



# Postcards

from the Road Less Traveled

By Ellen Notbohm

## Rx for Battle Fatigue

**A**fter you've been to a few hundred white-tablecloth business dinners, the food and the deal points change, but otherwise they are all pretty much the same. This one was ambling along that way, until the conversation veered off the path.

I'm sick of hearing about ADHD, announced the neatly pressed executive across the table. It's nothing but a convenient excuse for parents who don't have the guts to discipline their children.

Interesting, I replied. And is your experience clinical or practical? Do you work with these children, or are you parenting one? Are you a doctor, a psychologist, a teacher? Or do you live with a child with ADHD?

Oh, no, no, no, he said with a smug shake of the head. None of that. It's just what I think.

And here's what I think, I told him. I have invested thousands of hours and dollars with many devoted professionals who possess a body of factual knowledge strongly supporting that "what you think" is incorrect, unkind and judgmental. People like you make me more tired than an entire room full of "hyperactive" kids.

My response was, admittedly, one of exasperation. I was at that moment one step short of giving him my favorite

snappy comeback, the raising of three fingers together and telling him to read between the lines. I don't remember if I blew the business deal that night, but it never occurred to me that it wasn't worth it. There were six people at that table and if I caused even the slightest flicker of attitude shift in one of them, the evening was profitable enough for me.

As parents of children with autism, the list of what makes us tired is endless. The meltdowns, the sleeplessness (theirs and ours), the siblings who don't get enough attention, the grinding challenge of adequately feeding a child who only eats four things, the social isolation (theirs and ours), the endless carousel of service providers and how to pay for

them. But nothing makes me more tired than perpetually jousting with a large portion of the general public who feels that children who qualify for special education are some sort of societal add-on, a drain on the system, and that money spent on special ed somehow inflicts injustice on the "typical" learner. This is a real live letter to the editor that appeared in our newspaper:

"Mainstreaming special needs children hurts all children. My kids have been in classrooms with some of the special-needs kids who really can't do the work and require so much time of the teacher that all the normal kids get lost in the shuffle.

Our schools are failing the average student, who becomes the real burden to society. These are the kids who need help. Our schools are out of money now. What we don't need is to add more cost for a handful of "special people."

I know it must be heartache for the parents of these kids, but if it means relocating to be closer to a facility that is better suited for their child, so be it. My heart goes out to these families, but I have even more compassion for the kids who are shuffled through the cracks."

I'll bypass the question of how this woman's heart could go out to anyone when she so clearly doesn't have one to begin

with. Or how dangerous it is when we begin trying to define a “normal” child. As Canadian songwriter Bruce Cockburn put it, “the trouble with normal is it always gets worse.”

Having to face the bigotry of an uninformed world-at-large comes with the territory of having a child with an autism spectrum disorder. There is no gel-tab available to help you swallow that. But you do have a choice about how you confront it. The menu from which you can choose includes anger, denial, despair, frustration. Or it could include patience, resilience and a willingness to view ignorance as opportunity.

I have come a long way since the years-ago evening I told off Mr. Business Dinner; I can now respond more productively to such situations. I’ve authored several successful books on raising a child with autism, and with that comes cascades of mail from readers. At least 99% of the mail is positive, but there is the occasional missive from someone who is very, very angry with me. Am I crazy, they ask, or just full of bull? How DARE I voice such a viewpoint?

My husband never understands why I even respond to such vitriol. But I always do respond, because every point of contact is an opportunity to widen someone’s perspective. I counter in a thoughtful, respectful way that emphasizes how many different ways there are to approach the issues within autism, different answers for each different child and family, and that in our differences we are still pursuing the same end goal – that each child with autism achieve the fullest of his potential and be able to take his place in society as an adult carrying as much of his own weight as possible. I point out that this goal is no different from what most people want for themselves. Every time I get a return response along the lines of gee, I never thought of it that way or wow, I didn’t know that – I know I did the right thing in putting myself in the line of fire and “taking one for the team.”

Over the course of raising your child, you’ll face a spectrum of responses and attitudes just as wide and varied as autism itself: benign lack of information, open hostility, complete indifference, medieval thinking, Pollyanna thinking and everything in between. It gets a lot easier if you bear in mind at all times two things:

**1** Knowledge is power. *You* have the knowledge, therefore you have the power.

You have two kinds of knowledge, and therefore two kinds of power. The obvious one is that you have knowledge about autism, factual information as well as your own firsthand experiences. That’s the knowledge you use to counteract ignorance, misconception and prejudice in others. But even more powerful is the knowledge that you know your own child better than anyone else, and you know that the choices you’ve made based on your carefully accumulated knowledge and wisdom are the right ones. Hold fast to this solid core; use it as your support in the face of that ignorance, misconception and prejudice and you will not blow over no matter how stiff the wind. *Trust your instincts*, our very first pediatrician told us. *You know more than you think you know.*

**2** Making a difference one person at a time makes a huge difference over time. I’m happy winning over hearts and minds one by one because I have faith in the ripple effect. Maybe I wasn’t able to participate in the autism walk-a-thon or write the big check to the fundraiser. But every person who walks away from me understanding just a bit more than s/he did before will likely share it with someone else who will, in turn, do the same. That sort of “passing the talking stick” ultimately makes life easier for my child, your child...and you and me!

Running the marathon that is raising your child with autism is almost certain to make you tired. But think about how many different ways there are to be tired. There’s the tired that is laced with defeat, fear and loneliness. And there is the tired that says, I gave it a good effort and look how far I got!

*Dear Ellen,*

*Thank you very much for considering my critique and giving me some food for thought. The story of your son really does amaze me. Probably a big part of his progress has been your positive attitude and I really admire that.*

*Maybe I’ve seen autists too much of a lost cause, but I am glad that reality proves me wrong. ■*

**Ellen Notbohm** is author of *Ten Things Every Child with Autism Wishes You Knew*, a ForeWord 2005 Book of the Year Honorable Mention winner. Her newest book, *Ten Things Your Student with Autism Wishes You Knew* has received a 2006 iParenting Media Award. Learn more or contact Ellen at [www.ellennotbohm.com](http://www.ellennotbohm.com).



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