



The **EXCEPTIONAL**

of Raising Exceptional Children

by Oren W. Mason, MD

THE SIXTH-GRADE TEACHER looked Andrew's mom, Marilyn, squarely in the eye. "Andrew doesn't need an IEP," she said derisively. "He needs someone to *discipline* him to do his homework!"

Five-year-old Kara started screaming in the cereal aisle of the grocery store when her mom, Lisa, asked her to put the sugary cereal back on the shelf. Minutes later, Lisa abandoned the cart and carried the inconsolable Kara out of the store, followed by icy stares. "Child abuser!" muttered one shopper, loud enough for Lisa and other shoppers to hear.

Jerry stopped at his mother's house on the way to work to drop off his twelve-year-old son, Jason. He gave her a copy of the behavioral chart they were using at home and asked her to maintain the standards and rewards that Jason was beginning to respond to. "Oh, he won't need that here," she announced. "He's always just fine when he's with his grandparents."

Marilyn, Lisa, and Jerry each felt crushed to the soul. Each of them spent the evening rehashing events with their partners, wondering what they were doing wrong, why their parenting didn't seem to help, and what more they could do. Each of them is a diligent, intentional, loving parent

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who reads books, consults specialists and therapists. Each would walk barefoot on hot coals if that would make life better for their children.

So why do the people around them blame them for their children's difficulties? When a child is struggling, why is the first reflex of bystanders to blame the parents?

The guilt of normal parenting

Parenting is crazy difficult. It is the single most difficult task I've ever undertaken. I've been through medical school, started businesses, and run marathons. Those don't even come close to the effort required to parent children. Fact is, training for a marathon makes a nice rest and recovery break from parenting. That's how hard parenting is.

Raising one "normal" child from cradle to independence is heroic, and the fact that it's already been done billions of times doesn't make it less so. The sheer number of meals cooked, supplies acquired, instructions given, miles driven, dollars spent, and comforts foregone over twenty-one-or-so years is staggering, and that's not even the hard part.

Helping our children become their best is radically hard, and there are many failure points. We know they need encouragement, but harsh words slip out. We try to teach them honesty, but they overhear our white lies. We push too hard or not hard enough. We set high goals, but are too tired at the end of the day to follow through.

Guilt is the wish to have been a better person in the past. It is natural and necessary when imperfect people take on difficult tasks. Parent guilt, at its simplest, is the wish to have been a better parent, and all good parents experience it.





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“Make no judgments where you have no compassion.”

—Anne McCaffrey

Parenting children with special needs

Raising children with ADHD, bipolar disorder, learning disorders, PTSD, autism spectrum disorders, anxiety, depression, and (most commonly) combinations of these disorders is yet another order of magnitude more difficult. Parents often find themselves without guidance, navigating a complicated mental health network that almost seems to hide its assets while they search by expensive trial-and-error for the right people who “get it” and whose therapies actually make needed differences.

Academic and behavioral support for such children is complex and tiring. Disappointingly, some parents find themselves in battles with the very system that is supposed to support their extra needs. In the end, there is still less to “show off” or brag about for all the effort. Children with ADHD and other special needs have worse academic records, more need for “special services,” less sports participation, fewer honors, and more disciplinary issues than other students.

Their moms, as a result, are less likely to work outside the home. Their dads are less likely to be promoted. Their parents take fewer vacations, suffer more anxiety and depression, and are less likely to report satisfaction with the parenting they provide and with their family’s life together.

Mom guilt

The cost of accepting impossibly complex goals for children is the guilt of inevitably failed expectations. This is a cost that disproportionately falls on women who (a) usually provide the larger share of nurture and (b) have bigger guilt glands than men.

Accepting a challenge and rising to an occasion are respected in our culture. So do these especially hard-working moms experience community and family respect for accepting the extra challenge? If you ask such a mom this question, the nearly universal answer is incredulity, a pained expression, and maybe a tear.

Moms of the kids who are more demanding to raise are not feeling challenged, and they are not feeling respected. They are feeling misunderstood, underappreciated, and extraordinarily guilty. How is it that the remarkably diligent moms of children with special needs are saddled with guilt, not accolades, for their unending hard work?

It begins with the inner doubts and uncertainties that accompany every learn-while-doing adventure. And it is seared by outsiders’ critiques, their uncaring words and judgmental stares. Moms whose kids have meltdowns in the cereal aisle suffer the criticism of everyone who happens by and presumes to do a better job.

Moms have to do a fair amount of parenting in public places, and judging each other’s efforts is something of a national pastime. It’s similar to the Winter Olympics, where people who can’t even skate somehow feel free to mercilessly criticize a figure skater’s routine.

Actually, it’s nothing like the Olympics for two important reasons: First, parenting is much harder than competing in the Olympics. Second, the Olympics really don’t matter. They have little to do with How and Why Humans Exist, but parenting *is*, in fact, How Humans Exist. In the long history of human existence, parenting actually matters. No one wants to be so incompetent as a parent that they raise the next serial killer or reality TV star.

So when spectators watch a child melting down in the cereal aisle, they might be witnessing an incompetent parent issue and the mom might give in to the child to end the meltdown. But Lisa is, in fact, a great mom whose child has a low melting point. She happens to have done everything with love that a mother could, and Kara still screams.

How would strangers tell the difference between an incompetent mom with a ruined kid and a gifted mom with a challenged kid? Simple. They could spend day after day beside her, helping her, doing what she does

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Solutions for Guilt-laden Parents

Sometimes we need a better plan that will give our children a better shot at success. Sometimes there isn't a better plan, and we need to continue on with a plan that feels imperfect, that doesn't seem like it's working now, but will have long-term effects. More than anything else, parents of children with special needs need validation and encouragement.

Support Groups. Many communities have CHADD parent groups or other support groups where parents whose children have similar needs can network and support each other.

Other Parents. A cup of coffee with another parent who "gets it" can be powerful encouragement. Take a chance and strike up a conversation with the parents of other children at school or on the soccer sidelines.

Therapists. Counseling for parents in many cases provides more benefit to children than counseling with children directly. Finding the right therapist may involve some search, but finding one who "gets it" is worth the effort.

Parent Training. While any instruction in parenting is helpful, parents of children with ADHD face some unique needs. Parent-to-Parent is a training program developed by parents who "get it" in conjunction with renowned experts. It is succinct and effective.

Books. Any good parenting advice is helpful, but the empathy of an author who "gets it" can have a healing effect. *AD/HD Book* by Beth Ann Hill and *Late, Lost and Unprepared* by Joyce Cooper-Kahn and Laurie Dietzel are two books among many excellent choices. They are written with plenty of expertise, but importantly from the perspective of parents who have lived the journey and speak with compassion.

24/7. If the child has fewer meltdowns under their care, they could volunteer to be the nanny for her. Alternatively, they could keep their judgments to themselves. The world needs fewer critics and more leaders.

Well, at least that's the ideal. The reality, though, is that all manner of people are willing to pass judgment on a screaming child's mom, often within her earshot. Most don't actually speak the words, but there is definitely a glance that says: "Take your child outside," or "Soothe her better," or "Get a therapist and work on your need for control."

Viewed from afar, we know how wrong others are to criticize, and that ignorance deserves to be ignored. But a mom doesn't enjoy the luxury of perspective in the tear-filled cereal aisle. She has literally no time to devise a plan. She can't leave her child there while she sips tea, reflects, and calls her lifeline to chat about her options.

And there may be no good option to select. Give in to the child to quiet her? Scream louder trying to scare her child into quietness? Critics hit her when she is down, by all appearances failing, when it's almost plausible that she doesn't love her child enough.

Dad guilt

Have you ever been to an ADHD father's support group? Me neither. I've offered to start one on several occasions, but couldn't find enough takers. This is not surprising, because men, somewhere around puberty, stop needing support and become perpetually "fine." We don't need directions and we don't need help. All of us guys, all the time, are uniformly "fine."

I've been running with the same four guys every Saturday for over fifteen years, and all of them are always "fine." This is easy to remember, because each week my wife asks me how the guys are. She knows their wives and children and wants an update. Mystifyingly, she expects us to talk about each other's issues. These runs last two or three hours, which barely gives us enough time to catch up on the latest sporting events and to argue way too much politics. There's not really enough time to get into how we're feeling. So I tell her they're all fine. Every Saturday, they all show up at 7 AM, run long miles, and no one hallucinates. See? Fine!

The day of this writing, the only two guys who could run were me and my longtime best friend, Pete. Pete has seven children, several of whom are adopted and have special needs, and he is a remarkable father. One of the best I've ever seen. Sometimes he and I run together on weekdays, too, and, because he's the kind of guy who asks thoughtful questions. We do talk about parenting and feelings and how we're really doing.

Parent to Parent

Pete, to be honest, is not fine. Two years ago, his twenty-year-old son with ADHD died of an accidental drug overdose. The anniversary of that day is next week. I asked him if he had any thoughts on “dad guilt” when we were at the three-mile point of our run. Turned out he had several miles of thoughts.

The very first thing he said was, “I will never again believe someone who says, ‘I have no regrets.’ I’ve spent every day of the last two years figuring how I’m going to live now with thousands of regrets.”

Dad guilt, it turns out, runs very, very deep. Not talking about it or even acknowledging it doesn’t mean it’s not there. “I’m fine” more often than not means, “I can’t go there.”

A final thought

You probably didn’t read this far because you are neurotic or bored, but because you love your child and wish to do that well. You may have been criticized when you most needed support. You have probably been blamed for your child’s struggles.

Guilt feelings are all but guaranteed whenever parents appear to fail—however temporarily—their parental vows to protect and comfort their children always. Love cannot be perfected, and to fall short of our high hopes is poignant, not wrong. But the critics don’t love our child. Their evil is not that their criticism causes our guilt—but that it throws acid on it.

May you find a few people who “get it.”

*A family physician specializing exclusively in the diagnosis and treatment of children and adults with attention disorders, **Oren W. Mason, MD**, is an assistant professor at Michigan State University College of Human Medicine. He speaks about ADHD internationally to professional and lay audiences and is the author of the patient guidebook, *Reaching for a New Potential: A Life Guide for Adults With ADD From a Fellow Traveler*. Dr. Mason and his wife, who is also a family physician, are the parents of sons born in 1992 and 1995. In 2001, the Masons expanded their family to include five teenagers orphaned by the civil war in Sudan. The original version of this article appeared on Dr. Mason’s blog, *Attentionality*, attentionality.wordpress.com.*



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