Excerpt (Chapter 1) from The Natural Medicine Guide to Autism by Stephanie Marohn

1 What Is Autism?

"You know, Mommy, the world is full of sounds. When I listen to them, I realize that the sounds make patterns, and the patterns all turn into music in my head. Sometimes when you call me, I don't hear you because I'm listening to the music."¹

—Miles, 5 years old, recovered from the autism diagnosed at 19 months

After long being regarded as a mental illness or emotional maladjustment, autism is now recognized as a biological disorder, meaning that it is due to organic rather than psychological causes. More specifically, autism is a neurological or brain-based developmental disorder that particularly manifests in problems in cognition, communication, and interaction. The onset typically occurs before three years of age.

Despite the consensus of biological causality, the American Psychiatric Association's criteria remain the standard for an autism diagnosis, and autism is still classified as a mental disorder in the *Diagnostic and Statistical Manual of Mental Disorders–Fourth Edition (DSM-IV)*, the diagnostic bible for psychiatric disorders. As the criteria paint a portrait of the disorder, I include a summary here.

For a diagnosis of autism, according to the DSM-IV criteria, a person must have at least six items from the three areas delineated below, with at least two from the first area and one each from the other two.²

1. Impairment in social interaction

• impairment in nonverbal behaviors related to social interaction, such as eye contact and facial expression

• failure to develop peer relationships

• lack of spontaneous sharing of enjoyment or interests, as evidenced by showing or pointing out objects

- · lack of social or emotional reciprocity
- 2. Impairment in communication
 - delayed or nonexistent language development
 - impairment in conversation abilities if language is present
 - stereotypic, repetitive language or idiosyncratic language
 - · lack of make-believe or social imitative play
- 3. Repetitive and stereotyped behavior, interests, and activities
 - abnormally intense preoccupation with one or more interests
 - seemingly inflexible adherence to routines or rituals

• stereotyped and repetitive mannerisms, such as hand or finger flapping or twisting, or wholebody movements

preoccupation with object parts

While the *DSM-IV* description is a good starting place for understanding what autism looks like, there are many symptoms and conditions associated with the disorder that are not reflected in these criteria. This is especially true when autism is considered from a biological rather than a behavioral perspective, which involves looking beyond the outward signs to what is happening on the inside.

For example, many children with autism suffer from allergies, nutritional deficiencies, and/or intestinal overgrowth of the yeast-like fungus *Candida*. Many also have weakened immunity or autoimmune problems. See the sidebar to follow for an expanded list of the symptoms, behaviors, and conditions that have been found to be associated with autism.

An aspect of autism that has fascinated many is what is known as "islets of ability." Autism pioneer Leo Kanner (see "The History of Autism," which follows) coined the term to refer to the advanced skill areas of autistic children. The most well documented "islets" are in drawing, music, calendar calculation, and rote memory. Unusual drawing ability, perfect pitch, the ability to play an instrument that one has never been taught, and the ability to play a complex piece after hearing it only once are all examples of islets of ability.³

Another positive aspect of autism may arise from behavior that often drives family members to distraction. Temple Grandin, who was autistic from an early age and provides rare insight into the experience of autism in her book *Emergence: Labeled Autistic*, points out a potential benefit of the intense preoccupation with certain objects that is characteristic of autism. "High functioning autistic adults, who are able to live independently and keep a job, often have work that is in the same field of interest as their childhood fixations."⁴ In her case, an early obsession with livestock equipment turned into a creative adult profession as a designer of such equipment.

Grandin also illuminates the function of the puzzling, repetitive, almost ritualistic behaviors in which many autistic children engage. "I, as an autistic person, reacted in a fixated behavior pattern in order to reduce arousal to my overly stimulated nervous system. . . . By concentrating on the fixation, [autistic-type children] block out other stimulation which they cannot handle."⁵ Of her sensitivity to sound, Grandin says, "Sometimes I heard and understood, and other times sounds or speech reached my brain like the unbearable noise of an onrushing freight train."⁶

Symptoms, Behaviors, and Conditions Associated with Autism

anxietv attention deficit distractibility hyperactivity hypersensitivity to: sound light touch certain foods environmental toxins vaccines hypersensitivity or imperviousness to pain seeming lack of awareness of danger impulsivity self-stimulatory behavior (stimming) such as rocking or twirling hand flapping and other repetitive movements rhythmic rocking walking on tiptoe severe language deficits loud, monotone voice lack of use of the pronoun 'I,' referring to self in the third person echolalia (repeating others' words or phrases) prosody (singsong speech) abnormal nystagmus (eye movement)

islets of ability (perfect pitch, unusual drawing or musical talent, calculation or rote memory skills, etc) preoccupation with light switches or other objects spinning objects repetitively unusual and intense interests repetitive acts and thoughts (stereotypies, mannerisms, perseverations, obsessions, and compulsions) using someone's hand or arm as a tool, as if it is not attached to a human being absence of pointing lack of shared attention (showing or pointing to something) no playing peek-a-boo impaired nonverbal behaviors (eye contact, etc.) incomprehension of gesture impaired social interaction impaired communication seeming lack of interest in people seeming unresponsiveness to verbal cues (parents may suspect deafness, but hearing tests normal) blank remoteness seemingly expressionless face resistance to change tantrums or odd behavior in reaction to sudden change or for no apparent reason laughing, crying, or showing other emotion for no apparent reason lack of spontaneity lack of curiosity poor appetite allergies inability to process casein and gluten fungal overgrowth digestive problems leaky gut syndrome nutritional deficiencies autoimmune problems weakened immunity chronic or frequent colds, flu, and ear and other infections heavy metal toxicity

In addition to the above, research has discovered abnormalities in the brains of people with autism, variously in the cerebellum, limbic system, frontal cortex, and amygdala, and in brain waves. Studies have also found elevated blood levels of the neurotransmitter serotonin in autistic people, but reduced uptake in the brain may mean that the availability of this vital nerve messenger is actually limited.⁷

Donna Williams provides another glimpse into the inaccessible world of autism. She, like Temple Grandin, was autistic from early childhood and went on to write a book about the experience, entitled *Nobody Nowhere: The Extraordinary Autobiography of an Autistic.* She, too, offers an explanation for the fixed behavior patterns and repetitive actions. "The constant change of most things never seemed to give me any chance to prepare myself for them. Because of this I found pleasure and comfort in doing the same things over and over again."⁸

Jerry, who was five years old when Leo Kanner diagnosed his autism, painted a painful picture of what it was like for him as a child. At the age of 31, he told psychiatrist J. R. Bemporad about his experience of autism, which Dr. Bemporad reported as follows:

"According to Jerry, his childhood experience could be summarized as consisting of two predominant experiential states: confusion and terror. The recurrent theme that ran though all of Jerry's recollections was that of living in a frightening world presenting painful stimuli that could not be mastered. Noises were unbearably loud, smells overpowering. Nothing seemed constant; everything was unpredictable and strange."⁹

In Their Own Words

"Sara has an exceptional memory, particularly for dates and what happened on those dates. . . . She was a big [Eduard] Munch fan for a long time and I found an old Munch calendar in a remainder bin in a bookstore. . . . She spent an entire weekend filling in the events of every day of that preceding year—things that we had forgotten entirely. And when we checked back in my datebook or with friends, she was absolutely dead on as to what had happened, where we'd been, and even what people had worn."¹⁰

-Sara's mother

"I remember when [Sara] was four, maybe five years old, being inside the house, in the winter, with music on the stereo that was quite loud, and conversations going on, and trying to talk to her, and she reacted really strongly, wanted us to be quiet so she could hear the airplane. Of course, we couldn't hear the airplane. Everyone was quiet. We turned the stereo off, opened the door, and listened really carefully, and we could hear a small plane somewhere in the distance. But she heard that through everything."¹¹

-Sara's father

"My bed was also surrounded and totally encased by tiny spots that I called stars. . . . I have since learned that they are actually air particles, yet my vision was so hypersensitive that they often became a hypnotic foreground with the rest of 'the world' fading away. . . . The hypnotic fascination I had for the spots in the air left me with very little sensation of my own body except for the shock and repulsion of the invasion of physical closeness. . . . I learned to tolerate being hugged . . . being hugged hurt me and . . . It felt like I was being burned."¹²

—Donna Williams, university-educated author of Nobody Nowhere: The Extraordinary Autobiography of an Autistic, among other books

Who Gets Autism?

Today, over 500,000 people in the United States have autism. That number is increasing daily at an alarming rate, prompting many professionals to declare that we are in the midst of an epidemic of autism.¹³ The current incidence rate for the disorder varies, depending on the source consulted. The Centers for Disease Control and Prevention (CDC) places the number at 1 in 500 in the general population, and 1 in 150 in some places in the country (notably Brick Township, New Jersey, home to a toxic landfill).¹⁴ The U.S. Department of Health and Human Services, as represented in the Surgeon General's report on mental health, places the number at 1 to 2 in 1,000.¹⁵

The American Academy of Child and Adolescent Psychiatry cites "a conservative estimate for the prevalence of autism" of 1 per 2,000 people, and 1 per 1,000 if Asperger's syndrome is included.¹⁶ The incidence rate, according to the Autism Research Institute, is now 1 in 160 to 200, up from 1 in 2,500 in the 1980s.¹⁷ The American Medical Association (AMA) states that as many as one in five children today have a neurodevelopmental condition such as autism, a learning disorder, or attention deficit/hyperactivity disorder.¹⁸

While the exact numbers may differ, no one argues that there has been an enormous increase in the incidence of autism. Autism now affects 1 in 150 to 500 children in the United States. The incidence has risen by as much as 1000 percent in the last 15 to 20 years.¹⁹ One of the places where the 1000-percent increase has been documented is California. That percentage may be more than other places simply because the state keeps excellent records. It has what may be the world's best database on autism and other developmental disorders.²⁰

The cause for the increase is the subject of great debate and controversy. Some say it is an issue of awareness, but many long-time teachers, who have seen the sharp increase of autistic behaviors in their classrooms, independent of diagnosis, would contest this view. Many people—both autism experts and parents of autistic children—blame the increase on the rise in

the number and nature of vaccines given to children. This topic is explored at length in chapter 3, but suffice it to say here that the number of vaccines that children receive in the first two years of life has gone up from 8 in 1980 to 22 in the year 2001.²¹ In addition, the rise in autism has occurred in all countries that follow the World Health Organization's vaccination guidelines.²²

Other autism statistics of interest are:²³

- Four out of five people with autism are male.
- One in ten of those with autism show unusual abilities in art, music, calculation, or memory.
- The risk of developing autism is 25 times greater for those with an autistic sibling than for those without an autistic sibling.
- The risk of developing autism is 375 times greater for those who have an identical twin with autism.
- One doctor's clinical analysis revealed that in 60 percent of his autistic patients, their birth involved the use of the Pitocin (a drug to speed the contractions during labor); only 20 percent of all births involve Pitocin.

Types of Autism

In addition to the diagnosis of autism, other diagnostic labels are currently applied to children with autistic symptoms and characteristics. There are many labels used; following are a few of the more common. A holistic approach does not use such diagnoses to determine the appropriate treatment course, focusing instead on the particular manifestations and underlying imbalances in the individual patient. Further, the diagnoses are not distinct and, in many cases, one could be used as well as another. Many autistic children receive these labels, however, so it's helpful to know to what they refer.

Pervasive developmental disorder (PDD): This is a general term for autism and other developmental disorders that involve severe impairment in the three areas cited as diagnostic criteria for autism; that is, impairment in social interaction, communication impairment, and repetitive or stereotyped behaviors, interests, or activities.

Autistic spectrum disorder (ASD): This term encompasses the varieties of autism and reflects the relatively new view of the disorder; that is, that it manifests in varying degrees of severity along a continuum from mild to severe and in varying forms depending on which neurological functions are most affected.

Asperger's syndrome: In what is considered a milder form of autism than classic autism, language development is not as affected and the child may even be precociously verbal.

Atypical autism: This refers to a departure from the manifestations of classic autism in the three areas of impairment: impairment in social interaction, impairment in communication, and repetitive and stereotyped behavior, interests, and activities. Children with atypical autism exhibit effects in only two of the three areas.

Names are also used to distinguish the nature of onset. A diagnosis of classic autism, known as Kanner's autism, early infantile autism, childhood autism, or autistic disorder, generally involves the onset of abnormalities within the first two years of the child's life. Some practitioners make the distinction between classic autism and what they term regressive autism, meaning there was a period of normal development before the onset of abnormalities.

Many parents report that their child was fine until around 15 to 18 months. Most children are not diagnosed until they are at least three, however, because developmental delays are more obvious by that time. Diagnosis in autism is confusing, and made more confusing by the fact that the spectrum or continuum type of labels are in the process of being defined.

In Their Own Words

"My story, which is a really common one and a really sad one, is that I couldn't get anyone to accept that there was something wrong. I would always hear the same old line: 'Every child develops differently. You're worrying too much. You're overprotective.' I think parents know when their child isn't connecting with them. [Sara] would pull away when I would try to cuddle her. I didn't have a whole lot of experience—she's my only child—but I knew it wasn't right."²⁴

-mother of Sara, who was finally diagnosed with autism at the age of 12

Autism Myths

The following are common myths about autism.²⁵ The fact that myths related to the obsolete view of autism as a mental illness persist reveals how well disseminated that view was. Only equally good dissemination of the biological reality of autism will at last dispel that stigmatizing notion. The persistence of all of these myths indicates the need for education of the general public about this disorder.

Myth: Bad parenting causes autism.

This formerly widely held view has been thoroughly debunked in the scientific community. It is now known that autism is a neurological and developmental disorder, not one caused by psychological factors. "Poor mother/child bonding, if it is to be associated with Autism at all, must be seen as effect rather than a cause of Autism," states Uta Frith, author of *Autism: Explaining the Enigma.*²⁶

Myth: Children with autism choose to live in their own world.

Choice has nothing to do with it. Neurological dysfunction is the source of autistic children's manner of interacting with the world. Autistic behaviors arise from the different "wiring" inherent to the disorder. Hypersensitivity to sound, light, touch, and environmental factors as a result of neurological problems are additional features that often make such interaction stressful and even painful.

Myth: Children with autism avoid eye contact.

This is not necessarily the case. Many do make eye contact, although it may be done in a different manner from children who are not autistic. Uta Frith explains that they are not avoiding the gaze, as is typically believed, but rather lack understanding of and the ability to use the "language of the eyes," a vital component of social communication. "The child neither looks away at the right time, nor meets the gaze when this would be expected. . . . Whatever causes the inability to use the language of the eyes has nothing to do with avoidance of human contact."²⁷ As you will learn later in this book, the problem of gaze and other attributes of autism are often improved or disappear with natural medicine therapies that resolve the biological issues involved in an individual case.

Myth: People with autism are actually geniuses, or savants like Dustin Hoffman's character in the film Rain Man.

Only 1 in 10 people with autism have what are termed "islets of ability or intelligence," such as unusual artistic or musical talent or extraordinary calculation or memory skills. Like other children, the IQs of children with autism range throughout the scale, with only a small percentage falling in the lower and upper ranges. Dysfunction in certain areas of mental processing are common to autistic children.

Myth: Children with autism don't speak.

On the contrary, many develop "good functional language," while most others learn to communicate through sign language, pictures, computers, or electronic devices.²⁸ As with other features of autism, the more the biological factors can be ameliorated, the greater the possibility that the child will attain normal language skills.

Myth: Children with autism could talk if they wanted to.

One of the areas greatly affected by the neurological problems and developmental delays of autism is speech. Autistic muteness and lack of verbal response to questions is not a matter of stubbornness or noncompliance, but the result of developmental impairment of speech.

Myth: Children with autism can't show affection.

The Autism Society of America calls this "one of the most devastating myths for families." As with eye contact, the differences in their "wiring" may make autistic children express their love and affection differently from other children. This does not mean they can't give and receive love. Family members need to be willing to meet the child on her terms and recognize her capacity to connect.

Myth: Children with autism lack feelings and emotions.

Clearly, this is not the case, as evidenced by temper tantrums and happy laughter. The fact that many autistic children lack affect in their facial expressions and speak in a flat tone if they do speak aids in the survival of this myth. As with the myth above, it is the communication of emotions, not their existence, that is the issue. All aspects of communication are problematic for autistic children due to their neurological dysfunction and developmental delays, and emotional communication is no exception. A seeming disregard for other people's feelings also fuels this myth. The disregard does not indicate, however, that the child lacks emotions. One of the neurological impairments of autism is a lack of imagination, thus the child cannot imagine what another person is thinking or feeling.

Myth: Children with autism are just spoiled kids with behavior problems.

This myth brings the curse of autism back to the parents' door. It reflects the tenaciousness of the psychological model. It also shows a lack of understanding of the profound and far-reaching effects of neurological impairment on behavior, mood, and motor and language development, among other areas.

Myth: Autism is forever. If the condition improves significantly, it means the child was misdiagnosed and does not have autism.

This is a myth that persists in the conventional medical and psychiatric world, with its dismal prognosis for autism. Given the lack of means to reverse or ameliorate the biological factors involved in autism, the prognosis is understandable and the myth goes unchallenged.

As this book demonstrates, however, improvement and even reversal are possible when you can address the underlying factors in treatment. Many children who strictly met the criteria for a diagnosis of autism experienced significant improvement with natural medicine approaches. On the more conservative end of treatment, methods such as behavior modification, speech therapy, and occupational therapy are well known to produce improvement in autistic children.

In Their Own Words

"[T]here are still many parents, and, yes, professionals, too, who believe that 'once autistic, always autistic.' This dictum has meant sad and sorry lives for many children diagnosed, as I was in early life, as autistic. To these people it is incomprehensible that the characteristics of autism can be modified and controlled....I am living proof that they can."²⁹

-Temple Grandin, Ph.D., livestock handling equipment designer and coauthor of Emergence: Labeled Autistic

The History of Autism

The word 'autism' derives from the Greek *auto* (self) and *-ismos* (condition). Psychiatrist Eugen Bleuler coined the term in 1911 in reference to an aspect of schizophrenia characterized by withdrawal from the outside world into the self. In the 1940s, in the first papers published on the disorder, Leo Kanner and Hans Asperger both borrowed the term to describe autism. Kanner's description of the disorder became the classic autism of today, while Asperger's

description became what is now called Asperger's syndrome, despite the fact that his account was of classic autism rather than the less severe form that came to bear his name.

The psychiatric roots of the label *autism* continued in the long-standing belief that psychological factors were the cause of autism. This psychogenic theory, otherwise known as the "refrigerator mother" theory, which held that the mother's lack of emotional engagement with her child produced autism, enjoyed cachet for decades. In the 1960s, Bruno Bettelheim, a psychoanalyst and proponent of the refrigerator mother theory, went so far as to advocate removing the child from the parents as treatment. He detailed his views in his book *The Empty Fortress: Infantile Autism and the Birth of the Self,* which for some time was considered a classic work on autism.³⁰ The psychogenic theory of autism began to topple with the publication in 1964 of *Infantile Autism,* by Bernard Rimland, Ph.D. This book ushered in the era of biological causation.

The following years saw the emergence of evidence that indisputably disproved the psychogenic theory. Three compelling points in this large body of evidence are: autism is not associated with dysfunctional families, but strikes across families and cultures; the developmental abnormalities that result from extreme emotional rejection and social deprivation are different from autistic abnormalities, and since even severe deprivation fails to produce autism, it is hardly likely that a somewhat cool mother would do so; and one-third of adolescents with autism suffer from seizures, which indicates an organic problem, a brain abnormality.³¹

While the psychogenic theory, which brought so much unnecessary pain to parents of autistic children, is no longer considered valid, vestiges of it persist in public attitude and in professional circles. The survival of the previous myths of autism speak to the stigma of mental illness that still surrounds autism in the general public. As noted earlier, the American Psychiatric Association continues to classify autism as a mental disorder and its diagnostic criteria remain the standard.

While some medical dictionaries have modified their definitions of autism, a classic reference, *Taber's Cyclopedic Medical Dictionary*, still defines infantile autism as "a syndrome appearing in childhood with symptoms of self-absorption, inaccessibility, aloneness, inability to relate, highly repetitive play and rage reactions if interrupted, predilection for rhythmical movements, and many language disturbances," with unknown etiology.³²

The description and the omission of even possible organic causality leave the psychological bias in place.

In the early days of psychiatric diagnosis, autistic people were often labeled schizophrenic. Whatever the label, they were considered ineducable, and institutionalization was a common fate. While the views regarding educability have changed, conventional wisdom still holds that autism is not a treatable disorder, that the best you can do is train autistic children out of some of their limitations. A *Newsweek* cover story on autism in July 2000 reflected this view, focusing on a form of behavior modification as the treatment of choice and stating that "most [autistic children] end up in institutions by the age of 13."³³

As those involved in natural medicine approaches to autism know and as you will learn in this book, treatment holds the possibility for much more than simply working with the limitations.

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