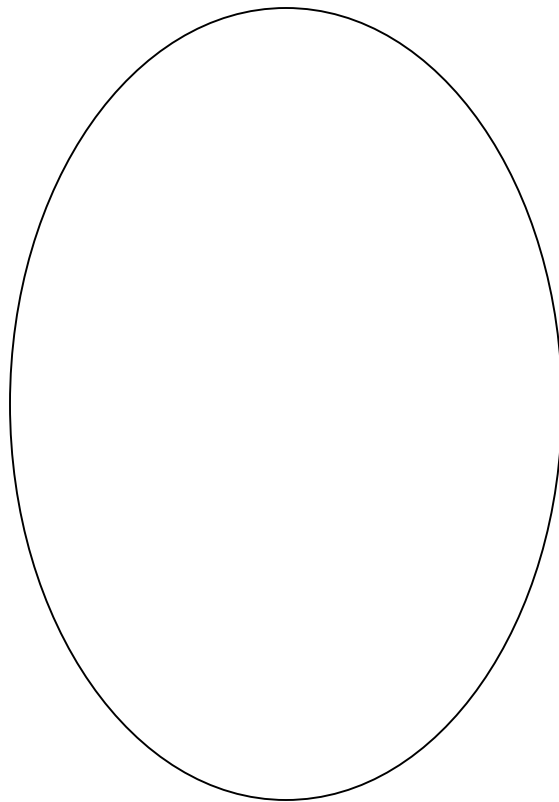


*baby book,
a mother's memoir*



*by
Peggy Heinkel-Wolfe*

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Executive Summary

The simple task of keeping a baby book descends into a
bizzare dissonance as a
young mother watches her toddler's Spartan social world
unfold.

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The book

As a young mother, putting "first tooth" and "first word" stickers on a baby calendar and filling in the entries of a keepsake baby memory book for my son, Sam, seemed simple enough. But as he grew, the recordkeeping descended into a bizarre dissonance. My baby met developmental milestones, yet each new achievement and each photograph cast a Daliesque shadow. He was growing, yet he wasn't growing. When I asked his doctors why, they asked me for information from his baby book - accurate data, yet all lies.

This little memoir recounts our lives and captures some of the conversations I had inside my head as the recordkeeping farce unfolded. We were finally able to right ourselves when Sam was diagnosed with autism at age 4.

People with autism - numbering about 1.5 million in the U.S. - create a Spartan social world for themselves, a way of being that profoundly affects the people who love and live with them. Many parents of children with autism have written memoirs, and many are wrenching tales of their search for a cure for autism. But recent titles, both in creative nonfiction and fiction, tap the quixotic possibilities in the story of an autistic life. These possibilities were hinted at in the early chapters of Uta Frith's *Autism: The Enigma*. But it is recent books such as Paul Collins' pastiche, *Not Even Wrong: A Father's Journey*, the Karasik siblings' genre-mixer, *The Ride Together*, and Mark Haddon's bestseller, *Curious Incident of the Dog in the Night-Time* that truly crossed over. Perhaps the popularity of these books reflects that the stories of people with autism, who must carve rigorously simple lives from our anxious, complicated world, resonate with many readers, not just those whose lives have been touched by autism.

I title the chapters of this book just as entries in a baby book. I shape the story through my own pastiche using Sam's favorite children's books, such as a quiet reference to Eric Carle's *Do You Want to Be My Friend?* and a side-by-side collage of Dr. Seuss' *Green Eggs and Ham*. (This chapter was published as an essay last year in *Windhover*, a literary magazine of the University of Mary Hardin-Baylor.)

This book will run about 35,000 words of narrative that cover the story of our son's birth through age 4½. We were, and continue to be, a lot like most families living

with the day-to-day realities of autism. We are not miraculously cured nor do we follow a single track of therapeutic or educational intervention. Love, trust and inner resilience get us through the daily chaos, and those themes are carried through the story.

Moreover, this book focuses exclusively on how autism looks and feels in infancy and toddlerhood. Besides relying on the dramatic arc of dubiously curing

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their child's autism, most parent memoirs recount the overwhelming daily battles with older children. Although it is not the purpose of this book, I hope that some young parents and those in the helping professions, can better recognize this disorder because of the close-up examination of one very young life with autism. Research has already begun in this area.

The market: who will buy this book

Potential buyers of this book include the millions of parents of children with autism and members of extended families touched by the disorder. This book chronicles the time period that is often the most bewildering for families; which is also the time they are likely to buy the most books in a quest to both understand and help their child.

It is important to know that autism is not as rare as once thought and may, in fact, be on the rise. As a neurological disorder, diagnosed variously as autism, Asperger's syndrome, or pervasive developmental disorder, it occurs in about 2 to 6 of every 1,000 births, according to the Centers for Disease Control and Prevention. A decade ago, when our son was diagnosed, autism was thought to occur in about 5 of every 10,000 births.

Another potential audience is those whose lives have been touched by a person with autism, whether they are in the helping professions or have been with someone who was mainstreamed at school or in the workplace. I believe this is where some of the reach came with the Collins, Haddon and Karasik books. In fact, *Baby Book*, rather than compete with this crop of books, could actually extend the market, since Amazon and other booksellers use a referral system that links similar titles together and makes bestsellers out of older books.

Some of the older "autism cure" memoirs, such as Maurice's *Let Me Hear Your Voice* and Kaufman's *Son Rise*, still appear on the shelves of major bookstores in the

"children with special needs" section, even though the stories are decades old. These books, in addition to Temple Grandin's autobiographical works and Clara Parker's classics, *The Siege* and *Exiting Nirvana*, have become the canon for young parents of children with autism. I believe strongly that my book, because of its focus on infancy, can find a place in that reading rite of passage.

People affected by autism and related disorders meet regularly at conferences around the country, often organized by the Autism Society of America or its numerous state affiliates. Many states have more than one affiliated chapter, with California, for example, having more than a dozen active chapters. These conferences are a natural avenue for selling the book. In addition, autism professionals also seek

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continuing education where the parent perspective is actively sought, creating another ready outlet for promoting the book.

A number of family support groups also meet online, giving great potential to build word-of-mouth support for a good read that respects both the perspective of the individual with autism and the family. The Autism Society of America organizes autism awareness activities each year and promotion of the book can certainly be folded into those major media market efforts.

Credentials

The author and her son, now a teenager, live in Texas with her husband and two other siblings. The author is a freelance journalist whose health news and feature stories have garnered awards from the National Association of Black Journalists, the American Heart Association and the Association of Women in Journalism. She holds a master's degree in journalism from the University of North Texas. Her writings have appeared in major magazines and newspapers, including *The Dallas Morning News*, *Fort Worth Star-Telegram* and *Texas Highways*.

The author was one of the early members of Families for Early Autism Treatment, or FEAT, which chartered in Sacramento, California, when she lived there. She served as a research funding consultant for autism researchers at the University of North Texas. And spurred by the tragic death of a North Texas teen with autism shot by a police officer dispatched to a group home when the teen got upset over missing a television show, she helped secure funding for a

police training program in disability awareness that is now available through ERIC, an education and curriculum database, and is used across the nation. She also served as a member of the parent advisory board to the Denton County Special Education Cooperative.

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Sample Chapter

First 50 Words

Mark braced himself over the kitchen sink for a moment and then turned back to me. Tears filled up his clear blue eyes making them look tired and gray. "You know, sometimes," he stuttered, "I just don't think ten fingers and ten toes is enough."

My heartbeat rattled my breastbone. It stopped any more words from reaching my mouth. It stopped tears from forming in my own eyes. I used to say that to everyone who asked whether I wanted a boy or a girl when I was pregnant. "I just want ten fingers and ten toes," I would tell them.

We finished the dishes in silence.

The way Sam took me by the hand when he wanted something didn't feel right. To the kitchen counter, he pointed for a cookie. To the sink in the corner, he pointed for a drink of water. To the front door, he pointed to ask for a walk around the block.

"Well, Patti said to make him use the word, make him tell you before you give him things," Mark relayed one night after talking to his stepmom on the phone.

She's in Houston, I thought, and she hasn't seen him for months now. How could she possibly know that he's not being willful?

We were so confused that we had considered wilder advice than Patti's, so I tried her suggestion.

"Do you want a cookie, Sam?" I asked after he took me to the cookie jar.

He grabbed my hand and pushed it toward the jar again. I pulled out a snickerdoodle, his favorite, and held it before him.

"Say 'cookie,' Sam," I insisted.

No words magically came out. But the look of betrayal welling up in his chocolate brown eyes stunned me. Sam needs to trust me, I thought. I abruptly handed over the white cookie crackled with cinnamon and sugar.

A few weeks later, in a free parenting magazine that Mark and I picked up mindlessly each month from the rack at Java Joe's, I found a short article about language development. If your child didn't have language by the age of two, the deficit could affect the future development of

his brain, the article quoted the expert. Call your county office of education, the article advised.

At last, I allowed myself to sink slowly into the feeling that I had been swimming against for more than two years. The first full wave hit. Sam was not going to grow out of whatever it was that descended upon him. It was going to get worse. I opened to the blue-lined pages of the phone book and found the number for the Sacramento county office of education.

"How old is your son?" the anonymous person on the other end asked.

"He's about two-and-a-half," I answered. Breathe in, breathe out, I coached myself.

"We have about a six-month waiting list for services, Mrs. Wolfe," Anonymous said. "By the time we get to him, he may already be three years old and in the jurisdiction of the school district."

What the hell does that mean? I thought.

"I don't understand. I read somewhere that you could help," I said as distinctly as I could. "Please, he's already two-and-a-half and he doesn't talk."

"Well, I suppose we can still schedule and intake appointment and get things started," Anonymous said. "I'll have one of the diagnosticians call you."

We hung up. Victory, I supposed.

A few days later, the phone rang and a quiet, probing voice identified herself as Nancy, a speech therapist from the county office of education.

"In order for us to best help your son, we start by doing a short evaluation," she explained. "We bring some toys and books to your home and watch him play for a while. Would that be alright?"

"Sure," I answered. What would toys reveal to a speech therapist, I wondered. If they handed him a car, he wouldn't push it around, saying "Vroom, vroom." Sam would turn it upside down, spin the wheels, and stare voicelessly into the vibrating illusion of mass.

"I can come next week Thursday afternoon. Another evaluator will come with me. It should take about an hour, maybe a little more. Will one o'clock be okay?" she asked.

"Sure," I answered.

The whirlwind schedule for Thursday at one o'clock began with oodles of toys, books, and pictures Sam hadn't seen before. The two women worked gently but quickly, trading tasks and challenges to keep Sam moving. Of course, he examined the toys for things that could spin, parts that could open and close. Does this make noise? I could see him

asking himself. He didn't have much use for the picture vocabulary cards. He flapped one up and down in his peripheral vision.

"It will take us about two weeks to work up the results," Nancy said when they were finished. "And can you fill out this parent report? It will be part of the evaluation. I'll call you to schedule another visit when we're ready."

I took the packet she held out to me. There were many questions, and some would take time to research. At Sam's baby shower, my girlfriends gave me a calendar to mark his milestones with a sticker. They knew I wouldn't painstakingly chronicle Sam's every sentimental moment. Sit up, crawl, first words, first steps - all were marked on the date with a sticker. "First time waved good-bye," the report asked with a short, blank line by the phrase. How do I describe that day when he was eight months old? Sitting high in his daddy's arms, eager for the favorite walk to the corner grocery store at Colonial and Stockton, he waved at me from the doorway. Overcome by our joyous reaction to his new skill, he stopped abruptly. And he refused to do it again for months. Did that count? Was that the first official time he began waving bye-bye? Does he have to keep waving good-bye in order to get credit for it on the parent report?

"Okay," I said. They left with instructions where to mail the completed report when I was finished.

Nancy by herself several weeks later carrying her dark vinyl satchel.

She pulled out a manila file with "Wolfe, Samuel Donald" written in the color-coded tab on the top and inside were several copies of a two-page report. She gave me one stamped "Copy." The little report touched on many domains of Sam's being: receptive and expressive language, self-help, social skills, educational aptitude, and achievement. Every category of evaluation had several sentences that summarized an hour of playing with Sam. The report gave us new words and phrases and ideas for describing Sam, such as "skill scatter." He was markedly ahead of his age on some tasks, but unbearably behind on others. Socially, the report said, he was at the level of a six-month-old baby.

"His language deficits qualified him for speech services," Nancy said. "That's about all the county can offer you right now. I can come for a visit once per week and work with you and Sam on developing his language. He

can probably get more from the school district when he turns three."

"That's great," I said. "But I'm not sure what to think about all this other information and what to do about it."

"Well, sometimes when you work in one domain, it helps the others," she said.

"Oh." I was skeptical that learning to say the word 'potty' would help Sam develop a desire to use it, but I took her observation as hopefully as it was offered.

"Could you keep track of all the words he uses this week and write them down?" Nancy asked. "It might be a good place to start."

"Sure, I think I could do that. There really aren't that many," I said.

Nancy slipped the manila file folder with Sam's name on it back into her satchel. As she stood up and we started toward the front door, I turned to Sam. He was putting the rainbow-colored donuts back on the stacking spindle.

"Nancy's leaving Sam, would you like to tell her 'bye-bye'?" I asked.

Nancy and I looked expectantly at Sam as he abandoned the stacking toy on the living room floor and dashed away into his bedroom. I shrugged my shoulders as the corners of my mouth rose in a surrendered smile. Nancy smiled back. She seemed to have as much hope as I did, but I wondered how she could get Sam to talk.

I walked her to the door.

"See you next week," she said.

"Next week," I echoed and watched her through the picture window as she put her satchel in the trunk of her sedan. As she slipped into the driver's seat, another car raced by before she pulled away herself. She drove straight down Sherman Way where it ended a Stockton Boulevard in front of the medical center, where either left or right was her next house call, to the next mom who wondered how she failed to help her child learn to talk.

Well, I thought, Sam certainly knows "bye-bye." I went back to the corner of the kitchen where we had set up the home office. I got a piece of white paper from the computer printer and a pen from the desk drawer. "Sam's Words" I wrote at the top and dated it.

Bye-bye, I wrote down the side of the paper.

Theodore Giesel's publisher made a bet with him. Could he write a book using just fifty words? Giesel took the gauntlet, of course.

Cookie, Sam, Dad, Mom, I wrote.

Copies of the little book's manuscript hung on the museum wall. Clearly, Giesel was counting his words as he worked out the poetry. "I would not like them here or there. I would not like them anywhere."

Water, drink, walk, I wrote.

"I do not like green eggs and ham."

Bee, ouch, I wrote. I listened to Sam all week. Once in a while, I logged a new word. The day before Nancy was scheduled to visit, I double-checked my count.

"I do not like them Sam-I-am."

Fifty. He had fifty words in all.

"I am Sam. Sam I am."