

Excerpted from **Retarded Isn't Stupid, Mom! Revised Edition**, by Sandra Z. Kaufman.

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Prologue: Nicole at 2 Years Old

The downpour stopped as quickly as it had begun — which was typical during the rainy season — and the sun again burned down. Steam rose from the tarmac around the troop transport plane.

"Probably saw a lot of use in Korea," Matt said, eyeing the old DC-3. He shifted our 2-1/2-year-old daughter, Nicole, from one arm to the other. Since the end of the war in 1953, 5 years before, troop transports had been used for more mundane purposes, such as carrying military families to and from the United States.

Airmen rolled out the stairs, and we fell in line to board the plane. Nicole reached over and patted the baby in my arms. To her delight, her brother made a bubble. She laughed and clapped her hands.

The line moved quickly, and we were soon settled in our seats. The plane taxied for the takeoff, and then it lifted into the sky, taking us away from the Panama Canal Zone and the army post that had been our home for the past 3-1/2 years.

Nicole cried and cried; the many changes from her familiar routine were too much for her. Finally, however, exhaustion won out, and she fell asleep in Matt's lap.

As I covered her frail body with a blanket, I again pictured Dr. McCall and Gorgas Hospital. Shuddering, I looked out of the window and forced myself to think of other, happier things — like Los Angeles, where we would be in a few hours. Matt and I had met in Los Angeles 4 years ago. How serendipitous it seemed, as I looked back — me, a dancer whose world was made up of ballet studios and theaters, meeting Matt, a lieutenant teaching armored tank maneuvers in the desert. Two months later we had married.

My throat tightened. Nicole had been conceived in Los Angeles. Were events coming full circle? Were we bringing her home to die? That's what the doctor had said, wasn't it — that she might die?

I looked down at her — at the wispy blonde hair and the dainty nose and mouth — and events from the past 2-1/2 years came tumbling back.

The spinning in my brain receded, and I opened my eyes. A blinding circle of light glared down on me. I turned away. Hazy figures in white moved about nearby.

The pain is gone. This must be the delivery room. I must have delivered the baby.

"You have a little girl," one of the figures said.

A girl. How marvelous.

"Is she all right?" My words slurred from the anesthesia. It was a routine question. I had no cause to think anything would be wrong.

"We had a little trouble getting her to breathe, but she seems to be just fine," the nearest figure said from behind his white mask. I recognized him as the on-duty medical officer from the night before. "She's very small though, in spite of being full-term . . . only 4 pounds, 7 ounces."

"May I see her?" I begged. Through my myopic eyes, she seemed to be lying in the drawer of a gleaming stainless steel cabinet.

"Just another second or two," he said. He completed his examination and then, lifting a bundle of white blankets, he placed her beside me. I laughed with amazement at the miracle Matt and I had created.

Slowly I worked my finger into her curled fist.

"Hi, Nicole," I whispered, for Matt and I had decided on that name months ago. She twitched and wiggled while I watched.

The doctor interrupted us. "She must go into an incubator because her birth weight is so low." He scooped Nicole up and handed her to a nurse who disappeared with her.

That was all right. Matt would get to see her. I drifted off to sleep thinking how pleased he would be.

Nicole and I went home 3 days later. I placed her in her bassinet, and then, unable to keep my hands off her, I picked her up again. Love for the tiny person that snuffled against my neck tore through me. I adored Matt, but this baby brought out something primeval.

She began to fuss. "That's all right," I said, patting her. "You can cry all you want in the daytime. Just don't cry at night. Your father works hard and needs his sleep."

It didn't happen that way. She insisted on being fed every 2 hours — day and night. After a week, I was hollow-eyed and dragging around the house. Matt quietly took on sterilizing the bottles (Nicole slept 2-1/2 hours when I stopped the breast-feeding), going to the commissary, and cooking supper.

But she gained weight. When she was 1 month old, we took her to Dr. McCall, the pediatrician at Gorgas Hospital, for her checkup. Nicole weighed in at 6 pounds. I was so pleased that I laughed — until I realized that the nurse, the doctor, and Matt were all noticeably sober.

"Her development will be slower than average because of her size," the doctor said. "She won't catch up until she's a year old."

That made sense. It explained why Ellen's baby, Ben, was so far ahead of Nicole. At 1 month of age, he had sat sturdily in his mother's lap and looked around. Nicole was still floppy and had to have her head supported. I was reassured.

Two months later, Nicole weighed 10 pounds, could smile, and could flip herself over. She could also "talk."

"And so, young lady, what would you like to do today?" I asked, as she sat facing me on my knees. She was holding her head up nicely then.

She opened her mouth, shaped it, took a breath, and out came "Ooooooooooooooh."

"You would?"

Her eyes watered, and her face turned pink with effort. "Ooooooooooh," she said, changing the intonation.

But, as the doctor had predicted, her development continued to be slow. Nicole couldn't sit until she was 8 months old. Then, when she began crawling, it seemed as if she were going to travel on all fours forever.

When at 18 months she finally began to walk, I thought she was doing splendidly, considering her slow start, but Dr. McCall expressed concern when I took her for her appointment the following week.

"I think we ought to run some tests," he said. "She's probably just delayed, but I'd like to make certain. Bring her in for a calcium and phosphorus blood test Monday. Perhaps we're overlooking something."

I nodded silently, but my heart began hammering. What did he mean? What could be wrong?

The fright of the actual test was soon behind us as Nicole and I returned on Monday, but the wait for results seemed interminable.

The following week, Dr. McCall finally called. Nicole's calcium and phosphorus levels were fine.

Of course they were. There was nothing wrong with my child! Why had Dr. McCall so unfairly alarmed us?

Eventually I cooled down. At heart, I had faith in the medical profession. Those people in white coats knew what they were doing, even if they did sometimes scare me.

The blood test episode faded as Matt and I enjoyed watching Nicole try out new activities after she could walk. She was making progress, but she seemed weary, too. Whether the climate had anything to do with it, I didn't know, but she grew more and more listless. She lost weight. At 2-1/2 years, she weighed only 18 pounds. Colds and flus plagued her. In spite of a diet loaded with vitamin B and cod-liver oil, her health was deteriorating. Matt and I watched her anxiously.

Nicole cried over everything and nothing, and she wanted to be carried everywhere. Sometimes she had to be transported in our arms because she was so weak. She and I practically lived at the pediatrician's office.

One day, Matt took time off from work and drove over to Gorgas Hospital with us. Dr. McCall undressed Nicole and gently examined her, as he had done so often. I tried to look at her clinically, and I was shocked to realize that except for her cheerful smile, she resembled one of the children in a World War II concentration camp I'd seen in *Life* magazine — all knees and elbows.

When Dr. McCall was finished with the examination, Nicole drooped in her father's lap. The overhead fan beat ineffectively against the heat.

"What do you see as the prognosis for Nicole?" Matt asked the doctor. Why on earth was he asking that, I wondered.

Dr. McCall paused. He looked down at his papers and then at us.

"She's mentally retarded . . . she may never advance beyond the mental age of 5 years," he said finally. The fan continued circling. "Nothing can be done for her," he added regretfully and then mumbled something about the retarded often having short lives.

I was caught totally unaware. Retarded? Our child, retarded? This isn't happening, I thought. I dropped into a void, plummeting, plummeting.

Escape? There was no escape.

I wanted to scream at the doctor, "How can you be so calm! You've just changed the course of our lives!"

Instead, I sat numbly silent. Matt and Dr. McCall continued talking. Matt got up; then I got up. He walked out of the room, and I followed him. We reached our car, and I started out alone toward the pharmacy for Nicole's prescription.

Somewhere on the walkway, the tears began to come. I fled to the car. There, in Matt's arms, all the incredulity and pity for Nicole came pouring out.

"I'm so sorry," Matt kept apologizing. "I thought you suspected. . . ." He'd known for months, he said, but he wanted to wait until the new baby was born before talking about it. Two months earlier, Nicole's baby brother, David, had entered our lives.

Through my tears, I looked back at Nicole playing with the window handle in the back seat, oblivious to the cruel sentence that had been passed on her. How could our precious child be doomed to grow into one of those weird unfortunates who drooled and said stupid things?

Even worse, would she ever grow up? We might lose her the next time she was sick. "The retarded often have short lives." That's what the doctor had said.

"How did you know?" I asked Matt.

"I saw how long it took her to do everything — to hold her head up, to sit, to walk. . . ."

"But that was because she was so weak and small! Yes, she was slow, but she walked and sat within what Dr. Spock says is normal."

"There were other hints something was wrong," Matt said gently. "Her feeding problems in the early months. The way she fights us if we try to cuddle her. The way she stiffens and holds her breath when I try to bounce her. . . ."

"But that's just her personality."

"Sandy, those things aren't right. I don't know what they mean, but normal babies don't act like that."

I wiped my nose with Matt's handkerchief and looked out of the car.

"You mean you never, ever thought of retardation?" he asked.

"No." The red blossoms on the hibiscus bush were wilting in the heat. "I don't know why. Maybe it was because she was my first child." I turned to face him. "Retarded or not, we've got to keep her alive, Matt. We're going home next month, and we're going to find a doctor who will make her strong and who will help her to grow. Who knows? Maybe she isn't really retarded. Maybe when she catches up in health and size, we'll discover her mind is just fine. . . ."

"Sandy, are you okay?" Matt asked. His voice brought me back to the plane and the drone of the engines carrying us northward.

"Oh, Matt," I said, reaching for his hand. "How can we stand it? Other people have retarded children . . . not us." I thought of the Colonel's wife whom I'd visited right after she'd given birth to a little girl with cleft palate. "I guess we forget these things can happen," she'd said to me. "We feel we're owed a perfect child. We shouldn't expect so much. . . ."

How had I come to expect so much?

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