

My Child's Map to Services



Place child's picture here.

We hope this booklet will support you in your journey with your child. Sometimes after receiving a diagnosis of autism or other developmental delays, parents are confused about what to do next. This template will help you know who to contact and how to start getting help for your child.

*Developed by the Washington State Department of Health
Children with Special Health Care Needs Program and
inspired by the amazing work of Katrina Davis –
mom and family support expert.*

How Do I Help My Child?

Therapies for autism are everywhere and you may be overwhelmed with suggestions for helping your child. We hope this information will help make decisions easier.

Some children who have a diagnosis of autism respond very well to certain treatments, but technically, there is no cure for autism.

In addition to educational and medical services, many parents turn to alternative and complimentary methods and therapies like herbs, treatments, supplements and mechanisms to help their child.

As parents of children with autism and other developmental delays, we want you to know there are well-meaning people working in this field who are trying to help parents and children. There are also unscrupulous people who are just taking advantage of the desperation some families face and charging astronomical fees for “cures”.

Here is a story from one family who was promised their child would drastically improve if they used the company’s therapy program:

At our intake appointment (at a private program), we were told about how intense the program should be for Eric to be successful. Our insurance had an annual limit for speech services. They arranged for us to use the entire yearly amount in a couple months and then they told us how to cash in our 401K on a hardship-withdrawal to continue funding the program, which we did.

They even asked about how much our families could be counted on to help pay for their program. At that intake appointment, the director actually said to me she was certain Eric would talk within 6 months. However, months later, he still wasn't talking, the money was gone and huge bills began to roll in. We had to quit the program. I remain hopeful that he will improve greatly but am no longer swept away by amazing recovery success stories, and I remain disappointed in the intervention services available to us. Amanda Loaris

Before deciding on a treatment, it is a good idea to ask an objective, trusted professional what they think of the treatment. Once you have this information ask yourself these questions.

- Could this harm my child?

Many herbs and supplements are not tested in laboratories and are produced for adults. Even natural occurring supplements may be very harmful to a child’s system. It is very important to tell all health care providers all of the treatments you are giving your child. Supplements and medications can have negative side effects when combined with other items.

- Is there any evidence this will help my child other than the seller's opinion?

Ask the person selling the item if there is any scientific evidence to show it works. Be wary of "research" only from the person who invented it. For instance, if a website shows 15 research articles for X therapy and they are all written by the same person who invented the device, tincture, etc. it may mean there isn't real research available. Also, look at where the research was published. True research is usually published in a well-respected journal such as Pediatrics.

- Do I personally know any child who has used this therapy and had positive results?

Don't rely on the website stories – they may be made up. Other parents may report improvement in their child that you don't see. Trust your judgment, as you know your child best.

- Do I instinctively feel anxious about using this treatment with my child?

If you are being asked to do something with your child that makes you uncomfortable take the time you need to make the decision to use it or not. Don't allow anyone to pressure you with statements such as "there is only a short window of time that this will work".

Also, be wary of "Autism Professionals" at conferences and presentations. Question statements like "all children with autism will be helped by this" or "all children with autism should use this treatment". Children with a diagnosis of autism, like all children, are unique and individual. There is no one size fits all program for children with autism.

Health Insurance and Medical Care

My child's Health Insurance Company or medical coupon number is:

Phone number _____

Address _____

My child's policy number is: _____

My child's policy covers: (see page 7 for information about these therapies)

_____ Hours of Occupational Therapy per _____

_____ Hours of Physical Therapy per _____

_____ Hours of Speech Therapy per _____

My child's doctor is: _____

Phone number: _____

Contact: _____

If you do not have insurance for your child please contact the Family Health Hotline at 1-800-322-2588 or visit the Parent Help 123 website at www.ParentHelp123.org.

The Information Referral Agents that answer the Family Health Hotline are trained to assist families in applying for medical insurance and finding many other resources. The hotline employs bilingual English and Spanish staff. They also contract with an interpreter line for many other languages.

Even if you have private insurance, your family may qualify for additional assistance from the state. This may help pay co-pays and other out of pocket expenses.

Early Intervention

For a Child Under Three

If your child is under age three, contact The Family Health Hotline at 1-800-322-2588 and ask for the name and contact for the *Lead Family Resource Coordinator* (FRC) in your area. Calling the Lead Family Resource Coordinator will start the process to see if your child qualifies for early intervention services.

The Lead Family Resource Coordinator for my area is:

Name _____

Phone number _____

Education

For a Child Three and Older

If your child is age three or older, contact your local school district and ask how to get an evaluation for your child. If you don't know the name of your local school, call the Family Health Hotline at 1-800-322-2588 or visit www.ParentHelp123.org.

The local school is:

School name _____

Contact _____

Phone Number _____

Your Child's Education Rights

A federal law titled The Individuals with Disabilities Education Act (IDEA) ensures a child with qualifying developmental delays will receive a free and appropriate education in the public school system, starting at age 3. To learn more about IDEA visit <http://idea.ed.gov/>.

Division of Developmental Disabilities (DDD)

Your child may be able to get special services from the Washington State Department of Developmental Disabilities. Call the main number at **1-800-737-0617** or go to this website www.dshs.wa.gov/DDD/contacts.shtml to find your local office.

After you file the paperwork, ask for a face-to-face meeting and a **“computerized assessment.”** Find out if your child will receive:

- Respite care (*this is when a certified person cares for your child to give you a break*)
- Family Support Funds
- Medical Personal Care

DDD local office name _____

Contact person or case manager _____

Phone number _____

Ask your DDD Case Manager if your child qualifies for Social Security Insurance.

Child Care

If your child attends a child care center, talk with the director about how staff can best help your child. You can request the early intervention staff or school district staff provide special training at the center for everyone that interacts with your child.

If you need to find a child care center for your child call your local Child Care Resource and Referral agency at 1-800-446-1114 or visit their website at www.childcarenet.org/.

Child Care Center _____

Phone number _____

Director's name _____

Teacher's name _____

Family Support

Washington State is fortunate to have established statewide support organizations available in many communities. Support from parents who have children with special needs, including autism spectrum disorders has many benefits. Parents, siblings, grandparents and other family members are able to discuss their hopes, dreams, fears, etc. with people who have been in similar situations.

In addition to the organizations listed below, check with your local hospital or medical clinic for support meetings.

You may find a support group with:

Parent to Parent

1-888-754-8798 or www.arcwa.org/parent_to_parent.htm

Fathers Network

(425) 653-4286 or www.fathersnetwork.org/

Partnerships for Action Voices for Empowerment (PAVE)

1-800-5-PARENT or www.wapave.org/

Family Voices

(505) 872-4774 or www.familyvoices.org/

Parent Education

Some parents feel overwhelmed with all the information available about autism spectrum disorders. We have compiled a few introductory resources to help you get started learning about your child's diagnosis.

The following websites have information you may find helpful:

www.autismspeaks.org

www.autism-society.org

www.autismsocietyofwa.org

www.autismoutreachproject.org

The American Academy of Pediatrics developed a small booklet titled ***Understanding Autism Spectrum Disorders***. Ask your child's pediatrician or primary medical provider if they have a copy you can borrow.

Many hospitals and universities have Autism 101 or similar courses, usually at a minimal charge. Call your local hospital to see what is available in your community.

Local health departments have Children with Special Health Care Needs Coordinators who may know of additional resources to assist you and your child. Locate the Health Department in your community at

<http://www.doh.wa.gov/cfh/mch/documents/coordlst.pdf>

The following will help you gain skills in being an advocate for your child:

Partnerships for Action Voices for Empowerment (PAVE)

1-800-5-PARENT or www.washingtonpave.org

Office of Education Ombudsman

1-866-297-2597 (*phone interpreter services available*) or www.governor.wa.gov/oeo/

Office of Superintendent of Public Instruction (OSPI)

(360) 725-6000 or www.k12.wa.us/

Available Therapies

Occupational Therapy (OT) - Helps a child with fine motor and vision perceptual skills. OT could help a child learn to play with toys, dress, eat, wash their face, brush their hair, and use the toilet independently.

Physical Therapy (PT) - Focuses on improving a child's large muscles and can help a child with sitting, walking, running and other types of movement.

Speech and Language Therapy (SLT) - Helps a child learn to talk or use other forms of communication, learn social skills, and may be used to help a child with chewing, drinking and swallowing.

(Note: Your child may be eligible for occupational, physical and speech therapy through the school district *and* through private insurance or Medicaid).

Applied Behavioral Analysis (ABA) - The goal of ABA therapy is to increase appropriate behavior and decrease inappropriate behaviors. Most insurance companies in Washington do not cover ABA therapy. Most people pay out of pocket if they wish to have ABA therapy for their child. Typically, a consultant designs and oversees the program and a therapist or tutor provides the one to one therapy. Learn about other in-home programs used by other parents at www.autismspeaks.org/whattodo/index.php.

Alternative or Complimentary Therapies - Many parents use alternative or complimentary therapies, either exclusively or in addition to medical and educational treatments. If your child sees a primary care medical provider, like a pediatrician or naturopath, it is important that you discuss any dietary, herbal, supplement or other alternative treatments with them. Some over-the-counter products can have potentially dangerous effects, especially on children.

My child's insurance plan covers the following alternative treatments:

I do do not need a referral for this service.

There is a lot of information on the Internet, in books, and on television about how to "cure" your child of autism. While it is a parent's right and perhaps even duty to investigate every treatment, please be aware that there is no scientific research or evidence that anything cures a child of autism.

My Child's Medication List

Medication name, dosage, time _____

Who prescribed it? _____

It treats _____

Refills needed by _____

Issues/side effects _____

Medication name, dosage, time _____

Who prescribed it? _____

It treats _____

Refills needed by _____

Issues/side effects _____

Medication name, dosage, time _____

Who prescribed it? _____

It treats _____

Refills needed by _____

Issues/side effects _____

Medication name, dosage, time _____

Who prescribed it? _____

It treats _____

Refills needed by _____

Issues/side effects _____

Important Tips

- ♥ If your child has private health insurance, this will be the primary source of coverage. Become an expert on your child's policy. Understanding your insurance policy is very important.
- ♥ If your child's medical bills are not covered by an insurance plan, hospitals and other providers may negotiate reduced or extended payments. You will need to talk to the individual providers for each billed service.
- ♥ Keep records of all phone calls, medical visits, Division of Developmental Disabilities (DDD) information, insurance paperwork, notices, school communications and other forms related to your child.
- ♥ You can request a free Care Organizer to keep information together in one location by calling 206-884-5735 or visiting <http://cshcn.org/care-notebook-and-care-organizer-order-form>
- ♥ Many families of children with special health care needs spend a great deal of time coordinating care for their child. This can create stress for you in many areas. Ask your child's doctor, teachers, therapists, and others involved in your child's care to help you.
- ♥ Remember to continue with recreational activities like exercise or meditation, eat healthy food, and get as much rest as possible.

For questions or comments, please contact Susan Ray, Family Involvement Coordinator at (360) 236-3504 or susan.ray@doh.wa.gov.

For persons with disabilities, this document is available on request in other formats. To submit a request, please call 1-800-525-0127 (TDD/TTY 1-800-833-6388).



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