



a parent's guide

CHILDREN
with
HIGH-FUNCTIONING
AUTISM

- Practical Advice to Help Cope With Your Child's Diagnosis
- Overview of the Various Types of Therapies Available
- Information on Support Networks and Resources
- Insight and Guidance From a Parent of a Child With Autism

Claire E. Hughes-Lynch, Ph.D.

CHILDREN

—*with*—

HIGH-FUNCTIONING

AUTISM

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Dedication

To Annalia and Nicholas

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and whose love I value every day. Mama's here. Mama's always here.

Introduction: How Did I Get Here?

If you're not sure where you're going, you're liable to end up someplace else. If you don't know where you're going, the best made maps won't help you get there.

—Robert Mager, psychologist, writer, educator

An Unplanned Journey Between Holland and Italy. Switzerland?

It's important to know that no one chooses autism—you, your child, and your family were drafted. You need to remember this when teachers, other parents, and total strangers feel free to tell you that you're using autism as an excuse for _____ (name your issue here: misbehavior, laundry piling up, financial failure, your lack of showering ...). Just like being drafted and being shipped off to another country, autism will change your whole life—your plans, your dreams, your family structure, and even your relationship with your local grocery store. Everything will be different than you expected, but not always in a bad way. Just ... different.

This book was inspired by the essay “Welcome to Holland” by Emily Perl Kingsley (see Figure 1). I love this essay and present it to my college students when teaching Introduction to Disabilities, but I never really appreciated its wisdom until I sat crying as I reread it one night. I also realized there was a lot of information about “Italy,” or typical development, and “Holland,” or children who had disabilities, but very little about children who were, well, different. Children who exhibited some but not all of the characteristics; children who had some really significant strengths that were both a result of and impacted by differences. There wasn't much information about children from “Switzerland” who aren't quite typical, but don't have classic disabilities—children like my child who has high-functioning autism. And so, the idea for this book was created.

Figure 1. Welcome to Holland essay.

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Welcome to Holland

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help

people who have not shared that unique experience to understand it, to imagine how it would feel.

It's like this ...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around ... and you begin to notice that Holland has windmills ... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy ... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very very significant loss.

But ... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Throughout this book, the metaphor of traveling and maps will be used frequently. I found that there were lots of coping guides, lots of informative books, some "cures," and reams and reams of technical books. Most importantly, there were a small and growing number of first-person books written by families and individuals with autism. I am hoping that in this book you find a familiar voice of someone who refused to let autism win over her, her family, and her child; someone who refused to get overwhelmed, but found that there was hope, growth, and a really wonderful journey through it all. Switzerland, like Holland and Italy, has its own beauty!

Maps and Autism

“Welcome to Holland” originally was written for a child with intellectual disabilities (formerly referred to as mental retardation). However, it is an analogy to which I could deeply relate: You think you’re going somewhere and suddenly you’re not there. Autism is more like the *Wizard of Oz*: You think you’re just like all of your friends and you think you’re on the way with a clearly defined map, but then you start getting strange signs that things are not the same as all of the baby books would have you believe. I had read Vicki Iovine’s *The Girlfriends’ Guide to Pregnancy* and laughed so hard I was sobbing. (Seriously, my husband was concerned about me. Perhaps it was an overreaction to hormones....) However, I truly bawled when I read the *The Girlfriends’ Guide to Toddlers*. That wasn’t what I was seeing. I didn’t get to laugh at funny things my child was saying. I had the child who wouldn’t leave the swings; I had the child who screamed at the idea of taking a bubble bath.

But I also had the child who could complete 100-piece puzzles at age 2; I had the child who at 18 months could understand when I told her that rocks broke apart to become sand and who could use that knowledge to bring herself back from the brink of overwhelming fear. I had the child who pulsed his baby seat to the Muppets’ song “Mahna Mahna” in perfect rhythm and banged on pots to Queen’s “We Will Rock You” over and over again. Autism, yes, but gifts, nonetheless.

Autism is so insidious because, to use the Holland analogy, for a while, you *are* in Italy. The language spoken for a while is Italian. But in small pieces, the language changes. The people change. The activities change. The landscape changes. It reminded me for a while of one of those *Star Trek* shows where part of you was in one world and the other part was in another.

Yet, high-functioning autism isn’t quite the Holland of “regular” autism. There are some real strengths, and there are traces of autism, but how much? There’s a reluctance of professionals to diagnose anything. It’s perhaps like being in Switzerland—a little bit of Italy, and closer to Holland than some of the other people in Italy, but not so close that you feel welcomed by the Dutch. Enough to see the abyss, but not to find the support. Switzerland can be very confusing.

There are several different metaphors about autism that people use. In her book *The Autism Trauma Guide: Postcards From the Road Less Traveled*, Ellen Notbohm (2007) noted how having a child with autism is like being on a strange trip; you have to communicate with others that you’ve arrived safely and that you want to share your experiences. In contrast, Karyn Seroussi (2002) called autism “The Jabberwock” and talked about defeating the disease that causes autistic behaviors. She also talked about saving children from the “Pied Piper” of autism. It’s interesting the different metaphors one finds—to some autism is a scary, demon thing; to others, it’s a process and a journey.

That’s autism: Something to be fought against while at the same time trying to understand the journey. It’s both a process and a condition. It reminds me a bit of trying to capture the dual nature of

light. Scientists have found that when they provide a substance to react to, light clearly acts as a particle. When they provide a slit, it appears to be a wave. High-functioning autism is something our children have, as well as a characteristic of who they are. For me, living on the coast of Georgia, high-functioning autism is like the marsh, where the salt water and fresh water combine to form a vast, unique and fragile ecosystem. It's a really fine line between "quirky" and "problematic." A gap between "talented" and "not quite right." Somewhere between "cute" and "hmmmm."

Mapmaker: Who Am I to Write This Book?

There are lots of books about autism out there: books written by people with doctorates and books written by mothers of children with autism, as well as numerous other books on the topic. This book happens to be written by a mother with a Ph.D. in special education and gifted education who has two children: one with high-functioning autism and another one with autistic-like behaviors. I'm writing this book because I read like a mad woman when I was going through my daughter's initial diagnosis and treatments. I was completely overwhelmed by information. There are so many sources of information available and so many viewpoints and so many arguments, I would turn off the computer in frustration after reading for hours, only to turn it on again the next morning to order the next book, to peruse another web page—trying to find someone or something to help. Some books really spoke to me; some books were a waste of my time. And some were, in my opinion, downright dangerous.

I am the mother of a daughter, "Elizabeth," who was identified with Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) at the age of 2 and identified as being gifted at the age of 7; and a son, "Raymond," who was diagnosed with Generalized Anxiety Disorder, Not Otherwise Specified (GAD-NOS) and Tourette's syndrome at age 6, and also identified as gifted at age 7. (For their own privacy, I have changed their names, as well as those of other children discussed in this book.) Because most of our lessons were learned through the experiences we had with our daughter, much of this book is based on our journey through the maze of her diagnosis, treatments, and future outlooks. However, where necessary, I also will focus on my son's issues. He is not diagnosed with autism, but has many similar issues. I've learned that this is not uncommon—siblings often will share characteristics, but have different labels.

However, in the irony of the universe, I received a doctorate in both special education and gifted education before I ever had children, and I am also a college professor in both of these areas. "I should" have been prepared for all of this, right? Wrong! I was familiar with the map of an educator, which is a vastly different map than that of a parent. This book is the middle ground of both parts of my life: my professional knowledge combined with, and at times, in conflict with, my personal role

“Mommy.”

I have been taught through my training to focus on children’s abilities. Twice-exceptional children, who are gifted with disabilities, are a particular passion of mine professionally. I have always loved working with children who have amazing insights and problem-solving abilities, but who can’t read for some reason. I loved the intellectual challenge of trying to figure out what would work with a twice-exceptional student—what reading strategy to use, what question to ask, and the like. What can I find to help *this* child develop his or her abilities, rather than be stymied by areas of challenge? But *this* child was now *my* child, and I had no professional knowledge of autism. I used to laugh ironically with my husband—give me a child who can reason but not read, and I’m all over that! But here, I have a child who can’t talk! Talking is a strength of mine, to put it mildly. I drove my parents crazy talking; I got in trouble at school for talking. I went into a profession where I talk for a living! And *I* had a child who couldn’t talk. Ah, the irony!

My own professional pride was a major “oughtism” that I encountered. I, of all people, with a Ph.D. in special education *ought* to know what to do. And I had not a clue. I now share a presentation with teachers called “The Other Side of the Table.” I have been at countless Individualized Education Program (IEP) meetings as a teacher or advocate, translating terms and concepts and processes to parents. I have reassured them that I will do my best to help their child read, behave, make friends, and so on. I have always (after the first scary year of teaching) felt capable of doing so—knowing that there were lots of things to try and I would keep trying, and hopefully, something would work. But I also knew that children are so highly individual, that sometimes, nothing does. My job was not to give up on the family or the child, but to keep trying. I knew that as a teacher.

And then, I sat on the other side of the table, and I realized how little I knew about special education, autism, and Early Intervention processes—about anything—and how much I was depending on the person across from me to love my child, to help my child, and to know exactly what to do. I wanted her to tell me that she’s seen lots of children like mine and all of them have been helped. I wanted her to see that yes, Elizabeth fixated on geography and could point to most of the states in the country, but this was not a problem, this was a strength. Perhaps Elizabeth would be a geographer one day and we could say, “It all started when she was 2.” I needed that therapist to see her not as a problem to be solved, but a wonderful collection of abilities to be developed and grown. I needed her to know everything I didn’t. I sat on that other side of the table and cried for someone to help my little girl because I didn’t know how.

I finally stopped crying when I read a marvelous book called *The Boy Who Loved Windows* by Patricia Stacey (2003). She is a phenomenal writer, and her story read like she was talking directly to me. She wrote of how her therapist said that one of the ways that parents of children with disabilities cope is by finding another child who had symptoms worse than their child’s. Patricia was the “bottom” of the group—no child was worse off than hers. “My God!” I thought, “This works! H

child is worse off than mine!” But, you see, her child got better! By the end of the book, which I read in one long night, her son was talking and interacting and asking questions and learning—all of the things I worked on as a teacher developing talents. If *her* son could get better, maybe my daughter could too! Her book was the first hope I had that maybe we were on a path where Elizabeth could get better and be more of who she is—who she truly is. I had found my map.

Second Thoughts: How’d We End Up Here?

If you’re reading this book, you’re probably researching autism, trying to get a handle on the “thing,” this “condition,” this “disability.” You’ve read countless books and web pages about autism that just don’t quite paint the full picture of your child, and they don’t quite capture that incredible ability that autism sometimes hides and sometimes makes more clear. You’ve read about autism and Asperger’s syndrome, but still aren’t sure what to tell your parents, your in-laws, or your child’s teacher. You’re almost certainly wondering what you can do and worrying about what you have done.

Second thoughts are like regrets: You can’t have ‘em because you can’t fix ‘em. You are making the best decisions you can right now with the information you have. Just like on any journey, you might wind up in a place that you’re not really thrilled with. You might look at your house (a mess), your marriage (a mess), your relationships with others (a mess), and your child (oh, such a mess), and want to start over. You will probably obsess a bit: “If only I had ...” The reality is that you did the best you could, and now you have to continue to do the best you can and get yourself through this mess one piece at a time. Some advice my mother once gave me was, “You want this fixed *right now*, and it’s just not going to happen. It will take time, and you have to give it that time.”

No second thoughts also means that you don’t give up, believing yourself to be a victim of circumstances, doctors, therapists, God, bad genes, or something else. As Rachel, a mother of a child with Asperger’s, says,

It can be extremely frustrating to deal with this disorder, but as much as a parent did not ask for a child with these issues ... the child did not ask to be like this either. Ben describes his confusion as “birds in his head.” We as parents need to take a step back, take a deep breath, and realize that the child is not intending to create chaos, he is just trying to cope with it. The more we understand this disorder and let the child know that we understand how he is feeling, the better off he will be.

As in any trip, you are certainly allowed to cry when you wonder, “How on Earth did I get here?” No, it is time to go and build yourself a map to get through it.

Why Do We Have to Go?

The causes of autism are fiercely debated. What we do know is that the rate of identified autism across all categories, has dramatically increased around the world in the last 20 years. There is a wonderful commercial, put out by the organization Autism Speaks and the Ad Council, which shows a cute little girl in a dance outfit. It states, “Chances of being in a Broadway show? 1:11,000. Chances of a child being diagnosed with autism? 1:150. It’s time to listen.”

It may be even more prevalent than that. Recent surveys, led by teams with Dr. Kogan from the Health Resources and Services Administration and Dr. Blumberg from the Centers for Disease Control and Prevention (CDC; 2009), found that 1 in 91 children have a diagnosis of autism spectrum disorders (ASDs), and because it is more commonly diagnosed in males, 1 in 58 boys do. In December of 2009, the CDC released a report that cited prevalence rates of 1 in 110 children in the United States having a diagnosis of autism spectrum disorders. Up until 1990, there were very few children diagnosed with any form of autism; it was considered a low-incidence disorder and only children with had extreme cases were diagnosed.

So, what happened in 1990?

It is true that along with autism, the rates of other disorders have increased as well, although not to the same degree as autism. According to Jun Yan (2008), using information from the Centers for Disease Control and Prevention, diagnoses of Attention Deficit/Hyperactivity Disorder (ADHD) also have dramatically surged. Between 1980 and 1990, the rates of learning disabilities (LD) dramatically increased. According to Drs. Wright and Cummings (2005), there has been a shift in the diagnostic paradigm from evaluating people as “normal” or “abnormal” to evaluating their symptoms as “problematic” or a “disease” to be treated. In other words, it is very natural for a person going through a divorce to be depressed and not function well at work. This is “normal.” However, is depression an inability to work a problem? Yes, and therapists are much more likely to encourage someone to seek counseling and to prescribe medication now than they were 30 years ago.

Even the concept of what is a problem has changed in our society. Matthew Smith, in a 2000 paper presented at the Congress of the Humanities and Social Sciences, noted that ADHD is a relatively new construct. In the 1950s, schools were pressured to produce students who could compete on an international level. The demands for children to sit and learn passively became an issue for children with more active learning styles and the rates of ADHD and learning disabilities skyrocketed.

Similarly, autism, meaning “state of being within oneself,” wasn’t even named until 1943, when Leo Kanner wrote a paper describing children who were very withdrawn and exhibited odd behaviors and language problems. In 1944, Hans Asperger also noted this, but his children did not have language delays, thus leading to the differences between children identified with Asperger’s syndrome and

those with autism. Although autism certainly has existed under other names (including insanity or mental retardation), many of the children on the spectrum now would not have been diagnosed with anything until recently. They were just considered “quirky.” Did they experience emotional and learning problems as a result of their quiriness? Of course, but that wasn’t perceived as enough of a reason to treat them professionally. Too often, parents and schools were perceived as the source of the problems, and therefore as the source of any solutions.

Now, insurance companies regularly cover mental as well as physical health as an awareness of our ability to work on problems, even if they’re normal ones, increases. Similarly, people are more willing to seek help for things that are considered problems now, when they would have been told to “buck up” 40 years ago. That guy in my mom’s high school class who thought he was from Venus? Probably Asperger’s. My husband who clears his throat frequently and has digestive issues when he’s stressed out? Probably Tourette’s syndrome. My tendency to procrastinate until the very last possible moment on an important task? Probably anxiety disorder. But such labels weren’t widely used 40 years ago (although there has been a gradual acceptance of them over time).

And with such a shift to diagnosing problems rather than disease, a more relaxed definition can be seen as coming into being. The numbers shift constantly; it is hard to get a handle on what criteria are being used. Are we diagnosing classic autism, or the full spectrum? Are we diagnosing more because the criteria have changed to include children who would have been excluded before?

Regardless of the shifting numbers, autism is being diagnosed at skyrocketing rates that appear to have only a little to do with our society’s acceptance of labels and willingness to provide therapy for such problems. A survey of autism labels in California schools by the organization Fighting Autism (n.d.) found that autism diagnoses had increased more than 1,100% over the last 10 years. In addition, according to Dr. Karp (2009) of the University of California, Los Angeles, it’s being diagnosed around the world in increasing rates. In other words, autism is being diagnosed now in England, Spain, Holland, and even Pakistan, in similar rates to the United States when using the entire spectrum rather than the more limited classic autism diagnosis (Maqbool, 2009). Epidemic? Perhaps ... but certainly a real problem. It did explain to me why it was so hard to tell people from other generations; why the word “autism” was whispered by my mother-in-law, why my children’s teachers flinched when I said that Elizabeth had autism. Expectations about autism in people of other generations or who had educational training more than 10 years ago are very different than the perceptions parents and educators have today.

Personally, all I cared about was that I had a child who was not speaking and who seemed to be struggling in her daily experiences; a child to whom sand sliced and hurt; a child with strong abilities I wanted to see developed and not neglected. A friend of mine has a son who could only relate to people by comparing them to colors. Another friend has a son who does not sleep. They are exhausted beyond belief and she and her husband are divorcing. The skyrocketing numbers

diagnoses do mean that there is more research, more funds, more insurance, more help. And more help is what is needed. I'm in favor of anything that provides help!

But what *causes* it? Regardless if there's a problem—why?

Causes—A Foggy Path

All symptoms have to have a cause. For a while I didn't care *why* Elizabeth had autism, just that she had it, and I wanted to know what could be done to help her. After a while, I realized that one's belief in the cause of autism impacts the choice of treatments. What I could *do* was directly related to *why*. I had to make sense of my beliefs of why in order to help her.

Refrigerator Mothers

I have to include this as a perception, *not* a cause, related to autism. In 1943, Leo Kanner, one of the first authorities on autism, noticed that there was a marked lack of affection between mothers and children diagnosed with autism. Furthered by Bruno Bettelheim in 1962, the theory placed the blame almost solely on the environment of parenting. You can hear traces of it in an older generation who urges you to just “love it out of ‘em,” or conversely blames you by saying something like, “If you were a better mother....” And we hear it in ourselves as we question our own parenting abilities.

Clearly, Kanner and Bettelheim (a) did not notice that these same mothers often had very loving relationships with their other children, and (b) were blaming the lack of closeness on the mother, not the inherent lack of response on the child. Rachel, a friend of mine, tells the story of the first time her son hugged her—at age 4!

I was dropping him off at preschool and gave the regular wave goodbye after an encouraging pat on the back and a wishing of a good day. As I was leaving the room, he stood up and said, “Wait Mom.” I stopped in my tracks, turned around, and saw him coming toward me with the most sincere face I had ever seen him have. He gave me a little hug. I hugged him back and told him I loved him. Then as he went back to his seat, I found myself in a daze, that had never happened before ... ever.

As a baby, Ben had colic and acid reflux. There were many days where I would go back to bed at night in the same clothes I had on the day before. The first 3 months were spent trying to comfort him and then just letting him cry himself to sleep in his room, with the door shut, because I had had all I could take. He would scream and cry for hours, and as hard as that is to believe, it would be literally for hours. I had a very hard time bonding with him as a baby and don't think I actually did. A lot of guilt came with that, and I would always blame myself when

he did not look at me or respond to me with a connection that I had seen with other mothers. He would hang off of me when I carried him and it seemed that I was just there to provide his needs. When you have tried hugging your child, only to have him stand there and not really hug back, it is hard. So when he finally initiates a hug, it is as if the sky opened and clarity rained down upon you ... the realization that you are doing something right.

Dr. Bernard Rimland, in his 1964 book *Infantile Autism*, was the first authoritative voice to debunk Kanner and Bettelheim's views that the parental bond was the environmental factor and to propose that autism has a neurological and physiological cause. But the damage was done, and we have spent decades since trying to persuade others that our children are loved and not "spoiled."

Genetics

Studies have found links to autism on 21 of the 23 chromosomes, with a great deal of emphasis being paid to the X chromosome in particular (Simons Foundation for Autism Research, 2009). Certainly, autism appears to run in families. We personally have traced many of my daughter's issues back to specific family members. However, it's not a clear-cut connection. It appears to be a series of "switches" at the genetic level that have to be "turned on." In other words, it appears that children might be created at conception with the *potential* for autism, which then is triggered by something in the environment, or a particular combination of genetic issues that together create autism—both during gestation and afterward. Merely having one genetic marker is not enough—they have to occur together in a particular sequence and interact with each other. Certainly, weeks 8–24 are the time of developing neurological growth during pregnancy, and trauma during this time could affect the brain without causing physical disabilities.

This is a belief that I hold. I certainly can see some of the tendencies of autism in both my family and that of my husband. I know that our family dynamics often are based around these tendencies, and we have come up with interesting coping strategies. For example, my uncle has always hated being touched. My great-aunts, grandmother, and mother recoil when they are touched on the face. Our favorite ice cream is any kind with nuts because of its texture. We laugh in our family about how we deal with our aversions to things; we use "close, but not touching" to indicate affection; we make sure to have textured foods available; air conditioning is adjusted away from the face; and emotional things are dealt with lightly. My husband's family is similar—emotional issues are dealt with in small doses, the house has to be arranged perfectly before one leaves; top sheets are left off because they are too "tickle-y;" and stressful situations are to be avoided at all costs. The keys for my being able to work with Elizabeth lived within the strategies our families had taught us, and perhaps other strategies were there. I have since become fascinated with strategies intervention because of my belief that her autism

lives in our genes.

Mirror Neurons

There is a link between the lack of mirror neurons in people and autism, according to D. Oberman (2005) and other researchers at the University of California, San Diego. Mirror neurons are neurons that turn on both when you do something and when you observe someone else doing the same thing. If you see a sad movie and cry, your neurological system is taking the information you've observed and turning on the same neurons that you turn on yourself when you're truly sad. In other words, you can cry at *Beaches* and you don't have to have your best friend actually die in order to feel distraught. Similarly, you can feel joy watching the winner from *American Idol* perform or anger reading about torture. It doesn't have to happen to you directly to feel it.

People with autism have a dysfunctional mirror neuron system, which means that they don't feel the emotions that other people around them are feeling, or have the same awareness of other people's emotions or feelings. In fact, although they may be aware of their own emotions, they might believe that others share their viewpoint. These mirror neurons are responsible for empathy with others, and a lack of empathy or even awareness of others can lead to significant social challenges. This dysfunction of the neural development can account for much of the self-absorption that children with autism exhibit.

Mercury Link/Immunizations

Children with autism act almost exactly like people who we know have been exposed to mercury. When neurons and nerves are exposed to mercury, they shrink and fairly dramatically die. Fierce arguments have grown up concerning the impact of mercury in immunizations and numerous conspiracy theories abound about the government's role in promoting immunizations over the health of its children.

Certainly there could be better immunizations. Children today receive enormous times the number of immunizations that children born in the 1960s received. In 2006, Jenny McCarthy called for the Centers for Disease Control and Prevention to "get the crap out" of immunizations. The list of heavy metals in immunizations is stunning. Certainly, it could do no harm to clear out the elements that are potentially harmful. Additionally, it could do no harm to look at the immunization schedule. Do we *really* have to bombard our littlest people with megadoses of immunizations before they've fully developed their own immune systems? Isn't it possible to spread out the immunizations and break them into smaller doses?

Plus, and this is big, folks, there are a lot more things that could more likely cause autism that we are *not* getting upset about. Mercury in the soil and the air? Mercury in your fillings? Hormones

your water? Phthalates in your plastics? Don't hear much about those things on the 6 o'clock news.

What is on the news are the court cases by parents who are suing the government, claiming that the Measles-Mumps-Rubella (MMR) shot caused their child's autism. Every single one of the court cases that claim autism occurred due to vaccination has been denied. However, and it is worthwhile noting, many court cases that have claimed *physical* damage from the overload of immunizations have won. Cases such as *Banks v. Secretary of the Department of Health and Human Services* (decided 1994) have found that the MMR shot led to acute disseminated encephalomyelitis of the brain. The court said in its decision that Bailey Banks' brain condition quite possibly led to behavioral change because he "more likely than not suffers from PDD, and not from autism" (p. 14)—a very fine discrimination, David Gorski (2009) noted, as Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) is on the autism spectrum, while Pervasive Developmental Delay (PDD) is not. Thus, *all* court cases claiming an immunization-autism link have failed, but many that have claimed compensation for intervening physical diseases have succeeded.

But my belief is that immunizations are not necessarily the issue—our global living is—a belief that is shared and being studied now by the federally funded National Children's Study (2009). The amount of hormones and various drugs in our water and our meat is staggering. The ubiquitous plastic containers that we store our food in and drink from have harmful substances. There are skyrocketing rates of mercury around the world in our soil, our oceans, and our air. The amount of just mercury in our ecosystem has gone off the charts. A 1995 study by William Fitzgerald of the University of Connecticut found that in the 100 years prior to the study, the amount of mercury in the air increased 300%, with most of the increase occurring since 1970. Emissions have dramatically increased in the United States since governmental oversights were removed. Other countries, such as India and China, have almost no governmental oversight. Certainly we see problems with mercury in the tuna pregnant women are not supposed to eat, the shrimp we're all supposed to eat in moderation, and the smog over our cities. Heck, mercury was in our tooth fillings until recently. The reality is that mercury is *everywhere*—if it's in the soil, the water, and the air, there's nothing we eat, nothing we drink, and nothing we wear that has never encountered mercury. Immunizations are certainly problematic, but there are much bigger problems with mercury and other environmental toxins than the trace amount found in the MMR shot. Our very ecosystem is threatening us.

Food Allergies

With the issues of headaches, skin problems, digestion, diarrhea, and general bowel disturbance that many children on the spectrum have, there is some evidence to indicate that some children are born with intestinal allergic reactions to irritants, particularly dairy, wheat, and for some children corn. Certainly the use of corn syrup, gluten, and milk are much higher in our foods today than the

were just 50 years ago. In her 2002 book, Karyn Seroussi wondered if such allergic reactions and the consequential autistic behaviors mimic typical people's reactions to hallucinogenic drugs, such as LSD or "magic mushrooms." Many other parents have noted that their children have inordinately high levels of yeast in their urine and stool samples. Many researchers, including Drs. Bernard Rimland, William Shaw, and others, have been investigating this linkage between diet and autism for some years now, but the mainline perspective is that it is unproven (see Rimland, Crook, & Crook, 2000 and Shaw et al., 1998).

Certainly, in our family, we are known for lactose intolerance. I personally was given goat's milk rather than cow's milk as a child because of my mother's observation of my sleeplessness and erratic behaviors when I drank cow's milk. My friend Tina's son tested as being not lactose intolerant, but she noticed significant behavioral changes when he had milk. My husband and daughter both have the flushed cheeks and dark circles under their eyes that often are symptoms of allergies. My husband and I have noticed that we go through phases of "milk addiction" when we're anxious because of the feeling of relaxation and calm we get from drinking milk. One of the most frustrating things about allergies is that children (and adults) often crave the very thing that they're allergic to. Many, many families of children with autism have noticed that before they cut off dairy products, their children craved milk and that milk or bread would be the only thing that could calm them down. Some researchers, such as Auld and Grootendorst (2004), have found that milk is more addictive than alcohol and cigarettes. Certainly, diet can impact behavior.

It should be noted that some doctors view allergies only as a reaction identifiable with a skin test. Reactions to food may not show up in a skin test, and they may use the term intolerances as opposed to allergies.

A friend of mine once referred to children with autism as the "canaries in our world." Living in Kentucky as we did for a while, mining references are common. In the days before monitors, mine workers would send down a canary into the mine before the first run to test the air that had been shut up a night. If the canary came back alive, the air was good; if the canary came back dead, the air was bad and they would have to take measures to make the mine safe again. The sheer numbers of children being diagnosed with autism are telling us something. What that something is, though, is hotly debated.

I refuse to become a victim, but I get so incredibly angry when I think that our own world might have poisoned my children.

Starting the Journey: From the Beginning—and Even Before

On March 6, 2001, our family began. Our daughter, Elizabeth was born at 5:25 in the afternoon after 12 hours of labor. She was a much-wanted child that we had been trying to conceive for more than a year. Because of fibroids and other issues, it had been hard to get her. I remember crying realizing that it seems so easy to conceive in your teens and twenties, but here I was in my 30s and with caution thrown to the wind, all of those years of desperately trying *not* to get pregnant were coming back to haunt me. We cried and celebrated that day in July when the stick showed two lines of pink.

Brain Development Issues

Often mothers of children with autism will report that they had a feeling of something “not quite right” even while they were pregnant. There are some genetic studies, according to Michael Szpon (2006), that seem to indicate that the genetic alterations that can turn into the propensity for autism occur around 8 weeks after conception. Sometimes not, but there often is the mother’s instinct that something’s off. I *loved* being pregnant, and I was always aware of another life force within me. I truly believed in God after being pregnant because of that connection to *life* and a sense of growing. However, 12 weeks into my pregnancy, we had a scare when an ultrasound found a fiber wrapped around her little tiny fetus head. Often found around arms and legs, these fibers could stunt the growth of the limb. We knew that there was no way the baby could survive with the fiber wrapped around her head. Our obstetrician took a wait-and-see attitude, and many prayers later, no sign of the fiber was present at 16 weeks. But there were fibroid tumors in my uterus that were *huge* and growing and the poor baby was curled around them. Throughout my whole pregnancy we were holding our breath. However, my water broke when she was 37 weeks and she was delivered vaginally and relatively stress-free—a healthy, 6 pound, 12 ounce little girl. The challenge of the pregnancy made me so relieved that she was “normal” at birth that I never questioned some of her odd antics as a baby. She was pink and beautiful and all potential.

Her birth story is different than many children with autism because it was the pregnancy that w

stressful, not the actual birth. Ray's birth is more typical of a birth reported by mothers of children with autism. His labor was about an hour from 0–10 dilation, with only 2 hours of active contraction. In the birth process, the muscles of the birth canal contracted so fiercely, he was born with a significant cephalohematoma or cone. Lots of babies are born cone-headed, but the lump on ours was almost as big as the rest of his head. It was quite disturbing. The doctors told us to watch the lump and that it could take up to a year to go down. There was a good deal of “Well, we’ll have to wait and see. It should be fine,” which was just vague enough to worry us. To our great relief, it had rounded off after about 4 months, but the pressure of those contractions pushed significantly on his brain.

Both children also were quite jaundiced and did not receive treatment in a timely manner. They were released from the hospital one day after birth, and we were told that they might be a little jaundiced and to put them in the sun. Not a real problem finding sun in Southwestern Florida! So, we bathed our little darlings in sunshine until their first appointments at one week. In both cases, the pediatrician found significantly elevated jaundice levels that were “coming down,” indicating higher levels before that would have required the bili lights. Even in the case of my son, where we were looking for problems, we were told “You’re fine” by the hospital and told later by our pediatrician that we had gone into the danger zone of bilirubin. Jaundice can carry the possibility of brain damage. Not often, but it can.

Ray also had a terrible fall onto a concrete floor where he hit the front of his head when he was 18 months old. He did not pass out, and the x-ray came back OK, but again I heard the cheery doctor's voice of “He should be fine. Just wait and see.”

Do we have MRI data that our children have brain trauma? No. But there is the underlying fear and niggling concern of what happened and “if only ...” thinking. I still sense that some of their issues were triggered by some form of brain pressure or injury—both in utero and afterward. In addition, there is a common theme of head trauma or high fevers noted among mothers of children with autism.

Rachel's Story

My pregnancy with Ben was as normal as could be. Blood pressure, weight gain, growth rate: all good. Then came delivery day. After 10 hours of unmedicated intense labor, I finally resolved that this was not going to happen without medication. I took the epidural and things calmed down, at least until it came time to push. I was ready to go and so was Ben. After just a few times, the nurse's face turned to grave concern, and she told me to stop immediately. Was I doing it wrong? Apparently my tailbone was digging into his forehead each time I pushed and his heartrate kept dropping in half. An emergency C-section had to be done and the nurse had to then push him back up through the birth canal. We have heard from other parents that they too experienced a traumatic

birth and that frontal lobe trauma is a common factor.

Ben also had to have surgery to correct a hydra seal in his scrotum when he was 4 months old. He was taken back to surgery with a smile on his face and woke up a few hours later a different baby. We were told that he would not even remember the surgery and be back to the happy baby we had in no time. It was a few weeks before we started thinking that something had gone wrong during the surgery because our happy baby was not back. He seemed more introverted and irritated. Neither of us had experience in raising babies, so we just kept trying our best to do the right thing. We later heard from a psychologist that it is unusual that we were not permitted to be with him while he was undergoing anesthesia, and I regret that I couldn't be with him during the surgery to protect him. We will never know if something did go wrong.

Hindsight Is 20/20: Isn't That Cute? ... But Something's Not Quite Right

Autism is sneaky. I can look back now and say, "Ahhhh, so that was the autism coming out." But at the time... I have backgrounds in both gifted education and special education, and my gifted education experience means I tend to look at kids from a strengths-based perspective. I see things that could be the germ of a talent or activities that show promise of great thinking. Even with a special education background, I tend not to look at things from a deficit view. One of the most significant challenges of working with two different sets of professionals is that one might see a behavior characteristic of a deficit, while the other sees the behavior as evidence of a strength.

For example, as an infant, Elizabeth would get the cutest expression on her face when she was startled. Her eyes would get round, her mouth would open, and arms would fly out at the slightest change in her environment. We were intrigued at this and said, "Wow! What an alert child we have!" and I would spend some time soothing her. It's a startle reflex that infants have and adults still have to some degree. It's more than surprise—it's an instinct that infants use to let themselves know that something has changed, and it activates their "fight or flight" adrenaline rush. Heart rates accelerate, pupils dilate, and the body tenses up, ready for action. All infants have it, but infants who later develop autism often have a very sensitive startle reaction. In other words, they don't normalize very quickly—the world is a very nerve-wracking place that causes high anxiety.

Another example: When she was 9 months old, my daughter would bang on the dryer and then listen to the differences as she banged on the washing machine. Then, she would repeat her action. Repeat. Repeat. For about 30 minutes. Isn't that cute? We were convinced she would either be a drummer or a repairwoman. She spent an hour at a time listening to the different sounds of the bang. She still has this skill of distinguishing little details and analyzing how things are alike and different.

Hidden Picture games are no fun for her because she just points right at the missing objects. I had to explain to her once that this is hard for most of us, and it's fun for us because it's a challenge. She just shrugged. Now, of course, I know that it's the autism combined with an eye for detail, but at the time we were very impressed with her ability to concentrate and discriminate.

As a baby, Elizabeth insisted very definitely on being held facing outward. She would cry and strain her head around trying to see around me when I held her facing me. So, I happily turned her around so that her back was to me and she was free to observe the world around her. I was pleased to have such a curious and exploratory child. Because of an old back injury, I couldn't carry her in one of those front sling-style packs, so I ended up with the baby on my hip, watching the world from a slightly tipped angle at times. However, putting her down was a real challenge.

Elizabeth *hated* tummy time—not just resisted it, but *hated* it. I was a good mommy of the early 2000s who laid her child down on her back to avoid Sudden Infant Death Syndrome (SIDS). We were deeply grateful that we lived in Florida so that the whole issue of blankets was not a concern. She would go into her little onesies, lie down on the big crib mattress, and play contentedly, often soothed by the mobile. But get her up and put her down on the floor face down and she would turn into the monster of a child who would shriek uncontrollably for hours. I at first thought that she would calm herself to sleep, but no such luck. For the first 5 months of her life, Elizabeth experienced this Jekyll-and-Hyde transformation every time we turned her over onto her stomach. Tummy Time became Torture Time—for everyone. I tried the nifty mat with the colors and activities. I tried no mat. I tried a soft texture. I tried the cold tile floor. In all cases, we had unrelenting crying.

Once she learned to roll herself over, around 5 months old, we would put her on her little mat and she would immediately roll herself over onto her back to play with her toes. All of the baby books said not to worry about this—that the baby's head will round out when she can hold her head up. But our baby spent so much time on her back looking out at the world that her actual head shape was altered. Needless to say, Elizabeth is now 8 years old and still has a flat spot on the back of her head. When I'm rubbing her head, I am always reminded of the Western Native American babies who were carried on flat boards, or “papoose boards,” and had flat heads. Flat heads used to be a significant cultural trait encouraged among some Native American populations in the West, and the White men and other tribes were called “round heads” when the cultures collided. There's even a Flathead Reservation and a Flathead River in Montana named after this practice. However, I know that for us, her flat head is a symptom and symbol of her autism—hidden, but still faintly perceptible.

Rachel's Story

Even at an early age, Ben was driven by color. He had to have a specific colored cup, plate,

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