are capable of doing themselves. Fight for them and be involved in their life.

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>
