

# Chapter 1

## In the Beginning

**The Facts:** As of April 2010, the Centers for Disease Control (CDC) website reports that an average of one in 110 children are diagnosed with autism, resulting in hundreds of thousands of people who need information and services immediately.



...but it takes  
a child with special needs  
to raise the consciousness  
of a village  
—Elaine Hall

**The Need:** Autism rates exponentially increased since the mid-eighties, and thousands of families have a child with autism who are reaching adulthood without a comprehensive resource to help them make that transition.

*Autism Tomorrow* gives you the comprehensive resource and life guide you need to help your child make a smooth transition into adulthood.

When you have questions about whether your child can work, go to college, live independently, date, get married, have children, be safe, have a secure financial future, or any one of a hundred others, the experts in this book will help you with important decisions on how to proceed. The goal is to help your child not only survive, but thrive in the real world.

We've combined well-researched information and weave in two families' real-life stories about how they handle all the challenges for their sons. One story is about Karen's son, Jonathan, diagnosed with high-functioning autism and refers to himself as Asperger's, and the other is about Bill's son, Chris, who is on the other end of the spectrum, with a more severe form of autism.

You'll read this book, crying one minute and laughing the next, yet always full of hope for your child and his future.

As you continue, you'll discover this is a book of real love and understanding, along with a roadmap for your child's future, no matter where he or she is on the spectrum. This comprehensive manual is for parents, educators, professionals, caretakers, first responders, people around you, and all people with autism. It has practical lists of things to do and not to do, beginning with when your child is young, and later, going out into the world. The topics include education, special training, independent living, college, jobs, families and many more.

We know that everyday life can be challenging when you have a child with autism, and some of the most difficult decisions relate to making plans for your child's care, whether you are around or not. You'll want to know who will care for your child, where she will live and how his or her lifestyle is funded. You'll also want to know more about what your child's daily life will be like and what kinds of documentation you'll need to implement today to ensure your child's best interests.

Families with autism in common can share joys, fears, challenges, and hopes, all within the covers of the book you're holding.

As Bill so eloquently talks about his son, Chris, throughout this book, telling stories, some about great pain, others about joy, he says it best:

*Suddenly, I am swept up in the beauty of the moment. My son glances up and smiles at me. That is his gift, his special skill. He taught me about life. I am blessed. Chris brought simplicity into my life. He gave me a new vision.*

### **Relentless Persistence: Making Autism Work**

Karen L. Simmons

My sister-in-law insisted I take my son, Jonathan, for an evaluation. When I heard the word autism, I was in a total state of denial. Not my son! But, rather than stick my head in the sand, I decided to prove others wrong by going ahead, not listening to their nonsense, and enrolling him in early intervention. After all, it couldn't hurt him.

Surely, they would recognize that Jonny (Jonathan) was a perfect, so-called, normal child. Eventually, however, the truth about Jonny's disability became obvious, and my decision for early intervention turned out to be the best possible thing for him.

I learned that kids with autism have a different perception of feelings. When Jonny was little, he didn't like to be hugged or touched, and even arched his back when I tried to pick him up. He didn't demand nearly the amount of attention as the other kids. When he went on the bus to school, he didn't hug me or wave good-bye. I took it personally when he pushed me away. I didn't think he had feelings for many years, because he didn't show them.

However, Jonny did have feelings. I realized that when I taught him how to ride a bike. One day, he zipped down the street and across a busy road. If a car had been coming, it would have hit him. I got angry and ran to him screaming, "Jonathan, do you know what you just did? You could have been killed!"

He asked, "What?" Then I said, "You drove your bike across that busy road without even looking to see if a car was coming." He said, "Sorry, Mom." I said, "Sorry doesn't cut it!" Great big tears began to roll down his cheeks. "You hurt my feelings", he said!

That was a first. He was upset because I said, "Sorry doesn't cut it."

Jonathan Sicoli turns 20 in 2010. He is attending the local computer college and says he is, at long last, learning something in school. He loves what he's learning, loves his siblings, his life, and is still the "life of the party." There is never a dull moment with Jonny, as we cannot possibly predict what he is going to do or say next.

People love and like Jonny, and he tells us he is incredibly happy. He knows he has autism, has appeared on television talking about it, and is fine with it. He says, "I wouldn't have it any other way, frankly!" And nor would we.

The important thing, when you have a child with autism, is relentless persistence. This makes autism work for you, and not against you. Persist with questions, and remain forever hopeful. Research new treatment options, attend conferences, on and offline, and connect with other families who have kids with autism too.

In *Autism Tomorrow*, we dig deep to help you answer your questions and include tremendously important subjects, such as:

## Chapter 1

1. The family dynamic
2. Siblings
3. Hygiene
4. Fitness
5. Safety
6. Women's issues and exams
7. Puberty
8. Bullying
9. Sexual abuse
10. Financial planning
11. School and reading solutions
12. IEPs, IPPs
13. Career training
14. First responders
15. Retailers
16. Special trusts
17. Advocacy
18. School bus drivers
19. Dating
20. Growing older and the future,  
And much more...

Ultimately, we want you to celebrate the future with us. We give you a roadmap of possibilities, and want you to make informed decisions regarding the direction and intention you have for your child's life. You are holding the guide, tailor-made, to do just that.

In addition, we interviewed top experts, asking what the future of autism means to them. These "Pearls of Wisdom," comments are from Elaine Hall, Dr. Stephen Shore, Dr. Temple Grandin, Jan Randall, Dr. Carolyn T. Bruey, William Stillman, Dr. Tony Attwood, Dr. Kathleen Quill, Donna Williams, Dr. Robert Naseef, Gail Stein, ACSW, Nancy H. Cale, Dr. Barry M. Prizant, Keri Bowers, Tiffany Sandlin, Shannon Johnson, Jennifer Parsons, Leighanne Spitzer, Eric Chessen, Pat Wyman, M.A., and Andrew Solomon.

## How Can You “Fix It” If You Don’t Know What is Wrong?

The thing about autism is you don’t know what’s wrong until you finally accept your child as is, and enter their world. This is when things move, and you notice changes that not only make your day, but your life. Here’s a funny story that shows what I mean.

Acknowledged by his fellow speaking professionals as “America’s Number One Humorous Speaker,” Dr. Charles W. Jarvis, DDS, tells this story about a man going to a pet store to buy a bird.

A man goes into the pet store to buy a pet bird. He sees dozens of caged birds with tiny price tags dangling from their little legs. He scans each price tag one by one: \$5, \$5, \$5, \$50! “Hmmm,” he wonders. “This \$50 bird looks like all of the others. What could be so special about this one?” He asks the store clerk. The clerk replies that this one is very special because it can talk. The shopper is impressed enough that he buys this special talking bird and takes it home.

The very next day he returns, disappointed. “The bird didn’t talk.” The clerk asks, “Did he look in his little mirror?” “Little mirror? I didn’t buy a mirror. Does he need a mirror?”

“Of course,” replies the clerk. “He looks in his little mirror and sees another bird in there. He thinks he’s not alone and starts to sing, starts to talk. You’ve got to have a mirror.” This sounds reasonable, so the customer buys a mirror and leaves.

The next day he is back again, disgruntled. “The bird looked in his little mirror, but he still didn’t talk.” “Well,” ponders the clerk, “did he run up and down his little ladder?” “Does he need a ladder?”

“Of course,” replies the clerk. “Don’t you feel better after you exercise? When your little bird runs up and down his little ladder, those endorphins start pumping in his little brain. Makes him want to sing. Makes him want to talk. Got to have a ladder.”

“How much is a ladder?” “It’s \$12.95.” “Give me a ladder.” And off goes the customer. The next day he is back with a scowl on his face. “The bird walked up and down his little ladder. He looked in his little mirror. But he still didn’t talk.”

The clerk listens to the angry customer and then asks, “Did he swing on his little swing? You see, when the bird swings, it makes him think he’s back in nature. Makes him want to sing. Makes him want to talk.”

“How much is a swing?” The customer grudgingly buys the swing and leaves. But the very next day he is back again, angrier than ever. “The bird swung on his little swing. He ran up and down his little ladder. He looked in his little mirror. But he still didn’t sing and he still didn’t talk.”

Hmm, thinks the clerk. “Did he tinkle his little bell?” The customer doesn’t even wait for an explanation. Determined to see this out to its conclusion, he grabs a little bell, throws some money on the counter and storms off. You guessed it. The very next day he is back again. “The bird’s dead!” he exclaims. “Dead?” “Yup, dead! His little feet stick up in the air. He got up this morning healthy as could be. He looked in his little mirror. He tinkled his little bell. He ran up and down his little ladder. He swung on his little swing. And then, just before he keeled over and died, he looked over at me, a little tear forming in his little eye, and he finally spoke to me. The little bird asked, ‘Didn’t they sell birdseed?’”

Okay, so our children don’t need bells, ladders or mirrors, but they do need many things “typical children” don’t need to manage their daily lives.

The point of this story is that without really knowing what our child needs, we can throw money, programs, training, ideas, concepts, doctors and more programs at them, to say nothing about the time it takes to do all these things. We can’t “fix it” if we don’t know what is wrong. We can’t decide who is best to treat autism if we don’t know who the experts are to help us. We can’t figure out how to work with schools and other professionals, determine our family’s needs, or weave our way through the always looming financial demands of this thing called autism, unless we empower ourselves with knowledge and support. Let’s begin this journey by dispelling the misconceptions people have about autism.

## 19 Myths About Autism

Bill Davis

### **Myth #1: People with autism are incapable of loving.**

Chris loves me with such passion. People with autism are angelic, loving

human beings. The other day my wife Kate ordered some very cool sneakers for Chris. She called him over and presented him with his new, sharp, teenage shoes. Chris put them on and began to jump all around the house with a big smile on his face. He slowed down, looked up at Kate, and whispered, “I love you, Kate.”

### **Myth #2: Everyone with autism is “Rainman” or a savant.**

What is your child’s skill? Autism is a spectrum disorder, a continuum of traits, gifts and strengths. I know people on the spectrum who have a Ph.D. and I know children on the spectrum who have Downs Syndrome. I have friends with autism who are married, as well as those who are embroiled in a terrific struggle with daily life, so everyone with autism is not “Rainman”.

### **Myth #3: Autism affects life span.**

People with autism do not die earlier than those who don’t have autism. Most lead long, rich and fulfilling lives.

### **Myth #4: If your child with autism does not speak by a certain age, he will never speak.**

My son, Chris, did not speak until age six. After age six, I asked him, “Hey Chris, what do you want to do tomorrow?” “I want to bath, I want to dress, and I want to go to Learning Center.” Thanks for exploding that myth, Chris.

### **Myth #5: All people with autism want to be cured.**

I know many people with autism who truly love and enjoy their lives. They don’t feel they have a disorder, and simply think and exist on a different plane. They resent the word “cure.” They are not diseased or broken, and thus do not need to be cured. I do believe in biomedical intervention and know recovered people, but a great portion of the population with autism is very happy the way they are.

### **Myth #6: People with autism do not develop friendships.**

Untrue! My son has many friends. He relates to people on so many levels. Chris has maintained all types of relationships. Albeit, they may not be typical friendships, but he truly enjoys his pals. My son and I are good friends, and Chris and Kate have developed an outstanding relationship.

### **Myth #7: People with autism will never make eye contact.**

Direct eye contact was very painful for Chris when he was young. He would catch glimpses of us by using his peripheral vision. One young man told me that he did not know what his mother's face looked like until he was ten! Eye contact can be overwhelming and facial expressions may be confusing, but eventually most of our kids will look right at us and smile.

### **Myth #8: Autism is a psychological disorder, although we treat it behaviorally.**

Autism is not psychological. We now know that autism is a complicated developmental disorder. It may be genetically predisposed, and some believe triggered by environmental factors.

### **Myth #9: Bad parenting causes autism.**

Do you remember the term, Refrigerator Mom? In the 1940s, psychologists decided that mothers of children with autism were so "cold" that they made their kids withdraw and develop strange behaviors with repetitive characteristics. Through the 1970s, because of this theory, mothers of children with autism suffered from blame, guilt and self-doubt, caused by the idea that their inadequate parenting caused the autism. Some children were actually placed with other "more responsive" families. They did not improve. Autism has nothing to do with parenting skills.

### **Myth #10: Autism is rare.**

Most current estimates say that about one in a 110 children are diagnosed with autism. Autism is growing at alarming rates. Nearly everyone knows, or knows of a person with autism!

### **Myth #11: Nutrition, by itself, can cure autism.**

Families have made tremendous strides utilizing the casein-free, gluten-free diet and other nutritional programs. Kids with autism tend to have digestive problems too, but nutrition is only one part of the puzzle.

**Myth #12: Teaching social skills will develop social relationships.**

Making friends can be tough for anyone, yet more difficult for people with developmental disorders. Kids and adults with autism do make friends, and we will discuss friendships for your child later in the book.

**Myth #13: Before attempting a treatment, it must have research to back it up.**

Our family has tried many therapies without clinical research behind them, and many proved valuable. Each child is unique.

**Myth #14: People with autism are dangerous.**

Most outbursts are due to pain, lack of communication, frustration or sensory overload. This is not a dangerous population.

**Myth #15: People with autism do not smile.**

The look on Chris' face when we take him to buy videos is one big smile!

**Myth #16: People with autism will outgrow it.**

Not true! Your child may appear to “normalize,” but will always have autism.

**Myth #17: People with autism don't want friends.**

Not true! Ask your child.

**Myth #18: People with autism cannot conceptualize.**

Not true! Again, watch and ask your child.

**Myth #19: People with autism do not have passion, energy, or emotion.**

Not true! Kids with autism can be emotional, passionate and energetic!

# 10 Tips for Parents and Professionals to Promote Positive Relationships with Those on the Autism Spectrum

Karen Simmons

1. **Understand the label:** The label is not the problem as much as the fear of the unknown and preconceived notions with the label. We must first understand the challenges facing autism, then the communication and sensory challenges that result in social skill deficits and behavioral challenges. In addition, get past the label drama by offering people a better way to understand what's happening with your child. This ultimately supports differences and discourages discrimination.

People on the spectrum can be very literal, so don't take what they say personally. Look for things that may cause miscommunication, such as lighting and uncomfortable clothing. Understand your child's lack of inability to process and express themselves. Also, teach your child to balance themselves physically, emotionally, mentally, spiritually and intellectually.

2. **Enhance empathy:** Tune into empathy, not sympathy. Imagine what they may be thinking or feeling. They have difficulties expressing, understanding, and showing emotions, which makes the world confusing for you, them and others, but with interventions you can help.
3. **Communication for community:** Help to bridge relationships between peers and those with autism. This is an intuitive process, so be careful of boundaries. Try to help your child find a buddy to coach him. Get them to volunteer, sign up for an acting class or try to find others who have something in common. Building and fostering, nourishing, young relationships with peers, employers, family and community enhances the fabric of humanity.
4. **Share the knowledge,** by raising awareness and understanding of autism and the issues surrounding it: Typically, kids have issues around what is and what is not safe, and due to their literal nature, they are often seen as blunt and offensive. Educate peers, teachers, family and the community.
5. **Remember learning styles:** All people learn in different ways. Whether they process their world through sight, sound or touch determines the quality of their communication. Since many people with autism are generally visual learners and think in pictures, it is important to

communicate with pictures and words. You can find out how your child learns best by using the free Personal Learning Styles Inventory at [www.HowToLearn.com](http://www.HowToLearn.com)

6. Scripting for success: If you want to communicate better, it is helpful to write the message. You can even use pictures to make your message easier to understand. This can be as simple as explaining the proper way to relate to friends, or writing a script for a movie or play.
7. Understand the “box.” The “box” is the family unit surrounding the person with autism, a complete entity unto itself. Many times, people inside the “box” either go into denial or have spousal challenges. Those outside of the “box,” such as teachers, in-laws, and others, who don’t “live” it, may not understand the many family dynamics. Keep an open mind and treat both sides of the “box” equally.
8. Be a team player: While working together for the common goal of helping a person with autism build relationships, include parents, educators and professionals on the same page. It doesn’t help the person if the support team can’t agree. Always choose your battles carefully.
9. Empower people with autism to be who they are. Your child knows much more than you might imagine. Once you let go a bit, it can help your child build self-esteem, while they learn to be as independent as possible.
10. Autism is all about your child, and it is critical you know it is not about your ego, personality or lack of understanding. Never lose sight that your child is the focus of attention. Don’t be afraid of what these special children know; be afraid of what they don’t know.

In the world of autism, there is always a beautiful tomorrow. With love, caring, and kindness, it is just around the corner.