

The Autism Resource Guide

A guide for families of children diagnosed with an Autism Spectrum Disorder

From the Autism Resource Center of Arkansas

So you've just found out that a child you love is on the autism spectrum.

This can take a long time to sink in, and it's OK to feel overwhelmed right now. Your pediatrician or psychologist has probably thrown a lot of terms around that you don't understand yet, along with ideas for treatment options you haven't heard of before.

Please take the time to process your feelings and understand that you didn't cause this. Remember that doubt and guilt have never been successful treatments for autism. What we know is that diligence, good therapy, and loving caregivers are what give these children the best shot at success.

And you don't have to do it alone. This resource guide will help to break down all the wonderful help available to you in central Arkansas.

Where to Begin

Start by reading some literature about your child's diagnosis. You don't have to become an expert just yet, but you will quickly learn some strategies to handle everyday living as well as therapy evaluations and school meetings. You may want to copy or print some of these resources for loved ones to help them understand what you and your family are going through.

Then, to get some real-life advice, sign up with a local support group. Post your questions on the message boards and attend the monthly meetings. At first, you may feel that you are living and breathing autism. But learning about other people's experiences will save you time, money, and stress in the long run. Best of all, these groups help you to celebrate successes with your child that others may not understand.

Getting Help

Many different kinds of therapy are available to help your child adapt and succeed. Central Arkansas has a number of private outpatient facilities that offer physical, occupational, and speech therapies. Consultants can work with your family on more intensive, in-home methods. Every school district has early childhood intervention programs for children ages 3-5 at no cost to the parents. Each public school has a team of professionals available to the children who attend. Some children are even eligible for homebound therapy services.

And since you have a definite diagnosis now, you can apply for financial assistance to cover the costs of intervention. Some government programs have long approval times or waiting lists, so it's best to get started on those applications as soon as possible. Ask someone at your therapy

facility for the application. Some have sample applications to use as a guide, or they may have someone on staff to walk you through the process.

And finally, you'll have to make some decisions about your child's education. No single school option is perfect for all children on the autism spectrum, but we fortunately have many choices in this area. With the help of your therapy team and support group, you can decide which is the best fit for your child.

It's a lot to take in, so get comfortable, and read on. Remember to take this one step at a time. Most importantly, you are not alone!

What IS Autism? Frequently Asked Questions

1. What IS autism, anyway?

The Autism Society of America defines autism as “a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others.

Autism is defined by a certain set of behaviors and is a ‘spectrum disorder’ that affects individuals differently and to varying degrees.”

Autism, once known as Pervasive Developmental Disorder (PDD), is now an “umbrella” term for what are formally called Autism Spectrum Disorders (ASDs).

There are five labeled disorders on the autism spectrum. These are:

- Autistic Disorder (classic autism)
- Asperger's Syndrome
- Rett's Disorder
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

2. What are some common characteristics of autism?

No two people with autism are exactly alike. But all people with ASDs have impaired communication and social skills, exhibit repetitive behaviors, and have narrow interests.

Some other possible characteristics can include:

- Language delays
- Gross and fine motor skill delays
- Self-stimulating behaviors such as hand-flapping or rocking
- Meltdowns (tantrums)

- Echolalia (repeating expressions over and over again at inappropriate times)
- Aversion to touch

3. What causes autism?

This can be a touchy subject, but there is no definitive, single cause of autism. We do know that MRI scans have shown a lack of important brain connections that contribute to social intelligence. Autopsies have shown differences in sizes and brain structure, as well as imbalances of chemicals like serotonin.

Many studies of autistic twins point to a genetic component. Children who regress suddenly after a series of vaccine injections or a traumatic event or illness suggest an environmental trigger to those who might be predisposed to autism. The working theory is that autism is caused by a combination of these genetic and environmental factors.

4. How is it treated? Is there a cure?

As of now, there is no cure for autism. But autism is highly treatable. Early intervention is extremely important because it is the best predictor of success for autistic adults.

Many therapy methods treat the symptoms of autism, such as speech therapy for language delays and occupational therapy for fine motor and sensory problems.

Intensive intervention methods like Relationship Development Intervention aim to treat the brain deficits themselves to encourage more flexible thinking.

Some parents opt for what is called biomedical intervention, which can include removing heavy metals in the body, vitamin supplements, and special diets.

5. Will my child have to attend a special school?

Your child can attend a school especially for children with disabilities, but s/he certainly doesn't have to. Public schools are legally bound to educate children on the autism spectrum. Depending on your child's abilities, s/he may spend time in a self-contained classroom with other special needs kids, or s/he may do better in a mainstream classroom with the help of a paraprofessional (aide). See the "Let's Talk about Public Schools" section for more information.

6. Will my child be able to live independently?

That depends a lot on the individual, but many autistic adults live successful, independent lives. With the proper intervention, people with moderate to high-functioning ASDs are able to memorize the routines and procedures to get through everyday life on their own. Social situations will always be a challenge, but they don't have to be impossible.

One very important thing to realize is that autistic children have unique strengths. Because they think in concrete terms, they can be honest and impartial, have strong memorization skills, and be loyal and hardworking. They are often excellent problem solvers.

Learning about Autism Part I: Useful Links

The first thing you'll want to do is get on your computer and learn everything there is to know about your child's diagnosis. Here are some links to get you started:

Asperger's Syndrome

www.aspergersyndrome.org

www.aspergersyndrome.com

www.asperger.net

Future Horizons, Inc.

www.fhautism.com

Future Horizons is a publishing company that specializes in books related to Autism Spectrum Disorders.

The Autism Asperger Publishing Company:

www.asperger.net

The National Autism Association:

www.nationalautismassociation.org

Remember: Not all information on the web is created equal. Fact-check everything. Bounce ideas off your child's doctors and therapists as well as your support group.

Autism Speaks 100 day kit:

http://www.autismspeaks.org/community/family_services/100_day_kit.php

The Autism Research Institute:

www.autism.com

The Autism Society of America:

www.autism-society.org

The National Institute of Health (NIH) Autism Resource Network:

www.autismresearchnetwork.org/AN/

AutismLink
www.autismlink.com

Eye Contact Arkansas
www.eyecontaktarkansas.org

Learning about Autism Part II: Books

The following books are a great starting point for building your library. After you read them, you can then lend them out to friends, family, and teachers who need help understanding your child's special needs.

The Official Autism 101 Manual, by Karen L. Simmons

Asperger's Syndrome: A Guide for Parents and Professionals, by Tony Attwood

Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASDs, by Chantale Sicile-Kira and Temple Grandin

Ten Things Your Student with Autism Wishes You Knew, by Ellen Notbohm

Ten Things Every Child with Autism Wishes You Knew, by Ellen Notbohm

1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders, by Veronica Zysk and Ellen Notbohm

Playing, Laughing, and Learning with Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Carers, by Julia Moor

The Autism Sourcebook: Everything You Need to Know About Diagnosis, Treatment, Coping and Healing, by Karen Siff Exkorn

The Everything Parent's Guide to Children With Autism: Know What to Expect, Find the Help You Need, and Get Through the Day, by Adelle Jameson Tilton

The Everything Parent's Guide to Children With Asperger's Syndrome: Help, Hope and Guidance, by William Stillman

Changing the Course of Autism: A Scientific Approach for Parents and Physicians, by Brian Jepson

Support Groups

You need a support group. You may need three. You will have many questions in the next several weeks as you piece together a plan, and being able to ask someone who has been through this is priceless.

The following is a list of support groups in central Arkansas.

The Autism Resource Center of Arkansas/Community Connections

www.communityconnectionsar.org

Community Connections is the nonprofit organization of Pediatrics Plus Therapy in Conway. CC sponsors four social and athletic programs for children with physical and developmental disabilities. These include soccer, flag football, theater, and dance.

Community Connections has also developed the Autism Resource Center of Arkansas, which focuses on providing information and support to area families with autistic children. This year, the ARC of AR has developed a kids' summer camp and has started an autism resource library.

The ARC of AR also hosts monthly support group meetings at New Life Church in Conway with guest speakers who present on a variety of topics.

For more information about Community Connections or ARC of AR activities, contact director Courtney Leach at (501) 733-1627 or courtneyleach@pedsplustherapy.com.

Conway Asperger Support Group

www.conwayaspies.com

The Conway Asperger Support Group is a group for anyone who loves a person with Asperger's Syndrome. Members meet on the fourth Thursday evening of each month at the Conway Regional Women's Center. Meetings can involve topical discussions, speakers, and workshops.

For more information about the CASG, contact director Amy Casavechia at info@conwayaspies.com.

Helping Educate about Autism Recovery (HEAR)

HEAR is a parent-run organization based in Little Rock that educates, advocates, and raises awareness about autism spectrum disorders. Meetings are open to anyone who wants to learn more about autism. HEAR runs www.arkansasautism.org, a comprehensive resource website for families of autistic children in Arkansas.

For information about upcoming meetings and events, contact director Dianna Varady at (501) 626-9048 or divarady@yahoo.com.

Arkansas Autism Network

health.groups.yahoo.com/groups/ArkansasAutismNetwork

The Arkansas Autism Network is a Yahoo! group for anyone whose life has been touched by autism. With over 300 members from around the state of Arkansas, the AAN is a lifeline of support and information for families of autistic children. The board has a database of recommended providers, information about public schools, and much more.

Your privacy is protected and all posts are completely confidential, so the AAN is a safe place to ask for help and share your thoughts. A completed questionnaire is required for membership.

To request your membership, visit the above link and contact moderator Susan Booher at hogfan@razorbackroad.com.

Little Rock Autism Families Meetup Group

Sometimes you just need to go out and play. This group is a wonderful source of activities, outings, and play dates for kids on the spectrum and their families. To get on the mailing list, visit the group's website at www.meetup.com/Little-Rock-Autism-Families and

If you have any questions about membership, contact organizer Marjorie Greenberg at chenaltutor@gmail.com.

Arkansas National Autism Association

The Arkansas NAA is a parent-led, non-profit group based in central Arkansas that supports families dealing with an autism spectrum disorder. The group holds monthly meetings that alternate guest speakers and social outings.

For more information, visit www.arkansasnaa.org. You can also contact organizer Cindy Fong at (501) 952-6508 or fongfam@charter.net.

Getting Help: Intervention and Therapy

Part I: Outpatient Treatment Options

Outpatient therapy is therapy that takes place in a clinic but doesn't require a residential stay. These methods include occupational therapy, speech therapy, and physical therapy.

Occupational Therapy

Occupational therapy can help kids participate in everyday life either by modifying their environments (like their homes and classrooms) or by teaching adaptive skills.

For example, an OT might help a child with fine motor delay to use a pencil by providing hand strengthening exercises and a rubber grip. Or they might recommend a beanbag in the corner of a classroom for a child to take breaks when s/he feels overwhelmed at school.

Occupational therapists also provide sensory integration therapy for children whose behaviors stem from sensory overload. In addition to doing sensory activities in the facility, the therapist can also provide a program for parents to do at home.

Speech Therapy

Speech therapy for autism can range widely depending on the child's needs.

High-functioning kids with no real speech delay often lack social language, so a speech therapist can offer pragmatic language therapy (teaching social skills) to help them along.

Children with mid-range speech delays can benefit from exercises that address vocabulary, pronunciation, attention and memory.

Spectrum kids who are completely nonverbal can be taught to use Augmentative and Alternative Communication (AAC) methods. These can include electronic speech devices or flash card systems to help the nonverbal child communicate.

Speech therapists can also address problems with food texture and swallowing that can lead to picky eating and poor weight gain.

Physical therapy

Physical limitations in autistic kids can range from very mild to severe. Some have trouble with gross motor skills, like walking or running, and others have trouble with fine motor skills, like writing or grasping. These can be caused by low muscle tone or just poor coordination. Either way, a physical therapist can provide activities to help strengthen these areas of development.

Physical therapists work with early intervention programs in schools as well as in outpatient facilities. Some also work privately to provide hippotherapy (therapeutic horseback riding) aquatherapy (therapeutic swimming), and other sorts of recreational methods to encourage motor development.

Free Programs

The state of Arkansas sponsors Early Intervention and Early Childhood programs and services for children up to the age of five. When your child turns five, s/he is eligible for services through the local public school district.

Your child's diagnosis and any previous evaluations will provide helpful information, but these are not required to receive services. Professionals working with the school district will conduct their own evaluations to determine what kinds of therapy your child may need. They will not provide their own diagnosis.

You do not need a diagnosis to be evaluated for these services. Since the process of developing a treatment plan can take several months, it's best to ask for an evaluation as soon as possible.

Early Intervention

Early Intervention services are available through the First Connections Infant and Toddler Program for children from birth to 36 months. Any child with a developmental delay, or a disability that will lead to a delay, is eligible for services.

Services include:

- Assistive Technology
- Speech therapy
- Occupational therapy
- Physical therapy
- Special instruction
- Service coordination
- Health services
- Social work services
- Nutritional services
- Transportation
- Vision services
- Audiology services
- Nursing services
- Multi-disciplinary evaluations
- Medical diagnostic services
- Psychological services
- Family training, counseling, and home visits
- Respite

Early Childhood

The Early Childhood program provides services for children with developmental disabilities and delays who are three to five years of age (or entering Kindergarten).

The Early Childhood professionals will form a team to provide a comprehensive evaluation and develop a program plan for treatment. This team will include parents, caregivers, teachers, and

therapists. Therapists can treat your child in a school or daycare setting as well as in an outpatient therapy center.

For more information about Early Intervention and Early Childhood programs, call 1-800-643-8258. You can also ask your child's daycare provider or preschool staff for a referral form.

Outpatient Therapy Facilities in Central Arkansas

Easter Seals Arkansas

ar.easterseals.com

Easter Seals Arkansas is located at 3920 Woodland Heights Road in West Little Rock, behind Christ the King Catholic Church.

In addition to a 40-bed inpatient facility, Easter Seals also offers occupational, speech, and physical therapy on an outpatient basis. The staff also conducts screenings, evaluations, and technology assessments. Pragmatics therapy is offered one-on-one for children 5 and up.

You'll need a physician's referral for an evaluation before you schedule an appointment. For more information, call (501) 227-3602 or (501) 227-3678 Monday through Friday or e-mail info@easterseals.com.

Pediatrics Plus Therapy Services

www.pedsplustherapy.com

Pediatrics Plus is a growing outpatient therapy facility based in Conway with satellite offices in West Little Rock and Russellville. Currently, Pediatrics Plus offers play-based occupational, speech, and physical therapy, as well as help with sensory integration and language pragmatics.

Conway (main branch):
2470 College Avenue
Conway, AR 72034
(501) 329-5459

Little Rock:
32 Rahling Circle (next to the Roosevelt Thompson Library)
Little Rock, AR 72223
(501) 821-5459

Russellville:

411 N Elmira Ave # 4
Russellville, AR 72802
(479) 890-5494

UALR Language Pragmatics Program

UALR Pragmatics Groups for Children and Adolescents and the UALR Teen Pragmatics Groups are run by Dr. Betholyn Gentry, a speech-language professor who specializes in pragmatics disorders.

The classes meet once or twice a week for two hours. Children are grouped by age and taught social skills with one another by carrying out structured, team-oriented activities.

For more information about the program, contact Dr. Gentry at bfgentry@ualr.edu.

UCA Speech-Language Hearing Center

The UCA Speech-Language Hearing Center in Conway offers a variety of speech therapies, including language pragmatics. These programs are run by graduate students of speech-language pathology and are supervised by qualified faculty members. Students and faculty attend free of charge.

For more information, call (501) 450-3176.

UAMS Child Study Center Social Skills Group

Directed by Dr. Rachel Bowman, the UAMS Child Study Center group targets young children and adolescents. For more information, contact Dr. Bowman's office at (501) 364-5150.

Getting Help: Intervention and Therapy Part II: Intensive Treatment Programs

In addition to occupational, speech, and physical therapy, some parents also choose more intensive in-home programs to help their children progress. Consultants for some of these programs are available in central Arkansas. You can also research any of these programs and apply the principles to your daily activities at home and in school.

Applied Behavior Analysis

Applied Behavioral Analysis (ABA) is widely accepted by doctors and parents, mostly because of long-term research and a track record of anecdotal success stories. ABA involves one-on-one reward-based interaction between the ABA therapist and the child. The therapist begins with simple activities followed by lots of positive reinforcement, then works up to more complicated social interactions. This is a program for kids with more severe symptoms and can involve between 20 and 40 hours of therapy per week.

ABA therapists in Arkansas:

Innovative ABA in Little Rock
Contact: Christopher Ewing, MS, BCBA
(501) 804-2533
info@innovativeABA.com

MiChild Enrichment Center in Russellville
Contact: Friendship Community Care, Inc.
(479) 967-2322
1-800-461-1793

The UAMS Child Study Center at Arkansas Children's Hospital
www.uamshealth.com/medical-services/behavioral-mental-health/child-study-center
Contact: Dr. Rachel Bowman
(501) 364-5150

Relationship Development Intervention

Relationship Development Intervention (RDI), developed by Dr. Steven Gutstein, is a long-term intensive program designed to address the core deficits of the autistic mind. Children with autism lack important connective pathways between areas of the brain responsible for social interaction, referencing, and self-regulating. Gutstein believes that the brain is flexible and ever-changing, and created RDI to help develop those missing pathways in the brain.

Unlike ABA, RDI is a parent-led program. Parents work with a consultant on a regular basis to develop an individualized program and then incorporate that program into their home lives.

You can find more information about RDI from Gutstein's book, *My Baby Can Dance: Asperger's and Success through the Relationship Development Intervention (RDI®) Program*, and on the web at www.rdiconnect.com.

RDI in Arkansas:

Pediatrics Plus Therapy Services of Conway
Contact: Lynne Holloway
(501) 626-7910
RDI@pedsplustherapy.com

Treatment and Education of Autistic and related Communication-Handicapped Children (TEACCH)

TEACCH is a classroom-based method designed for children with autism. Kids with autism have strong visual skills, so the program involves pictures and visual schedules for students to help

with routines and transitions. The goal is for the children to be organized and able to work independently once they understand what is expected of them.

Training and consultation for the program are conducted at and around the University of North Carolina-Chapel Hill, but materials are available on the Division TEACCH website at www.teacch.com.

Division TEACCH at UNC-Chapel Hill
(919) 966-2174
TEACCH@unc.edu

Developmental, Individual Difference, Relationship-Based Floortime

DIR/Floortime is a child-centered program developed by Dr. Stanley Greenspan and Dr. Serena Wieder. The aim of the program is to help each child develop developmentally, socially, and emotionally, rather than train the child to change isolated behaviors.

The *developmental* aspect of the program focuses on helping children attain six developmental milestones necessary for emotional and intellectual growth. The *individual difference* focuses on each child's biological learning style. The *relationship-based* part teaches children to develop learning relationships with their teachers, therapists, and peers. *Floortime* is an activity structure that follows the child's natural interests and emotions to better involve them in the learning process.

Together, DIR/Floortime is a comprehensive framework that allows caregivers, teachers, and therapists to create an individualized program for each child. Research indicates that children who are higher-functioning benefit the most from such a child-centered approach.

You can find more information about Floortime on the web at www.floortime.org.

Calling the Doctor: Medical Treatments for ASD

Part I: Developmental Pediatricians

While many families continue to use a regular pediatrician for their child's basic care, some may need a doctor with specific knowledge of developmental disabilities. In this case, a developmental pediatrician is the best doctor for the job.

A developmental pediatrician is a board-accredited pediatrician who has also received sub-specialty training and certification in developmental-behavioral pediatrics. Developmental pediatricians specialize in the diagnosis of autism spectrum disorders, medical evaluations, and medical management.

Developmental pediatricians primarily offer guidance for outpatient treatment and intensive treatment programs. They can also prescribe medications for symptoms that inhibit a child's functioning and ability to learn. These symptoms include:

- Hyperactivity (ADHD)
- Sleep disturbances
- Anxiety
- Obsessive-Compulsive Disorder (OCD) symptoms
- Over-arousal

Sometimes a child will only need medication for a short time. Other children need medications for extended periods of their lives.

Developmental pediatricians in Arkansas are located at Dennis Developmental Center in Little Rock. For more information, call (501) 364-1830 or visit www.arpediatrics.org/clinical-programs/dennis-developmental-center.

Calling the Doctor: Medical Treatments for ASD Part II: Biomedical Intervention

Biomedical intervention is a hot topic in the autism community these days.

The biomedical approach is a molecular-biological approach to treatment. The guiding principle is simple: remove what is causing harm, and add what is missing. This is the philosophy of the Autism Research Institute (www.autism.com), founded by Bernard Rimland, PhD.

Dr. Rimland was instrumental in dispelling the belief that autism was an emotional disorder caused by bad mothering. He brought together physicians, researchers and parents in a joint effort to work on the puzzle of autism. This grew into the “Defeat Autism Now!” project. Many people now refer to physicians who have received training through the Autism Research Institute as DAN! doctors.

Defeat Autism Now! (DAN!) is the largest national organization endorsing biomedical techniques. Proponents for the DAN! method strongly believe that environmental factors are a major cause and/or trigger of autism.

While not all traditional doctors include these methods in their treatment plans, many parents and physicians believe biomedical treatment is an integral part of the overall treatment of autism.

Biomedical treatment can include:

- **Chelation therapy**—Chelation therapy is based on the theory that children on the autism spectrum do not process and excrete heavy metals, such as aluminum and mercury, the way that typical children do. This can cause an unhealthy buildup that leads to gut disorders.

Chelation therapy involves an injection of EDTA, a man-made amino acid, into the veins. This amino acid binds to heavy metals in the blood and creates a compound that can be excreted in the urine.

- **Special diets**—DAN! proponents strongly believe in a gut-brain connection, and that intestinal disturbances can cause or exaggerate autism symptoms. These disturbances can be caused by food allergies, intolerances, or an overgrowth of yeast in the gut.

Many advocate a gluten-free, casein free (GFCF) diet, as many autistic kids seem to have intolerance for these proteins and function much better without them. This diet involves the total avoidance of wheat and related proteins, as well as all dairy.

A diet designed to treat yeast overgrowth is called the Specific Carbohydrate Diet. The SCD starves yeast out of the gut by cutting off its ready food supply of simple sugars. This diet was originally created by Elaine Gottschall, who suffered from Crohn's Disease, to treat intestinal disorders. In recent years, parents have used it with some success to help their autistic children.

For more information about SCD and autism, visit www.pecanbread.com.

- **Vitamin supplements**—Some studies have shown an improvement rate of 50-75% among autistic children who took vitamin B6 and magnesium. Other recommended supplements include B12, vitamin C, and cod liver oil.

B12 supplements are usually given in injection form. It's a difficult vitamin absorb, so oral supplements can have very little effect.

Doctors in Arkansas

The following doctors in Arkansas follow a biomedical approach when treating patients with autism.

Dr. Alice Laule is located in Harrison, Arkansas. While not a DAN! doctor, she does follow an integrative medicine approach and is board certified in holistic medicine. She offers biomedical services for children on the spectrum.

For more information about Dr. Laule's approach, visit her website at www.futurevisionsfoundation.org/autismpage.html.

Dr. Laule bills insurance and accepts Medicaid. To make an appointment, call (870) 741-9596.

Dr. Betsy Hendricks is a DAN! doctor who practices family medicine. Dr. Hendricks runs the Arkansas Center for the Study of Integrative Medicine in Conway, where she applies both mainstream and biomedical techniques to treat autistic children.

Dr. Hendricks does not accept Medicaid at this time but she will give you the paperwork to request reimbursement from your insurance company.

For more information about Dr. Hendricks, visit her website at www.betsyhendricksmd.com or call the Arkansas Center at (501) 327-2967.

Dr. Tara Hickman is a naturopathic physician at Northwest Arkansas Natural Health in Fayetteville. While Dr. Hickman treats a variety of ailments, her main focus is autism spectrum disorders and biomedical treatment.

For more information about Dr. Hickman, visit her website at www.nwanaturalhealth.com or call (479) 445-2220. Dr. Hickman offers a free 15-minute consult over the phone to discuss the benefits of naturopathic medicine.

Dr. Stephen Kahler is a metabolic geneticist at Arkansas Children's Hospital. As a DAN! doctor, he consults with families to discuss the advantages and disadvantages of various treatments for ASD. To make an appointment, call (501) 364-2966.

Paying for Treatment: Financial Aid

Now that you know what treatments are available, you can start to calculate the cost. Unfortunately, no law in Arkansas requires insurance companies to cover autism-related treatment. In fact, most of them don't, so be prepared to seek alternative ways to cover the costs of therapy. Luckily, many government programs will help you do just that.

All about Medicaid

Medicaid has several programs to help cover therapy and services for special needs kids. Depending on your financial situation, some of these programs can overlap.

Here's a breakdown of the terms you'll hear thrown around:

WAIVERS

Caregivers for children with disabilities can apply for the TEFRA Waiver and the ACS Waiver. These waivers were created to help disabled children remain in their homes rather than live in an institution for full-time care. To qualify, the child's needs must meet Arkansas State law's definition of a developmental disability, which is:

“Attributable to mental retardation, cerebral palsy, epilepsy or autism or any other condition closely related to mental retardation in that it results in an impairment of general intellectual functioning or adaptive behavior similar to those of persons with mental retardation or requires similar treatment and services to those required of such persons. The disability must originate

before the age of 22 and it must be likely to continue. A person may qualify categorically (meet established criteria) or through an adaptive assessment (that demonstrates life activity limitations).”

Start applying for services as soon as you have a diagnosis, because the waiting lists are long. Apply for everything at the same time so you don't have to dig out the same important information over and over again.

The **Alternative Community Service (ACS) Waiver** (mostly just known as “Waiver”) covers a network of providers who afford “supportive living” to people with disabilities. Supportive living can include respite care, babysitting services, after-school care, supplements and stipends. Waiver can also help to fund service dogs, specialized medical supplies, and home modifications.

The waiting list for the ACS Waiver is several years long. A family only moves up on the waiting list when another family no longer requires services. DHS has recently received funding that will expand the waiver program to include 150 more children.

The **TEFRA Waiver** (commonly called “TEFRA”) refers to provision 134(a) of the Tax Equity and Equal Responsibility Act of 1982. This is a part of Medicaid that applies to children with disabilities. Caregivers pay a premium based on their annual income, but family income does not affect eligibility. TEFRA can help to cover traditional therapy methods such as speech, occupational, and physical therapy, as well as contribute to evaluation expenses.

TEFRA applicants usually wait 4-6 months for approval. Many therapy facilities will delay billing during that time. If you pay for therapy during the waiting period, TEFRA will reimburse the costs.

In addition to meeting the state’s definition of disabled, the criteria to qualify for the ACS Waiver and TEFRA are:

- The child’s (not the caregivers’) income cannot exceed \$1,911 per month
- The diagnosis of autism must be made by a licensed physician, a psychologist, and a speech pathologist
- The child must be eligible to live in an Intermediate Care Facility for the Mentally Retarded. This is determined when the child has major limitations in the following six areas of life: self-care, language, learning, mobility, self-direction, and independent living.

If you’re thinking that your child is too high-functioning to qualify, don’t worry. A diagnosis in hand is the main thing required by these waiver programs. The staff at many therapy facilities will guide you as you fill out the applications.

Many parents agree that it’s best to fill out both applications at the same time. A lot of the questions are similar, and this way, you only have to gather your information once.

Find more information about the ACS Waiver online at www.arkansaswaiver.com. For information about TEFRA, visit www.state.ar.us and click on “TEFRA.”

Idea: If you need to bill your private insurance company for intervention and they don't cover autism treatments, talk to your health care provider about leaving the autism diagnosis out of the referral. For example, a simple diagnosis of “Fine Motor Delay” is sufficient for occupational or physical therapy.

ARKids First

ARKids First is a state-funded program that provides health insurance for children when their parents can't afford private coverage. ARKids will help to pay for certain therapies and office visits.

If your whole family already receives Medicaid for regular medical coverage, then your kids are covered under ARKids A until the age of 19. There are no copays, deductibles or premiums for kids under 18.

The ARKids program has recently expanded with the addition of ARKids B. ARKids B includes slightly higher income families who are having trouble affording health insurance for the kids. There are some copays and the coverage is not as complete. The cap on cost-sharing is 5% of the family's gross income.

For more information on ARKids First regarding eligibility and coverage, visit www.arkids.com.

Supplemental Security Income (SSI)

SSI is a monthly government check that can help with the extra costs of caring for a special-needs child.

To receive SSI benefits, your child must have a condition that causes “marked and severe functional limitations” that are expected to last for more than 12 months. Income of family members is considered, and the child cannot work and earn more than \$980 per month.

To apply for benefits, call the Social Security Administration directly at 1-800-772-1213 or visit www.ssa.gov to locate your nearest Social Security office.

School Choices

Part I: Day Treatment Programs and Preschools

The Center of Early Learning

The Center of Early Learning (CEL) is a Children's Health Management Services childcare center that adjoins Pediatrics Plus Therapy Services in Conway. The school specializes in caring for children who qualify for at least two types of therapy treatment. Though most of the children receive therapy, The CEL is an integrated setting where 20% of the children are typically functioning. With a nurse and psychological examiner on staff, the children who receive therapy are continually evaluated to ensure that they are progressing. And because the center is attached to Pediatrics Plus, therapists can walk the children to and from their appointments and work closely with the CEL staff to outline their specific goals.

For more information, call 501-238-5696.

Faulkner County Day School

The Faulkner County Day School is located at 1700 South Boulevard in Conway. The Milestones program at FCDS is a school and therapy program for children ages six weeks to five years with developmental disabilities or delays. The school also offers support for families and is a provider for Medicaid Waiver services.

FCDS also offers a Workforce Program for adults for disabilities.

For more information, call (501) 329-8102.

A Child's Place preschool (Easter Seals)

A Child's Place is an inclusive preschool located next to the outpatient therapy building at the Easter Seals campus in West Little Rock. Therapists from Easter Seals work with the kids on-site and can often integrate therapy into the classroom. Children with and without disabilities, ages six months to five years, are welcome. There is always a waiting list, so apply early.

To learn more, contact Sandy Billingsley at 501-227-3464 or sbillingsley@ar.easterseals.com.

Francis A. Allen School for Exceptional Children

The Allen School (www.theallenschool.org) is located in the historic Hillcrest area of Little Rock. The staff, which includes teachers, special education teachers, aides, and therapists, supports children with developmental disabilities like autism and cerebral palsy. The school accepts children with and without disabilities from birth to five years of age.

If you'd like to tour the school or set up an interview, contact Jackie Beatty at 501-664-2961 or jackiebeatty@francisallenschool.com.

Helping Hand Children's Center

The Helping Hand Children's Center (www.helpinghandcc.com) is located next to Crystal Hill Elementary School in North Little Rock. The facility houses both an outpatient therapy clinic and a preschool for children with and without disabilities. The clinic provides occupational,

speech, physical, and sensory therapy. The preschool uses a play-based curriculum where the teachers integrate therapy goals into the everyday classroom.

Helping Hand is open year-round, Monday through Friday from 7:00 a.m. to 5:30 p.m. For admissions information or to schedule a tour, call (501) 791-3331 or e-mail info@helpinghandcc.com.

Arkansas Better Chance (ABC) Preschools

The ABC preschool program in Arkansas allows three- and four-year-old children to attend public school free of charge. Three-year-olds may only attend if their parents have a qualifying low income; four-year-olds attend on first-come, first-serve basis. Because the program is publicly funded, the schools are bound by law to accept and educate children with special needs. Children who attend ABC preschools can receive Early Childhood evaluations and services in the classroom setting.

For more information about the ABC program, visit the Arkansas Department of Education on the web at www.arkansased.org or call (501) 682-4475.

Pathfinder, Inc.

Pathfinder, Inc. is an integrated day habilitation center for children three months to five years old. Structured like a traditional daycare, the staff at Pathfinder teaches self-help skills and social skills in addition to offering outpatient therapy. To be eligible for services, your child must have a medical diagnosis that involves a developmental delay.

Pathfinder, Inc. has facilities in Jacksonville and in downtown Little Rock at the Charles Bussey Child Development Center. Transportation is available for children at both locations.

For more information about the Jacksonville site, contact Pam Satterfield at (501) 982-0258 or psatterfield@pathfinderinc.org.

For the Little Rock location, contact Ralph Nelson at (501) 375-7811 or nelson@pathfinderinc.org.

MiChild Enrichment Centers

MiChild Enrichment Centers are childcare sites operated by the Friendship Community Care, a nonprofit organization based in Russellville that serves people with developmental disabilities.

MiChild West in Russellville is an integrated school geared specifically toward children with autism spectrum disorders and behavioral challenges. The program serves children aged three to five with outpatient services available for children ages two and under.

The Bryant and West Fork Centers are Child Health Management Centers that serve children with a variety of special needs.

For more information about MiChild and Friendship Community Care, visit the FCC website at www.friendshipcommunitycare.com.

KIDS FIRST

The KIDS FIRST centers (www.arpediatrics.org/kidsfirst) are pediatric day health clinic in association with the UAMS Department of Pediatrics. KIDS FIRST has 11 sites around the state of Arkansas. These clinics combine a preschool teaching staff with a team of medical professionals including doctors, nurses, social workers, dieticians and therapists. The result is a completely comprehensive approach to teaching kids from birth to age five with special healthcare needs.

You can find a KIDS FIRST clinic in:

- Little Rock- (501) 364-7510
- Pine Bluff- (870) 534-6067
- Morrilton- (501) 354-1170
- Fort Smith- (479) 785-9091
- Lowell- (479) 750-0130
- Pocahontas- (870) 892-0027
- Mountain View- (870) 269-2110
- Newport- (870) 523-2124
- Searcy- (501) 305-3305
- Warren- (870) 226-7844
- Magnolia- (870) 234-1597

Ascent Children's Health Services: Child and Youth Pediatric Day Clinics

Ascent's Child and Youth Pediatric Day Clinics are medical facilities located around the state. They provide occupational, speech, and physical therapy, as well as mental health services, for special needs children ages six weeks to six years. They are also known as Pediatric Specialty Care, Inc. clinics.

Visit their website at www.ascentchs.com.

Child and Youth Pediatric Day Clinics (CYPDC):

Paragould:

1910 Rector Road
Paragould, AR 72450
870-240-8500

Jonesboro:

806 Glendale Street

Jonesboro, AR 72401
870-933-9528

Mountain Home:
18 County Road 458
Mountain Home, AR 72653
870-425-5252

Trumann:
1005 Balcom Lane
Trumann, AR 72472
870-483-1461

Batesville:
2040 Fitzhugh Street
Batesville, AR 72501
870-793-3334

Pediatric Specialty Care, Inc. (PSCI):

Benton:
3214 Winchester
Benton, AR 72015
501-326-6160

Blytheville:
1510 Byrum Road
Blytheville, AR 72315
870-532-2600

Arkadelphia:
2410 Pine Street
Arkadelphia, AR 71923
870-245-2210

North Little Rock:
4107 Richards Road
North Little Rock, AR 72117
501-955-2220

West Memphis:
413 West Tyler Avenue
West Memphis, AR 72301
870-733-1200

For the Older Kids

Central Arkansas has two private K-12 schools for special needs kids.

Access Academy

www.accessgroupinc.org

Access Academy is located at 10618 Breckenridge Drive in west Little Rock. The teachers at Access use a multi-sensory, language-based curriculum geared towards children with autism, dyslexia, and similar disabilities. Therapists work with the students on-site and teachers implement new skills in the classroom and on field trips. All the students help to care for the school vegetable garden as an educational exercise. The school even offers character classes to teach the students how to be good citizens of the world.

Access also offers an integrative preschool for children up to five years of age.

For more information about Access Academy, contact Admissions Coordinator Beth Rice at (501) 267-8600 or bethr@accessschools.org.

The Academy at Riverdale

The Academy at Riverdale is K-12 school for high-functioning kids with disabilities like epilepsy and autism. The school is located at 1600 Riverfront Drive in the Little Rock Heights neighborhood. Classroom sizes vary, but a typical setting can involve one teacher and one aide for every five students. Students at Riverdale receive physical, occupational, and speech therapy from the staff at school.

For more information about the Academy at Riverdale, call director Joyce Pattillo at (501) 663-6965.

School Choices **Part II: Public Schools**

Most kids on the autism spectrum attend public schools.

Public schooling has three major advantages for autistic children. The first is that it is completely free. The second is that public school officials are bound by law to ensure that your child receives an adequate education. The third is that public school therapists provide treatment for your child at no cost to you.

When you get ready to send your child to public school, s/he'll be independently evaluated by therapists who work for the district. (If s/he has been evaluated recently for Early Childhood services, they may skip this step and just transition instead.) After the evaluation, the therapists will review the results with you and make a recommendation for in-school treatment, like speech or occupational therapy.

You, your child's teacher(s), therapists, and a representative from the school district will meet to form an **Individualized Education Plan (IEP)** for your child. The IEP can include modifications for the classroom, teaching, and assignments. It will also include a treatment plan for your child if s/he qualifies for therapy. The IEP will also address your child's classroom setting, such as whether s/he will be taught in a self-contained classroom or be mainstreamed into a regular one.

You can invite whomever you choose to an IEP meeting. Experienced parents recommend that you bring a behavior consultant who can help you formulate a Positive Behavior Plan for your child. You can also make any request you like for your child's school situation. If the school district representatives refuse your request, simply ask for **Prior Written Notice (PWN)**, a written explanation of why the school district cannot comply with your request.

Your child is entitled to what is known as a **Free and Appropriate Education (FAPE)** in the **Least Restrictive Environment (LRE)**. This means that s/he is entitled to an adequate education, at no charge, and in the most mainstream environment appropriate to the child's level of functioning. For example, a high-functioning child with Asperger's Syndrome will not be placed in a specialized classroom if s/he is capable of learning with typical students.

The Arkansas Department of Education offers the services of special education consultants known as CIR/CUIT (Centralized Intake and Referral/Consultant Unified Intervention Team). A CIR/CUIT consultant can visit your child's school, develop a Positive Behavior Plan for him or her, and help you to advocate for needed services. You can fill out a CIR/CUIT referral at <http://arksped.k12.ar.us/sections/circuit.html>.

If you have any other concerns, you can contact the Department of Education Special Education Division at (501) 682-4221 or visit their website at <http://arksped.k12.us>.

Wright's Law

It's important to know your rights when you help to create and implement your child's IEP. You'll need to understand the **Individuals with Disabilities Education Act** of 2004. Navigating the law can be difficult and intimidating, and new questions always seem to come up when creating an IEP.

Wright's Law (www.wrightslaw.com) is the premier website for special education law and advocacy. This will be your go-to website for all things IEP. Wright's Law was created by Peter Wright, a special education attorney, and Pam Wright, a clinical psychologist and special education advocate. Together they have published a series of books and journals, along with the website, to apply the complex IDEA law.

Advocates for Children and Adults with Disabilities

When the going gets tough, the tough need an advocate. The following is a list of advocates in the central Arkansas area.

Advocates Needed Today, Inc.

Arkansas ANT is a grassroots disability rights organization based in central Arkansas.

(501) 960-0333

www.advocatesneededtoday.org

Contact Rebecca Riggs at rriggs@ipa.net

Arkansas People First

APF is an organization based in Hot Springs that promotes self-advocacy for people with disabilities.

Contact Tommy Baker, State Coordinator at 1-888-488-6040

www.arkansaspeoplefirst.com

The Arkansas Governor's Developmental Disabilities Council

The DDC is a governor-appointed council of community members who advocate for independence and integration of persons with disabilities.

Contact Mary Edwards, Council Coordinator

(501) 661-2589

1-800-482-5400 ext. 2589

mary.edwards@arkansas.gov

The Disability Rights Center

The DRC is a private non-profit protection and advocacy organization located in Little Rock.

(501) 296-1775

1-800-482-1174

www.arkdisabilityrights.org

Child and Adolescent Service System Program

The CASSP is a division of the Arkansas Department of Human Services. CASSP assists in creating a multi-agency approach to help children with serious emotional disturbances.

You can reach Children's Services at (501) 686-9175.

Arkansas Department of Education: Special Education Division

Call the ADE special education division with any questions about IDEA, your child's IEP, or to resolve any disputes with the staff at your child's school.

(501) 682-4221

<http://arksped.k12.us>

Arkansas Human Development Centers

The state of Arkansas has six Human Development Centers around the state that provide habilitation training, employment training, and therapy services for persons with disabilities.

(501) 683-3619

Arkansas Office of Long Term Care (OLTC)

The Arkansas OLTC provides information about long-term care facilities for special needs children and adults, as well as assistance with investigations into fraud or abuse.
(501) 682-8487

You can also contact the **Arkansas Ombudsman**, a nursing home residents' rights organization. Your central Arkansas Ombudsmen are Herman Estaun and Tim Allen. For more information, call (501) 372-5300 or visit the Ombudsman website at www.arombudsman.com.

Arkansas Behavioral Health Services
Psychiatric Residential Treatment Facilities
(501) 686-9489
<http://www.state.ar.us/dhs/>

Arkansas Attorney General's Medicaid Fraud Control Unit
Contact the Fraud Control Unit if you think someone is abusing the Medicaid program or one of its recipients. Call (501) 682-7760 or e-mail medicaid@ag.state.ar.us.

Department of Human Services Division of Developmental Disabilities
Call the DDD for assistance and information regarding everything from Waiver services to disability rights protection. Contact Program Administrator Traci Harris at (501) 682-8678.

Americans with Disabilities Act Coordinators
Contact your Arkansas ADA Coordinators for help enforcing the ADA law with any public entity.
(501) 682-8920

Medicaid for Child Health Management Services
If you need help ensuring Medicaid coverage for your child's treatment at a CHMS, call Maryland Strickland at (501) 682-8330.

Governor Beebe's Special Education/Disabilities Liaison
Contact Joyce Dees at (501) 683-6393. This is a general office number, so you'll have to ask for her specifically.

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For the back:

This resource guide is a product of the Autism Resource Center of Arkansas' Autism Resource Library. To learn more about the library or to check out materials, contact Community Connections director Courtney Leach at (501) 329-5459 or courtney_leach@pedsplustherapy.com.