

Chapter 1

Autism: The Big Picture

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In This Chapter

- ▶ Consuming the known facts about autism
- ▶ Reviewing the diagnostic process and symptoms of autism
- ▶ Coping with the impact of an autism diagnosis
- ▶ Implementing interventions to help your child's condition
- ▶ Taking steps if you think you have (or know of someone with) undiagnosed autism

Parents *never* want to hear that their child has been diagnosed with autism — and, at least initially, they certainly find it very difficult to accept the fact that autism has no known cure. However, if you observe characteristics in your child that you can't explain or alleviate, and if you can associate some of these characteristics with autism, you need to discuss your concerns with your doctor immediately. And if your child already has an autism diagnosis, you need to take action as soon as possible. Educate yourself about treatment options, and work with your doctor to formulate a treatment plan that meets your child's needs.



With emerging science, autistic children *are* getting better. Through treatment plans, the care of extraordinary physicians, and the support of family members and caregivers, autistic children are looking healthier, behaving more appropriately, making friends, having conversations, having play dates, and being mainstreamed at school. Your child can significantly improve and go on to maximize his or her potential abilities.

But before you reap the benefits of and make decisions about your child's healthcare, you need to empower yourself with knowledge. This chapter is a great starting point, because it provides a big-picture look at autism: what it is, how doctors diagnose it, and how you can manage the symptoms to make a difference in your child's life and yours — and you can!

What We Know — and Don't Know — about Autism

If your child has a developmental disability, such as an autism spectrum disorder, it's very unlikely that anything you did, or any specific event, caused his or her condition. Autism is a complex and not very well understood condition. Researchers are working on finding answers, but the questions themselves still aren't clear. As a result, the research is fragmented, and many theories are in the testing stage. Researchers are rapidly gathering data, but in the meantime, they disagree about how to interpret it. For example, researchers may observe malfunctions in different processes in the body of an autistic individual, but they can't agree on whether a particular problem is a symptom or a cause of autism. So, debates are ongoing in the medical community about what causes autism and how to treat it. (See Chapter 3 for a detailed discussion on the causes of autism.)

Here are the facts that all professionals and caregivers *can* agree on:

- ✓ Developmental disabilities such as autism are brain-based, neurological conditions that have more to do with biology than with psychology.
- ✓ Autism is the most common member of a family called *autism spectrum disorders* (ASDs), also known as Pervasive Developmental Disorders (PDDs).
- ✓ Autism is usually diagnosed by the time a child is 3 years old.
- ✓ Autism is found in every country, every ethnic group, and every socioeconomic class.
- ✓ Autism affects as many as one and a half million people in the United States alone, with 24,000 children being diagnosed every year. This figure is comparable to other Western countries.
- ✓ Autism is diagnosed four times as often in boys than in girls.
- ✓ One in 166 children are being diagnosed with autism in the United States. That figure has skyrocketed in the last 30 years.
- ✓ Children who are diagnosed with an autism spectrum disorder need early intervention as soon as possible.

And here are the topics that professionals and caregivers are still debating:

- ✓ Autism is thought to be biologically based, although researchers are still trying to understand its exact causes. In other words, a child's genetic makeup must be predisposed to allow autism to develop, but genes are *not* the same as causes. A genetic predisposition provides fertile soil for

a trigger, but researchers haven't been able to pinpoint the exact triggers (see Chapter 3 for more on the topic of causation). Each diagnosed case of autism appears to have its own pattern, like a fingerprint.

- ✓ Some experts believe autism has one overriding cause, and others insist that it has multiple causes. Some research divides autism into different subtypes based on the supposed trigger.
- ✓ Biomedical treatments can improve autism symptoms, but the debate rages on about whether biomedical treatments deal with the root causes of the disorder or simply help children who were “not really autistic” in the first place. The medical community doesn't widely accept many biomedical treatments; however, some doctors practice the techniques and experience great success with their patients.



Despite what the medical community still doesn't know about autism, we have reason for hope. New techniques for studying the human brain may lead to cures, new treatments, and interventions for autism and other puzzling neurological riddles such as Alzheimer's and Attention Deficit/Hyperactivity Disorder (see Chapter 2 for more on disorders that doctors may associate with autism). In addition, advocates are proposing more funding and legislation that will expand knowledge of autism as of press time.

Making the Diagnosis: Learning Your ASDs

The typical diagnosis of autism is a trickle-down process:

- 1. You notice some atypical characteristics for your child at his or her particular age.**
- 2. You schedule an appointment with your pediatrician, and if she suspects a developmental disorder, she refers you to a specialist (such as a neurologist).**
- 3. The specialist tests your child to see whether any of the autism spectrum disorder categories apply and makes the diagnosis.**

Sometimes, a child can go undiagnosed until school age. With mild autism, a child may never be diagnosed. The pages that follow prepare you for the process at hand. See Chapter 2 for info on the different types of autism, Chapter 4 for more on receiving a medical diagnosis, and Chapter 18 to find out what to do after you receive a diagnosis of autism.

Looks can be deceiving

Because many people with autism seem physically healthy, some people — even parents of autistic children — believe the milder forms of autism aren't real disabilities at all. Outsiders may believe the diagnosis doesn't excuse poor behavior, and they blame the parents or the child himself for his lack of control. This blame

game is unfortunate, because a neurological disability left untreated can have a far-reaching impact on a person's well-being and ability to achieve potential in life. For a list of responses to this reaction and other unfortunate beliefs, head to Chapter 17.

Understanding the diagnostic criteria

Autistic disorder is classified in the *Diagnostic and Statistical Manual*, a reference published by the American Psychiatric Association, as having 6 or more symptoms from a list of 12 possible symptoms, which the manual groups into three areas: social interaction, communication, and behavior. The DSM is revised regularly, and so are the categories.



Your child must have at least six symptoms, with at least two symptoms indicating social-interaction deficits and one symptom in each of the communication and stereotyped-patterns-of-behavior categories. A child who has most of the symptoms — up to 12, according to the American Psychiatric Association — will usually be diagnosed as *autistic*, or sometimes as having *classic autism*. Others who have only a few symptoms may be classified as *developmentally disabled, with autistic-like features*. If you're thinking this sounds imprecise, you're right. Researchers are still debating which disorders belong on the autism spectrum. Chapter 2 goes into more detail about autistic subtypes and related disorders.

Asperger Syndrome is also listed as one of the Pervasive Developmental Disorders. Diagnosticians focus on the social and behavioral categories for this part of the spectrum, due to the *lack* of significant clinical delay in verbal communication in people with Asperger Syndrome. (See Chapter 5 for more about Asperger Syndrome.)

Here are the 12 symptoms listed within their respective categories:

✓ **Social interaction:**

- Marked impairment in the use of multiple nonverbal behaviors
- Failure to develop age-appropriate peer relationships
- Lack of spontaneous seeking to share interests and achievements with others
- Lack of social or emotional reciprocity

✓ Communication:

- Delay in or lack of spoken language development (with no compensation through alternative modes of communication) in verbal persons
- Marked impairment in conversational skills
- Stereotyped and repetitive use of language
- Lack of spontaneous age-appropriate make-believe or social-imitative play

✓ Behavior:

- Preoccupation with at least one stereotyped and restricted pattern of interest to an abnormal degree
- Inflexible adherence to nonfunctional routines or rituals
- Repetitive motor mannerisms and preoccupation with parts of objects
- Persistent preoccupation with parts of objects



Besides showing at least six of these symptoms, your child also needs to show a delay in social interaction, social communication, or symbolic or imaginative play. The DSM and diagnosticians agree that these symptoms generally must occur before the child is 3 years old. A diagnosis of autism can occur later (even up to old age) if it's clear that the symptoms began before the age of 3.

After looking at the symptoms, criteria, and the vague labels attached, you may begin to think that autism isn't a very informative label. However, the diagnosis is a starting point for getting treatment. Although the Food and Drug Administration (FDA) hasn't approved any medical treatments for autism itself, it has approved treatments for related problems that may occur, such as irritable bowel syndrome, anxiety, vitamin deficiencies, and other physical conditions from which autistic people frequently suffer. When you treat those health issues, you can reduce or even eliminate many symptoms.

Seeing the signs: Autism symptoms

Professionals diagnose autism based upon symptoms shown in the categories of social interaction, communication, and behavior (see the previous section). We take the following sections to explain the categories of symptoms in greater detail.



Early diagnosis and intervention — before the age of 3 — are very important, because research shows that many features of autism respond better when you deal with them early. Sadly, some children don't receive an official diagnosis until years after their parents first suspect that something is wrong, which means they lose valuable time. Even some doctors don't have the necessary facts to provide an accurate diagnosis. You know your child better

than any doctor, so if you disagree with a doctor's assessment, you should get a second opinion. Trust your instincts if you think your child isn't developing normally. (See Chapters 4 and 6 for more on finding the right doctors and choosing the best medication plans.)

Social development

People with autism — partly because of the problems they have with communication — have difficulty developing friendships and playing cooperatively with others. Often, kids with autism don't imitate others' behaviors, as children usually do, and they don't share their thoughts and observations. They also don't spontaneously try to connect with others, as other children will.



Despite the challenges children with autism face regarding social interaction, they still have the desire to interact. Children with autism may just need direct instruction to learn what others pick up by mere observation.

Even mildly autistic children who have normal language development (a diagnosis known as *Asperger Syndrome*, to which we devote Chapter 5) find it difficult to form peer relationships because of their problems in understanding social protocols and others' motivations. This social awkwardness can happen even if a child's IQ is off the charts. Children on this end of the autism spectrum display little understanding of appropriate behaviors, and they may be criticized for being "brutally honest," but many people note that they commonly lack pretension, dishonesty, flattery, and guile. However, they can also be quite hurt by their inability to connect socially, although they may not be able to express these emotions. Most people on this part of the spectrum lack the emotional vocabulary.

If you're a caregiver who wants to aid in your child's social development, the chapters in Part III can be of great help. If you're an autistic adult, head to Part IV to discover some tips on socialization.

Communication

Autistic individuals have trouble with language development, sometimes losing speech at 18-24 months (known as *regressive autism*), talking only late in development, or not talking at all. Children may repeat words and phrases like television commercials (a condition known as *echolalia*), having no apparent understanding of their meaning. The children may hear words but not be able to make sense of what they mean.

Non-verbal communication is also impaired in children with autism. Commonly, autistic individuals may not understand what gestures mean. They won't point to objects. They may not make eye contact or smile when smiled at. Their responses or lack of responses can be isolating, resulting in communication barriers rising between them and other people.

The chapters of Part III can take you from possible interventions to tips on how to improve your child's ability to communicate.

Behavior (activities and interests)

Autistic children often have obsessions or preoccupations with objects or with fantasy worlds (they may have trouble distinguishing fantasy from reality) that go beyond the normal interests of a developing child. For example, a child may play exclusively with string or believe she's an animal. She may have trouble transitioning from one activity to the next and insist on sticking to a ritual or routine — even one that seems to have no meaning. Repeated mannerisms such as hand flapping, rocking, or walking on one's toes may become habits.



Doctors are certain that autism affects the way the brain functions (and autopsies of autistic brains show abnormalities in different areas), causing a sometimes distinctive set of behavioral symptoms. Each behavioral symptom can range from mild to severe. To complicate things further, not all children diagnosed as autistic display all the behavioral symptoms. The behavioral symptoms govern the diagnosis, making treatment problematic.

Coexisting issues

Other conditions often coexist with autism, further complicating the diagnostic and treatment picture (and researchers are still debating whether the conditions are causes of autism; see Chapter 3). Some of the more common coexisting conditions include the following:

- ✓ Mental retardation
- ✓ Hyperlexia
- ✓ Obsessive compulsive disorder (OCD)
- ✓ Attention Deficit/Hyperactivity Disorder (AD/HD)
- ✓ Dyslexia

Conditions are considered *comorbid* if they occur at the same time as the autistic symptoms and are deemed to have roughly equal “weight” by the diagnostician. Other associative conditions such as depression are often secondary to the autism — in other words, a person's difficulties in interacting with the environment and connecting with others result in a depressive disorder.

Understanding the Far-Reaching Impact of Autism

An autism diagnosis has a far-reaching impact in your personal community. It affects not only the immediate family of the autistic person, but also extended family members, schoolmates, friends, medical providers, and many others with whom the person comes into contact. If you're a person with autism or the caregiver of a person with autism, you have to bear the brunt of the emotional impact of the diagnosis. But don't worry! With a positive attitude, you

can weather the storm and enjoy the calmer waters that result from greater understanding and acceptance of how autism makes you the valued person you are. The following sections explain how the disorder can affect different people and how you can cope and help others cope.

How autism can affect the diagnosed individual

An autistic child faces large obstacles. He most likely needs (or will need) academic support in school; interventions for behavior before entering school; and help in communicating and socially interacting with others. Autistic children don't pick up social cues and nonverbal language and behavior, so they need a great deal of social support in order to make friends, interact successfully in social situations, and eventually become adults who can hold jobs, relationships, and financial security. This support, combined with physical symptoms that can be debilitating if left untreated, can make the autistic person feel like an outsider, as if he were literally "born on the wrong planet."

Understanding your autistic child is half the battle. The sooner he's diagnosed, the better the prognosis. If you're an autistic adult, you may have gone through most of your life undiagnosed and feeling different or odd, but you never quite knew why that was the case. We hope to help you understand yourself better with the information and advice in this book. People who are diagnosed today face a better future than ever before. Knowledge about treatment options and educational interventions is expanding rapidly, and a body of evidence on what works and what doesn't is accumulating.

How autism can affect families, schools, and communities

The ripples of a child's autism diagnosis can be felt throughout the child's family, the school system he attends, and the community of which he is a part. Within the family structure, parents may have to shift many resources — time as well as money — to focus on helping the autistic person, which may put strains on their marriage, on work, and on their relationships with siblings. Autism can tear families apart, as evidenced by the high divorce rate among parents of autistic children. (We talk about relationships between autistic children and their siblings, extended family members, and peers in Chapter 13.)

The rapid rise in diagnoses of autism in the United States (see Chapter 3) has created an enormous challenge for schools and teachers, many of whom aren't trained to deal with this once-rare condition. Community services are available in many places to help parents of autistic children, but the rise in spending hasn't kept up with the rise in numbers. Autistic people often

require special-education services and have special health-care needs that schools and hospitals are just learning how to manage. But, as with the diagnostic process, awareness is getting better. You can help by becoming an advocate for autism. Find doctors and plans that work for your child, help your child's teachers learn how to give proper care and treatment, and know your rights under the law. Parts II and III will help you greatly in these areas.



An enormous, educational consciousness-raising project on the subject of autism is underway, and we hope to be part of it. For example, April is Autism Awareness Month, where autism-related organizations pay special attention to increasing awareness of the condition through conferences, articles, rallies, and other means of publicity. Get involved!

How autism can affect caregivers

If you're the parent or caregiver of a child diagnosed with autism, you have a new job to add to your résumé. You now have to spend large amounts of time trying to help your child. And if you have other children and a spouse, you have to focus on your autistic child while making sure you don't neglect those relationships.

You'll likely have to redefine what your child's success in school and life will look like. You should continue to have high standards for your child, but be aware that progress will likely come in small steps and require hard work. The success of many autistic people wasn't easily achieved; success is hard-won for both the autistic person and the parents.

And unless money is no object, the disorder can put a strain on your financial resources, which means you may be faced with some hard decisions about your lifestyle and priorities. You may need to put off some of your plans or be creative with your assets until your expenses stabilize. (Head to Chapter 16 for more on money matters.)

What does all this extra work and burden mean for a parent or caregiver? It means stress, and plenty of it. Dealing with the stress, grief, guilt, anxiety, and pressure of caring for your autistic child and continuing to try to carry on with day-to-day life is a challenge for all caregivers of children with autism. For instance, the caregiver is responsible (with the help of some exceptional physicians/healthcare providers) for

- ✓ Personal education about ASDs and other subjects that may be quite foreign
- ✓ Deciding which interventions to try among the myriad options
- ✓ Picking caregivers and any therapists who work with your child outside of school
- ✓ Choosing schools and behavioral programs

- ✓ Being the case manager for your child's healthcare
- ✓ Implementing all the choices into one treatment and education program

Meanwhile, you hope that you make the right choices. Not only do you have the stress of many options and choices, but also you live in fear — fear that if your child gets lost or runs away, he won't be able to say who he is or where he lives, for instance. And within the chaos of all these challenges, you must try to keep a house, a family, and perhaps even a boss happy. Your marriage may be strained like never before, and many marriages don't make it. On the other hand, if you work at it, you can strengthen your bond with your partner, with your family, and with the child with autism. You can pull together like you never could've imagined. It's crucial that you “keep it together” and don't let the strain become overwhelming.



You can get a major boost and some much-needed empathy by joining a face-to-face or an Internet-based support group, where you can meet other parents of autistic children and share your experiences (see the Appendix for more). When you have support, you realize that you're not alone in your feelings and that you *can* cope.

Navigating the Sea of Interventions

After a professional (or multiple professionals) makes the autism diagnosis, the real work begins. Autistic people need much help. And because they're so varied in their symptoms and medical issues, they need individualized programs. Parents and others involved with their treatment and education need to realize that an integrated approach works best to ferret out the exact issues and work toward achieving the highest potential of each affected individual.



You'll probably be working with more than one doctor and specialist, so you have to act as your child's case manager, coordinating everything that goes on. This responsibility can be daunting, so we devote Chapter 4 to explaining the process of medical treatment to guide caregivers through it.



Many parents elect to pay out of pocket for more experimental or cutting-edge treatments in hopes of hitting a results gold mine. We don't discourage this way of thinking, but we firmly believe in fully investigating all your options before proceeding with what can be expensive, unpredictable procedures. You want to avoid jumping on every trend that comes along and bankrupting yourself in the process.

Whatever treatment options you decide to explore, be cautious about believing everything you hear and read — even from other parents, whose situations may be different from yours. Unfortunately, unscrupulous people will try to make a buck on people like you. People will attempt to exploit your concern for your child by selling you a program or remedy that probably

won't work. Be on the defensive. Just because some treatment brokered over the Internet was the answer for one child doesn't mean it will work for yours. The effectiveness of the treatments you implement should be scientifically proven and, at the very least, safe.

The following sections go into more detail about the intervention options available to you. Be sure to find out which are covered by insurance or government mandates (many of them are).



One problem with using more than one intervention at a time is separating the effects of different treatments. If a child is undergoing biomedical treatments while working with educational/behavioral therapy, keeping the effects of the treatments straight shouldn't be a problem, because the effects of behavioral therapies are usually slower. We suggest that if you use more than one intervention at a time (which you probably will), make sure you make only *one* change at a time. For example, avoid beginning a new diet at the same time as starting a new educational/behavioral approach. Start with one to determine its effect and then layer on the next.

Using behavioral, developmental, and other educationally based interventions

Behavioral, developmental, and other educationally based interventions aim to change a child's behaviors by working on his communicative, cognitive, and social skills. Existing interventions don't cure "autism," per se, but they do improve its symptoms.

The following list outlines many of the intervention options available to you today (for a complete look at these interventions, head to Chapter 9):

- ✓ **Applied Behavioral Analysis (ABA).** ABA — sometimes called the *Lovaas method* after its inventor, Dr. Ivar Lovaas — is the most common behavioral intervention. It focuses on modifying behavior itself through a system of rewards and (much less commonly) punishments. The process is most often performed by trained therapists, who create a highly structured, individualized, and systematic learning environment for the children. ABA requires a large amount of time — at least four hours a day — to be effective. (Dr. Lovaas states that five to ten hours a week of behavioral therapy isn't enough to show a significant difference.)
- ✓ **Floortime.** This therapy is gaining wider acceptance today. Created by Stanley Greenspan, Floortime, also known as DIR therapy (Developmental Individual Difference Relation-Based Intervention), stresses emotional bonding with the child and requires the parents or guardians to do most of the therapy. Floortime concentrates on developing affection in the child with autism and looks toward closing the developmental gaps between where a child is and where he's expected to be. This program is also

structured, individualized, and systematic and requires a large amount of time to be effective (at least four hours a day).

- ✓ **Miller Method.** The Miller Method focuses more on cognitive development and aims to close the developmental gaps between where a child is and where she's expected to be. Practitioners of the Miller Method strive to understand the world from the child's point of view. They believe that every child, no matter how confused she seems, is just trying to make sense of a confusing environment — and that it's the practitioner's job to help the child. Another goal of the Miller Method is to enable the child to make choices about her interactions with the environment instead of being constrained by routines and rituals.
- ✓ **Verbal Behavior.** This is a more recent, updated version of ABA. It stresses techniques to obtain verbalization from the child.
- ✓ **TEACCH.** Developed at the University of North Carolina at Chapel Hill, the TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) approach focuses on employing other approaches as needed to provide an environment that enables the person with autism to be successful at using her strengths.
- ✓ **Daily Life Therapy.** This program, initially developed in Japan and now also residing in Massachusetts, focuses on balancing the physical, emotional, and intellectual components of a child. The program strives to teach children with autism to successfully interact in groups and, later on, in society.
- ✓ **Relationship Development Intervention.** This intervention concentrates on helping children with autism enjoy the pleasures of sharing experiences with others. Practitioners teach the children to be flexible in their interactions with others and to develop emotional connectedness.

When choosing a program for your child, you must realize that many approaches can be helpful — if you and the program's practitioners implement the therapy with the needs of your child in mind, and if the practitioners are skilled and caring individuals. Those are two BIG ifs.



The quality of the practitioners may be the single most important variable in your child's progress, whether you choose ABA, TEACCH, DIR, or some program you get off the back of a cereal box. You can find good and poor practitioners of all methods, and in many cases, the methods aren't really that dramatically different from each other in practice.

So, you should choose a program you feel comfortable with, but make sure to pay the most attention to *who* is working with your child and how the program is tailored (or not) to him. Is the teacher flexible and sensitive to your child's needs, yet disciplined in approach, for example?

Implementing occupational and speech-language therapies

People with autism are known to have difficulties in the areas of speech, motor skills, and sensory processing. If your child has trouble with speech and/or motor skills, you can ask for recommendations to speech-language pathologists and occupational therapists to help your child communicate better and improve her physical skills, including motor-coordination difficulties such as trouble with balance, clapping, or holding a pen steady to write legibly. (For more on these types of therapies, check out Chapter 10.)

Most people with autism have sensory issues they deal with. Usually, these sensory difficulties aren't due to any physical problems with the eyes, ears, mouth, or nose; they occur at the level where the brain processes input. So, the body may collect sensory information properly, but the brain doesn't interpret the information correctly. For instance, an autistic person may have trouble hearing and seeing at the same time. Autistic people also can have hypersensitive nervous systems, with senses that are so highly acute that fire sirens or scratchy clothes are physically painful. An autistic person may seem to withstand pain or fear better than the norm and do risky things such as walk on high ledges because he has no fear of falling.

If your child has sensory issues, you can employ *sensory integration therapy* to treat the sensory confusion that happens when some people with autism can't process sensory information correctly. The therapy is designed to reduce the sensory overload by bringing your child's sensory inputs in line. (For more information on sensory issues, look to Chapter 10.)

Practitioners often perform sensory integration, or SI, as part of occupational therapy or as one component of a behavioral intervention program (see the previous section). SI includes different types of *listening therapies*, which view autism as primarily stemming from a fundamental communication disorder. Doctors today use listening therapies to treat problems such as learning disabilities and AD/HD.

Medicating symptoms that can accompany autism

After you receive a diagnosis of autism for your child, you'll implement a treatment program that lasts until the child can function without support from that intervention. At that point, your doctor may prescribe medications to treat symptoms that accompany the autism disorder if needed, such as aggression,

self-injury, anxiety, OCD-like characteristics, and depression. (Medicating children with autism is often controversial, as Chapter 6 explains.) Medication treatment should focus on symptoms that put the person at risk of harming himself or others or that inhibit the person's ability to gain from other treatment programming.

Medications commonly prescribed for adults and older children with autism include the following:

- ✓ Antipsychotics, such as Risperdal
- ✓ Stimulants to treat hyperactivity, such as Ritalin
- ✓ Antidepressants, such as Prozac and Zoloft
- ✓ Antianxiety medications, such as Xanax

Although no medications can cure the underlying neurobiology of autism, researchers are working to isolate the mechanisms in the brain that create the difficulties experienced by autistic individuals.

Applying biomedical and natural interventions

A growing school of thought considers autism a biomedical disorder that can be helped or even cured by changing the person's diet or removing toxins from his system and his environment. As of this writing, much anecdotal evidence — but little clinical evidence (the kind that doctors look for to make judgments, and the kind the FDA uses to make regulations) — is available that demonstrates results with some, but not all, autistic children. Clinical evidence is minimal because researchers find it tricky — ethically as well as logistically — to do a controlled study with autistic individuals. A *controlled study* occurs when researchers test a treatment variable against a control group that receives no treatment. Although the science has been moving forward, parents don't have the time to wait and have tried many things in efforts to expand their options before it becomes too late for their children.



Some conventional practitioners claim that if a cure results from biomedical interventions, the person didn't really have autism in the first place. Because doctors don't have enough evidence to definitively answer the question "what is autism" in the first place, and because we believe many people just want to know what interventions are available for their children, we include information on biomedical treatments in Chapter 7 and on improving your child's diet in Chapter 8. Many of the interventions we provide, such as supplementation or special diets, have little or no risk when implemented under the supervision of a physician.

Educating and advocating

When you picked up this book, you started to learn about autism and what it means — an important first step. You have a great deal of information available, and you can work to educate yourself. It may be the most rewarding and personal learning experience you'll ever have.

When you know enough yourself to begin helping others, you'll find that you have an important role. You'll be teaching others about autism spectrum disorders and advocating for disabled people all over the world. We're not saying that you need to speak at conferences or lobby your local and state representatives (although many parents and autistic people do). However, we're confident that you'll care so much about increasing awareness and services that you'll find yourself explaining autism to others who don't understand it. Even a task that seems as small as making the special-education program at your local school more responsive to autistic needs makes you an effective advocate for your child and for others with autism. You'll also find that no task is "small" in the world of autism.

You'll run into many people who don't get it. You may feel the need to defend your parenting abilities or your decisions. People may give you funny or disapproving looks or make comments if you go out in public with an autistic child who does something to attract attention. You can try to explain to others about your child, or you can decide not to let others' erroneous assumptions affect your peace of mind. (For some clever responses to absurd questions, check out Chapter 17.)

Some parents and people with autism carry informational cards with them. These cards often give brief explanations of autism and list hints for interacting with autistic individuals. Handing a card to someone (unless the person thinks you're selling something!) usually helps the person to stop and reconsider his or her thinking. For a ready-to-go version of this card, check out the Cheat Sheet in the front of this book.

Here are some examples of biomedical interventions, which you can combine with behavioral interventions in an integrative approach:

- ✓ Vitamin therapy, such as B12
- ✓ Omega 3 supplementation
- ✓ Wheat-free/dairy-free (GF/CF) diet
- ✓ Chelation (removing metals, such as aluminum, from the body)

If You Think You (Or People You Care for) Have Undiagnosed Autism . . .

Perhaps you're reading this book because you've been diagnosed with an ASD (or you think you may have one), and you want to get a better idea of

what to expect. Maybe your child has been diagnosed recently. Perhaps somebody close to you has a diagnosis, and you think you may have a touch of it also. You may even be unsure that the diagnosis fits. We're here to help you sort all this out, no matter your situation.

Autism, as you'll find out in this book, isn't a terrible fate. People on the autism spectrum have a great chance to lead fulfilling and productive lives. With all the interventions now available, autistic people who lead successful lives can become the rule rather than the exception. Consider the achievements of the following folks with autism: Temple Grandin (animal science professor, cattle processing consultant), Liane Holliday Willey (presenter, communications consultant, author), Dena Gassner (recipient of a Masters in social work, educational advocate), Kassiane Sibley (nationally renowned gymnast), Valerie Paradiz (author, presenter, executive director of a school for Asperger students), Jason "J-Mac" McElwain (unexpected basketball star), Johnny Seitz (mime, body mechanics expert), William Stillman (author, educational consultant), Jerry Newport (author, presenter), Jerod Poore (Webmaster), and David Hamrick (recipient of a Masters in meteorology).

If you think you have autism, or know a person who does, you have a number of options (in addition to reading this masterpiece, of course):

- ✔ You can read more about the autism spectrum on Web sites we list in the Appendix to get more help.
- ✔ You can become familiar with autism literature.
- ✔ You can take the self-scoring Autism Spectrum Quotient (ASQ) test, created by Simon Baron-Cohen, at www.wired.com/wired/archive/9.12/aqtest.html.



The ASQ is only a screening instrument that tests for the possibility of Asperger Syndrome in older children and adults (see Chapter 5 for more on Asperger's). Scoring over the threshold merely means the possibility of an autism spectrum condition exists. For a true diagnosis and for help, see a qualified professional (start by checking out Chapter 4).

- ✔ If your concern is for a younger child whom you fear is more severely affected by autism, consider filling out the Miller Diagnostic Survey at www.millermethod.org/mds. Although you must pay a \$100 fee for obtaining a report written by the senior staff at the Language and Cognitive Development Center, the results can provide useful insights on how to understand and help your child.



You should think of this assessment as a preliminary informative tool, not as a substitute for a direct, personal evaluation of a child by a qualified professional.