

**Parents as
Case Managers:
A Roadmap for
ADHD Management
PART ONE**

**The
Parent's
Role**
Makes a
Difference

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.

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While parents are ultimately the CEOs of their families, they play dozens of roles in their children’s lives—cook, driver, nurse, referee, tour guide, teacher, counselor, buyer, and many others.

The parent-manager roles of **MEDICAL GUIDE**, **EDUCATIONAL ADVISOR** and **SOCIAL DEVELOPER** are particularly important in the lives of children with ADHD.

Many parents have their first child with no special training, with the exception of observing the style of their own parents. As a result, many new parents leave the hospital wondering how they could be allowed to take this defenseless baby home. Isn’t that dangerous?

After a month, when the baby is still healthy and alive, parents tend to sigh in relief. But the truth is that infancy is only a precursor to the expanded roles parents play when their children start interacting with the world more independently. Once a child is ready for preschool or elementary school, the whole playing field changes!

Throughout infancy, your child’s world is generally limited to your immediate family, doctor, friends, child-care providers and neighbors. Once your child is preschool age, a network of community programs, schools, sport coaches, dance teachers, and many others begin to interact with your child.

If your child has ADHD—even if it’s not diagnosed at this early stage—the intensity of your involvement with others can be more frequent, and less positive, than expected. For example, you may begin hearing from preschool staff that your child does not sit at circle time, doesn’t listen, or is annoying to other children (message to self: “bad parent”). Or, perhaps you’re hearing that a staff member has to be with your child continuously (message to self: “bad child”).

You are asked to stop these challenging behaviors. But, truth be told, you do not know how.

Parenting responses to such challenges in preschool are all across the board. Some parents will search for the help they need, tirelessly seeking guidance and support; others will throw up their hands and give up; and still others will turn to the schools to solve their problems for them.

The most successful role for parents of children with ADHD—both for the children and the parents—is to

see themselves as a “case manager” for their child in three critical areas of medical health, education, and social development.

What is a case manager?

According to the Case Management Society of America, a case manager is a person involved in the “collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s . . . needs.” In other words, a case manager coordinates services and ongoing support for someone with complex needs.

Professional case managers are trained and have on-the-job supervision. Their job requires that they be knowledgeable in their field, do research and assessments, understand the personalities of the people involved, offer options and recommend solutions. Generally, they aid with decisionmaking, find financial funding, and monitor and coordinate the details of a treatment or wellness plan.

As case managers for children with ADHD, parents do not have the benefit of training or supervision. They must design their own “instructional course” to:

- educate themselves about ADHD and executive functioning difficulties
- develop an in-depth understanding of school, health and social issues, and
- do research to find the people and resources that can help them.

While this can be a difficult role for parents, it is very effective and rewarding. With attention to all aspects of a child’s social, emotional, physical and educational development, a parent can take a comprehensive approach to managing the child’s ADHD. The long-term benefits support entire families, enabling success in elementary, secondary, college years and beyond.

In particular, children learn to develop healthy relationships, manage their health care, fulfill work and educational obligations, and become independent and successful. As an added benefit, they have an increased opportunity to grow into happy and fulfilled adults—which is, ultimately, what we want most for our kids.

Inherent challenges

While case management is an apt description for the role parents must play to effectively manage their children’s health, education, and social development, it is fraught with potential complications.

First, a case manager's effectiveness is improved by a certain amount of distance. That's not really possible for a parent, and even if it were, it's not preferable. A parent is the only person in the world whose "job" is to be totally invested in the success of a child. Professional distance is not exactly part of the plan.

Second, objectivity is also not generally part of a parent's job description. Investment is key to parenting. Sometimes that makes it difficult for parents to get a complete or unbiased picture of what is happening with their child. While a case manager looks objectively at the big picture, a parent might not be able to see the child's needs—or potential solutions—as clearly.

Third, clear acceptance of the challenges at hand is necessary for case managers, but can be a challenge for many parents. Denial is powerful and a common experience for parents. It's only natural—we don't want to see problems for our children, and we want to protect them whenever we can. But the best of case managers

aggressively fight for the rights of their clients. They are matter-of-fact about the challenges they are supporting, and this can be a difficult stance for parents to take.

Finally, case managers must be experts in their field. By contrast, parents are called upon to make complex medical, educational, and developmental decisions with insufficient training and information. Especially early on in the diagnostic process, parents are not likely to know the difference between:

- an IEP or a 504
- an accommodation or a modification, or
- special education or a gifted classroom.

Parents are often not well informed about the intricacies or range of support needed, and yet must serve as advocates, nonetheless.

Opportunities for parents

On the other hand, parents have opportunities available to aid them in the role of case manager that a professional case manager does not.

First, parents ARE invested. As such, they can be tenacious and relentless. We have seen parents become experts, advocate skillfully, testify, and argue. Some parents will go to great lengths to advocate for their child, and that investment fuels them in a way that is unlikely for any other advocate. Nothing motivates better than self-interest, particularly if it's the interest of a "mother bear" for her "cub."

Second, no one knows a child better than a parent who has been paying attention. Parents understand intuitively, deeply, what their children need. Sometimes they can't express it, but they UNDERSTAND it—and that knowledge is powerful. When parents begin to match their understanding of their child's needs with an awareness of the services and supports available, the possibilities for their children expand exponentially.

Finally, parents have their children's trust. To the extent that the case manager needs a child to trust her in order to advocate for her, the parent has a major head start in that department. At the end of the day, the goal is to help our children become independent, successful adults. We cannot do that for them. But we can empower them, teach them, inspire them and encourage them to do it for themselves. Children look to their parents for guidance and support, and want nothing more than to know that their parents believe in them.

What I love about being a case manager

Maureen:

Being a case manager taught me the skills I needed to help my child succeed. As a parent of a school-aged child with ADHD, it was like being in the middle of a riptide current. In a riptide, you experience the hopelessness of not being able to handle the currents coming at you, and you know that you may drown. The number-one rule is to stay calm and keep a clear head. Thrashing around and fighting against the currents makes things worse, and is exhausting. You can learn the techniques to reach smoother water, such as swimming parallel to the shore, by calling for help from people with expertise. This is similar for parents as case managers. As you learn what resources are available to guide you, you can learn the special ways that help your child survive in a turbulent world.

Dulce:

As a parent of a young adult with ADHD and three foster boys, being a mental health provider was my biggest challenge. There was an expectation from other professionals that I would be a "good" parent (because "she knows better") and that I knew how to manage their needs. In reality, as a parent, my emotions ran high—very high. I wanted my kids to get what they needed, but I was very intimidated with all those professional colleagues. Trust in myself and believing my children deserve the best is what gave me the courage to educate myself about the needs of my family, the needs of my foster children, and my own biological son. Getting to know my children, trusting them (as they knew what would work for them), and finding support were my greatest tools to become the best case manager/advocate for them.

Elaine:

Thinking of myself as my daughter's case manager can be empowering. When she was younger, before I understood all the complexities involved with ADHD and other co-occurring conditions, I had a lot of doubt about whether I was doing the "right" thing. Once I understood that my role was to be the case manager—that I was really the ONLY one looking at the big picture—my confidence improved. I realized that I needed to learn to trust myself and stop looking to every other professional out there to "fix" the situation or tell me what to do. I knew my child better than anyone, and once I really came to accept that, everything changed. I still get a lot of support from other professionals and parents, but my sense of myself is stronger.

Getting Started as a Parent Case Manager

The following resources can help you in your training to be a knowledgeable case manager.

CHADD. International nonprofit organization for children and adults with ADHD. www.chadd.org.

- 2013 Annual International Conference on ADHD, “Meeting the ADHD Challenge,” November 7-9, 2013, Alexandria, VA. Regional conferences held throughout the year.
- Parent-To-Parent Training—Multi-session family training program provides education and resources for managing children with ADHD. Classes in local communities, online, and on-demand.
- Local CHADD chapters—provide parental support and on-going speaker series.

National Resource Center on ADHD. Federally funded program that provides relevant and up-to-date information on ADHD. (800-233-4050) www.help4adhd.org

National Parental Information and Resource Centers (PIRC).

Funded by the US Department of Education, PIRC provides resource material and educational programs for parents, and links them with schools and local professionals. www.nationalpirc.org

Parent 2 Parent Organization. A nonprofit organization providing information and emotional support to families of children with special needs. Also matches parents with other “experienced parents.” www.P2PUSA.org

Impact ADHD. Founded by mothers who are ADHD coaches, supports families with training and coaching for parents to learn skills and strategies to improve life with ADD/ADHD. All services online and on the phone. www.ImpactADHD.com. (888-535-6507).

When parents can offer that guidance, that belief, and use it to shape and inspire their children to take responsibility for their growth and development—it’s a win-win for everyone involved.

Parents as case managers: Next steps

In this first of the three-part series, we’ve set the stage for understanding the role of the parent as case manager. Despite its inherent challenges, the benefits to families, and ultimately to children, is clear. When parents take a comprehensive approach to managing their child’s ADHD, families thrive.

So what are the steps to becoming an effective case manager?

The foundation is strong education. In the next article, we will focus on the three areas where parents would benefit from becoming well educated and informed in order to manage the complex issues surrounding their child’s ADHD. We will go into detail in each of these three areas: Medical, Educational and Social Development.

Finally, in the last of the three-part series, we’ll address the five steps parents can take to actively become their children’s case managers. 🗨️

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Maureen Gill 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, Elaine is a certified coach and public speaker. She writes regularly for ImpactADHD.com and other publications, is the author of the eBook, *ADHD in Reality: Tips FOR Parents FROM Parents*, and coauthor of *365 Ways to Succeed with ADHD*.

Glossary of Terms

EARLY INTERVENTION—process of assessment and therapy provided for children to prevent or manage developmental disability or delay and facilitate normal cognitive and emotional development.

EXECUTIVE FUNCTIONING—the brain’s ability to handle everyday functions related to learning and behavior, such as, memory, activation, emotions, problem solving, and impulsivity.

SOCIAL SKILLS—personal skills related to social and emotional development that are needed for successful communication and human interaction.

CASE MANAGER—someone who coordinates services for an individual with complex needs requiring help in multiple areas of life.

ADVOCATE—someone who represents or works with a person needing support and encouragement to exercise his/her rights.

EDUCATIONAL ADVOCATE—professional who works with an individual student and family, in coordination with school staff, to assure the student gets necessary services in school and is able to reach full potential.

PARENT TRAINING—short-term sessions, in person or online, with an ADHD specialist who educates parents about ADHD specifics, effective behavioral strategies, medical treatment options, and practical advice about school issues.

PARENT COACHING—private or group sessions for parents, in person, on the phone or via email, that focus on guiding parents to effectively foster independence and teach their children critical life and coping skills.

STUDENT COACHING—private sessions for students that focus on understanding the impact of ADHD on the student’s life and developing strategies for management and mastery.