THE PARENT ADHD SURVIVAL GUIDE



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FOREWARD

You're probably reading this because you're looking for resources. This is a resource guide I compiled to help caregivers new to ADHD, so you don't have to struggle the way I did.

When I found out my first child had ADHD, it was an emergency. My son at 7 yrs. old was talking about suicide. 7 YEARS OLD! I searched and searched for a doctor to manage my child's depressive symptoms (what I thought he had). I didn't know what kind of therapy he needed or who to call. A lot of places had long wait lists or required referrals and I was getting nowhere. I finally reached out to a family friend, and he called one of the doctors he went to school with. This is how I ended up finding a child psychiatrist. We were able to get my son in to see him and to my surprise the doctor told us it wasn't depression but ADHD. I was shocked but after he connected the dots for us, I understood. We got him started on meds and reached out to the school, they did an evaluation and we got him started on an IEP. Everything went smoothly for him from that point on.

Fast-forward a few years and my youngest son was preparing to go to kindergarten when we started wondering if he too might have ADHD. We took him to our child psychiatrist and the doctor noticed right away that my youngest was strong willed. My son challenged the doc on every question. The doc might say "Let's play with the blocks" my son would question him, "Why," "I want to play with this instead" etc. He was soon diagnosed with ADHD and Oppositional Defiance Disorder (ODD). As the year went on, he got increasingly aggressive and defiant. He was getting dysregulated at school, cursing at his teacher, banging his head against the wall, and even ran away from school. It didn't seem to matter how much we tried to reason with him and explain how his actions have consequences, it just kept getting worse. Even his therapy wasn't helping. The school district ended up creating a behavior intervention plan for him, and he was moved to another school. We were quickly falling into crisis and didn't know what to do. A friend suggested we investigate Parent Teacher Interactive Therapy (PCIT). I had never heard of PCIT, but we were desperate to help our son. There were long waiting lists of course and we couldn't wait so we paid out of pocket and took PCIT. PCIT saved our lives because it taught us how to parent differently and to communicate in the way our son needed. Today, both sons are stable, happy, and succeeding in school with support.

I started asking myself, what if we didn't happen to know someone who could get us into a child psychiatrist? What if my friend hadn't mentioned PCIT? What if we weren't living in a great school district? What if we were single parents and didn't have extended family to help us? What would we have done if we couldn't afford the therapy, meds, doctor's appointments and PCIT? I felt so helpless at the time and my own mental health was at stake. I don't think I'd be here to share these resources if I didn't happen to know the right people at the right time, in the right place with financial stability. That's why I put together this resource. I want everyone to have the support and direction they need now, regardless of circumstances.

I'm not a doctor, a lawyer, or a social worker. I'm a mom with ADHD, parenting kids with ADHD. I put this resource together to find pertinent information for parents and caregivers that are new to ADHD and neurodiversity. There is an overwhelming amount of data, terms, acronyms, and therapies so I've tried to list what I think will be helpful to you.

This resource guide is not meant to be read beginning to end. It's separated by different learning resource categories and individual topics. Check the resources for what you need in the moment and come back to it later for other areas you want to learn more about.

DISCLAIMER: Resources in this document do not replace consultation with a doctor or other provider working with a specific child, family, and their needs.

INTRODUCTION

Brain Science

Hey folks, I'm sure if you're reading this you are now very aware, ADHD is a real thing! It is a neurodevelopmental disorder that has been identified since 1798. Research shows that some parts of the brain tend to be a little smaller and/or take longer to mature in kids with ADHD. Below is an image that shows what parts of the brain are affected by ADHD. I found it helpful to see an image of the brain to better understand what some of these resources are talking about when mentioning parts of the brain.

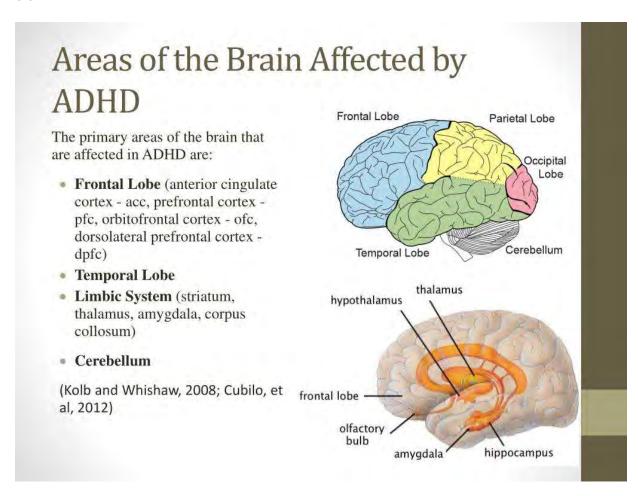


Image by SlideServe - https://www.slideserve.com/swann/areas-of-the-brain-affected-by-adhd

For the general population ADHD probably looks a lot like a hyperactive or defiant child or someone daydreaming on the job. For those of us with ADHD or raising a child with it, we know all too well that's just the tip of the iceberg. Look at the image below and I bet you'll recognize a lot of behaviors you didn't know were linked to ADHD. This image explains some of the many struggles of ADHD. Note, not everybody has the same symptoms.

THE ADHD ICEBERG

WHAT PEOPLE THINK ADHD IS: trouble focusing fidgeting poor sense sensory WHAT ADHD of time processing ACTUALLY IS: disorder financial 'all or nothing' problems difficulty maintaining anxiety trouble recalling relationships commonly used words uncontrollable depression fidgeting sleeping auditory problems difficulty following and processing hyperfixations maintaining conversations disorder mood rejective swings sensitive trouble regulating executive inability to focus emotions dysphoria dysfunction even if there are no distractions losing items chronic relentlessly unemployment poor impulse control forgetting to eat, sleep, difficulty switching tasks or inability to stick to one forgetting thoughts go to the bathroom 0.2 seconds after having them problems focusing on things choice paralysis even if they are of interest

Image by Tim Kiver Foundation - https://timkiverfoundation.org.uk/2021/02/04/adhd-iceberg-adhd-signs/

Receiving any diagnosis for a child can be overwhelming, receiving one like ADHD that varies so vastly from child to child can be even more so. My goal is to save you the time in searching for these resources and make your crisis more manageable. I filtered through resource after resource and immersed myself in all things ADHD. I read articles and books, watched documentaries and webinars, listened to podcasts and books on tape, joined listservs about policy and advocacy that pertains to disabilities, attended IEP advocacy training, and joined Special Education councils.

As you do your own reading and research, you may hear the term Attention-Deficit Hyperactivity disorder (ADHD) or attention deficit disorder (ADD) or even ADHD inattentive type, hyperactive type, or combined type. Don't be confused, it's the same thing. ADD is considered an outdated term for what is now called ADHD. Some kids have hyperactive behaviors, and some don't, but the diagnosis is ADHD either way.

Speaking of acronyms, you'll see a ton of them in materials about ADHD so below is a quick list of some common acronyms you'll see. There is also a glossary of ADHD terms at the end of this guide.

ADHD -Attention Deficit Hyperactivity Disorder

https://www.psychiatry.org/patients-families/adhd/what-is-adhd

https://www.cdc.gov/ncbddd/adhd/facts.html

CD - Conduct Disorder

https://www.hopkinsmedicine.org/health/conditions-and-diseases/conduct-disorder

ODD -Oppositional Defiant Disorder https://www.mayoclinic.org/diseases-conditions/oppositional-defiant-disorder/symptoms-causes/syc-20375831

SPD - Sensory Processing Differences

 $\frac{https://familydoctor.org/condition/sensory-processing-disorder-spd/#:^:text=Sensory%20processing%20disorder%20(SPD)%20is,that%20other%20people%20are%20not.$

RSD -Rejection Sensitive Dysphoria

https://my.clevelandclinic.org/health/diseases/24099-rejection-sensitive-dysphoria-rsd

Now for the resources! I have separated these references by media type because we all learn differently. As an individual with ADHD, I don't always remember what I'm reading (working memory problems!), so I have found audible books easier to digest than reading them, but to each their own.

Note: Many references are specific for those in the Kansas City area as that's where I live, but I've also included national level resources.

ARTICLES

I sometimes have difficulty finding the time and motivation to start a book but still want to utilize my time learning more about ADHD. That's when I turn to articles. I read each of these when researching what to include in this guide. I chose these articles because they provide a wide variety of topics, each one, I found myself wondering about at one time or another. They were found via the Centers for Disease Control (CDC), ADDitude Magazine and Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) and have tremendous amounts of helpful and informative information.

ADHD in Kids ADHD Treatment 101-Everything You Need to Know About Treating Your Child's ADHD https://parentingadhdandautism.com/2017/06/adhd-treatment-101-child/

ADHD Resources on Benefits.gov

https://www.benefits.gov/news/article/471?utm_source=enewsletter&utm_medium=email&utm_campaign=Editors%20Picks%20Selection%20Issue

ADHD Treatment Recommendations https://www.cdc.gov/ncbddd/adhd/guidelines.html

Articles and Key Findings About ADHD -Center for Disease Control (CDC) https://www.cdc.gov/ncbddd/adhd/pubs.html

Does Brain Training Work? ADHD Brain Games and Neurofeedback Evaluated (by Stephanie Sarkis, Ph.D., Ari Tuckman, Psy. D., MBA)

https://www.additudemag.com/does-brain-training-work-neurofeedback-games-adhd/?utm_source=eletter&utm_medium=email&utm_campaign=treatment_february_2023&utm_content=022323&goal=0_d9446392d6-7016505a05-319365942

Is ADHD a Disability? Your Legal Rights at Work https://www.additudemag.com/workplace-legal-protection/#:~:text=Yes.,ADA)%20covers%20individuals%20with%20ADHD.

Principles for Parenting a Girl with ADHD (by Dr. Stephen P. Hinshaw)

https://chadd.org/adhd-news/adhd-news-caregivers/principles-for-parenting-a-girl-with-adhdpy-2/?utm_source=NRC-CHADD+Master+List&utm_campaign=9974ad6f09-EMAIL CAMPAIGN 2018 12 18 04 09 COPY 01&utm_medium=email&utm_term=0_2985b6fcb_4-9974ad6f09-48785759

Rejection Sensitive Dysphoria (RSD)

https://my.clevelandclinic.org/health/diseases/24099-rejection-sensitive-dysphoria-rsd?utm_source=substack&utm_medium=email

Treatment of ADHD

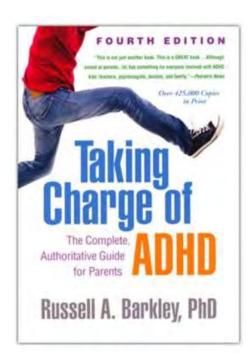
https://www.cdc.gov/ncbddd/adhd/treatment.html

The ADHD Conflict Resolution Guide: Tools and Scripts for Settling Disagreements https://www.additudemag.com/slideshows/conflict-resolution-skills-family-relationships-

adhd/?utm_source=eletter&utm_medium=email&utm_campaign=parent_april_2023&utm_conte_nt=040823&goal=0_d9446392d6-fdcdb58d78-319365942

BOOKS

I've researched some of the leading books on ADHD. I've read some of them below but not all. I found some of the books listed below by listening to a Podcast or a webinar by the authors. If I had to pick one book to start with-it would-be Russell Barkley's Taking Charge of ADHD. An audio version of this book is also available. If you need something even easier to digest, listen to his webinar on the 30 Essential Ideas Every Parent Needs to Know. (See the video section for a link).



PARENTING BOOKS

Taking Charge of ADHD by Dr. Russell Barkley

Russell Barkley guides you to:

- Understand why kids with ADHD act the way they do.
- Get an accurate diagnosis.
- Work with school and health care professionals to find needed support.
- Implement a proven eight-step behavior management plan.
- Build your child's academic and social skills.

Driven to Distraction by Dr. Edward M. Hallowell

Through vivid stories and case histories of patients-both adults and children-Hallowell and Ratey explore the varied forms ADHD takes, from hyperactivity to daydreaming.

The ADHD Workbook for Parents by Dr. Harvey Parker

This workbook guides parents through the daily tasks involved in raising children with attention deficit/hyperactivity disorder. Using a combination of helpful worksheets and practice exercises, this handbook offers practical instruction that allows parents to advocate for their child in the classroom as well as facilitate structure in the home.

The explosive child by Dr. Ross Greene

Dr. Greene provides a new conceptual framework for understanding their difficulties, based on research in neurosciences. He explains why traditional parenting and treatment often don't work with the children, and he describes what to do instead. Dr. Greene's Collaborative Problem-Solving model promotes working with explosive children to solve the problems that precipitate explosive episodes, and teaching these kids the skills they lack.

What Your ADHD Child Wishes You Knew by Dr. Sharon Saline

This book focuses on the importance and effectiveness of being an empathetically aware communicator, and how working together creates lasting results.

CHILDREN'S BOOKS

Here is a list of **ADDitude Magazine's 10 Riveting Reads for Spirited Kids** – A short list of great reads that help children with ADHD feel connected and less alone.

Hank Zipzer series, by Henry Winkler and Lin Oliver

Henry Winkler (of "Happy Days" fame) brings his childhood to life in the Hand Zipzer books. The books are full of humor for adults and children alike, and any kid who learns differently will really identify with Hank.

Taking Dyslexia to School, by Laruen Moynihan

This book, a cousin to Taking A.D.H.D to School, explains what's going on inside a child with dyslexia.

Ellie Bean the Drama Queen, by Jennie Harding

This book is the latest children's book about sensory processing disorder (SPD), a condition that affects at least 40 percent of kids with ADHD and/or autism.

Free Association: Where My Mind Goes During Science Class, by Barbara Esham

This book targets "twice-exceptional" kids: children with gifted levels of intelligence along with ADHD and/or learning disabilities.

This Morning Sam Went to Mars: A book About Paying Attention, by Nancy Carlson

This book focuses on lifestyle changes that should be considered before a formal diagnosis or decision to medicate is made.

Cory Stories: A Kid's Book About Living with ADHD, by Jeanne Kraus

This book offers an age-appropriate introduction to ADHD treatments like medication, counseling, and behavior modifications.

Joey Pigza series, by Jack Gantos

This book handles tough topics like feeling left out, taking medication, and more. It is recommending Parents rea these books before reading them to their children, because they deal with some heavy topics like divorce and alcoholism – and you want to make sure your child is ready for them.

Pay Attention, Emily Brown, by Linda Burton

Approaches the subject of inattention with grace, humor, and love.

Aloha Island: The Story of the Stones, by Frank South

Main character Eddie Akamai struggles with a learning disability that make it difficult for him to read. But with the help of his friends, family, and some fun alphabet-bearing plants, he overcomes his fears and saves the magical Aloha Island.

Get Ready for Jetty! My Journal About ADHD and Me, by Jeanne Kraus

An engaging, visually appealing approach to ADHD, told through the eyes of a 9-year-old girl-perfect for girls aged 9-13.

PODCASTS

I chose to include these Podcasts because I thought they were easy to understand and provided some sort of insight that hit home with me. I like to listen to Podcasts because I can multi-task while listening to them. ADHD 365 is a great one.



Images from CHADD.org

6 Principles for Raising a Child (with ADHD with Dr. Russell Barkley) 6 Principles for Raising a Child with ADHD (with Russell A. Barkley, Ph.D.)

CHADD's ADHD Podcasts All things ADHD and ADHD 365 https://podcasts.chadd.org/

How to Help your Teen with ADHD Engage in Self-Advocacy (ADHD 365 with Dr. Nerissa Bauer) https://podcasts.chadd.org/e/how-to-help-your-teen-with-adhd-engage-in-self-advocacy/?utm_source=NRC-CHADD+Master+List&utm_campaign=9974ad6f09-EMAIL_CAMPAIGN_2018_12_18_04_09_COPY_01&utm_medium=email&utm_term=0_2985b6fcb 4-9974ad6f09-48785759

Managing ADHD and Disruptive Behavior Disorders (All Things ADHD with Dr. Tish Taylor) https://podcasts.chadd.org/e/managing-adhd-and-disruptive-behavior-disorders/

New Digital Therapeutics for ADHD in Children (with Dr. Randy Kulman) https://www.additudemag.com/webinar/neurotechnology-options-adhd-treatment-children/

VIDEOS

I mentioned Russell Barkley's video earlier. Above all books, articles, webcasts I'd start first by listening to this. It is a recording of a Webinar he gave. He's speaking to a crowd and has slides, but they aren't shown so you don't have to be watching this video, just listen. The other videos were also informative, but you'll find I am partial to Dr. Berkey's teachings.

Prepped and Ready: Parenting into the Teen Years by Shayla Sullivant, M.D. Children's Mercy KC https://www.childrensmercy.org/departments-and-clinics/developmental-and-behavioral-health/learning-opportunities/prepped-and-ready/

Promoting Mental Health for Black Communities | For Families, Parents & Professionals by Harolyn M.E. Belcher MD

https://chadd.org/webinars/ask-the-expert-promoting-mental-health-for-black-communities-for-families-parents-professionals/

Ask the Expert: Promoting Mental Health for Black Communities

The 30 Essential Ideas Every Parent Need to Know by Dr. Russell Barkley https://www.youtube.com/watch?v=BzhbAK1pdPM&list=PLzBixSjmbc8eFl6UX5_wWGP8i0mAs-cvY

TOOLS For Success -Two min. animated videos for youth & the adults who support them by Dr. Andrea Chronis-Tuscano and her team at the University of Maryland ADHD Program. https://chadd.org/stroud-umdadhdtools/

WEBSITES

Each of these websites has been invaluable. They are packed with resources (many of which are included in this guide). They are well established organizations that you should use for support with your ADHD child.

Note: Families Together aids with early intervention, education, health care, transitions, and community resources to support the academic, behavioral, social, emotional, and mental well-being of children, youth, and families. If you live in Kansas, you must go to their website and see how they can help you.

A.D.D. Warehouse https://www.addwarehouse.com/

ADDitude- https://www.additudemag.com/

ADHDKC -https://www.adhdkc.org/

CHADD - https://chadd.org/

Families Together (Kansas) - https://familiestogetherinc.org/

Understood - https://www.understood.org/

ADVOCACY

Now that things are stable in our household, I've been learning more about advocacy and how I can help my kids and others with disabilities. Here are some resources that you can use to learn about advocating for your kids. When you can, please learn about it! We are our children's best hope and their strongest cheerleaders.



Image via @mamapsychologists - Facebook Positive Parenting Solutions

CHADD Advocacy Manual https://chadd.org/wp-content/uploads/2019/10/CHADD-Advocacy-Manual-2019-FINAL.pdf

Learning Disabilities Association of America https://ldaamerica.org/advocacy/

Very Well - How to Advocate for Students in Special Education <u>How to Advocate for Students With</u> Special Needs (verywellfamily.com)

COMORBIDITY

Comorbidity means you have more than one illness at once. A lot of people with ADHD may also have other developmental or psychiatric disorders.

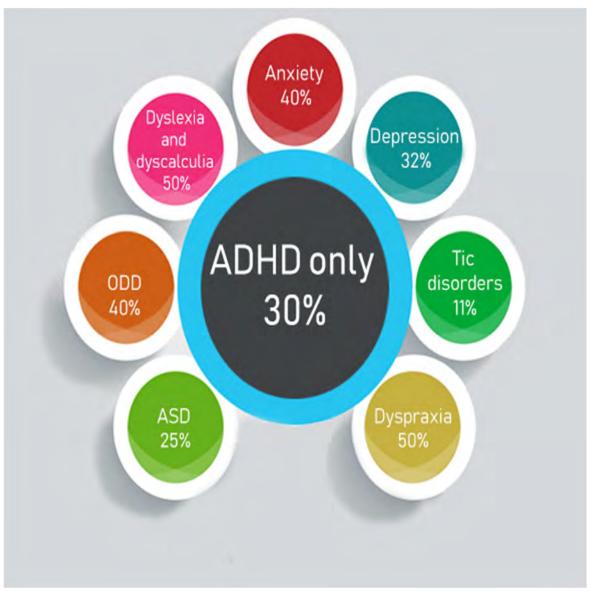


Image - University of Nottingham's Health E-Learning and Media Team on Understanding ADHD

Whether your child has just ADHD or a combination of other disorders, self-care is essential for you as a parent.

SELF CARE

Self-Care Tips for Parents of Special Needs Children https://www.goodtherapy.org/blog/self-care-tips-for-parents-of-special-needs-children-0810175

Why Self-Care is Essential to Parenting https://childmind.org/article/fighting-caregiver-burnout-special-needs-kids/

SUPPORT GROUPS

ADHDKC Parent's Group https://www.adhdkc.org/events

ADHDKC Women's Group https://www.adhdkc.org/events

ADHDKC Adults' Group https://www.adhdkc.org/events

CHADD Adult to Adult https://chadd.org/

Families Together Parent-to-Parent Support https://familiestogetherinc.org/programs/parent-to-parent-support/

MENTAL HEALTH RESOURCES

KC Healthy Kids https://www.kchealthykids.org/mental-health-resources.html

KC Today https://kctoday.6amcity.com/local-mental-health-resources-in-kansas-city

National Alliance on Mental Illness (NAMI) Kansas https://www.nami.org/Find-Your-Local-NAMI/Affiliate?state=KS

National Alliance on Mental Illness (NAMI) Missouri https://www.nami.org/Find-Your-Local-NAMI/Affiliate?state=MO

COMMUNITY DEVELOPMENTAL DISABILITY ORGANIZATION (CDDO)

CDDO's are the single point of entry for an individual or family to obtain services through the developmental disability system for Kansas. If your child has ADHD alone, a CDDO will not cover services. If, however, your child has a dual diagnosis like ADHD and an Intellectual or Developmental Disability (IDD), your local CDDO is where you should start. IDD includes many severe, chronic conditions that are due to mental and/or physical impairments and can begin at any time, up to 22 years of age. Examples include autism, behavior disorders, brain injury, cerebral palsy, Down syndrome, fetal alcohol syndrome, intellectual disability, and spina bifida.

Kansas CDDO -https://kdads.ks.gov/docs/librariesprovider17/CSP/HCBS/I-DD/cddomap9acd5ea0172e66d690a7ff00009edf98.pdf

Missouri Regional Centers -

https://moddcouncil.org/#:~:text=1%2D800%2D500%2D7878&text=Our%20Mission%3A%20%22To%20assist%20individuals,in%20every%20aspect%20of%20life.%22

Search by State- https://thearc.org/find-a-chapter/

DIET

I've heard that you should avoid giving anything with Red40 in it to your kids with ADHD. I was determined to get this answer for you, but there isn't one. Here's what WebMD says "To date, no conclusive evidence has been found to show that food coloring causes ADHD. Some studies, though, have suggested an association between the two." I decided not to stress too much. If you have the mental energy to fight the fight, go for it. I'm just going to focus on getting my kids to eat period and add in healthy foods.

Pro tip, hide the sweets and just set one or two out at a time. My kids have no self-control and eliminating tasty treats all together causes more stress for me.



Image from Attitude Magazine article Why Sugar is Kryptonite

ADHD Diet Resources

Diet and ADHD, Reviewing the Evidence: A Systematic Review of Met-Analysis of Double-Blind Placebo-Controlled Trials Evaluating the Efficacy of Diet Intervention on the Behavior of Children with ADHD- National Library of Medicine *Nation Center for Biotechnology Information* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5266211/

Dietary Interventions for ADHD: Emerging Research and Considerations https://www.psychiatrictimes.com/view/dietary-interventions-for-adhd-emerging-research-and-considerations

Does Diet Affect the Symptoms of ADHD?

<u>Does Diet Affect the Symptoms of ADHD?</u> | <u>Bentham Science (eurekaselect.com)</u>

Eating Tips for Children Taking Stimulant Medicines https://www.cincinnatipediatrics.com/uploads/ADHD Diet.pdf

The ADHD Diet Plan: Healthy Foods and Supplements for Kids & Adults https://www.additudemag.com/adhd-diet-for-kids-food-fix/

Why Sugar is Kryptonite: ADHD Diet Truths

https://www.additudemag.com/adhd-diet-nutrition-

 $\frac{sugar/\#: \text{``:} text=Foods\%20 rich\%20 in\%20 protein\%20\%E2\%80\%94\%20 lean, to\%20 communicate\%20}{with\%20 each\%20 other}.$

ELOPMENT

Not all kids with ADHD elope, but I chose to include a bit of information about elopement because both my sons "ran away" a block or two and it can be scary when they won't stay put. We ended up trying a few different tracking devices. Currently we have our son wear a watch with GPS tracking capability so we know which friend's house he's playing at, and we can text him to come home for dinner. He can text or voice message us back. This way he can reach us if his scooter's battery dies, or he gets hurt climbing trees etc. Better than an iPhone that he'll lose or break in a matter of seconds.

Kansas Elopement Awareness & Preparedness Toolkit; https://www.kumc.edu/documents/peds/resources/Kansas%20Elopement%20Awareness.pdf

Disability and Safety: Information on Wandering (Elopement) by Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html

The Best GPS Trackers for kids https://www.zdnet.com/article/best-gps-trackers-and-devices-for-kids/

SENSORY

People with ADHD can also experience sensory overload. Finding the root of the problem can be difficult, but there is almost always a solution and sensory sensitivity does not have to be a hinderance to how your child experiences life. Sometimes trial and error is necessary, my son was having meltdowns at restaurants. We noticed it was anytime we would sit in chairs rather than a booth. Another issue we had to conquer was wearing pants and in Kansas sometimes it's just too cold not to wear them. We found the solution in sports tights, now in winter I can at least get his legs covered. He also will now wear pants over the tights in extreme cold. Sometimes it just requires finding something for the short term before they can conquer the greater issue at hand. Below are some other resources I found helpful in finding soft clothing, fidget toys etc. Image below by Sensory Friendly Solutions.



Image from Autism Spectrum News Article by Claudia Rose Addeo https://autismspectrumnews.org/navigating-sensory-processing-disorder/

American Occupational Therapy Association – Sensory Processing Interventions https://www.aota.org/search#q=sensory%20processing%20interventions&sort=relevancy

Products

City Threads https://www.citythreads.com/

Fun & Function https://funandfunction.com/

National Autism Resources https://nationalautismresources.com/chewelry/?sscid=31k7 346mu

We are Teachers https://www.weareteachers.com/sensory-toys/

HOME & COMMUNITY BASED SERVICES

When my youngest was having behavior problems. The school told me to call my local County Mental Health Center who told me our son was eligible for Medicaid because he qualified under the SED waiver. Unfortunately, when in the middle of the crisis, navigating new doctors, therapists, and medications, this was not an option for us. I couldn't get PCIT covered which is what we really needed. We ended up paying out of pocket, but things may have changed, and you should absolutely investigate all the resources available to you.

SED WAIVER (Kansas 4-18 yrs.) Serious Emotional Disturbance (SED) (ks.gov)

I/DD Waiver - Intellectual & Developmental Disability (Kansas 5+ yrs.)

https://kdads.ks.gov/kdads-commissions/long-term-services-supports/home-community-based-services-(hcbs)-programs/programs/i-dd

Missouri - https://health.mo.gov/seniors/hcbs/

MO HCBS Provider Resources -

https://static1.squarespace.com/static/5fa07b5cf2db3a39784ab7e0/t/5faec6874aff1f2f851d51 bc/1605289607947/Contact+Handout+for+CQI+Provider+Meetings.pdf

Check your states HCBS for waivers.

See also Community Developmental Disability Organizations (CDDO) for additional services.

HEALTHCARE BENEFITS

I now know we could have had financial support via Medicaid but while in crisis, we didn't know that. Navigating Healthcare benefits and Medicaid can be overwhelming. Below are some resources I found helpful.

CHADD Insurance and Public Benefits https://chadd.org/about-adhd/insurance-and-public-benefits/

Can I Get Disability for ADD or ADHD? https://www.findlaw.com/legalblogs/personal-injury/can-i-get-disability-insurance-benefits-for-add-or-adhd/

KanCare Eligibility Guidelines https://www.kdhe.ks.gov/185/KanCare-Eligibility-Guidelines#:":text=Children,qualifying%20children%20under%20age%2019.

TREATMENT

Treating ADHD often requires medical, educational, behavioral, and psychological intervention. This approach to treatment is sometime scall "multimodal." CHADD -Treatment of ADHD https://chadd.org/about-adhd/treatment-of-adhd/#:~:text=Treating%20ADHD%20often%20requires%20medical,medication

My personal experience involved a combined approach of behavioral therapy, medication, parent training, school intervention and counseling. We started the medication journey early (it takes a lot of trial and error to find the right meds) and we were sending our kids to therapy, but we didn't realize we needed to parent differently to reach our child. That's where Parent Child Interactive Therapy came in. It was a game changer. If your child is having behavior issues, investigate PCTI or Behavioral Parent Training separate from your child's therapy.

Treating ADHD in Children

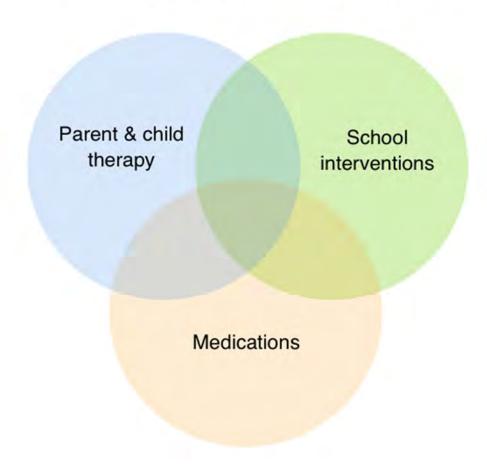


Image – GoodRX Health – Choosing ADHD Medication: A Guide for Adults and Children by Sophie Vergnaud, MD

Note: This guide does not replace medical advice. Talk with your doctor about the best treatment for ADHD. The treatment we found best works for us is a combination of medication, therapy, and school support.

THERAPY

Behavioral Therapy (BT)

 $\frac{https://docs.google.com/spreadsheets/d/1M23IuULTyQFrFndhnlYDIDHD2fjNReKqR80UAPq9Ae}{M/edit\#gid=0}$

Behavioral Parent Training (BPT) https://www.childrensmercy.org/departments-and-clinics/developmental-and-behavioral-health/adhd-services/understanding-and-managing-adhd/

Parent Child Interactive Therapy (PCIT) http://www.pcit.org/what-is-pcit.html

Digital Therapeutics https://www.additudemag.com/webinar/neurotechnology-options-adhd-treatment-children/

Music Therapy

Attitude Magazine: https://www.additudemag.com/music-therapy-for-adhd-how-rhythm-builds-focus/

Kansas City Music Therapy Association https://www.kcmmt.org/
https://www.childrensmercy.org/your-visit/family-support-and-resources/music-therapy/

MEDICATION

ADHD Medication

https://www.google.com/search?q=youtube+LEND+Dr.+Denosve+ADHD+medication&rlz=1C1C HBF_enUS913US913&ei=IzUGZNO0I4GhptQPjJub2Ak&ved=0ahUKEwiT0tjC-8f9AhWBkIkEHYzNBpsQ4dUDCBA&uact=5&oq=youtube+LEND+Dr.+Denosve+ADHD+medication &gs_lcp=Cgxnd3Mtd2I6LXNlcnAQAzIFCAAQogQ6CggAEEcQ1gQQsAM6CgghEKABEMMEEApKBAh BGABQoQdYnRRg_R9oAXABeACAAbEBiAGaBZIBAzAuNZgBAKABAcgBCMABAQ&sclient=gws-wizserp#fpstate=ive&vld=cid:7a636793,vid:I7QGn1Ri9cg

ADHD Medication Management: How to Use and Adjust Stimulants Safely (William Dodson, MD) https://www.youtube.com/watch?v=Q8I8JTRx7Pw

Attention-Deficit/Hyperactivity Disorder Parents' Medication Guide
https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/med_guides/ADHD_Medication_Guide-web.pdf

SCHOOL SUPPORT

If your child has ADHD, chances are they need support at school. Below is a flow chart from the Families Together Guide to Special Education.

How Special Education Works in Kansas

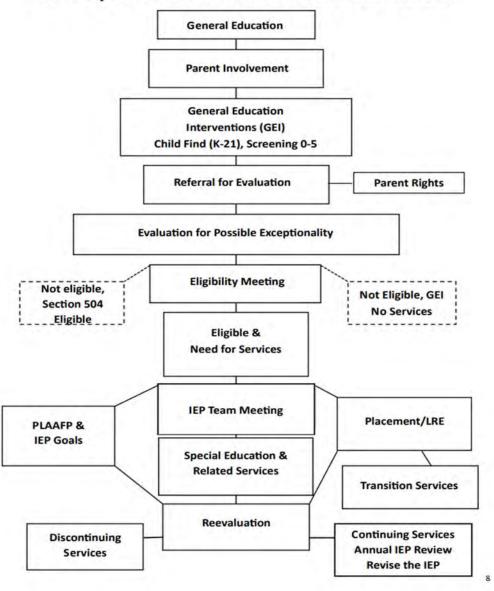


Image from Families Together – Guide to Special Education page. 8

https://familiestogetherinc.org/wp-

ontent/uploads/2022/10/Guide%20to%20Special%20Education%20for%20Families%20and%20Education%20Advocates.pdf

Perhaps your child doesn't need an IEP but could still use support in school, that's where a 504 plan could be used. See the resources below resources for more information.

504 Plan https://familiestogetherinc.org/spedrights/what-is-a-504-plan/

ADAPT Accommodations to Help Students with Attention Deficit Disorders https://www.addwarehouse.com/article4.htm

ADHD and School: A Toolkit for Parents https://chadd.org/for-parents/adhd-and-school-a-toolkit-for-parents/

Individualized Education Program (IEP) https://familiestogetherinc.org/resources/individualized-education-program-iep/

Least Restrictive Environment https://familiestogetherinc.org/resource/understanding-least-restrictive-environment-lre/

Practice of Informal Removal Limits Students' Education <a href="https://chadd.org/adhd-news/adhd-news-caregivers/practice-of-informal-removal-limits-students-education/?ct=t(EMAIL Weekly 11 17 2022 247 COPY 01)&mc cid=7a360ad48d&mc eid=562 a041106

Wrightslaw: Pop-Up Tool: Resolving Parent-School Disputes https://www.wrightslaw.com/info/iep.disputes.popup.htm

SUMMER PROGRAMS (KS & MO)

When things got tough for us and my kiddo was getting suspended from school, summer was just around the corner. I had planned to send him to our local parks and recreation summer camp. I knew that wasn't an option anymore. I couldn't just send him to a summer camp for the young teenage counselor to manage. They would probably quit working with kids and go home crying. I looked everywhere, I called all his current and past teachers, all the para's who had worked with him, all his therapists, social workers, counselors, and everyone they knew. This went on and on until I finally gave up. I ended up having to quit my job and stay home with him. This doesn't' have to be the case though, I found several helpful options, however it is incredibly important to sign up early.



Image Getty Images/iStockphoto

Joshua Center Summer Camp https://joshuacenter.com/summer-camp/ (816)763-7605

Children's Therapy Services Summer Camp https://www.childrenstherapycts.com/home (913) 696-5748

Heartland Therapeutic Riding - Bucyrus, KS www.htrkc.org (913) 897-3939

Horizon Academy Summer Program Day Camp - Roeland Park Ks (1st through high school) https://horizon-academy.org/admissions/summer-programs-2-2-2/ (913) 789-9443

For more information see the LEND informational handouts below (updated yearly) https://www.kumc.edu/school-of-edicine/academics/departments/pediatrics/outreach/family-resources/informational-handouts.html

GLOSSARY OF ADHD TERMS -CHADD.org

ADD: This refers to "attention deficit disorder," an older term for ADHD which some people still use, especially in reference to the presentation of ADHD that has less hyperactivity and is more characterized by inattention. This term has been replaced with the term "ADHD" to include all presentations of this disorder.

ADHD: This refers to Attention-Deficit/Hyperactivity Disorder, the official name given this condition by the American Psychiatric Association. It is described in the Diagnostic and Statistical Manual of Mental Disorders as a persistent condition that impairs functioning or development, and characterized by chronic inattention, hyperactivity, and often impulsivity.

ADHD Coach: A professional who is trained in both the field of coaching and ADHD who works primarily with adults and older teens to get past obstacles and reach their goals. Coaches often help those with ADHD with organizational and executive functioning challenges.

ADHD-Combined Type (ADHD-C): A subtype of ADHD characterized by both inattentive and hyperactive/impulsive symptoms of ADHD.

ADHD-Not Otherwise Specified (ADHD-NOS): A subtype of ADHD diagnosed when the inattention, hyperactivity and impulsivity symptoms are present, but the individual does not meet the full criteria for the other subtypes of ADHD.

ADHD-Predominantly Hyperactive-Impulsive (ADHD PH-I): A subtype of ADHD characterized by impulsivity and hyperactivity but lacking the symptoms of inattention.

ADHD-Predominantly Inattentive (ADHD-PI): A subtype of ADHD characterized by inattentive symptoms, but lacking hyperactivity and impulsivity symptoms.

Anxiety: Uneasiness of the mind, typically shown by apprehension, worry and fear about everyday situations. Anxiety can co-exist with ADHD.

Attentional Bias: Preferring to pay attention to certain objects, thoughts and activities that one finds interesting.

Behavior Modification (or Behavior Therapy): A type of treatment provided by a trained mental health professional that teaches clients how to identify the interconnection between thoughts, feelings, and behaviors, and learn new skills that replace negative behaviors with positive ones.

Behavioral Contract: A simple positive-reinforcement contract between student and teacher, or between parent and child, which is designed to change behavior. The contract explains the desired behavior that will be increased and the reinforcement that will be earned. In addition, inappropriate behavior is often listed, including the consequences for the behavior.

Child Behavior Checklist: A behavioral rating scale used by parents and teachers to evaluate emotional and behavioral problems in children.

CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder: A non-profit organization committed to helping people with ADHD, their families and the professionals who work with them.

Classroom Behavior Management: Strategies and techniques used by teachers to manage the behavior of students in the classroom and reduce classroom disruption.

Clinical Trial: Also called a research study, a clinical trial is designed to test an intervention, treatment, or new approach. Clinical trials may compare a new treatment to a treatment that is already available.

Co-Existing Conditions: When two or more mental health conditions are present in the same individual, they are said to be co-existing (also called co-occurring or co-morbid). For example, ADHD can co-exist with depression or anxiety.

Cognitive Restructuring: Changing self-defeating thought patterns brought about by earlier life experiences.

Comorbidity: Two or more disorders occurring in an individual at the same time.

Comprehensive Assessment: An evaluation process that takes into consideration any factors that contribute to an individual's current problems or functioning difficulties. These can include behaviors, education or employment skills, family history and relationships, emotional well-being, social skills, traumatic events, and co-existing mental health conditions. Strengths and abilities are also assessed. The process forms the basis for a diagnosis and treatment plan.

Conduct Disorder: A group of behavioral and emotional problems in children and adolescents that can be exhibited as aggressive behavior towards people and animals, destruction of property, lying, stealing, deceitfulness, and serious rule violations.

Daily Behavior Report Card (DBRC): A daily method of communication between teachers and parents in which the behaviors of the child throughout the day are reported. The card can be adapted to develop behavior goals, monitor the child's progress, or determine if behavior interventions are working to improve the child's behavior.

DSM-V Diagnostic and Statistical Manual of Mental Disorders: This manual, written by the American Psychiatric Association, describes how mental health disorders are classified, including the symptoms used for diagnosis. It is used by various health care professionals and insurance companies across a wide range of settings to classify mental disorders for diagnosis and insurance purposes.

Distractibility: The inability to sustain attention on the task at hand so that it disrupts a person's concentration.

Dyslexia: A specific learning disability that impairs a person's ability to read. It is characterized by spelling challenges, word retrieval while speaking and a lack of fluency, causing reading to be slower and require much effort.

Executive Function: Mental skills that allow us to control and coordinate other mental functions and abilities, such as planning or task completion. This deficit is common in those with ADHD.

Free Appropriate Public Education (FAPE): FAPE is a provision under Section 504 of the Rehabilitation Act of 1973, and the Individuals with Disabilities Education

Improvement Act (IDEIA). All children and students are given the right to have a free appropriate public education. The appropriate education service must be designed to meet the individual education needs of students with disabilities to the same extent that the needs of nondisabled students are met.

Functional Impairment Difficulties: These are life challenges which interfere with a person's ability to function in major life activities, including social situations, school, employment and in the community.

Hyperactivity: Having increased movement, impulsive actions, and a shorter attention span. A hyperactive person has constant activity and is easily distracted and impulsive. Other characteristics of hyperactive behavior also include inability to concentrate and aggressiveness.

Hyperfocus: A deep and intense mental concentration fixated on an activity, specific event, or topic.

Impulsivity: Acting with little or no thought of the consequences or reacting rapidly without considering the negative consequences of the reaction.

Inattention: Failure to pay attention to a specified object or task.

Independent Educational Evaluation (IEE): An assessment conducted by a qualified examiner not employed by a school district to determine if a student may be eligible for special education. An IEE is conducted if parents disagree with a school district's assessment of their child's eligibility for special education.

Individualized Education Plan (IEP): A written document that describes the educational goals at school, and the methods of achieving these goals, for eligible children with disabilities under IDEA. This plan is based on the child's current level of performance.

Individuals with Disabilities Education Act (IDEA): The current special education law in the United States which requires all states to provide a free appropriate public education (FAPE) in the least restrictive environment to children and students who have disabilities.

Intervention: A structured process (or action) that has the effect of modifying an individual's behavior, cognition, or emotional state.

Least Restrictive Environment (LRE): A requirement in federal law stating that students with disabilities should be educated in the same environment and alongside their typically developing peers, as well as have access to the same educational and social activities. Pullout and separation programs are determined by need on an individual basis.

Limited English Proficient (LEP): The term used by the federal government, most states, and local school districts to identify students whose difficulty in speaking, reading, writing, or understanding the English language will make it difficult to succeed in English-only classrooms.

Medication Holiday: A planned period, for medical or evaluation purposes, when prescribed medication therapy is temporarily discontinued. This should be undertaken only with the guidance of the prescribing medical practitioner.

Mental Health Therapist: A master's or doctoral level, licensed professional who is trained in assessment, diagnosis, and treatment of mental health disorders. Most mental health therapists practice in areas of specialty, which can include ADHD and related disorders. They are trained in a broad range of therapies such as Cognitive-Behavioral, psychodynamic, marital, family, parent-child interaction, coaching, to name a few. They can include psychiatrists, psychologists, clinical social workers, professional counselors, and marriage and family therapists.

Modification: Adjustments made to an assignment, test, or the general curriculum to meet the needs of a student when the expectations of the curriculum are beyond the student's ability. Modifications are written into the student's IEP or Section 504 Plan.

Multimodal Treatment: ADHD in children often requires a comprehensive approach to treatment. This "multimodal" approach includes multiple interventions working together, tailored to the unique needs of the child, including parent training, medication, and behavioral therapy.

Negative Self-Talk: Negative inner dialogue that brings out emotions such as guilt, fear, pessimism, anger, frustration, anxiety, and depression. These thoughts often damage self-esteem and can appear in times of increased stress or emotional turmoil.

Neurobehavioral: Related to the relationship between the brain and behavior.

Neurologist: A health care professional trained to diagnose and manage brain disorders.

Neuropsychologist: A psychologist trained in how the brain and the rest of the nervous system affect a person's behavior and cognition. They can administer neuropsychological testing which aims to identify any challenges to full brain functioning, including identifying learning disabilities or the impact of illnesses or injuries to the brain.

Neurotransmitter: A chemical in the brain that functions as a messenger to transmit nerve impulses between nerve cells (neurons) within the nervous system.

Non-stimulant Medication: A medication that has been approved to treat ADHD—generally considered second-line medication—prescribed to those who have an incomplete response or no response to stimulants, cannot tolerate stimulants, or have certain co-existing psychiatric conditions.

Occupational Therapist: A licensed health care professional who provides therapy centered on sensory integration to address the physical, behavioral, and emotional effects of ADHD, and identifies goals to help the child succeed at school and at home.

Peer Rejection: When someone is purposely excluded from a social relationship or social interaction by peers.

Planned Ignoring: A behavioral intervention strategy in which one provides no attention to negative and maladaptive behavior to reduce inappropriate behaviors.

Positive Behavioral Support (PBS): Rooted in research, PBS provides a systemic approach to decreasing problem behaviors and increasing socially acceptable behaviors in the individual and in the system, such as a school.

Prefrontal Cortex: The front part of the frontal lobe in the brain that plays a role in controlling attention, behavior, judgment, and emotion.

Progress Monitoring: A practice to assess a student's academic performance, record performance data, and evaluate how well the student is responding to instruction as well as the effectiveness of the instruction.

Prosocial Behavior: Positive actions to help others, motivated by a sense of empathy and caring, rather than for personal gain.

Psychologist: A licensed mental health professional trained in the study of behavior, emotions, and functioning. Psychologists are trained in psychological therapy, consultation, and testing.

Psychoeducational Testing: An assessment process that includes tests, observations, and history taking to identify a student's cognitive strengths and challenges, to develop a plan for the student's success in the classroom.

Rebound Effect: The tendency in some medications (including some ADHD medications), when withdrawn from use, to lead to symptoms of greater severity than were present before the medication was initiated.

Response to Intervention (RTI): A multilevel prevention system used by schools to maximize student achievement and reduce behavior problems. RTI is used to identify students at risk for learning failures, monitor student progress, provide evidence-based interventions, and adjust the interventions based on students' responsiveness.

Section 504: A civil rights statute (part of the Rehabilitation Act of 1973) that ensures children with disabilities are given equal opportunity, when compared to non-disabled children the same age, to participate in all academic and nonacademic services the school has to offer.

Self-Regulation: Managing (regulating) one's own behavior with appropriate behavior and actions to attain one's goals.

Sensory Integration Disorder (SID): Also known as Sensory Processing Disorder, SID is a condition in which the brain and nervous system are unable to correctly receive, organize and process information coming in from the senses, causing learning and behavioral problems.

Specific Learning Disability (SLD/LD): A disorder in the basic learning processes involved in understanding and using spoken or written language, that significantly interferes with a person's ability to listen, think, speak, read, write, spell, or do mathematics.

Speech or Language Impairment: A communication disorder including difficulties with articulation, stuttering, or a language impairment that adversely affects a person's educational performance.

Stimulant Medication: Medication that "stimulate" (increases) certain activity in the body's central nervous system, including the production and activity of neurotransmitters. Most medications approved for the treatment of ADHD are stimulant medications. When taken as prescribed, they generally help improve the symptoms of ADHD by promoting alertness, awareness, and the ability to focus.

Target Behavior: A specific behavior that has been chosen or "targeted" either to increase in frequency (if it is a positive behavior) or decrease in frequency (if it is a negative behavior).

Token Economy System: A behavior modification system in which a student earns tokens for showing the desired behavior. The tokens are exchanged later for a reinforcer which is typically selected by the student.

Working Memory: A system in the brain that temporarily stores and processes the information needed for much more complex tasks such as reasoning, comprehension, and learning.