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# The Autism Checklist

**A Practical Reference for  
Parents and Teachers**

**PAULA KLUTH, Ph.D.**  
with John Shouse



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*To those on the spectrum and their families  
who share freely, teach patiently, and  
inspire us to think differently*

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## About the Authors

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Kluth is the author or coauthor of numerous books, including *“You’re Going to Love This Kid!” Teaching Students with Autism in the Inclusive Classroom* (Brookes, 2003); *“Just Give Him the Whale!” 20 Ways to Use Fascinations, Areas of Expertise, and Strengths to Support Students with Autism* (coauthored with Patrick Schwarz; Brookes, 2008); *Joyful Learning: Active and Collaborative Learning in the Inclusive Classroom* (coauthored with Alice Udvari-Solner; Corwin, 2007), and *“A Land We Can Share”: Teaching Literacy to Students with Autism* (coauthored with Kelly Chandler-Olcott; Brookes, 2007).

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advocate for inclusive educational practices in local school districts across Tennessee and nationally. He is a frequent speaker at national and regional conferences on the special issues faced by fathers of children with autism and other disabilities and also on the joys and challenges of grandparenting a child with disabilities.

# Introduction

With so much to know about autism, Asperger syndrome, and life “on the spectrum,” it is hard for those with autism labels, their families, and their teachers to know where to begin in a search for answers. In the past, it was difficult to find information anywhere. In the last few decades, there has been an onslaught of information, but not all of it has been as useful or as sensitive as we think it should be.

For this reason, we sat down to write a book that could give people quick answers and basic information in a way that is not only helpful but also thoughtful, informed, respectful, and accessible. We drew heavily from the words and experiences of people on the spectrum in order to create our recommendations and suggestions. We also looked at relevant research and kept our own lived experiences in mind. We think the result is a straightforward guide that will give readers a place to start when seeking answers about diagnosis, health and safety, life in the community and the home, teaching and learning, schooling, and relationships.

The first section of *The Autism Checklist* is about the label and diagnosis itself and contains information on characteristics, diagnostic tools, and related conditions. Two other sections of the book are designed to meet the needs of different populations. One section is devoted entirely to the needs of school personnel and will help teachers, paraprofessionals, therapists, social workers, psychologists, and administrators meet the unique needs of the student on the spectrum. More than anything else, we wrote the

lists in this section with the aim of inspiring educators to create more relevant and gentle supports for students on the spectrum as well as more responsive classrooms. Another section was created for people on the spectrum and their parents. Our wish for this section was to provide suggestions that families can use to create experiences that are more safe, peaceful, and enjoyable. In this section, we cover everything from making the home comfortable to preparing for travel to advocating for your school-age child. Following these two sections, the reader will find a collection of lists offering “More Helpful Strategies for Home and School.” The lists in this section relate to topics including, but not limited to, sensory issues, movement differences, communication, and helping individuals deal with stress and change. Because we know this book is likely to be a first-stop resource for our readers, the entire final section of the book is devoted to our recommendations for further study and exploration.

No matter your experience with or knowledge of autism, we believe you will find some tip, morsel of information, or resource in this book that answers a question, affirms a belief, or provides new insight. Moreover, we hope we can help you learn about and understand not only autism but the *individual* on the spectrum who is in your life.



# The Autism Checklist



# 1

## **BASIC INFORMATION ON AUTISM AND ASPERGER SYNDROME**

### Introduction

- 1.1. What We Know About Autism
- 1.2. What Do We Mean by *the Autism Spectrum*?
- 1.3. Conditions Commonly Associated with Autism
- 1.4. Positive Traits Associated with Autism
- 1.5. Early Indicators of Autism
- 1.6. Autism Myths Versus Autism Facts
- 1.7. Tools Used in Autism Screening and Diagnosis
- 1.8. Social Differences
- 1.9. Communication Differences
- 1.10. Movement Differences
- 1.11. Sensory Differences and Sensitivity
- 1.12. Passions, Interests, and Rituals

## 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

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*

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.

- 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

autism. Those with Rett syndrome exhibit symptoms similar to those diagnosed with autism, including repetitive movements (such as wringing or clapping 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.