

# Love That Max

A blog about kids with special needs (and the parents who adore them)

**Tuesday, August 3, 2010**

[A Q&A with the authors of "Shut Up About Your Perfect Kid"—plus a giveaway](#)



I recently had the chance to ask a few q's and get a few a's from the two sisters who wrote [Shut Up About Your Perfect Kid: A Survival Guide for Ordinary Parents of Special Children](#) (originally published in 2007, an updated version is coming out today). Gina Gallagher is mom to Katie, a 15-year-old with Asperberger's syndrome; Patricia Konjoian is mom to Jennifer, a 17-year-old with bipolar disorder. It's not often you call a book about raising kids with special needs funny, but it so is. It's also very informational, helpful to moms of kids of all ages but particularly those with older kids. Here's what the ladies—[who also have a blog](#)—have to say:

*What I most adored about your book, besides the info and inspiration, was your sense of humor. I laughed out loud a bunch of times, like when you compared bragging parents' bumper stickers to ones you'd like to see—particularly:*

*Theirs: My honor student loves me*

*Ours: My bipolar kids loves me and hates me.*

*Here's my question: It's not always easy to keep your sense of humor about this stuff. What helps you?*

For many parents, the process of accepting their child's disability is a mourning process. We have to mourn the loss of the "perfect" child and let go of our expectations. We had to get through that process to be able to laugh. Now that we've been through this and time has passed, we are able to see the humor in raising an imperfect child in a perfection-crazed world.

*I liked the resourceful mom in your book who had a business card made that her child with autism hands out that says, "Ask me about my autism. (I'm nonverbal, so I may not answer.)" What other tactics have you found to be effective for helping people engage with kids who have special needs?*

One of the most valuable things we've learned is not to ignore children or people with disabilities. We were brought up not to stare at others with differences. We never realized that by doing so, we were making them feel ashamed. Now we try to engage kids with differences. It could be a smile or a brief conversation.

*In your "Tips for Success At Home," you mention that developing a structured, predictable daily schedule is important for making kids with disabilities feel comfortable at home, and not to plan any change in the schedule without allowing at least one full week for preparation. OK, here's the thing: I don't love routines. What can parents like me do to walk that line between what's realistic for their lives, and what's best for their kids?*

We'll be honest, structure isn't easy for either one of us. We fly by the seat of our pants. Of course, being self-employed with freelance businesses hasn't helped make that any easier. We never know when work will come. What we have learned to do for our anxious children is try to give them advance warning about events and also to recognize that transitions are very hard for them. For example, before Gina's younger daughter, Emily, started camp, Gina took her to the camp location so that she would know what to expect. Of course, there are certain events (such as taking Emily to the dentist) when it's best to spring it on them at the last minute. It will cut down on their screams.

*The book mentions that the grieving process for families of disabled children can last just as long as the grieving process for families with children who have died. Can you each share a little about what most helped you move past the grief?*

Gina: I think there were several things that helped. First of all, I hit rock bottom the day my daughter's teacher sent home a dark essay my daughter had written. I didn't realize the depths of my daughter's struggles until that point. I tried talking with friends and family members, but I think they were too closely involved to be able to help me. They were in pain too. I was fortunate to have a wonderful, older neighbor (a former counselor, teacher, and nurse) who was able to help me. She was what she called "a safe person." She didn't judge me or have any hidden agenda. Her goal was to get me talking and to help me arrive at my own decisions on what I needed to do. I was so overwhelmed with grief that I couldn't see straight. My friend helped me break things down into manageable parts. Once I did that, I was able to take back control and help my daughter. Once I started taking action, my tears subsided. That helped me deal with the grief, but what got me to see my child differently was speaking with positive parents of kids with disabilities. They shared success stories and helped me see the gifts my daughter has. They told me what books to read and what speakers to hear. Suddenly, I was looking at my daughter in a completely different way.

Patty: My experience was very different than Gina's. When Jennifer first began exhibiting severe

mood swings, I feared that maybe she had experienced some trauma that I wasn't aware of. Once we ruled that out as well as exhausted every diagnostic test, I knew it was a mental health issue. Know that depression runs on my side of the family, I was very concerned. It wasn't until three years after Jenn of bouts of severe irritability and sadness that we received an official diagnosis. As Jenn was being discharged from her second hospitalization, the psychiatrist told my husband and me that Jennifer was indeed bipolar. Even though we knew for three years that this was most likely to be the diagnosis, it was, nevertheless, very difficult to hear and I felt very sad. But as we left the office, I continued business as usual: trying to keep Jenn calm and to keep all three kids safe. I knew that if I became unglued, so would the rest of my family. It was critical for me to conduct our lives as if we were just like everybody else. So with two hospitalizations, various medications, therapist and psychiatrist appointments, I went about my business and never cried.

A couple of months later just as Jenn was about to begin middle school, my husband and I met with the school adjustment counselor. It was during our meeting when she said, "Your daughter has a severe disability." *Severe disability?* Throughout everything we had been through with Jennifer, I never once thought of her as disabled. Nonetheless, I found myself feeling terribly sad once again. The real gravity of the situation hit a few months after Jenn was released from the hospital. I was sitting alone in my living room watching home movies while everyone else was sleeping. As I watched the images of my little girl running and smiling and acting like any other kid, I began sobbing. "Was she bipolar then? How could I not know? I am her mother."

As sad as I was, I knew that I needed that moment of realization. And still I knew that we would go about trying to live our lives as normally as possible. I believe that God gives everyone a unique gift. Fortunately my gift from God was a wacky sense of humor. I knew that my sense of humor would continue to sustain me for whatever life had to throw my way. It was during a meeting with my therapist when I announced I was going to write a humor book about bipolar disorder. Her response was, "I know you will." And the rest is history.

*As you well know, dealing with other parents' responses can be tough. I liked your response to moms who say "I just don't know how you do it"—"You mean I could choose not to do it?" What do you do when moms act all sorry about your kid, like he's a tragedy or something?*

Gina: I actually don't get offended any more. I almost feel sorry for them that they aren't able to go beyond a child's differences to see what gifts they offer. Our children are such honest and compassionate kids. Their hearts are pure.

Patty: I am not offended either. Rather than focus on our kids weaknesses, I prefer to talk about their strengths, that way you educate as well as help to reduce stigma.

*What is your #1 tip for staying sane (more or less)?!*

Gina: White wine (just kidding...it's red). Take one day at a time. As parents of special needs children, life is full of unpredictable ups and downs. Just strap on your seat belt and get ready for the ride. But just remember that you're not on that ride alone. There are others that are screaming and smiling right beside you.

Patty: There is an instant connection between parents of kids with disabilities. When we meet people whom we connect with, we usually tell them, “You had us at hello.” And for those folks we really bond with, we will teach them the secret handshake.

The authors have kindly offered to give away two copies of their book. Leave a comment below—about what Gina and Patty had to say, about why you'd like the book, whatever you please—and I'll randomly pick two winners by Tuesday Aug 10 at 11:59 p.m., announce it in this post and alert you both by e-mail.

