

Book Review: The Autism Sourcebook (Karen Siff Exkorn), 2005

About the book:

Written by a mother whose son was diagnosed with autism, Karen introduces and describes the treatments she came across in a non-judgmental manner. She emphasizes the importance of an intensive early intervention program, acknowledges that some treatments may be effective for one child but not for another, and that treatment may need to be adapted over time depending on your child's needs.

The book includes chapters on Diagnosis [including understanding your child's behaviours: why some of the behaviours that appear typical in most children (ex lining up toy trains, spinning around, etc) can also be symptoms for ASDs, facts and theories, studies and information about ASDs], Treatment [including comprehensive list of standard treatments and interventions, advocating for your child's rights], Coping [including coming to terms with the diagnosis, coping with everyday life, sibling issues, coping with your marriage, your family and your self, coping tips for family and friends], and Healing [accepting ourselves, our spouses, our families, and our children with ASDs].

What makes this book different are the chapters on Coping and Healing, especially in covering the topic of how autism affects a couples relationship and their marriage as they journey along the path of ASDs; from its diagnosis, search for treatments, and through to the healing process.

About the author:

After her son's recovery from autism, Karen Siff Exhorn made it her mission to reach out as a consultant to other families living with autism. With a B.A. from Brown University and an M.A. from New York University, she is a frequent lecturer at universities and autism organisations across the US. She and her husband recently established the Siff Exhorn Family Foundation, which provides funding for research and treatment of autism. She lives in Rockland County, New York, with her husband, Franklin, and son, Jake.

Excerpts from the book:

On early intervention:

“Early intervention means that you step in and begin treatment for your child as soon as possible after he or she is diagnosed with an ASD: The earlier the better. Why so early? Studies show that a child's neural plasticity – or the brain's ability to be shaped – is at its maximum when the child is very young.” (page 88)

“According to the American Academy of Pediatrics, “early diagnosis resulting in early, appropriate, and consistent intervention has also been shown to be associated with improved long-term outcomes.” (p 88)

“What constitutes an intensive early intervention program? Intensive usually means giving a child between 25 to 40 hours of treatment services per week.” (p 90)

“According to the NRC (National Research Council of the National Academies of Science), “Services should include a minimum of 25 hours per week, 12 months a year in which a child is engaged in systematically planned, and developmentally appropriate educational activity



towards identified objectives... The priorities of focus include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behaviour problems.” (p 90)

Karen explains that because intensive treatment is recommended, usually one treatment is used a foundation, and others are added on, and that as your child’s requirements change, his/her treatment plan needs to be changed and adjusted as well:

*“In Jake’s case, when he was two, we used the more conventional treatments (one-on-one sessions of ABA, speech therapy, and OT) as the foundation of his treatment regimen, and added on others that may be considered alternative and complementary (cranial-sacral osteopathy, gluten-free/casein-free diet, vitamin supplements, such as B6/magnesium, homeopathy, and even energetic therapy). As Jake got older we discontinued some treatments (the GF/CF diet and homeopathy), modified others (fewer one-on-one ABA sessions, more group social skills therapy, and fewer visits to the cranial-sacral osteopath), kept some the same (vitamins, speech therapy, and OT), and added other treatments as well (auditory treatments like Earobics and Fast ForWord, music therapy, and piano lessons... to help improve his auditory processing). **Why did we modify his overall treatment plan? Did we drop the diet or stop the one-on-one ABA sessions because they weren’t working? No. We simply modified Jake’s schedule to meet his changing needs. Your child’s treatment plan is like a breathing and living organism – it will change and evolve as your child does.” (p 113)***

On telling your child about his/her ASD:

“In the beginning while you’re trying to sort out your own feelings about the diagnosis, it’s not necessary for you to tell your child about her condition. In fact, in most cases, your child will be too young to understand.

How to explain ASDs to your child depends on your child’s age and her level of understanding. Children with ASDs who have average or above average intellectual ability can be told about their conditions, but in a way that they can understand and with sensitivity to their feelings.

Telling your child about her ASD is a personal decision. If you do decide to talk to your child about it, do it earlier rather than later. It’s better that your child hears about ASDs from you rather than from her siblings or from other family members or friends. School-age children with ASDs often begin to develop an awareness that they are different, and self-esteem issues can arise if you’re not honest with them about their diagnosis.

Some parents report that telling their children about their conditions made it easier for them to accept themselves. Understanding the reason why they had trouble in certain situations, like paying attention in noisy classrooms or finding buddies in field trips, helped these children feel more empowered. Giving them a reason for their challenges actually enhanced their self-esteem.” (p 240)

Some stories we can identify with:

This book also includes the following stories, both poignant but describe exactly how many of us with children with ASDs feel.

Welcome to Holland

(an essay by Emily Perl Kingsley, as quoted from The Autism Sourcebook by Karen Siff Exhorn, pages 175-176)

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.

The Mountain

(by Jim Stovall, as quoted from The Autism Sourcebook by Karen Siff Exhorn, page 274)

There were two warring tribes in the Andes, one that lived in the lowlands and the other high in the mountains. The mountain people invaded the lowlanders one day, and as part of their plundering of the people, they kidnapped a baby of one of the lowlander families and took the infant with them back up into the mountains.

The lowlanders didn't know how to climb the mountain. They didn't know any of the trails that the mountain people used, and they didn't know where to find the mountain people or how to track them in the steep terrain.

Even so, they sent out their best party of fighting men to climb the mountain and bring the baby home.

The men tried first one method of climbing and then another. They tried one trail and then another. After several days of effort, however, they had climbed only several hundred feet.

Feeling hopeless and helpless, the lowlander men decided that the cause was lost, and they prepared to return to their village below.

As they were packing their gear for the descent they saw the baby's mother walking toward them. They realised that she was coming down the mountain that they hadn't figured out how to climb.

And then they saw that she had the baby strapped to her back. How could that be?

One man greeted her and said, "We couldn't climb this mountain. How did you do this when we, the strongest and most able men in the village, couldn't do it?"

She shrugged her shoulders and said, "It wasn't your baby."

--- Review and excerpts compiled by Charissa Ramirez

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