



Asperger's syndrome in young children

A DEVELOPMENTAL GUIDE
FOR PARENTS AND PROFESSIONALS

Laurie Leventhal-Belfer
and Cassandra Coe



Asperger's Syndrome in Young Children

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and Professionals

Laurie Leventhal-Belfer and Cassandra Coe



Jessica Kingsley Publishers
London and Philadelphia

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First published in the United Kingdom in 2004
by Jessica Kingsley Publishers
116 Pentonville Road
London N1 9JB, UK
and
400 Market Street, Suite 400
Philadelphia, PA 19106, USA

www.jkp.com

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Library of Congress Cataloging in Publication Data

A CIP catalog record for this book is available from the Library of Congress

British Library Cataloguing in Publication Data

A CIP catalogue record for this book is available from the British Library

ISBN-13: 978 1 84310 748 4

ISBN-10: 1 84310 748 1

ISBN pdf eBook: 1 84642 033 4

Printed and Bound in Great Britain by
Athenaeum Press, Gateshead, Tyne and Wear

Contents

ACKNOWLEDGMENTS	7
PREFACE	9

Part One: Understanding Asperger's Syndrome in Young Children

Chapter 1. The World of the Young Child	17
Chapter 2. The World of the Young Child with Asperger's Syndrome	32
Chapter 3. The Diagnosis	53
Chapter 4. The Many Faces of Young Children with Asperger's Syndrome	81
Chapter 5. The Parents' Journey	105

Part Two: Interventions

Chapter 6. Paths of Intervention: From Traditional to Alternative	131
Chapter 7. Parent–Child Therapy: An Intervention for Building Relationships <i>Lori Bond</i>	144
Chapter 8. Building Connections with Peers: Therapeutic Groups	160

Chapter 9. Enhancing Relationships through Speech and Language Intervention <i>Christine Bate</i>	190
Chapter 10. Building Connections through Sensory and Motor Pathways: Occupational Therapy <i>Teri Wiss</i>	211
Chapter 11. Building Connections with the Child's School	238
Chapter 12. The Ongoing Journey	262
APPENDIX I DIAGNOSTIC CRITERIA	270
APPENDIX II BEHAVIORAL STRATEGIES CHART FOR GROUP SETTINGS	274
APPENDIX III ELIGIBILITY CRITERIA FOR SPECIAL EDUCATION SERVICES IN THE UNITED STATES	280
APPENDIX IV ASPERGER'S SYNDROME WEB SITES	284
THE CONTRIBUTORS	285
REFERENCES	286
SUBJECT INDEX	296
AUTHOR INDEX	301

Acknowledgments

The book is dedicated to the parents in the Friends' Program, a play-centered therapy group for young children with Asperger's Syndrome (AS) and their families, which we directed at the Palo Alto Children's Health Council. The parents have given us the opportunity to learn from them and learn what it means to have a child with AS. They have shared with us the dreams they have for their children, the barriers they have sometimes faced in seeking help, and the pleasures and rewards they have experienced with their children. Each and every parent's journey has informed us and educated us on how to be better clinicians working with young children with Asperger's Syndrome. We are also indebted to the children who have shown us that they, like all other children, love to play, have strong feelings, treasure having others interested in their ideas, and yearn for friends. What they have taught us informs and shapes the core of this work and reminds us how unique and individual children are.

We would also like to thank our husbands, without whose endless support, editing, childcare, and encouragement this book would never have been written. And our thanks to our children for providing us with the front row tickets to observe and engage in hours of play at the playground, birthday parties, play dates, and at their schools. And to Isaac, the oldest, we would like to express our thanks for his patient assistance on the computer, a tool he seems able to use as easily as we use the pen.

Preface

It seems as if a month does not pass without an article appearing in the lay press about the subject of Asperger's Syndrome or Autistic Spectrum Disorders. Since Asperger's Syndrome was officially recognized in the United States in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV: American Psychiatric Association 1994) and in the tenth revision of the *International Classification of Diseases* (ICD-10: World Health Organization 1993) there has been a dramatic increase in the number of children diagnosed with this condition. This has been accompanied by an increase in the number of books and papers written about its history, diagnosis, etiology, and intervention approaches (Klin, Volkmar and Sparrow 2000). Historically the diagnosis was not made until the child was in elementary school. However, earlier identification is now occurring, due in part to the increase in the number of young children participating in group programs (e.g. childcare, preschool, and full-day kindergarten) and the consequent identification of children who have difficulty adapting to the social demands of these settings. Additionally, with the increase in the number of school age children being diagnosed with Asperger's Syndrome, there has been a growing awareness of the disorder and much interest in how it might present in younger children.

Our experiences in working with young children with Asperger's Syndrome and their families over the past 15 years have underscored the need for a book that provides parents and professionals with a working understanding of the Syndrome in young children and models for intervention. This book was developed with these goals in mind.

The history of Asperger's Syndrome

The Syndrome is named after the Viennese pediatrician Dr. Hans Asperger who coined the term “autistic psychopathy” in 1944 to describe four boys, ages 6–11, who displayed problems adapting to social situations despite having good language and cognitive skills. The children were not thought to be unique but rather representative of a much larger set of children in his practice. In addition to having social problems the children were also described as being preoccupied by topics such as the weather or trains that dominated much of their lives and interfered with their work and play. He also observed that they were awkward and clumsy in group sports activities. They had difficulty understanding and being empathic to other children’s feelings and social cues. Asperger described these children as being like “little professors” who could talk endlessly about their area of special interest but were oblivious to the nonverbal and verbal cues of others. These qualities often led to noncompliance and negativism towards teachers and peers who were not interested in their views, and resulted in aggression or withdrawal if they felt insulted. Still, Asperger viewed these children as having a relatively positive outcome since their parents often had similar qualities and were relatively well adapted (Klin, Volkmar and Sparrow 2000).

When Asperger wrote this paper he was not aware of Leo Kanner’s original writing on childhood autism. Asperger’s paper did not receive much attention until it was translated into English by Dr. Uta Frith in 1994 and applied in a clinical setting by the British psychiatrist Dr. Lorna Wing. Dr. Wing described a group of children who fit Dr. Asperger’s original description. She elaborated on the diagnosis by presenting them as children who were bright and curious, but had a triad of challenges in the areas of social interaction, communication, and imagination. She went on to describe them as rigid, having a narrow range of interests, and repetitive patterns of activities. In contrast to autism these children did not show impairments in cognitive and language abilities early in life. Dr. Wing also dispelled an earlier belief that these children’s difficulties were caused by poor parenting, asserting instead that Autistic Spectrum Disorders are caused by atypical development. Although Dr. Wing moved the conceptual framework of Asperger’s Syndrome closer to autism there is still an ongoing debate as to whether it should be viewed totally apart from autism, as Dr. Asperger originally thought, or within the same classification system.

Overview of the book

How does one begin to understand the world of these children as described initially by Hans Asperger and later by Lorna Wing? Part One is devoted to answering this question.

We will begin in Chapter 1 by exploring the world of the young child and the developmental tasks of children between the ages of three and six. We feel that it is important to have knowledge of this stage of early childhood in order to understand how a young child with Asperger's Syndrome copes with the developmental undertakings of this period. The second chapter will look at these same developmental areas and the various ways that they may differ for a young child with Asperger's Syndrome. Chapter 3 will take a closer look at what a developmentally based assessment for a young child with Asperger's Syndrome entails, the different diagnostic criteria and diagnoses that may be considered, and how they are pertinent to young children. Because we are taking a multidisciplinary approach, the chapter will describe components of a mental health and cognitive evaluation, as well as evaluations in speech and language (Christine Bate) and occupational therapy (Teri Wiss). Chapter 4 presents a detailed description of three different young boys with Asperger's Syndrome. The case studies provide a rich example of how varied the children can be, each having different strengths, degrees of adaptation, and challenges. Chapter 5 will examine the developmental shifts that many parents go through as their understanding of their child grows.

Part Two of the book is devoted to interventions for children with Asperger's Syndrome. As we have emphasized, the young child's capacity to interact, communicate, and play with his peers plays a central role in his development. For this reason we have chosen to review interventions that we believe are best suited to understanding and facilitating the young child's social interactions, communication, imagination, and flexibility. Chapter 6 provides an overview of interventions that may help both the child and his parents utilize a range of services. Dr. Lori Bond writes the next chapter in this part, Chapter 7, on parent-child therapy. Dr. Bond is the director of a diagnostic and treatment program for young children with Autistic Spectrum Disorders. In this chapter her emphasis is on helping parents understand the diagnosis, and what it means to them and to their relationship with their child, and techniques for intervention. Chapter 8 describes a therapeutic group program for young children with Asperger's Syndrome and their parents. We see this type of program as a natural step for parents to take as they move from viewing their child solely within the context of their relationship to seeing

their child within a peer group. The chapter explores the “nuts and bolts” of a group program as well as the therapeutic processes. The next two chapters are written by invited authors because of their expertise in the areas of speech and language intervention and occupational therapy. Christine Bate, in Chapter 9, explores the important role that speech and language intervention can play in expanding the young child’s capacity to engage in social interactions, reciprocal communication, and imaginary play. In Chapter 10, Teri Wiss examines the valuable role that occupational therapy can play in helping us understand the motor and sensory challenges often experienced by young children with Asperger’s Syndrome. From the perspective of an occupational therapist, people need to know how to connect with their own bodies before they can easily connect with their environment and other people. Chapter 11 is devoted to school-based interventions and emphasizes the importance of having collaborative relationships between the child’s parents and teachers. The last chapter will provide an update on the children we first presented in Chapter 4 as well as a reflection of what we have learned about AS from working with these children and their families for the past 15 years.

To the parents of young children with Asperger's Syndrome

For many of the parents reading this book, perhaps because the diagnosis is so new, there is a very good chance that different professionals have offered different diagnoses and/or varying recommendations for interventions. Some may have said that your child has a serious developmental problem, others that all your child needs is better limit setting, and still others that nothing is wrong with your child. We hope that this book will provide you with a model for understanding normal development, Asperger’s Syndrome in general, and what it means specifically for you and your child. We believe that reading this book will make you more empowered to ask professionals about your child and determine with them the best path of intervention to take. We realize that both your understanding of your child and the intervention choices that you make can change over time depending on the needs of your child and the resources available to you through your schools and community. Our goal is that the book leaves you with a feeling of hope. Our wish is that with early diagnosis and developmentally guided intervention the journey you travel with your child will be less stressful and more rewarding for everyone involved.

To the teachers and childcare providers

For many of you the term Asperger's Syndrome may have been first heard from a parent or a friend whose child had this disorder. This book was written to provide insight into how these children present themselves, experience the world, and turn to you for support. They pose a special challenge because there can be many apparently conflicting aspects to their presentation; they may appear so bright and have so much to say, yet surprise you when they grab things from another child or demand your full attention. We hope to provide you with a framework for understanding their behavior and models for intervention that can be easily integrated into your classrooms. Lastly, we hope that this book leaves you feeling supported for the important and challenging work you do with these children on a daily basis. In our opinion you are an invaluable resource for the family and professionals involved in the care of a young child with Asperger's Syndrome and deserve to be seen as a valued member of the child's treatment team.

To the medical and mental health community

We hope that the book provides you with insight into the world of young children with Asperger's Syndrome, the diverse ways they may present, the challenges that they pose for their parents, and paths parents may want to explore for intervention. Parents treasure a clinician who they feel is interested in learning about their child with them and supports them in this process.

Part One

Understanding Asperger's Syndrome in Young Children

CHAPTER 1

The World of the Young Child

Parents of a young child with Asperger's Syndrome often question if their child's behavior is within the "normal" range. The world of the young child is a rich and complicated place with so many things happening developmentally that this can be a difficult question to answer. Given the complexities of the world of the young child, we feel that it is important to develop a shared understanding of the developmental tasks salient at this age. This chapter will provide an overview of the areas of developmental growth that characterize the young child. What can make this time period both rewarding and challenging for parents, teachers, and children is that the children are undergoing major changes at varying rates in differing areas of development. With this in mind we will examine the developmental tasks which are characteristic of the young child in the areas of sensory-motor development, communication, cognition, play, emotional and social functioning, relationships with caregivers and peers, and the child's capacity to cope with stressful events.

Due to the fact that Asperger's Syndrome is much more prevalent in boys than girls, we have chosen to use the male pronoun "he" throughout the book, recognizing that the diagnosis also applies to girls. We also strongly encourage all readers to consider the impact that culture plays in our understanding and interpretation of behavior. All families have their own cultural framework from which they perceive and respond to the world around them. When interpretations of behavior are being made, sensitivity to this cultural lens is important for working with the family in a culturally respectful manner. Similarly, professionals working with these families (e.g. teachers, pediatricians, mental health professionals, and other clinicians) also wear their own cultural lens. The awareness of each other's cultural background and potential biases will help one gain a better understanding of the developmental tasks of the young child.

Let us now take a step into the young child's world by describing a common scene from the playground and invite you to think about the play, communication, and socialization of the children in this vignette.

A story common to many four-year-olds

As soon as John and Ben were let out of the car they ran to the large climbing structure and headed to the driver's wheel at the top of the climbing structure. Ben climbed to the top and announced, "All aboard, the ship is taking off for the sea." John quickly got on the "bridge" and pointed out the approaching pirate ships that he could see through his binoculars (fists). He told another boy who was digging in the sand that he better get on board or he would be attacked by a killer whale. John told him that he was the captain and that he could join the crew. Sam accepted the invitation, took hold of his shovel and joined John and Ben on the top of the structure. The boys looked out into the ocean announcing what they saw, warning the crew of dangers, and testing how far they could lean away from the boat's poles (the poles surrounding the slide) without falling off. With authority in their voices John and Ben informed each adult and child who approached the slide that they were on their ship in dangerous waters. A battle almost erupted as a toddler tried to take hold of the captain's steering wheel, leading to a confrontation between John, the "captain," and the toddler's mother. The crew decided to abandon the boat rather than include the group of pirates (toddlers) climbing on board.

As soon as they landed on the ground Ben pointed out that there was gold in the sand, and they quickly became a group of pirates, searching for the buried treasure. The two girls who were playing quietly under the structure watched with a look of disgust and found another place on the playground to have their private discussions. The boys, looking pleased with the girls' decision, continued digging as they announced their discovery of dinosaur bones and a "treasure map" (an old flattened paper cup) which John used to lead the crew on a rambunctious run across the park searching for the buried treasure. Ben's father, noticing that the boys were getting very excited and overheated, suggested that the "pirates" take a break and have some juice and snack. The boys seemed to alternate between eating the dinosaur cookies which Ben's father provided and moving them across the sand as they talked enthusiastically about which type of dinosaur was the most powerful, the fastest, and the smartest of them all. When the snack was finished they were told that they had ten more minutes before they had to go home. Ben announced a race to the tire swing where they

stayed until it was time to go. The boys asked Ben's father to spin the swing around and they giggled with delight as they turned rapidly in the air and dared each other to jump off the swing, a dare which none accepted.

This vignette of these four-year-old boys visiting their neighborhood playground is just a snapshot of the rich, complex, and fast-paced play that characterizes the interactions between these children on a regular basis at the neighborhood park. The vignette illustrates many aspects of development so pertinent to the young child. As we have pointed out, their world is full of imagination, movement, social interactions, and problem solving. We will now look more closely at each area to fully appreciate all that is evolving in the young child. The first area we will examine is motor and sensory development.

Sensory and motor development

The park and school playgrounds are the best places to observe the dramatic leaps in the young child's *gross motor* development skills. In one section of the preschool you can see the two-year-olds tentatively climbing up ladders step by step and going down the slide with a teacher's assistance. In the next play yard there are the three- and four-year-olds running around the obstacles (other children, adults, and playground equipment), turning sharp corners between the swings, and skipping on one foot as they smoothly move between the tires on the ground. The tricycles, which were approached with apprehension at two, are being zoomed around the yard, constantly slowed down by the teacher on yard duty. Similarly the climbing structures that the toddlers used to walk under or hang from using the bottom bars are now being occupied on the highest point by boys and girls demonstrating their speed in climbing and their confidence in balancing and jumping onto the ground. The preschool child has also developed ball skills, as displayed in the ability to guide the course of a large kick ball or dribble a soccer ball across the field.

The child has also made major strides in the area of *fine motor* development. By age three-and-a-half most children can hold a pencil with a large grasp (fingers and thumb forming a fist around the pencil), draw a face, and write at least one letter of their name. They are beginning to use scissors and often enjoy stringing objects, such as beads or cereal, and painting. By age four they are able to draw a stick figure, copy a shape, draw identifiable objects, and copy numbers and letters. They enjoy playing with small blocks

and figures that they can manipulate in and out of cars, toy houses, castles, and planes. They are also able to build elaborate block structures out of blocks of varying shapes and sizes (Linder 1993).

It is also helpful to look at the wide range of *sensory input* that a young child is "typically" exposed to at their preschool setting. If the preschooler is going to have success in any of the motor tasks we just described they need to have a keen sense of where their body is kinesthetically in space. Most children naturally do this each time they stand up in the block area and do not destroy their own or their peers' structures. They can avoid running into them on the tricycle and they are able to find their spot at circle time without stepping on another child. They tolerate a never-ending background of sounds ranging from a child giggling on the swing, a hero yelling at the bad guys, the ringing of the teacher's bell to come inside, a child crying in distress, and musical instruments, to list just a few. They are also exposed to a wide range of smells from their friends' lunches, the school's snacks, the teacher's perfume, their peers' body odors, or a new batch of clay. They will also feel a wide range of tactile sensations as they touch wet sand in the bathroom, dry sand on the playground, clay on the table, crumbs and sticky juice from snack, different types of carpet texture, paper towels, and finger paint. And they can enjoy eating food that is served and tastes differently from what they are familiar with. It is surprising how many variations of graham crackers there are on the market, or how attuned children can be to the taste differences in types of apple juice. Still, the majority of children are able to take these sensory inputs in stride. They may have preferences but they do not have a "melt down" because they feel overloaded or cannot tolerate any changes from ways they are familiar with. One can imagine the problems that can quickly arise in a preschool setting if the child feels overloaded and strikes out at another child or has a melt down, requiring the teacher's undivided attention for reasons that are not immediately apparent to the teacher.

Kopp (1982) proposed that the child's ability to acquire skills in *self-regulation* is related to both biological and social factors that are being impacted from birth. The child is born with its own temperament, sensitivity to external stimuli, and attentiveness to its internal cues. Obviously no infant can survive in isolation. The infant needs a nurturing caregiver that is responsive to his cues, is able to comfort him when distressed, and provides him with a predictable routine so that he is assured that his needs will be met. By the end of the second year the child begins to display some restraint without constant reminding. He knows not to pull the cloth off the table, grab

the dog's ears, or pour the water on the floor. By three the child can display more self-regulation across settings, not just in specific, previously experienced situations. He is more adaptive and self-reflective about his behavior. By three years of age the child is expected to adapt to numerous activities in preschool, share with peers, be able to cooperate during play, and apologize if he hurts another child intentionally or accidentally. These are tasks that require the child to be aware of the impact that his behavior has on others, to know what is considered socially acceptable behavior, and to be able to restrain himself when he desires to do something differently.

Table 1.1 Key components of young children's sensory and motor development

- Fine motor development
- Gross motor development
- Muscle tone and motor planning
- Visual-motor planning
- Sensory modulation – hypersensitivity or insensitivity to sound, touch, smell, taste, and/or visual stimuli

Communication

The child's *expressive language* takes off like a rocket in the third year of life. The preschool period follows a time when the child's vocabulary has just had a growth spurt of at least 1000 words from the ages of two to three years. This growth continues at a rate of approximately 50 words a month (Davies 1999). Beginning around the age of three, the young child can engage in a simple dialogue with an adult and peers for more than a few turns, using language that is clear and easy to understand. By the age of four, children are speaking in grammatically correct long sentences, they can tell a story using words alone, and they have learned that words are powerful tools that can be used to get attention and determine the direction of symbolic play. The child is able to use prepositions like "behind" and "in front of" correctly, is constantly asking questions beginning with "what" and "how," and is able to talk about his own ideas, feelings, emotions, and attitudes when he feels secure and supported (Linder 1993).

The children's *receptive language* also blossoms during this period. They can sit quietly for long periods of time listening to a story and acquire a wealth of information from conversations with adults and peers, books, videos, and their daily adventures. Beginning at three years of age children can follow three-step commands given in a complete sentence such as, "Put the doll on the chair, pour her a drink, and then put her in bed." By age four they understand and use the prepositions "above," "below," and "at the bottom."

Pragmatic language refers to the child's ability to use new language skills in reciprocal social interactions with peers. Around four years of age children understand that they need to talk differently to their teacher than to a peer or a younger child. They understand the importance of getting another person's attention before talking to them and they are able to use words to get their attention, unlike toddlers who pull on their caregiver's body or clothes to get their attention or grab a desired object from a peer without using words. The three- to four-year-old uses words to request things ("May I?"; "Could you?"; "Please"), and communicate their approval ("That's beautiful"; "This is my favorite") and disapproval ("Stop that"; "That is not nice"; "That is not fair"). If one listens to the conversations on the playground one is sure to hear comments from the "local police officer" and "expert on proper etiquette." This is not to say that these same "playground authorities" are able to follow the advice they are so willing to give out to others when it is they who feel hurt or anxious. What is so striking about the preschool child is how much of his or her language is directed toward social interactions with adults and peers. Around four years of age one can hear preschoolers verbalize out loud their "private speech" which is an ongoing monologue about their thoughts, hopes, and feelings: "I am the doctor, I'm not going to hurt you. I just need to give you seven shots so you can go to Kindergarten. If you hold still and don't cry it will be over very quickly and you can go get a treat. I need to give you the shots." "John" repeats this monologue as he approaches his friend, grasping the thermometer from the pretend doctor's kit with a look of determination that he will administer the shots (Davies 1999). As one can see, the child's developmental paths in communication are very closely linked to the next areas we will review, the child's cognitive development and capacity to play.

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