

WHAT'S OLD, WHAT'S NEW: BOOKS & FILMS WORTH KNOWING

“Just Who Are the Experts?”

Trust yourself. You know more than you think you do.
Dr. Spock

After the birth of our son, Mark, Gloria did not suddenly become a cold, rejecting “refrigerator mother.” I thought that there must be another cause for autism.
Dr. Bernard Rimland

In just the past few years the list of films and books by parents, especially by mothers, who took charge often in direct opposition to the advice of the “experts” in the medical and psychiatric professions, is a long and an impressive one. The advice quite often was simply “Put the child (usually a boy) away in an institution and forget him.” However, the mothers, and at times the fathers, ventured out into often unknown and dangerous territories to confront the status quo and to discover strategies and therapies to help their children to come back from the brink of isolation and the ravages of autism to be acknowledged as contributing and productive members of the human community. They had found hope and promise where there had only been hopelessness and despair offered by the experts.

The initial beginning made by Dr. Bernard Rimland in 1964 with the publication of *INFANTILE AUTISM* to challenge the accepted psychological model of “refrigerator mothers” with a biomedical approach was slow to gain acceptance among the medical experts of the day. See www.autism.com.

I am reminded of a quotation by Leo Tolstoy:

I know that most men (or women) including those at ease with problems of the greatest complexity, can seldom accept even the simplest and most obvious truth if it be such as would oblige them to admit the falsity of conclusions which they have delighted in explaining to colleagues, which they have proudly taught to others, and which they have woven thread by thread into the fabric of their lives.

The equally ground-breaking work of Barry & Suzi Kaufman in 1976 with the publication of *SON RISE* focused on a behavioral approach. “Experts had offered them little hope so they decided that they must act on their own—alone.” (a personal note: in 1978, I was given a copy of *SON RISE* by our 14 year old daughter when we lived in the tiny fishing village of Bucks Harbor, Maine. That was the first time I had ever heard the word “autism” and that book and concept helped to bring about a major shift in my life and career.) Learn more about *SON RISE* and the Option Method at www.autismtreatmentcenter.org.

Gradually the public’s attention and awareness of autism began to change. *Rain Man* in 1987 certainly shifted the cultural consciousness. Then in 1991 Annabel Stehli published *THE SOUND OF A MIRACLE: A CHILD’S TRIUMPH OVER AUTISM* which “triggered a revolution in the field of developmental delay and learning disabilities,” said Paul Millard Hardy, M.D., Medical Board, Autism Society of America. Contact at georgianainstitute@snet.net

2000 saw the publication of Karyn Seroussi's UNRAVELING THE MYSTERY OF AUTISM: A MOTHER'S STORY OF RESEARCH & RECOVERY. It is the stirring story of the relentless search by a mother to discover and slay the dragon that had invaded her son, Miles. The book is a fascinating read and is filled with many helpful resources. See www.autismNDI.com.

From 2007 to 2009 the pace of publication of stories of recovery has exploded. A day hardly goes by without the announcement of another book telling another story. (If I fail to mention one of your favorite books, please write to me and tell me about it.) At long last, people are speaking out, and the public is paying attention to stories of change. There is now a substantial hope for successful treatment modalities. But the number of cases of autism continues to rise and the end of the increase in incidents seems nowhere in sight.

Kim Marie Lesso tells her story to help inform other parents in BACK IN MY ARMS: A MOTHER'S VICTORY OVER AUTISM. Kim is the mother of two children on the autism spectrum. Kaitlyn has been diagnosed with Asperger's Syndrome. Tad has Regressive-Epileptic autism, one of the most serious types. Kim was told by the experts that her young son would never speak, would never go to school, and quite possibly would never even recognize her as a human being! How wrong they were. She proved them wrong on all counts. Her book is filled with specific practical strategies and advice to empower parents to take charge and become the primary advocate and authority for their child. See www.autismguru.com.

2008 saw a totally different kind of book from the previous account. I WISH MY KIDS HAD CANCER: A FAMILY SURVIVING THE AUTISM EPIDEMIC by Michael Alan is written by a father of two young children with autism. It is a poignant story of a family fighting for emotional and financial survival. The toll of ineffective expert advice has been enormous and has driven the family to the very edge of survival. The story was so compelling that it touched the heart and musical talent of renowned singer, song writer Sara Hickman, who has recently been named "Texas Musician of the year for 2010" by the Texas Legislature.

Sara wrote and recorded "State of Emergency," and it can be downloaded at www.sarahickman.com or www.iwishmykidshadcancer.com. Proceeds go to the Mattelia Foundation "Hope through Recovery," a domestic non-profit organization dedicated to providing assistance and guidance directly to families affected by autism and autism spectrum disorders. See www.mattelia.org.

Now hang on. 2009 has brought numerous excellent films and books to the public's attention. I will briefly mention only a few of these and follow up in future articles with a more detailed description of some of them. I wanted to bring them to your attention here.

Four films stand out. The first is a documentary that was actually premiered prior to 2009, but sets the stage for those that follow. The next two films are fiction and the fourth, also a documentary, provides a bridge between films and books.

Beautiful Son by Don and Julianne King details the, at times, painful and desperate search to reach Beau, their young son who regressed into autism between the age of two and three. This is a personal, up close, and extremely moving look at the manner in which every member of a family is impacted when autism enters. See www.beautifulson.com.

The Black Balloon, produced in Australia, is based on the personal experiences of the screenwriter, but unlike *Beautiful Son*, this film focuses on how the autism of an older brother

impacts the life of his teenage brother whose family has just moved to a new town and school. Each actor powerfully portrays his or her part to draw the viewer into the ever explosive drama of autism. See www.theblackballoonmovie.com.

The next film to make its entrance into the public consciousness was *Adam*, which presents a young adult with Asperger's who enters a whole new and strange world of relationships through his beautiful and talented young neighbor. See www.foxsearchlight.com/adam.

The fourth film, *Over the Hills and Far Away*, is the story of a father's quest to heal his son's autism. The film received rave reviews at the Sundance and SXSW (South by Southwest) Film Festivals. It is the story of a family's trip by horseback across Mongolia to visit five different shamans. The idea for the trip presented itself when the family perceived the transforming effect of both contact with horses and shamans alike had on the behavior of their young son, Rowen, who has autism. Interestingly enough, the Autism Society of America has fully supported the effort, I suspect, because the family chose to see autism as an adventure, a learning experience for the whole family, and not as a disaster or a burden. My guess is that ASA is not suggesting that shamanism is to be a recommended therapy for autism, but rather that the attitude taken by the family to listen to and to learn from their child is an approach well worth considering. Such an attitude is not unlike that of Barry & Suzi Kaufman in SON RISE. Rupert Isaacson, Rowan's father, has followed the release of the film with a blockbuster book, THE HORSE BOY. See www.horseboymovie.com

Several other books have appeared and would warrant a closer, more careful look:

- 1) **THE FIRST YEAR: AUTISM SPECTRUM DISORDERS** by Nancy D. Wiseman gives a first hand look at how to approach a diagnosis of autism in a family. So often a diagnosis seems to be understood by the experts and the parents alike as a lid (a way of putting the child into a category or a box—of putting the child away—case closed) rather than seeing the diagnosis as a ladder (a place to begin and an opportunity to move beyond). Many specific, helpful strategies are included in this book.
- 2) **ANDREW'S STORY: ONE BOY'S JOURNEY BACK FROM AUTISM** by Julie K. Heinks is yet another compelling story by a mother who says, "As parents we were desperate to help him. Alternative care coupled with our gut instinct (Kim Marie Lesso would certainly affirm this element) finally gave us the first glimpse of hope. Through hard work, proper diet, nutrition, and focused educational programs, Andrew came out of the world of autism in which he was trapped. He is now an easygoing, happy, athletic teenager. See www.publishamerica.com
- 3) **SACRED SPARK** by Lisa K. Sykes relates the story of the ongoing recovery of her son, Wesley, from autism and of her strong advocacy to eliminate mercury in vaccines. See www.sacredsparkbook.com.
- 4) Yet another mother, Ann Millan, tells the story of her adult daughter whose life began to change in significant ways at age 28 when they attended a DAN (Defeat Autism Now) conference in Orlando. The personal and social results have been remarkable over the past 10 years as she has carefully followed the DAN protocol. The story is clearly presented in **AUTISM: BELIEVE IN THE FUTURE: HOW**.

- 5) Finally, yet another mother stands out, as Robyn O'Brien shares her journey in **THE UNHEALTHY TRUTH: HOW OUR FOOD IS MAKING US SICK AND WHAT WE CAN DO ABOUT IT**. She dares to take on powerful Big Agriculture, government agencies, and associations that should know better than to support the current state of food production and processing. The Forword is written by Kenneth A. Bock, M.D., and author of **HEALING THE NEW CHILDHOOD EPIDEMICS: ATUSIM, ADHD, ASTHMA, AND ALLERGIES**. See www.rhinebeckhealth.com. Dr. Bock points out that some 30 million children in the US—more than one third—are affected by one or more of these childhood epidemics. Robyn, an honor college graduate and Fulbright Scholar, has given us a thoroughly researched and fully documented book that tells the truth of the food industry like it is. And it is far from a pretty picture. She is the mother of four small children, all of whom she discovered have food allergies, some serious. The book is filled with useful, if at times startling, information, recipes, and other valuable resources to aid every family in its search for food that promotes true health. **THE UNHEALTHY TRUTH** cuts across the entire landscape of health for our population, and it reads like a detective story as she follows one clue after another, some leading to dead ends and then some to surprising connections and conclusions. You will not be disappointed, and you will undoubtedly be far wiser for having accompanied her on her journey. Robyn is also the founder of AllergyKids. See www.allergykids.com or www.robynobrien.com.

I conclude with two quotations well worth your consideration. They speak directly to the question, "Just Who Are the Experts?"

*In the past 40 years the major advances in the treatment
of autism have not been made by men researchers
in white coats, but by mothers.*

Dr. Bernard Rimland

*The first man (or woman) to see an illusion by which men have flourished
for centuries surely stands in a lonely place.
In that moment of insight he and he alone sees the obvious
which to the uninitiated (the rest of the world) yet appears
as nonsense or worse as madness or heresy.*

Gary Zukav THE DANCING OF WU LI MASTERS