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BASIC INFORMATION ON AUTISM AND ASPERGER SYNDROME

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Introduction

Autism is a fairly new diagnosis and has only been identified and studied since the 1940s. In every subsequent year more has been learned about autism and the autism spectrum, but most of what we know today has been learned in the last few decades. Families who had children in the 1950s, 1960s, and 1970s thus had a *very* different experience with diagnosis, treatment, and education than most families have today.

The past ten years in particular have seen an explosion of newspaper and magazine articles, books (including autobiographies), television programs, movies, and research studies on autism and Asperger syndrome. We know more than ever before, but at the same time this label and the disability are so new that our ignorance still surpasses our knowledge.

Adding to the difficulty of defining autism is considerable disagreement in the field about terminology, labeling, and the nature of life on the spectrum. Some camps, for instance, see autism as a disability, disorder, and collection of deficits. Others see it as a collection of differences, some valuable and useful, and others challenging. Even people on the spectrum may disagree about these conceptualizations, with some desiring a cure and others feeling pride in their diagnosis and valuing their autistic characteristics. And some have mixed feelings on the topic, feeling frustrated by symptoms of autism but grateful for the gifts it brings. We feel strongly that individuals on the spectrum, those who love them, those who support them, and those who engage in research on autism and Asperger syndrome must be aware of this diversity and not presume that any one of these perspectives is shared by everyone in the community. It should also be noted that not everyone on the spectrum experiences autism in the same way, so it is not only our worldviews but actual manifestations of autism that vary.

These particular differences made writing Section One particularly difficult, even from the starting point of deciding what

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language to use in our definitions and descriptions of the autism spectrum. We have handled this problem in many different ways. First of all, we use several different labels in this section in an attempt to illustrate the different ways people are seen and described in the literature. We sometimes talk about the *autism spectrum* and other times use *autism and Asperger syndrome*. The word *disorder*, however, is not used in this book at all, because we feel strongly that it is too limiting and, for some, it is clear a misnomer.

Another choice we have made in an attempt to honor the various ways our audience may see or understand autism is to keep our language fairly neutral (for example, using *differences* instead of *deficits*). We also feel this language is more precise, because those on the spectrum often have as many curious and unique abilities as they do struggles in the areas often seen as deficit areas. We have also tried to be fairly tentative when discussing what we know about autism, because it is constantly changing. Finally, as a researcher (Paula) and a parent of a child with autism (John), we tried to bring at least two different vantage points to the construction of these lists. To get a third and absolutely key perspective—the views of people on the spectrum themselves—we relied on observations from our own lives, conversations with friends and colleagues on the spectrum, and dozens of autobiographical works by people with autism and Asperger syndrome.

We hope the twelve lists included in Section One will clear up some of the confusion you may have about autism, Asperger syndrome, and related diagnoses. Because the autism spectrum is very complex and diverse, we have included several lists that are designed to simply provide information on the fundamentals of the autism spectrum, as in *What We Know About Autism* and *What Do We Mean by the Autism Spectrum?* One features conditions associated with autism, and a fourth contains all the positive traits associated with life on the spectrum. The final list that offers readers basic information is called *Autism Myths Versus*

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Autism Facts and deals with misinformation about many aspects of autism including cognitive abilities, savant-type behavior and skills, and social tendencies.

Two lists in this section are reserved specifically for information on diagnosis and screening. One is dedicated to the early signs of autism and covers four different areas: language and communication, social skills, sensory issues, and behavior. The other features a range of tools used in screenings and in comprehensive evaluations.

The rest of the lists provide information on the various markers of autism, including communication differences; social differences; movement differences; sensory differences; and passions, interests, and fascinations.

We hope this opening section provides some clarification, answers questions, and sets up readers to learn and understand from the rest of the book.

1.1. What We Know About Autism

In 1943, Leo Kanner published the first paper identifying what we know today as *autism*. Kanner observed children who did not fit the patterns of other known disabilities. He thus invented a new category, which he called “early infantile autism.” Independent of Kanner, Hans Asperger was making the same discoveries at the same time, but the patients he identified all had speech; Asperger syndrome, therefore, was used to describe that population. Following are some of the basic principles we have learned since the 1940s about autism and Asperger syndrome:

- Some people, including many on the spectrum, do not see autism and Asperger syndrome as disabilities. Some, in fact, understand autism as a natural part of what it is to be human, and many celebrate the gifts that are part of life on the spectrum.
- In 2007, the Centers for Disease Control and Prevention released data indicating that about one in 150 eight-year-old children in the United States was on the autism spectrum.
- Autism is sometimes called a developmental disability because it develops before age three and causes delays or significant differences in a variety of areas throughout the person’s life span.
- The cause or causes of autism are unknown.
- Genetic origins of autism are suggested by two things: studies of twins and an increased incidence among siblings. It is unknown, however, exactly what role genetics play and whether there is a genetic root for each case of autism.
- Autism is diagnosed using interviews, observational tools, and checklists. There are no biological markers for autism or Asperger syndrome. There are no blood tests, brain scans, or other medical assessments that can be used to diagnose autism.

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- Autism is often diagnosed by age three and in some cases as early as eighteen months. Researchers are currently working on assessments that could lead to diagnosis at age one or before.
- Many on the spectrum are not diagnosed at all in childhood; it is not unusual for people to be diagnosed in adulthood (sometimes because their child gets a diagnosis). This is especially true for those with Asperger syndrome.
- Many more autism spectrum labels were assigned in the 1990s and 2000s than in previous decades. Between 1994 and 2006, the number of school-age children classified as being on the spectrum increased from 22,664 to 211,610. (IDEA data, 2009)
- Currently there are no medications that can “cure” autism or the related symptoms. Some medications, however, are helpful in easing or relieving related symptoms. For example, fluoxetine (Prozac) and sertraline (Zoloft) are approved by the FDA for children age seven and older with obsessive-compulsive disorder.
- There are many stereotypes associated with autism and Asperger syndrome. For instance, people may believe that everyone on the spectrum resists human touch. Or that they *all* love music. We know now, of course, that those on the spectrum are individuals with their own needs, abilities, gifts, talents, and challenges. There is no one set of difficulties that those with autism and Asperger syndrome experience and no one set of supports that will help every person with an autism spectrum label.

1.2. What Do We Mean by the *Autism Spectrum*?

The term *autism spectrum* is used to describe conditions including autism, Asperger syndrome, pervasive developmental disorder/not otherwise specified (PDD/NOS), childhood disintegrative disorder, Rett syndrome, and fragile X syndrome. Because different individuals with autism have very different symptoms, characteristics, and abilities, but also some core commonalities, autism has been described as being part of a spectrum. Following are some basic features of the conditions most commonly included in the autism spectrum:

- People with autism tend to have differences—some subtle and some very significant—in at least two realms: social and communication. They are also characterized as having unique differences in behaviors related to movement, objects, and routines.
- Asperger syndrome is characterized by differences in social interaction and patterns of behavior, interests, and activities, but no general delay in language, cognitive development, or adaptive behavior.
- PDD/NOS is diagnosed when the criteria are not met for autism or Asperger syndrome, but the individual exhibits the same types of differences as individuals with those diagnoses (such as differences in social skills, differences in communication skills, or differences in behaviors related to movement, objects, and routines). These individuals may, for instance, have speech problems, engage in repetitive behaviors, or have auditory sensitivity.
- Rett syndrome is also housed under the spectrum because individuals with this share a lot of characteristics with people with autism and Asperger syndrome. It is a unique developmental disability that is recognized in infancy and seen almost always in girls. It is often misdiagnosed as

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autism. Those with Rett syndrome exhibit symptoms similar to those diagnosed with autism, including repetitive movements (such as wringing or claspings their hands), gaze avoidance, and toe walking. These individuals also have weakened muscle tone and motor problems.

- Childhood disintegrative disorder is another condition that can also be found under the autism umbrella. Those labeled with childhood disintegrative disorder develop typically until age three or four and then seem to lose social, communication, and other skills. Childhood disintegrative disorder is often confused with late-onset autism because both involve normal development followed by a loss of skills. The differences—according to the medical profession—between autism and childhood disintegrative disorder are that autism typically occurs at an earlier age, it is less rare, and the loss of skills appears less dramatic.
- Fragile X is sometimes mentioned as part of the autism spectrum because some, but not all, individuals with that disability also have autism. Symptoms include characteristic physical and behavioral features and delays in speech and language development. Fragile X can be passed on in a family by individuals who have no apparent signs of this genetic condition. Fragile X is more common in boys. Physical characteristics include wider and longer ears and, in boys, enlarged testicles. Like those with autism, individuals with fragile X syndrome may have sensory motor problems, anxiety, and learning differences and may engage in repetitive behaviors.

1.3. Conditions Commonly Associated with Autism

Because autism itself is so complex and people with autism labels experience such different problems and have such varied needs, it can be difficult to see, sense, or observe physical problems, psychiatric conditions, or even disease in people on the spectrum. A person who is nonverbal, for instance, may be depressed but not physically able to cry easily or show changes in facial expression. Therefore, it is critical that all stakeholders, including people with autism labels, be aware of some of the most common co-occurring conditions. Some of those on the list may need special attention or support, and others will need to be simply acknowledged and considered in the development of education or vocational plans, in any medical treatment, or in the crafting of potential supports.

Following are some of the conditions that co-occur most frequently with autism and Asperger syndrome:

- Anxiety disorders
- Bipolar disorder
- Bowel disease
- Depression
- Dyslexia and other learning disabilities
- Gastrointestinal disorders
- Obsessive-compulsive disorder
- Phobias
- Pica
- Seizures and epilepsy
- Sleep disorders
- Tourette syndrome
- Tuberous sclerosis

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1.4. Positive Traits Associated with Autism

We believe there is far too much discussion in both research and in the popular media about the deficits and struggles related to autism and not enough conversation about what people with autism *can* do or—perhaps even more critical—what they can often do *better* than those who are not on the spectrum. This is not to say that we don't see or understand all the difficulties people on the spectrum face. We have all too often seen the pain and challenge of the many sensory, communication, and movement problems that can be part of life with an autism label. However, we feel that learning about the abilities, strengths, and skills that may accompany autism is key. From this knowledge, supports can be built, understanding can be strengthened, and success can be realized. For this reason, we have compiled the following list on some of the most common positive traits associated with life on the spectrum:

- Artistic ability
- Attention to detail
- Creativity
- Energy
- Exceptional skill in mathematics, music, or learning new languages
- Fastidiousness
- Good memory
- Honesty
- Individuality
- Integrity
- Keen observational skills
- Methodical habits
- Neatness

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- Nonjudgmental attitude
- Out-of-the-box thinking
- Passion
- Perfectionism
- Quirky sense of humor
- Refreshing perspective
- Reliability
- Stick-to-itiveness
- Strong mechanical skills

Keep in mind, people on the spectrum are individuals and these characteristics, like others, are only seen and experienced in some people. Like everyone else, people with autism and Asperger's syndrome have their own *unique* set of gifts.

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1.5. Early Indicators of Autism

Other lists in this section provide detailed information about the many differences seen in and experienced by those on the spectrum. This particular list is not an attempt to illustrate all the characteristics seen in people with autism and Asperger syndrome; rather, it is a collection of things that parents and professionals often note in small children who are diagnosed. The following brief list can thus be used as starting point for considering an evaluation:

Language and Communication

- Starts talking later than other children or does not speak at all
- Does not respond to his or her name
- Does not babble, point, or make gestures that can easily be interpreted as communication
- Speaks with an unusual tone or rhythm (such as a singsong voice)
- Uses language in unique ways (such as “playing with” words, but not using them in a way that appears functional or communicating using lines from movies or even whole scripts)
- Appears to use his own language or method of communication (one that others don’t understand or that only some people understand)
- Acquires language skills and then seems to lose them, either gradually or abruptly

Social Skills

- Is very independent
- Avoids eye contact and/or uses peripheral vision
- Connects with people in unique and very personal ways, such as pacing near them (instead of sitting next to them),

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giving them objects (instead of hugging them), or playing a favorite game near others (instead of engaging in an activity or game with others)

- Plays with toys differently from most children (such as lining up toy cars or trucks instead of “driving” them on the floor or spinning a Frisbee instead of tossing it)
- Stays on task and focuses for long periods of time on certain activities (such as lining up marbles or filling up cups with water)
- Spends a lot of time and energy on organizing toys or environments
- Has a particular attachment to certain toys, objects, or events (such as examining a certain pamphlet repeatedly or carrying a favorite hairbrush around)
- Acquires certain social skills and then seems to lose them, either gradually or abruptly

Sensory Issues

- Resists some types of cuddling and holding and craves others (such as loving to be held tight and “smushed,” but disliking holding hands)
- Enjoys feeling or rubbing certain textures, running hands through water, or pushing hands through sand
- Is unusually sensitive to light, sound, touch, and smell and may experience discomfort or even feel pain when experiencing “sensory overload”
- Resists certain foods and prefers a very limited diet
- Has a high tolerance for pain

Behavior

- Needs a lot of movement and exercise
- Toe-walks or moves in unusual ways

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- Has sleep problems
- Engages in repetitive movements, such as rocking, spinning, or hand flapping
- Has specific rituals and routines (such as keeping all the doors in the house closed or organizing LEGOs by color)
- Appears frustrated or even distressed by changes in routines or rituals
- Fascinated by parts of an object, such as the spokes of a wheel or the moving pieces of a toy train bridge

1.6. Autism Myths Versus Autism Facts

More than ever before, information on autism is available to those seeking it. Sources for this information include the Internet, television, movies, books, and conferences. With this avalanche of research, how-tos, and stories, however, come not only accurate answers but misinformation as well. In the following list, we do our best to clear up some of the most common myths about autism.

Myth: Most individuals with autism have the same characteristics, needs, and strengths.

Fact: Because those on the spectrum share so many traits, some may believe that “If you know one person with autism, you know them all.” In other words, some may assume that if you meet one child on the spectrum, you will know what to expect when you meet another. Nothing could be further from the truth. If you know one person with autism, you know just one person with autism. Those on the spectrum are incredibly diverse in their abilities, gifts, struggles, and difficulties. This diversity is one of the reasons diagnosis is so complicated; some on the spectrum find snuggling and hugging pleasant, others find it overwhelming. Some individuals are very precision-oriented and desire order in all areas of their lives; others are more flexible and seemingly unbothered by clutter or disorganization. In sum, people with autism are an incredibly diverse population.

Myth: Students with autism are often “in their own world” and become easily detached from people and experiences in their environment.

Fact: It is certainly true that people with autism report “slipping away” and focusing inward at times (especially in response to stress, boredom, or frustration). It is also true, however, that those who seem to be inattentive or focused elsewhere are sometimes simply unable to attend visually or maintain body language that others associate with focus, attention,

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interest, and engagement. Gaze avoidance, for example, can mean simply that the person cannot listen to the speaker and process her message while taking in all of the nonverbal communication in the eyes and face. So in order to listen to the verbal communication, the individual may look away. Similarly, a child who is flipping his fingers in front of his eyes and has his back turned toward the teacher may be very much aware of and tuned into the lesson. In fact, in some cases and for some people these behaviors may reflect the child's attempt to stay seated and calm. The repetitive behavior may in fact help the person relax and listen longer than if she were sitting still or facing the teacher.

For others, this detachment can be a form of protection. A child may focus inwardly because of loud noises in the environment or because of an inability to comprehend a novel situation. In these instances, blocking out external stimuli could be viewed as a helpful competency or skill and should therefore not necessarily be seen as evidence that the person does not want to socialize, be with others, or engage with the group.

Myth: Those on the spectrum prefer to be isolated and are not interested in socializing or having friends.

Fact: Children and adults on the autism spectrum often have a strong desire for friendship and socialization, but struggle to learn or use the behaviors needed to cultivate relationships or “operate” in a social situation. As John Elder Robison, a man with Asperger syndrome, notes in his autobiography, “I can’t speak for other kids, but I’d like to be very clear about my own feelings. *I did not ever want to be alone.* And all those child psychologists who said, “John prefers to play by himself” were dead wrong. I played by myself because I was a failure at playing with others” (Robison, 2007, p. 211). What many on the spectrum need, therefore, is help with developing social skills and with interpreting social

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behavior. Those of us without autism labels may also need to open our eyes to the fact that each individual socializes differently. Not everyone likes to socialize by attending parties or engaging in long conversations. Many would rather connect by playing a game, taking a quiet walk, or simply by listening to music with others.

Myth: Most adults on the spectrum do not have a high quality of life.

Fact: Many people on the spectrum lead full and satisfying lives. More than ever before, people on the spectrum are pursuing postsecondary education, are employed in fields that interest them, and are living outside their family home independently or with support. Those on the spectrum are also enjoying a more robust social life than would have been possible in years past. Many marry and have children as well. People with autism have been successful across different professions and are particularly well represented in the computer industry in academia, in engineering, and in the sciences. It should also be noted that some of the leading minds in the field of autism are on the spectrum as well.

Along with this good news, it is also true that many people on the spectrum continue to face barriers to an appropriate education, a satisfying community life, and employment. Not only do many people on the spectrum need access to more options for supports and services in their lives, but there is also much work to be done in the way of advocacy. Negative stereotypes and misconceptions of autism often lead to missed opportunities, exclusions, and even abuse. So, while quality of life has improved for many, the journey to a full life continues for others.

Myth: All people on the spectrum are savants with amazing talents and gifts.

Fact: Most people with autism do not possess the extraordinary talents that are so often associated with life on the spectrum.

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Most people, that is, are not able to play musical instruments without instruction or solve complicated equations without putting pencil to paper. An awful lot of people on the spectrum, however, are very skilled, capable, and gifted in areas that their peers outside the spectrum are not. For instance, many have exceptionally sensitive hearing or notice details that others miss, some are very good at keeping things organized, and others have a razor-sharp memory.

Myth: Many children and adults on the autism spectrum have cognitive disabilities or “mental retardation.”

Fact: The truth is that we need to learn a great deal more than we currently know. For many individuals on the spectrum, especially those without reliable communication, there is no test that can measure what they know and can do. Therefore, most of the instruments used in evaluations measure autism *symptoms* as much as, if not more than, *abilities*. On top of the inadequacy of the instruments used in these assessments, many aspects of the evaluation process itself make accurate assessment challenging, if not impossible. There are many barriers to accurate testing for students with autism, including problems with language (such as understanding directions). In addition, many children and adults with autism cannot participate in many assessments due to movement problems, sensory differences, or related difficulties. It is not uncommon for a student with significant disabilities to get a low score on an instrument because she did not have a reliable pointing response, but was able to point. In other words, when asked to point to a monkey, some students point to a giraffe instead, even though they know which image is the monkey. This type of problem with motor planning is widely reported by people with autism.

1.7. Tools Used in Autism Screening and Diagnosis

No specific medical tests are available to diagnose those on the autism spectrum, so these labels are assigned based on the observations of parents, physicians, and others, along with assessments of developmental progress. The two steps to diagnosis are screening and comprehensive evaluation.

Screening

In most cases initial screening will be done by a family physician. In recent years tools have been developed to better identify children not just with autism but with Asperger syndrome as well. Screening instruments do not provide a diagnosis but help parents, physicians, and others determine whether the individual needs a comprehensive diagnostic evaluation. It is important to remember that many of the screening instruments cannot identify all children on the spectrum, especially those with Asperger syndrome. Following are just a few of the many available screening tools:

- Ages and Stages Questionnaires® (ASQ-3™)

ASQ is a tool for screening infants and young children for developmental delays during the first five years of life.

This test focuses on communication, gross and fine motor skills, social skills, and problem solving. This questionnaire can be purchased at www.agesandstages.com

- Australian Scale for Asperger's Syndrome (ASAS)

This twenty-five-item questionnaire is designed to identify behaviors and abilities indicative of Asperger syndrome in school children ages six through twelve. It takes five to ten minutes to complete and is available at www.udel.edu/bkirby/asperger/aspergerscaleAttwood.html

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- Autism Behavior Checklist of the Autism Screening Instrument for Educational Planning (ABC-ASIEP-3)

The ABC consists of several behavior descriptions in five areas and is used to conduct a structured interview with a parent or other caregiver. It is less effective with high-functioning forms of autism. Available at www.proedinc.com

- Childhood Asperger Syndrome Test (CAST)

These thirty-nine questions, designed for parents to answer about their children (ages four through eleven), are related to the core features of the autism spectrum. If parents suspect autism, they can complete this test and take it to their family doctor or pediatrician. It is available at www.autismresearchcentre.com/tests/cast_test.asp

- Checklist of Autism in Toddlers (CHAT)

The CHAT is a screening tool developed for pediatricians to use at the eighteen-month checkup for children. Clinicians complete five items based on observation and ask parents to answer yes or no to an additional nine items. It is available for free at www.depts.washington.edu/dataproj/chat.html

- Modified Checklist for Autism in Toddlers (M-CHAT)

A revised CHAT with additional questions is now available that may pick up more cases of autism and Asperger syndrome. It is available free at www.firstsigns.org/downloads/m-chat.PDF

- Parents' Evaluation of Developmental Status (PEDS)

The Parents' Evaluation of Developmental Status is designed to assist parents determine whether their child has developmental delays. The questionnaire contains only ten questions and can be used for children from

birth to eight years of age. The PEDS takes only about two minutes to administer and score if conducted as an interview. More information about PEDS can be found at www.pedstest.com.

- **Social Communication Questionnaire (SCQ)**

The Social Communication Questionnaire, formerly known as the Autism Screening Questionnaire, contains forty items that are useful in identifying possible pervasive developmental disorders. This forty-item yes-or-no questionnaire is focused on communication and social skills and can be completed by a parent or primary caregiver in less than ten minutes. The SCQ determines whether a child or adolescent should be referred for a complete diagnostic evaluation. Get the SCQ at www.wpspublish.com

Comprehensive Diagnostic Evaluation

A comprehensive evaluation includes observations by your pediatrician and interviews with you as parents to find out more about your child's developmental history. It should also include assessment of language and speech and the use of one or more autism diagnostic tools. The second stage of diagnosis must be comprehensive in order to accurately rule in or rule out an autism spectrum condition or other developmental difference. This evaluation may be done by a multidisciplinary team that includes a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children on the spectrum.

- **Autism Diagnostic Observation Schedule (ADOS)**

ADOS is a standardized instrument for diagnosis of autism. It is used with children older than age two. General ratings are provided for four areas: reciprocal social

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interaction, communication and language, stereotyped or restricted behaviors, and mood and nonspecific abnormal behaviors. ADOS measures both nonverbal and preverbal communication components and should be conducted by clinicians who have been intensively trained to assess the child's use of language. Get more information about the ADOS at www.wpspublish.com

- Autism Diagnostic Interview–Revised (ADI-R)

The ADI-R has been used by clinicians for decades and is used for the purposes of formal diagnosis. The ADI-R consists of ninety-three questions that fall under one of three functional domains: language and communications; reciprocal social interactions; and restricted, repetitive, and stereotyped behaviors and interests. The ADI-R can be purchased at www.wpspublish.com

- Childhood Autism Rating Scale (CARS)

Developed over a fifteen-year period using more than 1,500 cases, CARS includes items drawn from five prominent systems for diagnosing autism. The CARS targets the child's body movements, adaptation to change, listening response, verbal communication, and relationship to people. This fifteen-item behavior rating scale helps to identify children older than age two with autism and to distinguish them from other children with disabilities who do not have autism. The CARS is available at www.wpspublish.com

- Gilliam Autism Rating Scale (GARS)

The GARS helps to identify and diagnose autism in individuals ages three through twenty-two. The entire scale can be completed and scored in five to ten minutes. The instrument consists of forty-two items describing

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the characteristic behaviors of persons with autism. The items are grouped into three subscales: stereotyped behaviors, communication, and social interaction. Learn more about the GARS at www.pearsonassessments.com/gars2.aspx

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1.8. Social Differences

It is often reported that students with autism are not interested in social relationships. Although some individuals with autism do report that they need time alone or that some social situations are challenging, many of these same individuals also state that they crave social interaction and friendship. Thus, it is possible for a person with autism to both struggle with and want relationships. This tension in personal life is one of many that may be experienced by a person on the spectrum. Following are some other common social differences experienced by people on the autism spectrum:

- Some may find social situations difficult because they lack the skills necessary for successful typical social interactions. A person may be unable to successfully read social overtures, participate in the give and take of conversation, or understand how to make small talk.
- Conversations in general can be overwhelming for people on the spectrum. Some people have a difficult time figuring out whether and when others are inviting them to participate in an exchange or knowing whether and how to enter or exit the conversation.
- Some of the norms of social behavior may also be hard for a person with autism to learn, manage, or use. For instance, a child may love to be with her classmates and really want to go to Friday night football games, but struggle so much with learning the rituals of cheering and fandom and figuring out the rules of small talk and “football speak” that she finds the evenings stressful and unpleasant. In some cases, people on the spectrum may find these behaviors too challenging to learn, and others may find that they are not comfortable engaging in them once they are learned, so they will resist using them. For instance, many on the spectrum find eye contact very uncomfortable. These individuals may find that

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they can attend better to the speaker when they are looking away from the person's face. This accommodation can be very helpful to the person with autism, but it can be misunderstood if the conversation partner doesn't know about it.

- Individuals with autism may struggle to read subtle social signals or to decode what they experience as social secrets. For instance, if a conversation partner yawns or begins putting on a jacket, most people would read this as a signal that the partner is getting ready to end the conversation and go home. For some individuals with autism, such subtle signs are hard to read, so they may not bring the conversation to a close (even when the other person adds, "Well, I'd better go").
- Students with autism may also struggle socially because those around them don't understand their attempts to be social or to interact. Some children, for instance, like to socialize with their father by playing a game or tossing a ball around. A child with autism might do the same *or* might try to show the same connection, affection, and desire for togetherness by following dad around the house, walking circles around him, watching him do projects, or bringing him a favorite object or toy.
- Play may look very different among those on the spectrum. Individuals with autism and Asperger syndrome may not play symbolically as other children do, for instance—that is, the child with autism may not feed the baby doll or pretend to grill a hamburger on the play stovetop. This does not mean, however, that they are not creative or imaginative in their play. Some show their creativity in the things they build or in the unusual ways they engage with their materials. A child may make a tower out of train tracks, for instance.
- Some sources suggest that those on the spectrum lack empathy or are egocentric. Although we know that some on

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the spectrum report struggling to see the viewpoint of another person, we also feel that the issue of empathy is sometimes overstated or misrepresented. While some on the spectrum are certainly more inwardly focused, some of the reported problems with empathy could also be seen as problems of expression. In other words, those with autism might have problems understanding empathy and feeling it, and just as many might simply have problems *showing* concern and care. In other words, a child might know that his sister is sick and care about her person and her suffering, but not know how to offer comfort (or even be aware that he should). Our loved ones and friends on the spectrum are some of the most empathetic and caring people we know and, in some cases, we have met many people who claim they are so attuned to the feelings of others that they themselves can feel emotional distress just by being around others who feel this way.

For recommendations on how to support or help someone in the area of social skills, see Checklist 4.7: Strategies for Encouraging and Supporting Social Relationships and Checklist 4.8: Strategies for Building Social Skills, both in Section Four.

1.9. Communication Differences

Individuals on the spectrum may have unique challenges with both verbal and nonverbal communication (such as facial expressions and body language). Some problems with verbal communication include difficulties with word retrieval, fluency, and speaking in general. Some of the problems with nonverbal communication include using gestures and making eye contact. Following are the communication differences most frequently experienced by people on the autism spectrum:

- Commonly, the tone of voice of a person with autism fails to accurately reflect her feelings. This can be problematic for a variety of reasons. Those on the spectrum may be seen as cold, aloof, uncaring, or unfeeling, simply because they cannot easily modulate their voice. They may also be seen as odd (and even intellectually disabled) because of the quality of their voice, especially if they use a monotone, singsong, flat, husky, or very unusual-sounding voice. Poor control of volume or intonation is also common.
- Some on the spectrum have difficulty modulating facial expression. Similar to problems with voice modulation, having little or no control over facial expression can be devastating because communication partners may believe the person with autism does not feel. In other words, the inability to express emotion is often assumed to be a lack of experiencing emotion. Again, many with autism report sadness and frustration about living with this movement problem.
- Some children (especially those with Asperger syndrome) speak like “little professors” or little adults. They may use sophisticated vocabulary, have clear and precise pronunciation, and be able to carry on a long and impressive conversation about a range of topics and especially about their topics of interest.

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- Some people have trouble processing speech at times. An individual may not respond to his own name or may hand you a fork when you ask for a spoon. In most cases, people who behave in these ways are not experiencing hearing problems—they are experiencing processing difficulties. They have a hard time making sense of some of the sounds, words, or sentences they hear. Or they may understand what they are hearing, but are not able to respond appropriately. In other words, a person who knows that you are asking her to shut the door may unintentionally shut the window instead. Donna Williams, a woman on the spectrum, calls these “misfires” and admits that she has experienced them regularly: “I’ve said things like ‘I want my shoes’ when I meant ‘I want my jacket’ and been surprised to get things I apparently asked for” (Williams, 1996, p. 89). Because of these problems, individuals on the spectrum may seem inattentive or stubborn at times.
- Students with autism also have difficulty understanding some types of language. For instance, students with autism interpret language quite literally, so they may need help understanding figurative language and idioms (such as “sitting on the fence” or “hold your horses”), metaphors (such as “he was on fire”), jokes or riddles, phrases or slang expressions with double meanings, and sarcasm (as when we say “How graceful!” to someone who has just tripped).
- Some students repeat phrases or expressions over and over again across weeks, months, and even years as when the teacher says, “Be a gentleman” to the student, and he repeats this every time his manners are corrected for the next several years. Others repeat words, phrases, or expressions immediately after hearing them. For example, when the pastor says, “Good morning, everyone,” and the individual with autism repeats, “Good morning, everyone.” This phenomenon is called echolalia. If the student uses the

words or phrases immediately after hearing them, the behavior is considered immediate echolalia. When the student repeats something that was said hours, days, weeks, or years ago, it is called delayed echolalia.

- Students who struggle with speech are sometimes blamed for saying inappropriate things or for not trying hard enough to speak “the right way.” Some people who use language in unusual ways may even be assumed to be mentally retarded. For instance, a teacher who hears a student repeat “Oh, go fly a kite” several times might assume the student is not smart enough to know that his speech is silly or inappropriate. People with autism, however, often report that they have little or no control over their speech or that they have to use the speech they have because they lack specific words or phrases (the person cannot say, “I want to go to the park,” for example, but he can say, “go fly a kite”).

For recommendations on how to support or help someone improve communication skills, see Checklist 4.5: Strategies for Encouraging and Facilitating Communication and Checklist 4.6: Strategies for Supporting Those Without Reliable Communication, both in Section Four.

1.10. Movement Differences

Movement differences encompass both excessive atypical movement and the loss of typical movement and involve difficulties with starting, stopping, combining, executing (speed, control, target, and rate), and switching. These difficulties with movement may impede postures, actions, speech, thoughts, perceptions, emotions, and memories (Donnellan & Leary, 1995; Leary & Hill, 1996). Following are the movement differences most frequently experienced by people on the autism spectrum:

- Individuals with movement differences experience a host of problems, including but not limited to walking with an uneven gait, engaging in excessive movements (such as rocking, hand flapping, or pacing), producing speech that is unintentional, stuttering, or struggling to transition from room to room or situation to situation.
- The complexity of movements that are disturbed can range from simple movements (such as raising one's hand) to movements affecting overall levels of activity and behavior (such as completing a task). Many individuals who experience movement disturbance also report differences in internal mental processes such as perception and changes in attention, consciousness, motivation, and emotion.
- Motor clumsiness is part of movement differences. Those on the spectrum may be delayed in acquiring motor skills that require motor dexterity, such as opening a jar or buttoning a shirt.
- People with autism may appear awkward or uncomfortable in their own skin. They may be poorly coordinated, have an odd or bouncy gait or posture, poor handwriting, or problems with visual-motor integration, visual-perceptual skills, and conceptual learning.

- Many with autism experience these movement problems constantly. Although all of us may struggle to combine thoughts and movements, engage in excessive pencil tapping or nail biting, get lost in repetitive or obsessive thoughts, or sing the same tune repeatedly without realizing it, we are seldom negatively affected by these experiences. Many people with disabilities do experience serious movement problems, however, and are affected by them significantly and chronically.
- Atypical movements often mask the competence of individuals who exhibit them and may have an impact on their ability to communicate and relate to others. For example, “delay in responding or inability to regulate movements may affect the ability to turn attention from one event to another in a timely fashion, or use conventional signs of communication” (Donnellan & Leary, 1995, p. 42). In many cases, these movement differences are assumed by observers to be symptoms of mental retardation (Donnellan & Leary, 1995) when they are in fact symptoms of autism.
- A person with movement problems may find it difficult to know where parts of his body are in space without looking at them. He might also find it difficult to attend to, label, and interpret the signals of his body and may not recognize particular messages as feelings indicating his mental state (such as fear or frustration) or sensations indicating the physical states of his body (such as pain).
- Repetitive behaviors are seen in individuals on the spectrum. Rocking, hand clapping, finger flicking, or arm flapping are examples. Some repetitive behaviors are signals of distress. They may also be signs that the individual is bored or disengaged. Repetitive behavior can also be a kind of pleasant escape. The person may enjoy the sensation or it may be a tool for relaxation. When repetitive behaviors are

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being used to manage stress, they should be seen as purposeful and not as things to “extinguish.”

- Crying or screaming that seems inappropriate or unprompted often occurs among those with movement problems. Some of this may be a result of discomfort, anxiety, pain, or confusion. In other instances, individuals may scream or even bang their heads in order to feel “organized” or to become more aware of and in control of their own bodies. As Birger Sellin, a man with autism, shares, “[I] am not hurting anyone when [I] scream and [I] need to do it so much to get my balance” (1995, p. 216).
- Inappropriate laughter is often seen in people with movement differences. This behavior appears to many observers to be evidence that the person is carefree or thinks others’ behavior is funny. In reality, many on the spectrum indicate that unprompted laughter (especially under stressful circumstances) is actually a signal of distress, panic, or fear.
- Self-injurious behavior may be seen when the student is experiencing extreme anxiety or frustration.

For recommendations on how to support people with movement problems, see Checklist 4.9: Addressing Movement Differences in Section Four.

1.11. Sensory Differences and Sensitivity

People on the spectrum may have difficulties and sensitivity in one or more areas. Individuals may have visual or auditory sensitivity, difficulties with their olfactory system, or unusual responses to touch and temperature. Their sense of taste and thus their eating habits may also be affected. Following are the primary sensory differences experienced by people on the autism spectrum:

- Certain kinds of touch may be very difficult for people on the spectrum. Firm touch may be preferred over gentle touch, for instance. Unexpected touch can also be a challenge for some.
- Some people on the spectrum find the feel of certain clothes unbearable. People with autism may want to wear the same clothes over and over again, may prefer very soft garments, and may enjoy the sensation of certain fabrics over others.
- Some clothing may also be very soothing to a person with autism. The cling or grip of Lycra (such as bike shorts) can feel soothing to a person with sensory problems.
- Tactile problems may be apparent when the individual with autism avoids or prefers certain foods. The texture of food is very important to some and may even result in some individuals eating a very limited diet (only noodles and oranges, for instance).
- The sense of taste is often affected in people with autism. Differences in this area are often apparent in how the person prepares food. Some enjoy their food as bland as possible, while others use amounts of spices and seasonings that would be intolerable for many people.
- Temperatures can have a strong effect on people with autism. Some cannot tolerate, for instance, sitting too close to air conditioners or heaters. Cool or warm blasts, for some, can feel downright painful. It is important to realize,

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however, that the same sensation can feel very pleasant to another person on the spectrum.

- A range of noises and sounds may cause anxiety in a person on the spectrum with autism, including sounds that seem benign and even unnoticeable to the average person. For instance, a person might be completely distressed by the sound of a pencil moving across a tablet. And sounds we all may find annoying or painful such as a siren, alarm, or chalk screeching on the chalkboard can send the person with autism into an absolute panic. Sounds that tend to bother a lot of people on the spectrum include crying babies, vacuum cleaners, dishwashers, washing machines, lawnmowers, heavy equipment and sounds related to demolition and construction, alarms, sirens, repeating beeps (as made by large vehicles backing up), the buzz of fluorescent lights, and large or particularly noisy crowds.
- Vision may also be affected. Students may be sensitive to certain types of light, colors, or patterns. For instance, if a person is wearing an outfit with several bright colors or with big patterns, it may be hard for some on the spectrum to look at that person. Another vision-related issue some have concerns visual clutter. Some people become overwhelmed in disorganized or confusing spaces and crave order and neatness.
- Those with autism and Asperger syndrome may also have a heightened sense of smell. The individual may find some smells unbearable and others pleasant, helpful, or calming. Smells that may bother students include air fresheners, art products, perfumes or colognes, food, school supplies, cleaning agents, chemicals, pet odors, and plants or flowers.
- The pain threshold for a person with autism may be different from the thresholds of people without these labels. A person on the spectrum may gash herself or even break a bone, yet never cry out in pain. At the same time, a gentle hug or light

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tickle on the arm can make the same person jump, scream, or run away.

- When overloaded, people with autism may have trouble concentrating or may feel tired and irritable. Too much sensory overload may lead to behavior problems, emotional outbursts, or even physical pain.

For recommendations on how to support people with sensory differences, see Checklist 4.10: Addressing Sensory Issues: Visual; Checklist 4.11: Addressing Sensory Issues: Tactile; Checklist 4.12: Addressing Sensory Issues: Auditory; and Checklist 4.13: Addressing Sensory Issues: Olfactory; all in Section Four.

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1.12. Passions, Interests, and Rituals

Many individuals with autism have deep interest in one or a variety of topics. Some interests are commonly seen across individuals with autism. Some of the most common of these are trains, weather, and animals. Other interests seem more unique to an individual person. One person we know loves to talk about and study John Wilkes Booth. Another is passionate about socket wrenches. Following are more of the passions, interests, and rituals enjoyed by people on the autism spectrum:

- Some of the most common fascinations across people with autism are trains, vehicles, transportation systems, machines, weather, natural disasters, geography, astronomy, gadgets, animals, nature, dinosaurs, computers, historical dates or events, calendars, timetables, numbers, chemistry, cartoon characters, drawing, artists, music, pop stars, and television shows (Hippler & Klicpera, 2004; Mercier, Mottron, & Belleville, 2000). Some people remain interested in one area for their entire lives; for others, interests change and evolve from month to month or year to year.
- Individuals may also have rituals that are important in their lives. Some people have rituals for organizing their time and the space around them; others have rituals around how and when they engage in certain behaviors. Individuals on the spectrum (and those without autism labels too) may have rituals attached to any number of activities in their lives, including eating (such as separating food by colors), numbers and counting (such as insisting on leaving the house exactly at 7:35AM), dressing (such as always putting socks on first), cleaning (such as vacuuming in the same pattern each time), exercising (such as walking the same number of laps each day), shopping (such as doing errands in a certain order), or interacting with others (such as preferring to talk to people with names that begin with B before talking to others).

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- Other types of ritual you may see in students with autism involve repetitive behaviors. An individual may spend a lot of time engaged in certain tasks such as turning in circles, spinning a toy, playing in water or sand, stacking things up, or putting things in order.
- Individual objects may also be dear to the person on the spectrum. Some individuals carry around tokens, trinkets, or comfort items. We have known individuals on the spectrum who have carried wrenches, plastic money, tennis balls, wristbands, rubber bands, bracelets, marbles, paintbrushes, watches, rocks, video boxes, strings, and mechanical pencils, to name only a few. Sometimes the person is content to have special items on his person. Others may want to use the item to fidget and may like the sensation of holding or playing with their favorite things.
- Collections may be part of the life of a person with autism or Asperger syndrome. The individual may collect things that are commonly associated with hobbies such as dolls, coins, CDs, movies, photographs, or stamps. It is not uncommon, however, to meet a person with autism who has a very unique collection that would not be seen across many different individuals. For instance, people on the spectrum may collect pencil stubs, antique railroad lanterns, pieces of denim, magazines from 1999, or gum wrappers.

For recommendations on how to support the fascinations and special interests of individuals on the spectrum, see Checklist 3.6: Addressing Student Passions and Fascinations in the Classroom in Section Three.

