



Transitioning to Adulthood Plans and Services for Adults With XXYY Syndrome

Part 8: Disability Services

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Why You Need Government Disability Services & What is Available

Why do you need disability services?

Disability services strengthen your son's safety net and provide assistance for him to get a job, have meaningful activities to do and help to live independently or in a supported environment.

These services are part of a larger plan and are especially beneficial for your "after you are gone" plan. They ensure that your son has a place to live and has the help he needs for living independently or in a supported living home. (Also see the booklet *Where Will He Live?*)

The needs of our adults with XXYY are pretty clear as outlined in the first booklet in this series, *Laying the Groundwork*. Even if your son is considered to be "high functioning," it is still worthwhile to investigate disability services thoroughly. While he is younger, you won't really know how XXYY is going to impact his ability to work and live independently. If your son absolutely does not need services, you will know it. All others who are in that gray area, should look into services.

What services are available?

If your son qualifies for the services, he can receive:

- A job coach and supported employment
- A representative payee if you can't do it
- Supervised community activities
- Various types of supported living environments and long-term care
- Cooking and cleaning assistance
- Behavioral services
- Transportation
- Assistive Technology
- Mental health services
- Dental Services
- Vision Services
- Respite Services
- Supported Employment
- Outside of the U.S.: Services are coupled with disability income rather than separately in some countries.

Waiting Lists

The U.S. is not the only place that has waiting lists for these services. We have heard about waiting lists in Canada as well, and we imagine that any country that provides services in a similar way to the U.S. and Canada has waiting lists. In some U.S. states your son needs to get on the waiting list when he is 14, not 18, and others will receive services before your son if he didn't get on the waiting list at the right time. This can be highly problematic because the waiting lists can be decades-long and your son might not get the services he needs right now until he is in his 30s or 40s. It's a horrible problem. But when you do get services, they are extremely helpful. We have had parents get on the waiting list later and receive services, so please apply anyway.

How to Access Government Disability Services

Where to go

We have gathered resources from the places in the world where the majority of our members are located or where people gave us information. However, at the end of this list under “other countries” is a great link to services in all countries. Be sure to look at that list as well because it is very comprehensive.

Australia

The [Disability Services Commission](#) works in partnership with service providers and other government departments to provide information, supports and services to people with disability, their families and carers.

[The National Disability Insurance Scheme \(NDIS\)](#) in Australia is a relatively new program of Australia and is rolling out to new territories gradually. They began the launch in 2013 and say that they will be fully launched by July 2016.

Canada

Similar to the United States, services for people with disabilities are accessed through your province. We can't do a better job of giving you the information you need than you can find in [this booklet by the Canadian Down Syndrome Society](#). They have outlined where to go in every province.

Germany

In Germany, the place to start is the social agency in your area (link below). (Please also refer to the next page under “Other countries” for a comprehensive list in Germany.) The social agency pays for assisted living and government disability income.

Social Agencies:

[Sozialaemter](#)

[Federal employment agencies](#) are also an important part of services in Germany. Parents recommend that other parents contact them for assistance.

Lebenshilfe

Every federal state has its own Lebenshilfe state association that provides services.

Where to go (continued)

India

We know that services in India are very limited. But we discovered that an agency that began in Germany also has a program in India. They are called [Lebenshilfe](#)

United Kingdom

Services in the UK are accessed through your local council. Parents have told us that you contact a social worker at your local council who will put together a “package” to address your son’s needs. We understand that services vary drastically from one area to the other in the UK.

[This Web site explains what is available](#)

United States

All services for people with developmental disabilities or mental health issues are paid for by the Medicaid Waiver program in your state (please refer to the booklet *Addressing His Medical Needs* for an explanation of Medicaid Waivers). The waiver programs are run by a state department (they all have different names). Many parents don’t realize this because they are working with an agency that provides the intake and services for the program, such as the California Regional Centers, which contract with the state. Every state administers these programs differently. Some states contract with quasi-governmental, nonprofit agencies like the Colorado’s Community Centered Boards and some states have only a state-run agency that is the gate-keeper or the place to start. In New York, for example, nonprofits actually compete with one another to provide these services whereas in Colorado, you can only use the agency that serves your county. No matter what, the services you can receive are all dependent on what your state has decided to do with its Medicaid waivers and they can vary significantly. Eligibility for services also varies from state to state, which we will explain in another section.

The Web site below is a fantastic place for all families in the U.S. to start. It explains the Medicaid waiver services in your state and where to apply for them. Please note that this site is a little out of date but it is an easy place to start:

[Medicaid Waiver](#)

Other countries:

Our understanding of what is available in other countries is very minimal. For example, we know that India has no services at all outside of institutions. We would appreciate it if families would explain service access to us in detail so we can include it in this booklet with as much detail as possible. We want our families to understand the ins and outs of these services.

[The Independent Living Institute](#) lists services for people with disabilities in all countries.

Qualifying for Government Disability Services

Developmental Disability Services

Every government agency “defines” who qualifies for Developmental Disability (DD) Services in their Medicaid Waiver program in the U.S. and this is probably true outside of the U.S. as well. Australia, for example, has a similar definition of who qualifies for services shown on the [Disability Services Commission](#) Web site.

Herein lies the biggest problem we have in the XXYY Community. If you are unlucky enough to live in a state or province that has “defined” a developmental disability solely as “a person with an IQ of 70 or less” and your son’s IQ is higher than 70, you cannot access these much-needed services. If this is the case, and we say this with all seriousness, if you have to move (the whole family or him) to a state or province where he will qualify, **DO IT** if at all possible. It’s best to do it before he turns 18 but if you try to get services and can’t, a move may be in order.

But in some places, the definition of developmental disability also includes an additional qualifier, based on his adaptive functioning, which is measured by a test. 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 the area where guys with XXYY have the greatest deficits** and it explains the reason why our guys struggle in adulthood. The test that is used to measure adaptive function is called the Vineland Adaptive Behavior Scale. This is the most important test your son can take. If you haven’t had it and your son’s IQ is over 70, that is where to start before applying for services.

We do want to emphasize that if you live in a place that has the additional qualifier and your state turns your son down for services, you need to appeal the decision, based on his adaptive functioning score. Make sure that you know if his score is low or not!

Some U.S. states also have special waivers for people with Autism. So, even if your son has an IQ over 70, he may still qualify for DD services through an Autism waiver.

The way you know if there is an additional qualifier in the U.S. is to look back at the [waiver site](#) we pointed you to before. Look in the left column where it says “What is considered a developmental disability.”

For example:

Alaska says: a severe, chronic disability that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; and is likely to continue indefinitely.

This definition tells us that it is not based solely on IQ and doesn’t even mention IQ. Several states do mention IQ specifically. States can have additional requirements beyond what you see on that site, such as rules that determine what they mean by “mental impairment.” And some of those rules can be narrowly defined as IQ of 70 or less. Do your best to find out what you are in for when you apply by seeking out local organizations who will tell you. Try Autism Societies and Fragile X groups or support groups for parents of children with disabilities, like [Parent to Parent](#).

Mental Health Services

There are mental health services waivers in the U.S. that are very similar to DD waivers. To qualify for a mental health services waiver, your son needs to be diagnosed with a mental illness that requires long-term support. In other words, these services are only available to those with significant mental health problems that would qualify him for institutionalization. Don't let that throw you completely though, because the same is true in the DD system as explained in the section on Medicaid Waivers in the booklet *Addressing His Medical Needs*. The Web site we provided on the previous page will bring you to all of the Medicaid Waiver services in your state, including those for mental health. Other countries may do something very similar in that services for people with mental illness are separate from services for people with developmental disabilities.

Additional qualifiers

In addition to qualifying for services by the definition of who qualifies for developmental disability or mental health services, your son must also qualify for SSI and Medicaid to receive Waiver services. Please read our previous booklets on these subjects: *First, He Needs an Income* and *Addressing His Medical Needs*. There are also financial qualifiers, which you will see on your state Web site concerning services. Other countries may not have these qualifiers because they may bundle all of these considerations together when you apply. In other words, they may limit your son's income as part of his package of care.



Other Services & Resources

Fee for Service Community Programs

Even if your son did not qualify for services through the DD or MH government systems, there are still community programs that you can access on a fee for service basis. In other words, you pay for them out of pocket or with government disability income if your son receives that.

Most providers that contract for services through Medicaid Waivers and probably even social services in other countries also do fee for service community programs. The downside is that they can be expensive on an hourly rate basis. In some places, this may be your only choice.

Please also refer to the booklet *Where Will He Live* because many of the residential facilities listed in that booklet also provide other community services.

These programs typically provide some kind of social program, job program, animal or specialized therapy, for example. There are event programs that take people on vacations and trips.

Here are some examples of what you can find. Take a look at these even if they are not in your area so you can see all the fun things you can find.

[Praying Hands Ranch, Parker, CO](#)

[Hope Farms Project, Elizabeth, CO](#)

Community Life Support, Michigan

We were unable to find a link for this organization which was recommended by one of our parents.

[Community Living Services, Wayne, MI](#)

[Hills, Lakewood, CO](#)

(Fun activities and even vacations)

[Sprout, NY, NY](#)

[Therapeutic Recreation Programs](#)

[CAP Program, North Carolina](#)

[People Creating Success, several California locations](#)

[Disability Services and Legal Center, California](#)

[Becoming Independent, Santa Rosa, CA](#)



We are providing this information to give you ideas. We cannot endorse any of these places because we do not know them. Listing them does not imply endorsement, even if an XXYY family is involved with it. We have not talked to any of these organizations.

Other resources

Autism organizations

Even if your son does not have Autism, autism organizations are often a great way to find services. We have many families using autism services or providers who also provide services to people with autism. Here are two the types of organizations that provide services. Look for the ones in your area.

[National Autistic Society, UK](#)

[Marcus Autism Center, Emory University Hospital, Atlanta, GA](#)

The Arc

The Arc has chapters all over the United States. Some of what they do is advocacy but some Arcs are also service providers for their area. Find an Arc in you area here:

[Arc Chapters](#)

YMCA

The YMCA is a great place to find activities for your son to do. They are everywhere.

[Find Your Y](#)

Community Recreation Centers

Community Recreation Centers often have programs for people with disabilities that they call therapeutic recreation. But recreation centers are great resources for activities for your son even without therapeutic recreation. These centers are typically run by your local parks and recreation service.

Easter Seals

Easter Seals provides many programs and camps for people with disabilities.

[Connect to your local Easter Seals](#)

Centers for Independent Living

There are Centers for Independent Living virtually all over the world. They have really great resource lists.

[Independent Living Centers World-Wide](#)

[US Map with links to Centers for Independent Living](#)

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Other resources (continued)

Community Mental Health Centers & other mental health services

Community Mental Health Centers are nonprofit organizations that provide all kinds of mental health services including independent living services. Here's an example of one in Aurora, CO but all you need to do is google Community Mental Health Center and the name of your city to find them. If you live in another country, google mental health services and the name of your country.

Even if you find that the Mental Health system does not have community services that you need, it is still valuable to contact these agencies to learn what they know that could help you.

[Aurora Mental Health](#), Aurora, CO
[CAP Program, North Carolina](#)
[Mental Health Services, Australia](#)

Transportation

Sometimes transportation can be a barrier for your son to get to his activities and services. Your local bus service or transportation district has special transportation options for people with disabilities. You can get discounted bus and light rail passes and other special transportation or what they call para-transit. You have to apply for these but they are well worth it if your son cannot drive. If your son is on a Medicaid Waiver, he can receive a bus pass for free.

Here are two examples:

[Trans-Aid in NC](#)
[Access-a-Ride, Denver, CO](#)

Transition to Adulthood, other resources

While writing these booklets, we found a fantastic resource for transition to adulthood:

[Life After IEPs](#)

Free transition planning tools!

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If this booklet has helped you,
please donate to the XXYY Project
<http://xyysyndrome.org/main/donate/>

We need the donations of parents and other supporters to continue to improve the lives of boys and men with XXYY. There just isn't funding from "somewhere else" for rare conditions like XXYY.

[Go back to page 3 for the list and links to the rest of the booklets in this series](#)