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A must-read guidebook for parents of autistic children.”*

Bernard Rimland, Ph.D., director, Autism Research Institute

F A C I N G

# AUTISM

GIVING PARENTS REASONS FOR  
HOPE AND GUIDANCE FOR HELP



L Y N N M . H A M I L T O N

F A C I N G  
A U T I S M

G I V I N G P A R E N T S R E A S O N S F O R  
H O P E A N D G U I D A N C E F O R H E L P

L Y N N M . H A M I L T O N



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This book is dedicated to our precious children

— **Ryan and Tori** —

for whom we would climb any mountain.

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## Chapter 1

# The Early Days

*The field cannot well be seen from within the field.*

RALPH WALDO EMERSON

In a month we would be leaving for a summer in Siberia. The work Roger and I do in Christian ministry had taken us there for the summer of 1991, and now two years later we were anxious to return. But this time we were going to Russia with a thirteen-month-old child. We were excited about showing Ryan off to all our friends, but taking a child to Russia wasn't an easy task. Items that could be easily purchased in the States, like diapers, weren't available in Siberia, so we would have to pack everything Ryan needed for the summer. What toys should we take? What kind of food would they have for Ryan, and what additional food should we carry with us? And just how many diapers *does* a toddler use in nine weeks? The questions and the preparations were different this trip.

I began making careful lists of what we used each week in caring for Ryan, from diapers and wipes to shampoo. I also watched Ryan closely as he played and noted which toys and books he liked best. The toys needed to be small enough to carry easily but exciting enough to keep his attention on the long flights to and from Moscow.

In preparation for our travels we discussed medications and vaccinations with our doctor. Ryan had already had several ear

infections, so we wanted to take along some antibiotics. We also wanted to have him vaccinated before we left since we didn't know how commonly vaccines were used in Russia. He was current on all his shots, but he would soon need the MMR (measles, mumps, and rubella), so we gave it to him at twelve and a half months old.

With everything ready, we left for Russia. Overly prepared for the trip, we checked nine bags and carried three on the plane. After arriving in Russia, we faced a three-day journey on the Trans-Siberian Railroad. Ryan enjoyed the train and its constant rocking, but he seemed fussy and cried more often than normal. I remarked that we had hit the "terrible twos" at only thirteen months old.

Once we arrived and settled in, Ryan did better. He liked exploring the apartment that we had rented. Our bedroom had white lace curtains, and Ryan would hide behind them and play peekaboo with us. Or he would play outside in a sandbox, digging in the sand and sifting it through his fingers. He also loved petting the dogs in the neighborhood, especially a little brown puppy that two children upstairs owned. He would chase it and giggle when it jumped on him and licked his face.

Ryan enjoyed his days in Siberia. Although I had brought a lot of packaged food from home, like tuna and macaroni and cheese, Ryan liked the Russian food and ate and drank everything offered, except the milk. He learned to wave good-bye when spoken to in English or Russian and understood whatever we said to him. Although he spoke only a few words, I attributed it to the confusion of hearing two languages and was certain his vocabulary would blossom once we returned home.

All in all, it was a typical summer, except we spent it in Siberia.

### Signs of Change

When we returned from Siberia, my parents met us at the airport to drive us back to Madison. Mom had brought us our favorite soda and snacks, which made Roger and me extremely happy, but Ryan was only interested in some balloons he saw. He kept saying, “Bbboom, bbboom,” and reaching out to the balloons. With this new word, *balloon*, he now had six or seven words.

When we got home to our apartment, we went to visit our close friends Dawn and Scott. They had two children: Zac, who was a couple of years older than Ryan, and Lynsey, who was only eight days older. Unlike Ryan, Lynsey was quite a talker. Over the summer she had learned many new words and was even putting them together in phrases. This caught my attention, but I brushed it aside. After all, girls generally talk earlier than boys.

But as I watched Lynsey learn new words in the following weeks, I realized that not only was Ryan *not* learning new words, but the words he had previously spoken were gone. Was I imagining things? I dug out Ryan’s first-year calendar and flipped through the months. Yes, I had written down some words, so he had said them. Where were they now? Perhaps Ryan had become confused in the transition between Russia and America, I thought, but as I continued to compare Ryan to Lynsey, Ryan fell further behind each day.

One day we had friends over for a cookout in our backyard. While Sarah and I were in the kitchen preparing the food, Ryan came in and began to scream. As usual, I tried to figure out what he wanted. I pulled out cereal from the cupboard, but he kept screaming. I opened the refrigerator and took out the milk, then juice and then water. Ryan’s screaming increased. He didn’t point to anything or give me any clue as to what he wanted, but since we were in the



kitchen, I assumed he was hungry or thirsty. I continued to pull out items one by one, until I finally stumbled on what he wanted—a cookie. Taking the cookie, he calmed down and left the room.

Seeing my stress, Sarah shared how she required her children from an early age to speak to her either in words or in sign language to get what they wanted. She stressed the importance of not giving in to children until they communicate their desire clearly. I didn't feel as though I was giving in to Ryan, but she had four talking children and I had none, so I tried. The next time Ryan came to the kitchen and screamed, I tried to get him to say what he wanted. I gave him words to choose from, but I didn't show him anything from the cupboards. This made him scream more. In my determination to help him learn to talk, I pushed even harder until another friend, Marie, approached me with her answer to my problem.

Marie felt I was pushing Ryan too hard. If I would only relax about his language and allow him to develop at his own speed, he would speak. I liked this better and it was a lot easier on my ears, but still the language didn't come.

One week when I picked him up from Sunday school, I mentioned my concern about his language delay to the teacher. He didn't seem concerned, saying, "Einstein didn't speak until he was four." I had heard that many times.

Our concern about Ryan's language skills kept us from realizing that other skills and behaviors were deteriorating as well. Daily, Ryan became more difficult to handle.

### **Strong-Willed or Out of Control?**

Late in November, when Ryan was about eighteen months old, we went to walk the mall with three friends, Dawn, Linda, and Heidi, and their kids. All the Christmas decorations were up, and the kids

were excited. We started our excursion at the food court. I put Ryan in a chair and set some food in front of him, but he wouldn't sit still. He immediately got out of his chair and ran away. I called after him, but he didn't stop. I chased him down and brought him back, and again he scurried away. "No" and "stop" seemed to have no meaning to him at all. Never did he look back to acknowledge my commands. In fact, it was as if he didn't hear me. The other mothers enjoyed their lunch with their kids, while I just tried to contain my son in the area. As my frustration grew, I wondered, *Can't he sit long enough for me to eat?*

Feeling bad for me, my friends finished their food quickly, and we began walking around the mall. Ryan, of course, led the way with me in close pursuit. He was driven to touch everything. When I told him no or disciplined him, he would turn right around and do it again. When Lynsey touched something she wasn't supposed to, Dawn told her "no, no" in a calm, gentle voice, and, lo and behold, Lynsey stopped! Why wouldn't Ryan? The other children, all about the same age as Ryan, stayed close to their moms and enjoyed the decorations with childish glee while my child ran wild.

As Linda's son, Isaac, said something cute, Linda commented, "Isn't this a wonderful age?" I looked at her as if she had just landed from another planet. I thought, *No! This is not a wonderful age. I hate it! I can't control my child. I can't eat in peace. I can't talk to my friends. All I do is chase this child, and he won't listen to a thing I say! Why am I such a bad mom? Why can't Ryan behave like the other kids? What am I doing wrong? Why do I even try to leave the house? I hate this!*

Within moments Ryan was getting into the decorations again, and I couldn't get him to stop. I'd had enough. Breaking down in tears, I picked up Ryan, who was screaming in defiance, and excused myself to go home.

Ryan wasn't always out of control. He was normally happy, playful, and affectionate—if things were done his way. He loved to cuddle and hug and run and laugh. But if demands or limits were put on him or if I told him to do anything other than what he had chosen, he would let loose a bloodcurdling scream and throw a tantrum as if he were terribly hurt. His body would shake, sometimes as he stood, other times as he lay on the floor.

Believing Ryan was a strong-willed child, I read every book about raising a strong-willed child that I could get my hands on and tried every technique, but none worked. Again I thought I must be a bad mom. Having been given the techniques to tame my child's behavior, I couldn't make them work. It *had* to be my fault.

The blame I felt for Ryan's behavior may have been partly due to my insecurity, but it was confirmed by the stares and comments of those around Roger and me. Looks of disapproval were commonplace. When Ryan would stand on the chairs at McDonald's and make noises, adults stared openly. If our eyes met, they would shake their heads and look away. One man in the Denver airport swore at us as Ryan screamed because of the loud noises, and another time a man grabbed Ryan by the arm and yanked him off the ground during a tantrum. It was open season for judging our parenting skills, and with no other explanation for his behavior, we accepted the blame.

We weren't the only ones who couldn't handle Ryan. At one point I joined a Bible study for mothers of young children. They provided childcare filled with wonderful activities for the kids while the moms got a break and had a chance to learn. Each week I would go, looking forward to the day's speaker and Bible study time, but each week ended the same. About a half-hour into the lecture, someone would come find me to let me know they were

having a hard time handling Ryan. Apologetically, they would ask me to come get him. Often I would hear comments like, “He sure is all boy.” After several failed attempts, I dropped out.

### **Dietary Changes**

One area in which Ryan was no different from his friends was eating. He seemed hungry all the time. As a toddler he had eaten any food we gave him, but somewhere along the way things began to change. While in Russia, Ryan drank water from a cup and milk from his bottle. But as he was closing in on two years old, we felt it was time to make the bottle disappear. When we moved from an apartment to a house, we decided to “lose” his bottles in the move. In our apartment, he knew where we stored them and would point and scream until we would give him a bottle, even if the bottles weren’t there. But in the new house, there would be no cupboard assigned to them. They would just disappear.

When the move came, we put our plan into action. The bottles were gone and the cups took over. What we didn’t count on was that Ryan refused to drink milk from a cup. To him, milk came from a bottle and water from a cup. Every time we gave him a cup of milk, he would throw a tantrum and refuse it. Eventually we gave up. Refusing to bring back bottles, we settled on allowing him to drink just water for the time being, assuming that one day he would be willing to drink milk in a cup. We were wrong.

Besides his drink limitations, his eating habits were also changing. This child who used to eat everything was becoming a very picky eater. He used to eat cottage cheese, but now he wouldn’t touch it. The same was true for most vegetables and fruits. One by one Ryan began refusing foods, and the foods he would eat became more defined. I had grown up eating chocolate-chip pancakes, and

we passed this tradition on to Ryan. He loved them, but he began demanding extreme consistency. When we made pancakes, there had to be two of them and they had to be the same size. If we gave him just one pancake, he would tantrum uncontrollably. To him, pancakes came in twos.

Other foods began to follow suit. He liked to eat fish sticks, but now they had to be Fisher Boy square fish patties. He would accept no other brand and no other shape. The same was true with chicken nuggets and fruit-grain bars. Ryan's once varied repertoire of food was whittled down to just a few items. He would eat pancakes, waffles, and French toast—all of them plain, without butter or syrup. He would eat grilled cheese but only with mozzarella cheese. He ate chicken nuggets, corn dogs, and Doritos. In fact, he loved Cool Ranch Doritos and would have been content to live on Doritos alone or on most other junk food, like chips, cookies, ice cream, and cake, but he refused to eat any fruits or vegetables or to drink juice or milk.

The strangest thing was that Ryan was still growing well, and despite occasional ear infections or bouts of diarrhea, he looked healthy. Since he was still at the upper end of the chart for height and appeared healthy, our doctor told us not to worry. “Kids are often picky eaters,” he said. “Just keep offering him healthy food, and someday he will eat it.”

### **A Place for Everything**

Ryan's rigidity with food transferred over into other areas of his life. Ever since Ryan was little, he had loved to watch movies while rocking on his horse. He rocked on it so much that he actually wore through the thick metal rings connecting the springs to the horse.

To him, the rocking horse and movies went hand in hand. He

would watch movies every waking hour if he were allowed. And he didn't like to vary the movies but repeatedly watched the same ones. Disney's *Snow White* was one of his favorites, and he knew it so well he would often imitate the dwarfs' actions before they happened. At certain parts he would squeal and wiggle with delight. It was fun seeing him enjoy these movies, but there was a nagging feeling that he was unusually attached to them. Did all children respond to movies like this?

In Ryan's world everything had a place where it should stay, including his movies. Our two-story home had a finished basement, which we made into three rooms: a playroom, a laundry room, and an office for Roger. The basement playroom had the TV and many of Ryan's toys. In most playrooms toys lie on the floor until Mom or Dad comes to put them away. However, Ryan insisted we leave certain things on the floor. He would place his *Pinocchio* video in the middle of the floor, just to the left of his rocking horse. Whether he was watching *Pinocchio* or not, the video cover had to remain there. When I would pick it up and put it away, Ryan would throw himself into an extreme tantrum. His hands would shake, and he would scream as if he were being tortured until he could return the video to its designated place on the floor. This behavior bothered us, but discipline didn't seem to correct it. He wasn't acting out of defiance. He seemed to need the video in its spot to have peace within himself.

Ryan also liked order in objects that surrounded him. When outside, he would find rocks and line them up by size. Inside, he would take stuffed animals or cars and place them in straight lines or perfect semicircles. Since Roger and I like order in our lives, his behavior didn't bother us. We just figured he was a bright, organized child.

## Daily Life

With Ryan more difficult to understand and handle all the time, the stress in our daily lives grew. With each regression, Ryan screamed more and my nerves became more strained. I was now pregnant with our second child, so my tolerance was probably lowered by all the changes in my body.

Although I loved my little boy more than I ever thought I could love a child, I was fearful of having another one like him. It took everything I had to keep up with him and survive each day. How could I handle the stress if my second child acted the same way? Bathing and diapering Ryan required two people—one to hold him down while the other tried to change the diaper. Being kicked by Ryan in the process wasn't unusual. Dressing him wasn't any easier. He would run around the house with us trying to catch him long enough to get a shirt or pair of pants on him. Having raised five children, my mother often wondered why it took two of us to do such simple tasks like bathing or dressing Ryan.

I've always considered myself a strong person with a high tolerance for stress, but this was getting the best of me. Each day I would feel ready for the battles, but by the time Roger came home from work, I would literally be shaking. Why was this so hard? Was I not cut out to be a mother? The very thought made me feel guilty.

## A Hearing Problem?

When Ryan was about two years old, we took him to our pediatrician to have his ears checked because we were becoming increasingly concerned about his lack of language. We thought that perhaps his ears were plugged with wax so he wasn't hearing properly. If we could get his ears cleared, maybe his speech would develop.

When we arrived for the appointment, Ryan seemed anxious.

As we waited in the examining room, Ryan, with his usual high level of energy, opened every cupboard door and drawer he could find. He would take out the dressing gowns, and I would put them back. He would grab the doctor's equipment, and I would frantically try to pry it out of his little hands. It amazes me how strong little hands can be when they want something they aren't supposed to have. I tried to redirect him with books and toys, but it didn't work. He had his own agenda.

When the doctor arrived, Ryan was turning the lights on and off. It drove me nuts, but at least he wasn't breaking anything and he was happy. The doctor tried to examine him while Ryan sat on my lap, but Ryan wouldn't cooperate. I held his head with one hand, wrapped my other arm around his stomach, and tried to contain his legs with mine. The doctor looked into his ears, but he really couldn't see much because there was too much wax. *Great*, I thought. *Let's get the wax out and fix this.*

When I released Ryan, he fell to the floor in a tantrum. I looked at our doctor and asked, "Is this normal?" He commented that it wasn't, but he didn't know what to make of it. We flushed out Ryan's ears with a warm water solution and waited to see if things improved.

Unfortunately, they didn't. Over the next few weeks we noticed more strange characteristics of his "hearing" problem. Sometimes he appeared to hear well; other times he seemed deaf. One day when he was in the bathtub, I called his name but he didn't respond. Trying again, I called out, "Ryan!" but he didn't answer. I spoke louder and moved closer, but he didn't bat an eye. Finally I got within five inches of his face and called his name again. Nothing. He wasn't trying to look around me; it was as if I didn't exist. How could this be? Ryan loved to be affectionate with



us. He loved to run into our arms and laugh. He enjoyed being chased in circles around our living room. How could he then, at other times, so totally ignore us?

We decided to try our own hearing test. One day while Ryan had a movie on but was facing away from the TV, we muted the sound. He instantly noticed and turned around to see if the TV was turned off. Then we tried making a variety of sounds around him in the room. He seemed to notice all those sounds, too. We called his name and got no response. We tried again. No response. We tried a third time. This time he looked at us. Did he focus so intensely that he could tune us out? We doubted it. Then what was wrong?

### **Sleep Disorder**

Ryan was never a very good sleeper; I, on the other hand, was extremely gifted in sleeping. I could sleep anywhere, anytime, and I needed a whole lot of it. When Ryan was first born, his sporadic sleep was not unusual, but as he got older and still didn't sleep through the night, it became more noticeable. By the time Ryan was two and a half and was still not sleeping through the night, I'd had it. My nerves were raw, and my sleep deprivation was affecting other areas of my life.

We had heard many methods of training a child to sleep through the night, so we began to explore them. We read a good book called *Solving Your Child's Sleep Problems*, which gave us some understanding of why Ryan might not be sleeping through the night, as well as practical solutions. They helped for a while, but we still hadn't solved the problem.

As Ryan got older, not only did he not sleep through the night, but he also needed me to lie down next to him to get to sleep. I was his comfort. When he awoke at night, he needed me beside him to

fall back asleep. One night I got so frustrated that I grabbed a baby blanket and threw it across the room. “I can’t take this anymore! I need to sleep!” I said as I broke down in tears. “We have to find an answer!” Roger agreed, but where to look for those answers?

### Uneven Skill Levels

Although the volunteers at the moms’ group were unable to handle Ryan, Roger and I were able to leave him with the Sunday-school teachers. Each week we would drop him off before the worship service, nervous about how he would do. Some days they would come and get us, but often they were able to keep him the whole hour. Since volunteer teachers ran our Sunday-school class with parents rotating as helpers, I welcomed my turn in the classroom. Then I’d be able to watch other two-year-olds in action and, hopefully, prove to myself that I was worrying about nothing.

When the week came for me to help, Ryan and I eagerly went to the classroom. We were the first ones there, so I began to set up the room with puzzles, books, and toys. Ryan liked puzzles, so he chose some to do. The kids trickled in and the class began.

First on the agenda was craft time. All the kids sat around the table to color and make a special craft about our lesson. Ryan refused. He wouldn’t sit down or color. In fact, I realized that he had *never* colored. Our neighbor’s children loved to color, but when Ryan didn’t, I just thought he wasn’t old enough. Yet he was the only child in the class who couldn’t color.

Next we had circle time. All the kids came running over to the circle and started singing songs with the teacher. One shy little girl wanted to sit right next to me, but as I sat there with her, my eyes were glued on Ryan. He wouldn’t come to the group. Even when another parent tried to bring him over, he screamed and refused.

He preferred to wander around the back of the room looking out the window or staring into space. During story time we again tried to get Ryan to come listen to the story. After all, he used to love having stories read to him at home. But no luck. Ryan would have nothing to do with story time.

Next was snack time. Surely Ryan would want the snack. I was wrong. Ryan drank the water but wouldn't eat the apple slices or cheese. He used to love fruit and cheese. When had he stopped? We tried to get Ryan to sit at the table with the other kids for the snack, but he threw a tantrum. In order to maintain peace in the classroom, we gave in, and he went back to his wandering. Now I knew why they were able to handle him in Sunday school. As long as he wasn't expected to participate in anything, he was happy.

For the first time I really knew something was wrong with Ryan. I leaned up against the wall and slid to the floor, weeping. I didn't know *what* was wrong, but I knew deep in my heart that Ryan was different. One of the other parents came over to console me by reminding me that boys develop later than girls and that I shouldn't compare him with other kids. That sounded nice, but I knew better. Ryan couldn't do anything that came so naturally to the other children. What confused me was that Ryan could do some things much better than these children. They were struggling with simple puzzles, putting a circle into a circle opening and a duck into a duck opening. Ryan, on the other hand, worked complex, interlocking puzzles with thirty or more pieces. What was going on?

When Roger came to get us after the service was over, I shared with him what I was feeling. He took me in his arms and tried to console me. "Give Ryan some more time. He'll catch up." But I knew the problem went deeper than that.