

In this three-part series, three experienced “parent” case managers share their insights and make suggestions to parents and caregivers. If you are ready to tackle your child’s challenges head-on by learning from the experts about how to advocate for your child’s health, education and social development, read on.

Parents as Case Managers: A Roadmap for ADHD Management PART TWO

What Are Parent’s

by Dulce Torres, LPCS, BCC,
Maureen Gill, MSW, and
Elaine Taylor-Klaus, CPCC, ACC

YOU’RE READY TO BECOME YOUR CHILD’S CASE MANAGER.

You’ve made the effort to get educated about ADHD and other issues your child faces. You have a good understanding of what specific challenges need to be addressed in each of the three focus areas: medical, educational, and social/emotional. What’s next?

Before you develop an action plan, you need more specific information about your options. If you were visiting a new city, you’d want to see a list of attractions before you plan a touring agenda. Similarly, before you start randomly choosing therapies or schools, you want to know

your options for support.

In this article, we will go into greater depth about those options. There are three areas that parents must understand thoroughly, and attend to, in order to make the best decisions for their children and set them

up for the greatest success possible. These are:

- medical and therapeutic support
- educational support
- social-emotional development

Let’s look at each a bit more closely in terms of what is required to advocate for children in each of these areas.

MEDICAL Case Management

by Maureen A. Gill, LCSW

A parent becomes a case manager *as soon as* a child’s ADHD is first suspected. Suspicions may come from something parents read, concerns from a teacher, or people telling them “your child doesn’t listen or moves too much.” Investigation is the first step. You can read about ADHD and speak to school staff about your concerns. If you still suspect that your child may have ADHD, the next step is to ask for a medical evaluation by your child’s pediatrician or primary care doctor.

Ideally, a diagnosis of ADHD is made in combination with two thorough processes:

- A pediatrician, family practitioner or pediatric psychiatrist evaluates the child, using the American Academy

of Pediatrics (aap.org) Toolkit for Diagnosing ADHD, which contains checklists that parents and teachers fill out and return to the doctor. While not all doctors use the AAP toolkit, it is the best standard of care: Home and school feedback is highly recommended for a diagnosis of ADHD, since symptoms may be more evident in school, where there are increasing cognitive and behavioral demands on a child. A medical doctor should also look to rule out other medical conditions.

- If the above medical treatment and parent training are not working well, or other learning or psychological problems are suspected, three other evaluations are recommended: social, psychological, and educational. The assessment is performed by a licensed psychologist. Social workers and educational specialists may also assist in this. There are three ways to obtain this thorough evaluation for ADHD:

the Tools in a Tool Box?

- Insurance *may* pay for private psychological testing, as ADHD is considered a medical/emotional diagnosis. However, social/family evaluations and educational testing are not covered by insurance and must be paid for privately.
- A child having *significant* problems in school may meet state guidelines to have a school screening. The school's social, psychological, and educational testing can be used in conjunction with the medical evaluation by the doctor for diagnosis.
- Some states have state-supported developmental centers that will do this extensive testing and evaluation for families at no cost, or sliding scale. Your school systems' parent resource center, county community service board, or Parent2Parent USA (p2pusa.org) can tell you if there is a center in your area.

Treatment options

Once your child/teen is diagnosed, what is the next step? Get support, as there are many options to help you. One of the biggest mistakes parents make is that they do not take advantage of outside resources to assist them. Some of the help is free, some is covered by insurance, and some is private pay. Knowledgeable community and school professionals can help you find financial or state assistance to get services for parents and children.

The following are important resources for parent case managers to know about:

- **ADHD education, parent training, and parent coaching.** It is critical that parents educate themselves about the ramifications of ADHD for their home life, their child's social well being, and for success in school. Organizations like CHADD provide education about ADHD and services that parents need to know about. Local ADHD professionals and school programs, and parent coaching organizations can work directly with parents to increase their skills. Books, workshops, conferences, and support groups are also ways parents can increase their competency as ADHD parent case managers.
- **Medical treatment—medication.** ADHD is a neurobiological disorder and research has shown that medication is a very effective treatment. Medication can help the dopamine system in the brain function properly in such areas as attention, concentration, and emotional control. A parent's role as a case manager is critical when medication is started, as finding the correct medication can be complicated; it is individually determined, and dosages are not calibrated by weight. Medication rating

checklists are recommended to evaluate for medication effectiveness, especially in school. Medication trials can be very difficult times for parent case managers, but are important for future success. Medicating ADHD is a complicated process and is best prescribed by a pediatric psychiatrist, developmental pediatrician, or a pediatrician with in-depth knowledge of ADHD and medications.

- **Behavioral interventions, social skills training, and rehabilitation services.** Parents coordinate all services that their children or teens need, including some basic programs like:

- **Behavior management.** Behavioral issues can be a major problem for some children with ADHD. Some children are very aggressive or may be overly anxious or have poor emotional control. Parents can learn special ADHD behavioral techniques to help their children. These services tend to be provided by psychologists, social workers, therapists, and counselors.

- **Social skills training.** Some parents find it useful for their children to attend social skills training groups. Children with ADHD may not be conscious of how their behavior affects others. These groups help them learn and practice social interactions for home and school.

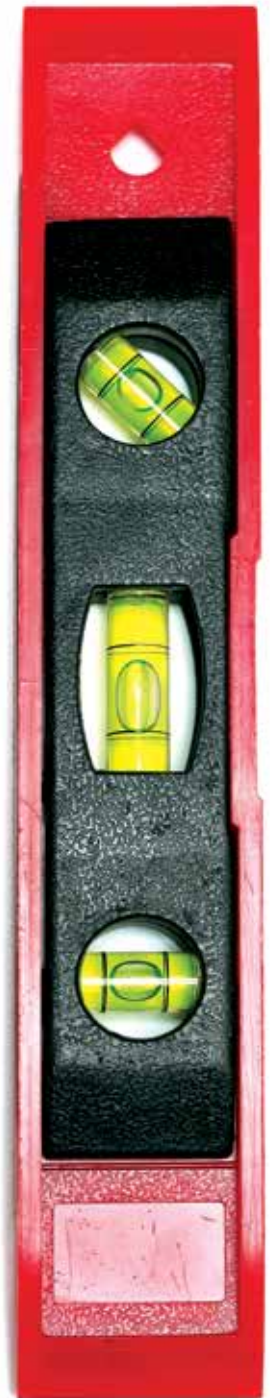
- **Rehab services.** ADHD is a neurobiological disorder and some children may have communication problems or issues with coordination or with physical activities. Referral to physical, occupational, or speech therapists may be needed. These services can be accessed in school or in the community.

The practitioners mentioned above can provide great support for parents who actively seek understanding and assistance. But the medical arena is not the only area where a parent is called upon to manage a broad range of complex decisions. School tends to be another challenging area for parent case managers. During the week, children actually spend more waking hours at school than at home. The next section offers some tips for *how to navigate* a successful experience at school.

EDUCATIONAL Case Management

by Dulce Torres, LPC-S, BCC

They noticed something at school. You are told your child is constantly fidgeting in class, talking excessively, always spacy, daydreaming, bumping into others in line, or joking too much. You begin to realize that you see





Helpful Websites

aap.org—American Academy of Pediatrics, Toolkit for Diagnosing ADHD

aamft.org—American Association for Marriage & Family Therapy, To locate a therapist

adhdcoaches.org—ADHD Coaches Organization, To locate an ADHD coach

adhdpartnership.com—ADHD Partnership, Education about ADHD and advocacy training

apa.org—American Psychological Association, To locate a psychologist

chadd.org—Children and Adults with Attention-Deficit/Hyperactivity Disorder, Information and support for people affected by ADHD

counseling.org—American Counseling Association, To locate a professional counselor

edgefoundation.org—Edge Foundation, To locate an ADHD coach

help4adhd.org—National Resource Center on ADHD, Information about ADHD

impactadhd.com—ImpactADHD, Parent coaching

khanacademy.org—Khan Academy, Tutoring

nasw.org—National Association of Social Workers, To locate a social worker

nichcy.org—National Dissemination Center for Children with Disabilities, Information and resources on children with disabilities, RtI, etc.

p2pusa.org—Parent to Parent USA, Emotional and informational support for families of children who have special needs

schoolcounselor.org—American School Counselor Association, Information and resources

wrightslaw.com—WrightsLaw, Information about special education law, education law, and advocacy for children with disabilities

some of these behaviors at home as well. At some moment you understand that something is different. You guide your child through the diagnostic process, and now you know you're dealing with ADHD. Now, it's time to focus on school, where the challenges are getting on the way of your child's education.

How can you help your child be successful in school?

- Start by creating a binder for all communication between school and home. Train yourself to write things down. Logs, calendars, and journals are simple tools that can help you get started. Keep copies of all letters, reports, consents forms and any other documentation, including some examples of your child's work.
- Ask your child's teacher for assistance. Find out what interventions have already been put in place, and how are they keeping track of the progress.
- Learn more about advocating for your child through Parent to Parent, Teacher to Teacher, or ADHDPartnership.com.
- Become familiar with the Response to Intervention (RtI) process, and find out when it starts. RtI is a multi-tiered service delivery model used when academic and behavioral concerns are first identified. Federal mandate requires that schools put this proactive model of instruction into place, allowing all students to receive effective instructional and behavioral interventions in the general education setting. (Refer to your state education agency for more details).

Getting the support your child needs at school (i.e., your rights)

- **Option 1.** If the Response to Intervention (RtI) in place is working, it may be all you need and there is no need to proceed with more complicated interventions.
- **Option 2.** If the RtI is not working—if progress is minimal or none, and the behaviors or the academics have not improved—then it's time to step things up a notch. The student needs more specific accommodations. In writing, parents request a meeting with the school to set up a 504 meeting (all requests need to be made in writing and signed by the parents and the school).
- **Option 3.** Section 504 is a civil rights law that prohibits discrimination against individuals with disabilities. Yes, ADHD is actually a disability. Section 504 ensures that the child with a disability has equal access to an

education. The child may receive accommodations and modifications; learn more at wrightslaw.com.

- **Option 4.** The Individuals with Disability Act (IDEA) states that all children have the right to receive a Free and Appropriate Public Education (FAPE). Students whose challenges continue to be a struggle may demonstrate that the disability adversely affects their educational performance. They can be evaluated by the school to determine eligibility for IDEA, indicating the need for special education in order to receive an appropriate education. If this is determined, the student will be provided with an Individualized Educational Plan (IEP).
- **Option 5.** A Functional Behavioral Assessment (FBA) is a strategy used to define a problem behavior, devise a plan to collect data, compare and analyze the data, formulate the hypothesis, develop and implement a behavior intervention plan and monitor the plan.
- **Option 6.** A Behavior Intervention Plan (BIP) is a set of strategies to teach a student more acceptable ways to get what they want by decreasing the number of occurrences of the misbehavior, increasing the expected behavior and addressing any repeated episodes of the misbehaviors. Students respond best to BIPs that use positive methods to encourage and teach appropriate behaviors.

The Cost of Diagnosing and Supporting ADHD



ADHD IS A MEDICAL DISABILITY, and as with any medical condition, it has its costs. There are channels to get help, though. Scholarships are available for parent training and support, many practitioners offer a sliding scale, and a vast array of services are offered through the school system (in the United States).

Insurance will pay for some medical costs associated with getting a medical diagnosis and treatment, such as medical doctor/specialist visits or medication, but this varies depending on the insurance plan. Testing by psychologists or other nonphysicians and counseling are

Gifted children

While there is still limited research in this arena, some literature shows that gifted children with ADHD are better served when strategies are used to develop their talents. In other words, students do well when attention is placed on what they are good at—their strengths—rather than on remediation of their deficits. In addition, not all ADHD interventions are appropriate for gifted children. For example, shortening work time and simplifying tasks might actually increase frustration when it's employed in an area of strength for the student.

To develop better strategies, it is important to work with people who are very knowledgeable about ADHD and gifted children, so that they can collaborate with the other professionals to create a plan. When a teacher understands how ADHD affects the child, and which executive functions are getting in his/her way, that teacher is better suited to set a plan (with data) that the child will benefit from, following the same principles of the FBA.

Advocacy

It is the parents' responsibility to understand ADHD and their child's rights, and begin to teach their children about how to advocate for themselves from the earliest age possible. The ultimate goal of advocating for our children is to enroll them in taking ownership of their own education.

Who can help?

- In the schools—administrators, teachers, nurses, school counselors, psychologists, behavioral specialists, paraprofessionals, occupational therapists, speech language pathologists, special education teachers and coordinators, school case managers, tutors and any other school personnel you identify as a potential or key player of your child's team (such as a librarian, cafeteria staff).
- In the community—educational advocates, mental health providers such as psychiatrists and psychologists, counselors, social workers, therapists, nurse practitioners, physician assistants, coaches who specialize in ADHD, support groups (such as CHADD), parent coaching programs (such as Impact ADHD), and training programs such as Parent to Parent and Teacher to Teacher.

When advocating for your child, define the problem (academic and/or behavioral). Systematically collect data, compare, analyze, and develop a plan. Then, monitor the plan. Create a multidisciplinary treatment team and insure everyone on your team knows and understands your child's ADHD. Educate yourself and the school. Don't hesitate to ask for help when needed.



insurance-specific, though many do get coverage for these services. Educational testing is not covered by insurance. Parents frequently seek psychological, educational, and social testing in the school, which is free if the child is eligible. County or state testing and training programs are available in some states. Services of a tutor or a coach, or enrollment in parent training programs, are generally private pay, though there are many avenues for scholarships and discounts, and a great deal of support is available online for free at khanacademy.org (tutoring); impactadhd.com (parent coaching); chadd.org (parent support).

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SOCIAL-EMOTIONAL Case Management

by Elaine Taylor-Klaus, CPCC, ACC

As with education and medical care, parents must understand the common social and emotional challenges that children with ADHD tend to face. Then, we must have a sense of who might be available to help us help our kids!

On the surface, understanding the social-emotional dynamics around managing ADHD may seem vague, as the needs may not appear concrete and specific. And yet, according to Russell Barkley, PhD, emotional management is a critical skill for employment success in adulthood. When adults with ADHD run into challenges in the workplace, it tends to be caused by poor emotional management, rather than problems with work performance.

Here's the good news: Emotional self-management is something parents can teach children. So, in our role as parent case manager, we must understand and learn to manage social and emotional development.

What social-emotional issues are most important?

- **ADHD impacts all relationships.** There's no aspect of our children's lives that is not impacted by ADHD. Whether they're struggling with how to relate to friends, grandparents, teachers, siblings, or even you, their parent—it's up to you to understand how the ADHD shows up for your child, and where it's impacting relationships as specifically as possible.
Strategy: Educate yourself and family members about ADHD.

- **It's hard to make friends.** Kids with ADHD don't necessarily and naturally know how to make friends. In fact, they actually need to be taught how. It can be awkward to get to know someone, especially when it looks like everyone else does it so easily. You need to understand how the ADHD is impacting the development of friendships so that you can guide your child to success. For example, your child might need some "pick-up lines" or role-play practice to provide key skills for social situations.

Also, it's important to understand that your children may be quite fine with just a few friends, and they may happy to have friends of dif-

ferent ages. Sometimes, strong relational connections may start with animals, not people. It's okay. Foster good relationships wherever they are possible and healthy.

Strategy: Start by inviting a friend over for a short period of time.

- **Keeping friends.** The care and feeding of relationships is another skill that children must learn. There is, after all, an art to maintaining friends, and it requires initiation, effort and memory—not exactly easy tasks for our kids. For example, a child might need to learn how to express interest in her friends, or how to follow up when she knows things are happening in her friend's life.

Strategy: Model by telling your child when you do something to maintain a friendship.

- **Build self-esteem and confidence.** Our kids are constantly getting re-directed, and they tend to feel "wrong" a lot! This can rob them of their confidence and lower their self-esteem. It's critical for you to counter that cycle and help them see all the things they do well, however small they might be. If you believe in your kids, they will begin to believe in themselves. If they feel like you don't, chances are they won't, either.
Strategy: Acknowledge even the smallest successes, repeatedly.

- **Create a team environment at home.** Sibling squabbles are quite common with annoying or constantly chattering brothers or sisters who have ADHD. But siblings are the longest relationships your kids will have in their lives, and it's critically important to create a team environment in your family. You'll want to help your children learn to cheer each other on, instead of competing with each other—or worse, dismissing each other.

Strategy: Play games as a family that teach cooperation and encourage following the rules without drama (use humor).

- **Teach emotional management.** The healthy and appropriate expression of emotion is fundamental to relationship success. Our kids need to learn to manage frustration, communicate clearly, and regulate their highs and lows. This often starts with setting a tone in the home that is calm and supportive, providing structures that reinforce positive communication.

Glossary of Support Professionals

PEDIATRICIAN—Medical doctor who specializes in the care of children and teens.

CHILD NEUROLOGIST—Medical doctor who can diagnose ADHD and neurological disorders that may exist concurrently.

PEDIATRIC PSYCHIATRIST—Medical doctor who diagnoses and treats ADHD and other mental and emotional disorders in children and teens.

PSYCHOLOGIST—Licensed professional who administers psychological testing, and does counseling with parents and children and teens.

NEUROPSYCHOLOGIST—Performs psychological testing and specializes in brain functioning and its effects on thinking, reasoning, and learning.

BEHAVIORAL SPECIALIST—Helps parents and children or teens learn how to deal with behavioral problems that arise at home and at school.

PHYSICAL THERAPIST—Helps clients with coordination and mobility issues.

OCCUPATIONAL THERAPIST—Works to improve skills and activities of daily living to increase performance and participation.

SPEECH THERAPIST—Diagnoses and treats communication disorders.

PARENT COACH—Helps parents set goals and take action, set clear expectations, and manage behavior, improve communication, and instill confidence.

CLINICAL SOCIAL WORKER—Helps parents and children or teens identify areas of need, evaluates mental health issues, and finds supportive services for families.

PROFESSIONAL COUNSELOR—Works with families on strategies to overcome the obstacles and challenges they face.

SOCIAL SKILLS TEACHER—Works directly with children or teens to teach communication and life skills.

Strategy: Make staying calm your number-one priority.

● **Model attention to relationships.** Parents are constantly modeling relationship dynamics. Work on your marriage, your relationships with teachers, even with friends and neighbors. Try to get on the same page with your spouse.

Strategy: Give your loved ones the benefit of the doubt, and try to focus on the positive, not the disappointments.

So, who are the players to help parents create a team to support their child? As we've mentioned, dozens of specialists are available to help us help our children. In the social and emotional realm, we can find particular support from psychologists, therapists and counselors, social workers, school counselors, social skills teachers, parenting coaches, and sometimes coaches for our kids.

Next steps?

In the first two parts of this series, you've learned what's involved with becoming a parent case manager, and you have an understanding of the topics that need to be addressed. What's left to get you started? You need a plan.

In the last of the three-part series, we'll address the five steps you can take to actively become your child's case manager. 🗣️

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Maureen Gill, MSW, is a licensed social worker and parent of two adults with ADHD. She gives local and national parent workshops and is a CHADD Teacher To Teacher trainer. Her latest endeavor is coaching parents of children with ADHD (ADHDcoachingforparents.com).

Elaine Taylor-Klaus, CPCC, ACC, is the cofounder of *ImpactADHD*, a training and coaching support resource for parents of children with ADHD. The mother of three children with complex needs, she is a certified coach and public speaker who writes regularly for ImpactADHD.com and other publications.

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