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THE PERFECT-BABY DREAM

Some men see things as they are and ask why. Others dream things that never were and ask why not.

—George Bernard Shaw

Welcome to Chapter One: The Perfect-Baby Dream.

You are beginning an amazing journey filled with unexpected challenges and incredible rewards—gifts you cannot begin to understand when you first start walking down this demanding road. Parenting a child with special needs will be the greatest challenge of your life, and if you make good choices, it may also prove one of the most rewarding.

Unfortunately, too many people feel sorry for these families and believe their children lack value or need to be *fixed*. Prevalent and outdated stereotypes of special needs families are fueled in part by ignorance, and in part by society's obsession with human perfection and physical beauty, including for children. You can help change those stereotypes.

This chapter will challenge you to see your child's life as worth celebrating, while motivating you to make more dynamic parenting choices. You will learn that accepting and valuing children with special needs is the first step toward becoming a healthier special needs family and that a combination of hard work, a family's determination, early intervention, and unconditional love will lead to brighter futures for most children, regardless of their diagnosis.

Beginning with this chapter, you will benefit from the guidance of those who have walked in your shoes. By sharing their stories, these experienced parents will help you learn how to embrace your challenging new role. They have been where you are right now, and they know what lies ahead. Their words will inspire, motivate, and energize you and give you hope.

The information included in this chapter and others won't change the reality of your child's special needs diagnosis. But it may help change how you perceive and respond to those needs. That's a powerful shift in thinking.

So let's begin this journey together with a story from a real-life expert—the mother of two children with Asperger's Syndrome.

A SUCCESS STORY

Annie Lewis's spirit of adventure began long before she became the mother of two children with Asperger's Syndrome, a role that today often defines her.

The forty-eight-year-old mom was a ski patroller in Aspen, Colorado, a millionaire's nurse, a chef in a five-star restaurant, and Cher's maid. Amid the beauty and pristine air of the Colorado Rocky Mountains, Lewis also trained relentlessly, pursuing her dream of biking across China and Europe with her husband, Mark Pullano.

As an athlete, she was used to pushing herself to the limits of physical and mental endurance. But Annie Lewis couldn't train hard enough for autism.

"Autism is a broad spectrum, neurological disorder," Lewis, a nurse, explains. "That means people with autism vary in their abilities and exhibit an entire range of intelligence, responsiveness, and social functioning, from mild to severe."

To the layperson, that means everything from the familiar stereotype of someone rocking in the corners, seemingly oblivious to the world around them, to a child who bites classmates and is

obsessed with trains. It can also mean someone with the ability to work with and influence millions of people through impressive life achievements.

Lewis's sons both have Asperger's Syndrome (AS), a form of autism found in high-functioning children and adults, who exhibit some but not all tendencies of autism. Her thirteen-year-old son, Gregg, was diagnosed with Asperger's Syndrome at age four. His eleven-year-old brother, Max, was diagnosed with AS when he was six years old.

Lewis says that all individuals with autism exhibit three key tendencies: impaired socialization, impaired verbal or nonverbal communication, and restricted and repetitive patterns of behavior. "One of best definitions of autism I have ever read is morbid self-interest," she adds. "The one trait universal to all people with autism is the inability to ever see the point of view of another person."

The incidence of autism in the general population is 0.2 percent, but Lewis says the risk of having a second or additional child with autism jumps to nearly 10 to 20 percent. Some have argued that environmental factors play a role in autism. Lewis believes the cause is solely genetic.

One thing she knows for certain, parenting two sons with AS is the toughest life challenge she's ever faced. She's handled it successfully for more than a decade.

Taking Charge of Autism

According to Kathy Johnson, associate director of the Autism Society of Michigan, autism is a neurological disorder that impairs both socialization and communication. Autism is the most common of a spectrum of disorders, including Asperger's Syndrome, with challenges ranging from mild to severe.

Johnson says that the lifelong disability usually appears during the first thirty months of a child's life and occurs in 1 out of every

166 births. It is four times more common in males than females and there is no cure. But early diagnosis and aggressive intervention can help children with autism lead more productive lives.

The number of cases of autism has skyrocketed in recent years, but its cause remains a mystery. Unlike children with lower-functioning autism, children with Asperger's Syndrome have communication and language skills and normal IQs; some are highly intelligent, even gifted.

They may do well in school academically and have successful careers. Many people with AS may be considered odd or eccentric, especially because of their challenged social skills, including the avoidance of prolonged eye contact and difficulty developing meaningful peer relationships.

Johnson says that some people now believe that some of the most brilliant and accomplished individuals in history, including Albert Einstein and Thomas Jefferson, may have had undiagnosed AS.

People with autism have difficulty seeing connections between life events. "It's as if everything that happens to them in life is new," Annie Lewis explains. To help others better understand this autistic tendency, Lewis likes to tell a story:

"If you were to tell a child with autism or Asperger's Syndrome to go knock on the neighbor's door, they would probably understand that request. But they might stand there all day knocking on the neighbor's door, waiting for what's going to happen next," she says. "They don't understand they are waiting for someone to answer the door."

As a nurse, Lewis knew something was wrong before her first-born son was diagnosed with AS at age four. Gregg exhibited many familiar autistic tendencies. His social challenges made it tough for him to play with other kids or form lasting friendships. He had an inability to tolerate the kind of excessive noise and unstructured play that is common during recess and riding the school bus, and he showed a lack of empathy for the feelings of others.

Gregg began hitting and biting classmates at his preschool, throwing tempter tantrums, grabbing toys away from his classmates

as if they didn't exist. He lacked the ability to focus in group settings. The staff worked hard to find an intervention that worked, but when their efforts failed, Gregg was asked to leave the school. His mother calls it the worst day of her life.

But she refused to give up on her son and for the next five months searched for elusive answers about Gregg's challenging behavior. "When I first started reading about Asperger's Syndrome," Lewis explains, "Gregg was right there on the page."

Armed with hope for a firm diagnosis, and what Lewis calls "the Michael Jordan of preschool teachers," she was successful in returning Gregg to his preschool. The staff agreed to take him back after he'd had a few months of growth and development. Upon his return, the school had a system in place to deal with him one on one. "It was part of thoughtful planning, overseen by a brilliant and compassionate school director," Lewis says. "We were very, very lucky."

But it was more than just luck. The crucial decision that Gregg's mother made to educate herself about his special needs early on, combined with her determination to help Gregg return to the only preschool that would accept him, has made a big difference in his life. "Addressing your child's needs early can mean the difference between having a functional or nonfunctional child with autism," Lewis stresses.

When asked to rate the effort that went into this stage of the parenting game on a scale of 1 to 10 (10 being toughest), Lewis calls it a 55. "It was 24/7," she explains. "Gregg was out of school for five months and I cried nonstop."

Lewis also read voraciously, using her career as a nurse to access the National Library of Medicine (NLM) online services. She read every article about autism written in 1994. "We were still in the dark ages about autism and what I read frightened me," Lewis explains. She wanted something better for her son. "I never believed we would not be successful," she says.

Lewis understands well the importance of aggressively addressing the toddler and preschool years, when a child's brain is still

developing. Research now indicates that many children with autism have better outcomes if they receive solid intervention during those critical developmental years. More about early intervention in Chapter Four.

Still, many of these children are not correctly diagnosed until they are older, often due to concerns about labeling or misdiagnosis because of a lack of universal availability of routine screening tools. Gregg wasn't officially diagnosed with autism until he was age four.

According to a report by the *American Academy of Neurology and the Child Neurology Society* (www.aan.com/professionals), the average age of diagnosis of autism is age six, even though most parents felt something was wrong by age eighteen months and had sought out medical attention by age two.

That angers Lewis. "We have got to do a better job of diagnosing these children early," she stresses. "The brain is like a sponge during those early years," Lewis says of this important focus. "It's the difference between writing in sand at age two and chipping away at granite at age ten."

Lewis had to fight her insurance company to have Gregg tested. "They didn't know autism is a neurological disorder," she says with disbelief. "They kept telling me he needed mental health care, not a neurologist. It took months of begging and phone calls for me to get the authorization necessary for the comprehensive testing I knew my son needed, testing that is today a standard of care."

Thanks to his family's persistence, Gregg is now an eighth grader in a regular classroom, with the support of a skilled paraprofessional that Lewis calls "her angel." "Jane understands Gregg well," Lewis says. "She helps him see the connections between things that are happening in his school day and make sense of it."

Children with autism are often unfairly viewed by society as being unruly children, the result of nothing more than bad parenting or lack of discipline. Nothing could be further from the truth. Preparation time and familiar routines are important to children with AS. "We are asking them to come out of their autistic worlds,

to be fully present in our world and do things our way,” Lewis adds. “It is an incredibly hard thing for them to do.”

At age thirteen, Gregg still exhibits some classic autistic traits, including sensitivity to external stimuli. “He doesn’t do well with unstructured chaos,” Lewis says. That includes noise in the school hallways and riding the bus. But Gregg carries an A average in most of his classes. Lewis now schedules two hours after school each day to allow her son to be totally absorbed in his love of trains. “Gregg needs to spend time in his autistic world,” she explains.

As Lewis struggled to bike up a steep mountain incline years ago, a friend warned that the greatest challenge facing her was mental not physical. When her second son, Max, was also diagnosed in 1999 at age six with AS, obsessive-compulsive disorder (OCD), and an IQ placing him in the top 1 percent of the population, Lewis finally understood the true power of that message:

A tough mental attitude gives you an edge in surviving life’s tough challenges.

Lewis credits her son’s preschool teacher for voicing concern when, at age five, Max had difficulty interacting with other kids, something his mother had never witnessed. Lewis immediately had him tested, and at age six, he was also diagnosed with AS. “Max was so different from Gregg. He was so smart and verbal and high functioning. It never occurred to me that he might also have AS.”

Max’s multiple special needs diagnosis presents its own challenges. “I’ve learned that every child is different,” she stresses. “What is right for one child may not be right for another, even in the same family. There is no magic formula for meeting the challenges of autism.”

Today Max is in the sixth grade with the same teacher his brother once had. “She gets him,” Lewis says of this important educational partnership.

Lewis has chosen to respond to special needs parenting in the same way she’s faced other life adventures—with cutting wit, solid focus, and a winning attitude. Her life hasn’t been free of heartache,

and Lewis knows another tough parenting demand is always just around the corner.

For the sake of her sons, she works hard to keep her role in perspective and finds solace in simple things like humor and gratitude. “I’ve learned how to just be grateful for something as simple as a hot cup of morning tea and time alone to drink it.”

It’s an important lesson for all parents.

LETTING GO OF THE PERFECT-BABY DREAM

One of the most important decisions that Lewis and other successful parents of children with special needs make is to view their children as *children first*, not as disabilities. With perfect-baby images assaulting us at every diaper change, that’s no easy task. Popular mainstream parenting magazines help fuel the perfect-baby dream with their glossy publications featuring picture-perfect cover kids.

Care to guess if any of these magazines have included a child with Down syndrome on its cover? Or whether a child using a wheelchair has appeared in a photo essay for magical birthday parties, next to the advertising for premium cotton pajamas?

It will happen when enough adults advocate for societal change that celebrates diversity and redefines our definition of a child’s beauty. That means you!

Annie Lewis raised \$11,000 for an accessible playground in her neighborhood, spent fourteen days camping outside a Krispy Kreme Donuts shop to create greater awareness of Asperger’s Syndrome, and has future plans of group-home ownership! More about advocacy in Chapter Six.

What will your parenting legacy be?

Debunking Perfect-Parenting Mythology

Every year, businesses spend millions of dollars marketing perfect-baby images that do little to prepare anyone for the reality of parenting. We love talking about babies using high-pitched baby



ANNIE LEWIS'S TIPS

Asperger's Syndrome

Having been through the experience of parenting two sons with special needs, Annie Lewis offers five key strategies for success with Asperger's Syndrome:

- *Stay focused on your child.* “Everything in my life has changed, but not my solid focus on and love for my kids.”
- *Address the child's needs early in life.* “Spending even ten minutes with your child at age three or four to impact brain development can equal a month or more of working with that child at age ten. It's like working with wet cement versus drilling away at granite. You cannot get those developmental years back.”
- *Know when to ask for help.* “I am a strong person who can handle anything I set my mind to. But no matter how strong you are, there are times when you need to ask for help—and 98 percent of the time, people are just waiting for you to ask.”
- *Find a way around the obstacles presented, whatever it takes.* “Never give up. There is *always* a way to get around life's obstacles to meet your child's challenges.”
- *Put your child's diagnosis in perspective.* “I've learned just to be grateful for all that we have. There are so many people worse off than we are. Addressing autism is tough, but we can handle it. We're educated and we have jobs and health insurance. Some families don't have any of these things.”

voices. We laugh just thinking about nuzzling silky baby hair, savoring sweet baby smells, and buying cute little yellow rubber duckies that float in the tub.

But we don't dare talk about smelly diapers that make you gag, sleep deprivation, postpartum depression, kids using wheelchairs or leg braces, surgeries for babies born with heart conditions or other health challenges. We can't imagine that one day our child might be included in the alarming statistics for mental illness, teen depression, suicide, or drug abuse.

We don't prepare families for the heartbreaking reality that despite their best efforts and most heartfelt prayers, their seriously challenged children may die.

When we first become parents, most of us are incredibly naive. Parenting is a tremendous responsibility, especially if your child has special needs. Raising our children to have brighter futures means that families must first let go of their perfect-baby dreams. It is the toughest parenting role that anyone will ever undertake, and one of the most rewarding.

It deserves our full commitment and respect.

Accepting Your Child

Having a child with special needs *demand*s that you take your parenting role seriously and become increasingly less selfish. Or pay the steep price.

Regardless of what messages society constantly feeds us, perfect families don't exist. Most children and their parents face challenges during the child's developmental years. Every one of these children, including those with special needs, has value. Understanding that value is the beginning of accepting your child and becoming an increasingly empowered parent.

Repeat after me: my child is worthy of my time, efforts, patience, respect, and love, no matter what challenges he (or she) may face in this life!

To all those creative marketing geniuses and magazine editors who virtually ignore the needs of millions of gutsy families who are looking to create better lives for children with special needs, we boldly wave our disposable income in the competitive retail air and shout, “Shame on you!”

To the parents of these children, I say, “Demand better!”

FORGING NEW PARENTING DREAMS

At some point on this special needs journey, most parents find themselves yearning for the freedom to again pursue romantic interludes and exciting careers, read current magazines cover to cover—and enjoy a full night’s sleep.

It’s the lack of personal freedom that comes with this demanding new role that makes adjusting to special needs especially tough. Your life has been forever changed, often in unexpected and dramatic ways. No wonder it’s so easy to lose your bearings and focus on the negative and even think about giving up on your child. I challenge you to make better choices.

You will not adjust to this new parenting reality overnight. Forging new parenting dreams and becoming a confident parent of a child with special needs take time, tears, teamwork, a deep commitment to your child, and an abundance of unconditional love and patience. You are in this for the long haul.

The parenting rewards you desire come in stages and may not be fully realized until your child is older, especially if your child is facing a particularly challenging diagnosis. No one can predict with certainty what your child’s future outcome will be, not even professionals with the most impressive credentials. Still, the choices you make today may well help determine how bright that future is for your entire family.

Every single moment spent with your child matters—even if the only thing you have the energy to do that day is tell your children that

you love them. This helps boost your children's self-esteem and sense of value, which will serve them well on the most challenging days.

Speaking from Experience

I was fortunate to parent a child with cerebral palsy for nearly thirteen years. Eric was a wheelchair user with limited speech and mobility. Together we survived many tough life challenges. Despite his many challenges my son was one of the brightest, most joyful, and determined spirits I have ever known.

Being Eric and Jenna's mom has been the most humbling and rewarding experience of my life.

The early years of my son's life were rough. As his parents, we were fed many negatives regarding Eric's life and future, or lack thereof. We were told that he would never achieve much in life and would probably never progress beyond the developmental age of six months.

Professionals kept waiting for him to stop developing, but he never did. Why? Because from the moment of his birth, we chose to raise him as loved and valued. We gave him every opportunity to thrive and sought out important programs that nurtured his potential and celebrated his value, not those prejudging his worth. We treated him like the valued member of our family that he was, just like his sister.

Eric knew he was loved and it served him well. At the end of his life, our son was fully included in his neighborhood school. He had many friends and had begun composing music. He wanted to go to college and study music, a dream we planned to fully support. Eric's life was filled with challenges. Because we chose to roll up our parenting sleeves right from the start, it was also full of dreams and opportunities and great joy.

We accepted and addressed the needs of Eric's disability, but we also focused on nurturing his entire being. That big shift in thinking equaled positive results. It was hard work each and every day of his life, but our parenting efforts were rewarded over and over again

with the love and remarkable achievements of an enchanting young child adored by many. Today our son's lessons live on in the lives of many.

I *know* that helping your children have better lives is worth every ounce of your energy, sweat, and tears—no matter how painstaking or small those gains may seem at first. If given the parenting opportunity, I would do it all over again. That's how deeply my son, and daughter, changed my life.

Celebrate your child's life, no matter how rough the start. You are building the foundation of his future life success. Build it rock solid and cement it with love, acceptance, and possibilities. Then be patient with your child—and yourself—as you both work toward achieving your life goals, wherever those dreams may take you.

Recognizing Your Child's Value

When expectant parents are asked whether or not they want a baby boy or a baby girl, they often recite a familiar response: “We don't care, as long as it's healthy.” I'm still amazed at how many people said this to me in front of my son! After the delivery, another simplistic statement helps many parents believe they've escaped infant imperfection:

Our baby has ten fingers and ten toes!

I can hear a loud collective sigh of relief from parents counting baby digits across the planet. Guess what? Most children with special needs have ten fingers and ten toes, too! Kind of tosses that perfect-newborn test right out of the incubator, doesn't it?

We are a nation obsessed with physical beauty and perfection. The idea that we could give birth to anything less than a perfect child is too frightening to even consider, so we don't prepare families for the possibility. No wonder when it happens so many parents feel overwhelmed and cheated, as if they have somehow failed at the perfect-baby game.

Celebrating your child's value, while those around you are loudly citing human imperfection and scary statistics, is the beginning of

acceptance. Stop listening to all the negatives being spouted about your child.

Take in important facts, not uninformed opinions or worst-case scenarios. You need good information, including an accurate diagnosis, to help your child achieve the kind of life success that rarely can be predetermined at the moment of birth. All the negative garbage will only weigh you down. Throw it out!

No child's life should be considered less valuable because they have special needs. It is only one part of who they are and who they may become with your love and support. Work hard to connect with your child in one positive way every single day. It's worth it. *They* are worth it.

CONFRONTING SPECIAL NEEDS PARENTING MYTHS

Allow me to dash a couple of other pervasive myths about children and special needs.

Myth Number One: If your child enters the world without challenges, your family has escaped the dreaded curse of special needs parenting.

Have you seen children in your neighborhood riding bikes or scooters without wearing helmets? Do you know kids who are engaging in risky behaviors like snowboarding, skateboarding, or playing chicken with cars in heavy traffic—a game they usually lose? Do your children play hockey or football or drive recklessly or abuse alcohol and other drugs? All of these behaviors may increase the risk of having special needs, especially if your child suffers a brain injury. Having special needs can happen to anyone at any time.

As a society, we need to better understand the power of this message so we can change the way in which we view and interact with people with disabilities. There is no shame in having a child with special needs, unless you put it there. Don't do that to your child or yourself. You'll regret it later.

It's far too early in the parenting game to give up on your child.

Myth number two: Children with special needs are born only to the poverty-stricken, the mentally ill, those who abuse drugs and alcohol during pregnancy, or moms with poor prenatal care.

The need to blame parents for their children's special needs is common and rarely justified. It does nothing to help families successfully address their demanding new roles. Parents can do everything right during pregnancy and beyond, and life circumstances may still intervene harshly and without permission. During the endless days that my son spent in pediatric intensive care units, I found out how quickly unforeseen circumstances can transform the lives of so-called perfect families into families with special needs. It happens more often than most of us want to believe.

Children with special needs live in families crossing all socioeconomic lines. They are born to the richest and poorest of households, to well-educated parents and high school dropouts. They enter the lives of moms who exercise and eat right and moms who smoke crack during pregnancy. They are born to women over forty and to fourteen-year-old girls.

They join families like mine. As tough as it was to meet all of Eric's needs, I don't feel the least bit cheated, because he taught me so much. When I think of my son today, what I most remember is how much I loved him—and always will

Of the 54 million Americans with special needs, more than 8 million are children and young adults, numbers increasing each year. Many other children have significant needs that may go undiagnosed. Special Olympics (www.specialolympics.org) sites 170 million people worldwide with mental retardation.

You are not alone in this parenting adventure.

Myth number three: Once you have a child with special needs, your life is over.

If you consider your life over because you have a child with special needs, then that's exactly what it will be. Make another choice. Reclaim your personal power and turn a worst-case scenario into something better. Life dreams don't have to end because you have

this challenging new parenting role. It does take more energy, more time, and tons of hard work to make your life the best it can be in light of special needs parenting.

But nothing worth having in this life comes easily.

Far too many families end up creating the very prisonlike existence they fear simply because they lack good information, helpful resources, and the positive role models they need to create better outcomes. This book provides you with the necessary tools to create better lives for you and your family. You can use these tools to your advantage to build a life that's still filled with possibilities and personal dreams, or you can become stuck.

Don't become imprisoned in your daily life because your child has special needs, no matter how tough the day may seem. You deserve more—and so does your child.

There has never been a better time to be raising a child with special needs. Many families today are choosing to raise their children as valued family members. These parents have become successful child advocates, nurturing their children's hopes and dreams and fostering independence, just like other families.

You are the beneficiary of all the positive actions of the amazing families who have walked this road before you. With their passionate commitment to their children, they have opened doors once nailed shut and have helped create greater awareness of all children with special needs, including yours. You are fortunate to be following in some amazing parenting footsteps.

You have a responsibility to continue their work—for the sake of *your child*.

I realize that at this moment you may feel like you have been dumped into the middle of a dark, foreboding forest with no apparent way out—especially if your child has just been diagnosed with special needs. Most of us have felt like that at one time or another.

Use this book as your compass, and a breath of fresh air, to help you successfully navigate the special needs parenting woods. With good support, you can find your way.

To become an increasingly empowered parent (IEP), read on!



DID YOU KNOW?

Special Needs Hall of Fame

Here are just a few famous people with special needs to provide you with some daily parenting inspiration and help you focus on the value of your child:

Dyslexia

Cher

Thomas Edison

Tom Cruise

General George Patton

Walt Disney

Blindness

Andrea Bocelli

Ray Charles

Stevie Wonder

Helen Keller

Deafness

Heather Whitestone,
Former Miss America

Ludwig van Beethoven

*Mental Illness**

Lenny Bruce

Sylvia Plath

Judy Garland

Mark Rothko

Ernest Hemingway

Brian Wilson

Charles Mingus

Virginia Woolf

Marilyn Monroe

Parkinson's Disease

Michael J. Fox

Katharine Hepburn

Muhammad Ali

Down Syndrome

Christopher Burke

Wheelchair Use

Christopher Reeve

John Hockenberry

Franklin Delano Roosevelt

*(This list has been drawn from the book *Divine Madness* by Jeffrey Kottler, published by Jossey-Bass/John Wiley & Sons, 2006.)

Information (with the exception of the mental illness list) courtesy of ERIC: Education Resources Information Center/Institute of Education Services of the U.S. Department of Education/ERIC.ed.gov.

SPECIAL TIPS

Here are some tips that you can use right away, immediately after birth or when you receive an unexpected diagnosis of special needs:

- *Believe in your child's value—no matter what.* Every single decision you make to help your child realize his or her full human potential stems from this one powerful belief. Don't ever doubt your child's value!
- *Bond with your child as soon as possible after birth, including in the intensive care unit.* Research strongly indicates that parent-child bonding and human touch may help the most challenged newborns survive and thrive. Don't waste a moment of this critical stage of your child's life. This bonding will pay off as your child grows. Try not to be intimidated by staff—you are the child's parent, and you have a right to spend time with that child whenever possible.
- *Send out birth announcements with your child's photograph.* This single, important act helps validate your child's value from birth, while granting others permission to offer congratulations as they would for any other family. Have a photograph taken of your newborn in the hospital, or take it yourself. If your child should die, you will be eternally grateful to have this sacred reminder. Such photos also help you look back to see just how far your child has come developmentally.
- *Encourage visits from supportive family and friends.* The support of those you most trust can prove comforting as you work toward accepting your new parenting role. These supportive visits can also protect you from becoming isolated or depressed, which are concerns for many parents of kids with special needs. This is a great time to reach out to others.
- *Seek out immediate support if you feel overwhelmed.* This support can come from other parents you trust, close friends and fam-

ily, your faith community, or professional counseling. Learning to ask for help when you need it is an important part of becoming a confident parent of a child with special needs. There is no shame in asking for help. This is a tough adjustment for most families. Don't pretend to be brave.

Special Resources

Here are a few resources to get you started on the path to becoming an **IEP** (increasingly empowered parent!):

Books and Journals

- *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*, by Stanley I. Greenspan, M.D., and Serena Wieder, Ph.D.
- *Asperger's Syndrome: A Guide for Parents and Professionals*, by Tony Attwood.
- *The OASIS Guide to Asperger Syndrome*, by Patricia R. Bashe and Barbara L. Kirby. OASIS online support Web site: www.aspergerssyndrome.org.
- *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals*, by Catherine Murice, Gina Green, and Stephen Luce. Addresses the intensive, expensive, and increasingly popular *applied behavior analysis*.
- *Exceptional Parent Magazine*, www.eparent.com.

Organizations

- Autism Society of America (ASA): www.autism-society.org or 1-800-3-AUTISM. Featuring AutismSource: ASA's national, online directory of autism resources.
- The Doug Flutie Jr. Foundation for Autism, Inc.: www.dougflutiejrffoundation.org.

Internet Search Engine

- www.Google.com. This is a great search engine to help you uncover a wealth of online special needs parenting resources and support throughout your child's life.

Special Note

The Internet is a valuable tool for parent-to-parent networking and accessing important resources. If you don't have a computer, make getting one a priority. If finances are a concern, seek out organizations that now provide computers to those in need. Be proactive.

OK, now you have a better understanding of what it really means to be the parent of a child with special needs—with all its joys and challenges. So let's turn to Chapter Two and continue our discussion about autism. We'll also talk about grief, blame, and asking for help . . .