



Transitioning to Adulthood Plans and Services for Adults With XXYY Syndrome

Part 9: Long-term Planning

Part 9

Long-term planning

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Transitioning to Adulthood Plans and Services for Adults

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 XXYY 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

Long-term planning

Consult an attorney

We cannot give legal advice and nothing in this document should be construed as legal advice. We have included this booklet mostly to remind you that you may need to consult with an attorney about a special needs trust.

Why do you need a special needs trust?

Not everyone is going to need a special needs trust but you might need one if:

- Your son is on government disability or Medicaid and...
- You or someone in your family is planning to leave money to him for his care
- If you are expecting a large back payment from Social Security
- There's money saved elsewhere in his name before you apply for government disability or Medicaid

The Special Needs Trust is set up to protect the money he has for his care from being counted as income which would disqualify him from Medicaid or SSI. The money in the trust can only be used for very specific purposes that are not covered in his public benefits (talk to your attorney). It can be really useful for things that otherwise would not be covered, but only according to the rules.

How do you fund a special needs trust?

Typically, trusts are funded by family members who leave money in their wills. So it is important for you to talk to family members whom you think might be leaving money to your son to make sure they understand what needs to happen.

Another way to fund a special needs trust is through a life insurance policy on family members of the boy or man with XYYY. If your son's grandparents have life insurance policies that they plan for you to use for his care, make sure you talk to your attorney about that. You can also take out life insurance policies on yourself to fund a trust for him when you are gone.

Finally, if you have been saving for college for your son and he is not going to use those funds, consider putting that money into a trust.

Pooled Trusts

There are organizations like the [Colorado Fund for People with Disabilities](#) that manage pooled trusts for people with disabilities and provide many other services. Check to see if you have one near you and talk to them about the difference between a pooled trust and a regular special needs trust. Our understanding of the difference between pooled trusts and special needs trusts is very limited. They do very similar things but are structured differently.

ABLE Accounts in the U.S.

ABLE accounts are an exciting new alternative in the U.S. to special needs trusts. If you are familiar with 529 college savings plans, then you have an idea of how ABLE accounts work. They are 529A savings plans that are protected when it comes to counting as a resource for public benefits. ABLE accounts are easier to set up than a trust and may not require an attorney. However, you should talk to an attorney familiar with all types of long-term planning for people with disabilities or an investment advisor to understand the differences and choose the right vehicle.

At the time of this writing, ABLE accounts are rolling out in states across the U.S. In at least one state where they have officially rolled out (approved by the state legislature), they are run by the same organization that operates the 529 college savings plans.

For more information about ABLE accounts, read these links:

[National Down Syndrome Society](#)

[Forbes article](#)

[US News and World Report article](#)

National Disability Institute

<https://www.realeconomicimpact.org/public-policy/able-act>

Austism Speaks

[10 Things to Know about the ABLE Act](#)

To find out who is managing ABLE accounts in your state, simply google ABLE accounts and the name of your state.

Disability Savings Plans in Canada

Canada has a great, unique way of supporting people with disabilities through [disability savings plans](#). The Registered Disability Savings plan is similar to a Special Needs Trust. This site provides information on all disability savings plans in Canada.



Wills

We recommend that you talk to an attorney long before your son is an adult about what your intentions are for your son with XYY. But if you do not have this done yet, please put it on your list. It's really important to outline who will be his caregivers and what is expected of them. Your will can't do all of this, but you can do some of this through a letter of intent, which we will describe next. There are people in the disability community in your state who will have good information on where to find an attorney who understands special needs planning. Find the right attorney, recommended by those who have done it.

Letter of intent

A letter of intent is not a legal document, but it does explain to everyone who will be caring for your son what his needs are. It tells people the things you know about him and his preferences in life. It explains his idiosyncrasies. You know, those things about XYY that people would not know if you didn't explain it. For example, the fact that he tells tall tales sometimes or says everything that he is thinking out loud.

The letter of intent is an extremely valuable tool to tell people the things that you feel they would be lost without.

There are some great resources and even samples of letters of intent on this Web site:

[Life After IEPs](#)

If you decide to write a letter of intent, please know that other parents in the XYY community are a great resource for helping you to make sure that you have covered all of the bases. We would really like our parents to share their letters of intent with one another so we have the opportunity to make them the best they can be for boys and men with XYY.



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>
