



Things to Think About!

Researching Programs & Services State-by-State

By Linda Jorgensen

Last year the most frequently asked question we received was, “Where can I find information on the services and programs available in each state?”

The second most frequently asked question was, “How do I find out how my state ranks in services for the disabled and what those services are?”

There is no one place where all the information regarding state disability programs and services exists. Rather, it is a compilation of information gathered from a group of sources that will give families and individuals a larger picture of “what’s out there”. It’s a bit of work finding the information you need but in the end the information you gain will be well worth your time spent doing research. To make things easier we’ve compiled a list of the main sources for this information below.

Informational Resources

1. **United Cerebral Palsy's Case for Inclusion** study. This is a yearly document generally published in March or April every year. It contains a general comparison of all 50 states regarding general services for older children and adults. Some of the data does cover younger children as well but not all of it. Since disability services are a life-long need this gives a general idea of what a state is doing for those with disabilities over a longer time span. DO NOT look at the state rankings as an absolute number as there are several other sets of data that should be added as well. You can find that report here: <http://cfi.ucp.org>
2. **Annual Disability Statistics Compendium** This yearly report is a web-based tool that pools disability statistics published by various federal agencies together in one place. Not all the categories will apply but be sure to look at the demographic information, special education and disability by state information.
<http://www.disabilitycompendium.org/home>
3. Contact your state's **Medicaid Waiver** programs and compare. All waiver programs are not created equal, do not exist in all states, and a majority have lengthy wait lists. We recommend you check out the programs listed, first, and then contact the program that matches your needs directly and ask them questions. It's important to find out all the information you can as the majority of children with disabilities will most likely need to use a waiver program. A good place to start is the state-by-state listing found at **Medicaid dot Org**, here: <http://medicaidwaiver.org>. ***Please note:** Medicaid programs do not transfer. If you're planning a move you'll want to do some homework. Start here then go to the official page of the state you are considering.
4. Contact state **Divisions of Services for Developmental Disabilities** for the state(s) you are interested in. Ask about programs for respite, family assistance and any other programs they may have that could help you. Each state is different in the programs and services they provide.
5. **STATE Board of Education**. Look them up online or contact them directly. Ask about special education programs in each district or parish, ask for data, and request recommendations. Every district is unique and

some states are better at educational services than others. Compare this information with the information found in the **Annual Disability Statistics Compendium, Special Education section**.

6. Find the nearest **Children's Hospital** in your vicinity to find medical services available in your community. Check out their specialties, their national ranking, and look for outreach clinics, outpatient clinics and other programs. You should be able to find a Licensed Clinical Social Worker in the administrative office or parent education center who can give you some great information about the hospital AND the surrounding community. Find out what medical facilities they recommend older children go to when they "age out" of the pediatric system. A large number of states don't have good children specialty hospitals and an even larger number don't have programs for older young adults.
7. Looking for **housing**? Contact the State Board of Realtors to find a knowledgeable realtor regarding accessible housing in your area. Keep in mind you'll want to find housing that you can "grow into" that is accessible immediately. Even if I'm only looking for housing in my area I always call the State Board of Realtors to find someone that knows what they are talking about.

Don't be afraid to network! If someone you talk to recommends a resource, check it out. Or, better yet, find out if someone can recommend another program or person to contact. You never know what you may find by simply asking.

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