

Proven methods based on the breakthrough Early Start Denver Model

An
Early Start
for Your Child
with Autism



Using Everyday Activities
to Help Kids Connect,
Communicate,
and Learn

Sally J. Rogers, PhD

Geraldine Dawson, PhD

Laurie A. Vismara, PhD

An Early Start for Your Child with Autism

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*To all parents of children and adults with autism, for their courage,
their hope, their generosity, and their perseverance*

—S. J. R.

*To my loving husband, Joseph, and my wonderful children,
Chris and Maggie, who have supported my work with patience,
understanding, and a shared commitment to improving the lives
of people with autism*

—G. D.

*To my father, for his commitment to improving the lives
of individuals with autism, and to all the courageous individuals
and their families who are overcoming the challenges of autism*

—L. A. V.

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Authors' Note

To protect the identities of the families with whom we have worked, all the stories about families and the examples in this book are composites of real people created to reflect common challenges and successes that we have witnessed many times. The comments from parents scattered throughout the book have been reprinted in their own words with their permission, but their names have been omitted to protect their privacy. We are grateful for their candor and support.

A word about our use of pronouns in this book may also be helpful. In most of the text, we alternate between “he” and “she” to refer to your child with autism. However, in items for your personal use (such as forms, boxes, Activity Checklists, and tables), as well as in the Part II Chapter Summaries and in Chapter 14, we use “he or she.”

Acknowledgments

We want to begin by expressing our deep appreciation for the support we have received from Rochelle Serwator, Chris Benton, and Kitty Moore at The Guilford Press, for motivating and encouraging us, believing in the value of this book, and helping us produce a better one than we would have thought possible. We also want to share our individual acknowledgments.

From Sally:

My preparation for writing this book began with the very first parents and toddlers with whom I worked in Ann Arbor, Michigan. My experiences with children like Laura Ann and Peter, as well as their parents, taught me so much about the first few years of a family's life when a child has developmental disabilities. I appreciate what I learned from them about supporting their relationships, their interactional styles, and their child-raising and family values as they provided interventions for their children. I am extremely grateful to the families in Denver with whom my colleagues and I worked. They are the families from whom I learned not only about early autism and its effects on families, but also about the resilience, hope, and determination of parents to seek out what is best for their children—who persist, across years and decades, to improve the quality of their children's day-to-day lives and prepare themselves and their children for the future. I appreciate all that I learned from my Denver colleagues in the Developmental Psychobiology Research Group about parent-child relationships and measurement approaches, and I appreciate their challenges to me (especially those of Bob Emde and Gordon Farley) to move from clinical services to well-controlled studies of early intervention.

I particularly appreciate what I have learned in the collaborations with my two coauthors, who are also friends and colleagues. Geri's work allowed for tremendous growth in the definition and rigor of the intervention approach, and she has been a tireless, enthusiastic, and optimistic partner in our shared work with the Early Start Denver Model (ESDM). Laurie and I together worked out much of the methodology for the ESDM parent training package, which she first

studied and published in her postdoctoral research program. The three of us share both belief and experience in the power of parent-delivered interventions embedded in daily routines to teach young children with autism language, play, and social engagement, and these beliefs and experiences were linchpins for developing our research programs in parent interventions and for writing this book.

I also want to thank my two daughters, Sara and Amy, for giving me my only direct experience in parenting toddlers, and for embracing my autism work throughout their lives. My assistant, Diane Larzelere, provided talented and speedy help for manuscript development, and constant cheerful encouragement.

From Geri:

I want to begin by thanking the many parents and children with whom I have had the privilege of working over the past 25 years. They are my true heroes and best teachers. Nothing is as rewarding as sharing the excitement of a new ability being achieved. It has been my delight to watch parents interacting with their young children with autism, drawing them into closer interactions, and helping them learn to communicate and play. It was my privilege to provide suggestions and advice from the perspective of a seasoned clinician and developmental psychologist and then to witness the unfolding of each child's skills over time. Throughout the process of therapy, the persistence, humor, insight, and unconditional love that family members show have been my inspiration.

Early on, my perspectives on autism were shaped by Eric Schopler, Michael Rutter, and Marian Sigman. At a time when other professionals were blaming parents for autism, Eric, a pioneer, showed us that parents are our most important partners, ideally positioned to help their child with autism. Michael's insights about the interface between the social and thinking brain ring truer today than ever and are consistent with the ESDM. Marian's landmark studies described the development of autism in exquisite detail, providing a roadmap for creating developmentally informed treatments.

I gratefully acknowledge my graduate students and colleagues at the University of Washington for their openness to new ideas and willingness to pursue them, and for their humor and passion for improving the lives of children with autism and their families. I especially want to acknowledge the hard work of the UW team in completing the randomized clinical trial of the ESDM, which helped lay the foundation for the work discussed in this book.

Finally, I wish to thank my husband, Joe, and my children, Chris and Maggie, whose constant love and support made this book and my life's work possible.

From Laurie:

I did not intentionally set out to become an autism researcher or clinician. Rather, autism chose me—my half-brother was diagnosed at a very young age. At the time,

I did not fully comprehend what it meant for him to have autism or the minute-by-minute challenges that he and so many other individuals with autism would come to face. What I did come to grasp was the amount of pain my father and stepmother experienced in coping with his diagnosis, coupled with the unconditional love and desire to protect and help him in whatever way humanly possible. Their commitment and dedication to creating an enriched and dignified life for my brother has been my daily inspiration for helping other parents do the same for their children with autism. This book represents the unselfish willingness of parents to share the trials and triumphs through which they have helped their children with autism learn, as well as to help others understand what living with autism is like.

I would also like to acknowledge the incredible mentoring of Drs. Robert and Lynn Koegel and Sally Rogers. The Koegels taught me the value of embracing parents as equal, collaborative partners in helping their children overcome daily challenges. It was because of the Koegels' teaching that my own brother found his voice, and for this accomplishment I will always be indebted to them. When I came to work with Sally, she expanded my thinking and approach to interacting with families. She helped me listen better to families' needs, understanding their emotions and struggles with the everyday demands that their children face. I admire her and Geri Dawson's lifelong dedication to finding answers, through science, to improve the quality of life for individuals with disabilities and their families. I am honored to be a part of this book with them and hope to follow their example of using science to better individuals' lives. Lastly, thank you to my parents and friends for their unending love and tolerance for my work schedule. They have always understood my passion and at times compulsion to pursue a career in research and academics, and I am grateful for their encouragement and patience.

Introduction

If you are a parent of a child recently diagnosed with autism, you are not alone. A 2009 study by the U.S. Centers for Disease Control and Prevention in Atlanta, Georgia, found that autism spectrum disorders (ASD) affect 1 in 110 children in the United States, meaning that hundreds of thousands of parents have learned that their child has an ASD. This year, more children will be diagnosed with ASD than with cystic fibrosis, AIDS, and cancer combined. Children from all economic and racial backgrounds are affected equally. You are not alone in the chaos of feelings, questions, and concerns that you have now. Please be assured, however, that, equipped with solid knowledge and skills, parents of a child newly diagnosed with ASD can put the pieces in place to have satisfying and happy lives. Children with ASD can lead meaningful, productive, and fulfilling lives. This book will help you take action right now that will put you and your child on the road to that kind of life.

The goal of this book is to provide parents¹ like you, and the other people who love and care for your child, with tools and strategies to help your child move onto a positive developmental path as soon as possible. No matter how difficult life may seem right now, there are things you can do starting tomorrow that will, over time, make a tremendous difference in your child's future. You can teach your child to interact with you and others, communicate, enjoy social exchanges, and play. You can be hopeful that your child can learn, engage, and relate to others.

We know that many parents are left to fend for themselves for quite a while after their child has received a diagnosis of ASD. Either trained therapists are not available in their area, or there are long waiting lists to get into intervention programs. We know you are eager to begin helping your child. So to ease your frustration and worry while you wait for intervention to start, or to enhance the

¹Although we generally use the term "parents," this book is designed more broadly for all types of caregivers, including extended family members, legal guardians, and others who provide care for a young child with ASD.

intervention your child may be receiving now, in this book we offer information, tools, and strategies that you can use immediately, on your own. The strategies described here are designed to be used during your everyday interactions with your child—playing, changing, dressing, bathing, meals, outings, book time, and even household chores. They can transform your day-to-day experiences with your child into enriched learning opportunities, and they can also give your child’s treatment a boost as you continue to use them once intervention begins.

With these strategies in hand, we are confident that you will help your child learn, communicate, and play. You will likely see changes in your child day by day, week by week. As you begin to use these strategies, you will see how effectively you can help your child with ASD and how responsive your child can be to new learning opportunities. We hope that some of your feelings of fear and frustration will be replaced with a sense of hope, determination, and confidence in yourself as a parent, in your family, and in your child.

This book is based on our extensive and ongoing work with families like yours, using the Early Start Denver Model to help children become active, curious, and engaged learners in the world. The strategies you’ll learn come from formal scientific studies that show children’s accelerated development when the Early Start Denver Model is delivered combined with parents’ use of these skills. Although children with ASD benefit from and need intensive early intervention services from trained professionals, we believe that parents and other family caregivers can make an enormous difference in their child’s learning.

We three authors of this book have all worked for many years directly as clinicians teaching families how to promote engagement, learning, and communication during the daily routines that naturally occur with children. We have found that parents are as effective as therapists in teaching core skills affected by autism. They can use these strategies to make every interaction with their child count toward learning. Parents also have the opportunity to teach skills or behaviors at home that children may not learn elsewhere or may not have much opportunity to practice in other settings.

The Early Start Denver Model supports parents’ relationships with their children. It helps parents develop learning opportunities via simple games, communicative interactions during caregiving, and fun exchanges during other daily routines. No special background or prior knowledge is required. The strategies described here are designed to help parent–child interactions become more fun, more emotionally rich, and more meaningful, while at the same time providing children with more learning opportunities. We hope that parents from many different walks of life and many different backgrounds will find the strategies helpful for developing richer learning experiences for their children from the everyday activities involving playing with toys, bathing, eating meals, grocery shopping, or other activities in their daily lives.

We also understand that each child with ASD is unique, with a personal set of special gifts and challenges. As someone once said, “If you have met one child

with autism, you have met one child with autism.” Like each typically developing child, each child with ASD has a unique personality, set of likes and dislikes, talents, and challenges. But all young children with ASD, by definition, have trouble relating and communicating with others and playing with toys in a typical way.

From decades of research on early development and intervention in children with ASD, we have learned a great deal about the kinds of difficulties that

Areas in Which Most Children with ASD Have Difficulties

- Paying attention to other people
- Using social smiles
- Taking turns and engaging in social play
- Using gestures and language
- Imitating others
- Coordinating attention (eye gaze) with others
- Playing in typical ways with toys

young children with ASD have. It can be hard for them to pay attention to the people around them—including others’ language and activities. It is often hard for them to share their feelings—happiness, anger, sadness, frustration—with other people by sending emotional messages to others through their facial expressions, gestures, and sounds or words. They experience a full range of

emotions but may not share them in a way that is easy to understand. They may not be very interested in playing with other children and may not respond very well to other children’s efforts to play with them. They often do not use many gestures to communicate and don’t seem to understand the gestures of others. They are less likely to imitate others readily, so it can be hard to teach them by showing them how to do something and expecting them to copy it. Many children with ASD enjoy toys, but they often play with them in unusual ways, and their play can be very repetitive. Developing speech, and responding to others’ speech, can be very difficult for many children with ASD, even for those who learn how to repeat other people’s words. It is also not unusual for children with ASD to have some “challenging behaviors.” These challenging behaviors are often seen in other young children as well, but young children with ASD do not respond to the typical ways parents try to teach children how to behave. They may throw tantrums, hit or bite others, destroy objects, and sometimes hurt themselves (this is called *self-injurious behavior*).

This book will teach you strategies for helping your child in each of these areas. Many studies, including studies we authors have conducted ourselves, have shown that early intervention can be tremendously helpful for children with ASD, resulting in significant gains in learning, communicating, and social skills. Some children even lose their diagnosis of ASD as a result of early intervention; others may still have challenges but are able to participate well in regular classrooms, develop friendships, and communicate well with others. Still others may

continue to have significant challenges requiring ongoing special services, but early intervention will help them progress.

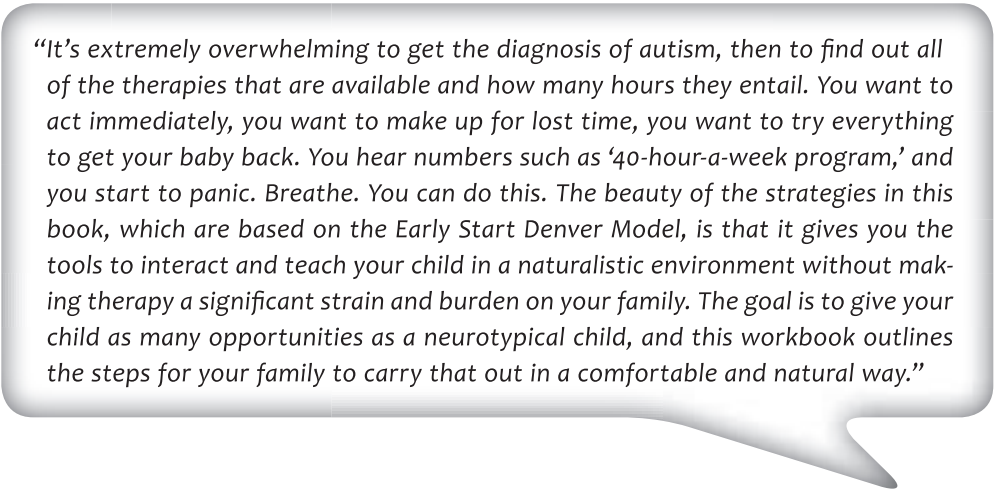
Most of the research on early intervention has focused on studies in which the treatment is delivered by trained therapists. The research on *parent-delivered* early intervention is still at an early stage. However, studies show that parents and other caregivers can learn to use many treatment strategies as well as trained therapists, and that when parents use these strategies, the quality of their interactions with their children improves and the children become more socially engaged and learn to communicate better with others. We have helped many parents learn to use these strategies at home with their young children, and they have told us again and again how helpful these approaches are for teaching their children to learn, interact with others, communicate, and play in more typical ways. In our work with many children over the years, we have discovered that *every single child with ASD can learn* to communicate, improve social interactions with others, and increase play skills. We are confident that these techniques will help you feel more effective as a parent, a playmate, and a first teacher for your child. And as you use the techniques and see your child learn from them, you will experience a sense of parental pride and pleasure that comes from seeing your child achieve and knowing that you are part of your child's successes.

This book is designed for parents of young children with symptoms of ASD who are in the infant through preschool years/kindergarten. You can use it whether you only suspect your child has ASD or your child has already been diagnosed. It will provide you with step-by-step instructions and examples through which you can use your typical everyday activities to help your child become more engaged, communicative, and interactive with you and with your family.

How to Use This Book

Each chapter of this book is designed to address questions, concerns, and challenges that most parents of young children with ASD experience. Among the issues that we address are feelings and concerns related to leading your life as a parent of a child with ASD, including knowing what you need to do at this early stage. Getting the best professional help will be uppermost in your mind, so this topic is covered in Chapter 1. Because parenting a child with ASD can be stressful, it will be essential that you begin this journey by considering how you will make sure to take care of yourself and the rest of the family, and avoid setting aside those needs to focus solely on the child with ASD. Doing so would mean that you would be less effective and more likely to become worn out in the process. These issues are addressed in Chapter 2. Then, to lay the groundwork for the intervention strategies described in the remaining chapters, Chapter 3 offers a fundamental understanding of what is known about ASD. This provides a context for the treatment approach offered in this book. Each of the remaining

chapters describes the intervention strategies in detail, with each chapter building on the previous ones. So it will make sense for most people to read the chapters in order. However, Chapters 9 and 13 are not as dependent on earlier chapters as are the others. You may find it helpful to read them earlier in the process and refer to them as you move along in the book. We recognize that some parents will find some chapters more helpful than others, however, depending on their child's unique challenges.



“It’s extremely overwhelming to get the diagnosis of autism, then to find out all of the therapies that are available and how many hours they entail. You want to act immediately, you want to make up for lost time, you want to try everything to get your baby back. You hear numbers such as ‘40-hour-a-week program,’ and you start to panic. Breathe. You can do this. The beauty of the strategies in this book, which are based on the Early Start Denver Model, is that it gives you the tools to interact and teach your child in a naturalistic environment without making therapy a significant strain and burden on your family. The goal is to give your child as many opportunities as a neurotypical child, and this workbook outlines the steps for your family to carry that out in a comfortable and natural way.”

As you begin to practice the intervention strategies and incorporate them into your everyday interactions with your child, please keep in mind that the goal of this book is not to transform you from a parent into a therapist! Nor will you spend many hours with your child “providing therapy.” Rather, these strategies are meant to be used during the typical routines that are part of your daily experience, such as during bath time, at the park, or while you are putting your child to bed. They should not take more time than your typical activities with your child would. The strategies build on the loving, caring relationship you already have with your child, and they use that foundation to help your child overcome some of the difficulties that are part of ASD. So let’s get started.

Part I



Getting Started

1

Setting Up Your Child's Early Intervention Program

Carmen and Roberto received a diagnosis of autism for their 3-year-old, Teresa, last week. They spent a whole day at a clinic where Teresa saw person after person who asked her to play with toys, draw, swing on a swing, and do all kinds of other things. Carmen and Roberto were surprised at how much Teresa did for the doctors. These people really seemed to understand Teresa and know just what to do to encourage her to play. Teresa enjoyed herself and did some things for the doctors that her parents had never seen. They were proud of her and glad that it had gone so well.

The doctors were kind and friendly to Carmen and Roberto. They spent a lot of time with them, asking them all sorts of questions. At the end, the parents met with the psychologist on the team, Dr. Avila, who spoke both Spanish and English. She said that Teresa had some talents and abilities—she was already beginning to read! But she was also having problems learning to communicate and play. Dr. Avila said that Teresa had autism. This was the reason for her lack of speech, her odd finger movements, her big tantrums, and other problems, too. The doctor was so sure about this. That helped Carmen and Roberto. Their daughter wasn't stubborn or spoiled. She had autism, a biological condition. The diagnosis explained everything about her. And she was smart.

Dr. Avila reassured Carmen and Roberto that they had not caused Teresa's autism, nor could they have prevented it. However, they could help Teresa a great deal by finding her a good treatment program. The doctor also said that autism was something that did not go away by itself. That was hard to hear, but also, in a way, a kind of relief. Carmen and Roberto now had a name for what was wrong—a diagnosis, a way to explain Teresa.

Dr. Avila gave them phone numbers and names of people to call, as well as handouts to read (even some in Spanish for the grandmas), a list of books and websites, a fact sheet about autism, and names of parent groups. Carmen and Roberto went home in a sea of worry, grief, and questions. For a few days they were just numb

and couldn't talk about it or even think clearly about anything. They went through the next few days like robots—going through the motions of everything they had to do at work and at home, but feeling numb and sad.

On the weekend, though, over breakfast, Carmen started to talk to Roberto about it all. So many different feelings were going through her at once. She was desperately worried about Teresa, about her future, about what to do, about how to help her do well. She wanted to start finding treatments as the doctor had advised, but she didn't know where to begin. Roberto listened closely to Carmen as she expressed her feelings. Carmen had words for the thoughts and feelings that he was having, too. They were a close couple. He reached out and squeezed her hand. "We'll get through this," he said. "We'll pray, and we'll work with her, and we'll get through this." Carmen squeezed his hand back, wiped away a few tears, and felt grateful for her husband—he listened, he joined, he was there with her. She was not alone. "But what should we do now?" she asked. "Who should we call first?" There was so much information on the sheet the doctor had given them; she had no idea where to start.

The news about autism probably opened up a huge new set of feelings and thoughts for you, as it did for Carmen and Roberto, including those involved in finding and beginning treatment for your child. On the one hand, you may feel a sense of urgency to get started. On the other hand, you may find yourself somewhat overwhelmed and even a little reluctant to start the process. The amount of new information and new terminology can be daunting. The numerous phone calls and appointments can make the process seem never-ending. Perhaps you even feel that if you can put off seeking help for a little longer, things will get better on their own. All of these feelings have been shared by countless parents and other family members who have stood in your shoes. We hope to make the process a little easier for you by providing straightforward information and techniques that can set you on the right path.

Starting in Chapter 4, we describe concrete ways to help your child increase his social and emotional interactions, communication, and play during your typical daily routines, so that you can increase your child's learning opportunities throughout the day. These parent-delivered strategies can be used together with other interventions for your child, which may involve a number of different people. In this first chapter, we offer information and tips for finding and pulling together the essential ingredients of a successful early intervention program for your child.

Getting Started: Knowledge Is Power

At first, the new terms, the difficulty in finding good treatment, and the uncertainty that lies ahead make many parents feel like getting into bed and hiding

under the covers. Fortunately, this feeling is soon overshadowed by the determination to find out what is best for their child and to find the best intervention available. But getting these answers can be difficult. There is so much out there—so many different opinions and so much disagreement among people.

A recent survey of thousands of parents found that a large majority of parents (81%!) turn to the Internet to gain an understanding of and help for ASD.¹ The Internet allows parents across the globe to access an enormous amount of information, much of which is valuable. However, the information found on the web can also be misleading and unreliable. As you read and listen to others, keep these questions in mind:

- Who is the author? Does the author have the background and expertise needed to provide reliable, authoritative information?
- Has the information been tested thoroughly by research? Has it been published in scientific journals?
- What is the date of the information? Is it current?
- Is the website trying to sell you something? Products, assessments, treatments?
- Does the website claim to have a miraculous “cure” for ASD?
- Does the site seem biased? Does it discuss different points of view or only one?

Be skeptical! If you don't feel comfortable with your answers to any of these questions, question the truth of the information you are reading on the Internet.

To make it easier to sort through the information and options presented on the web, one group—Autism Speaks, the world's largest autism science and advocacy organization—brought parents and professionals together to create a set of tools to help parents walk through those first overwhelming days after diagnosis.



Helpful Tip

The National Cancer Institute offers these tips for evaluating health-related information on the Internet:

- A website should make it easy for people to learn who is responsible for the site and its information.
- If the person in charge of the website did not write the materials, the original source should be clearly identified.
- Health-related websites should give information about the medical credentials of the people who prepare or review the material on the site.

¹Law, P. *Interactive Autism Network Survey*. Presented at the conference on Ethics of Communicating Scientific Findings of Autism Risk, Drexel University, Philadelphia, PA, October 6, 2009.

As a parent of a young child with ASD, you will find a lot of useful information on the Autism Speaks website,² under “Family Services.” If you still have questions about whether your child has ASD or what the specific symptoms of ASD look like, you can check out the ASD Video Glossary at www.autismspeaks.org/what-autism/video-glossary. The glossary contains more than a hundred video clips of children’s behavior, illustrating the sometimes subtle differences between typical and atypical behavior. The ASD Video Glossary can help you learn more about your child’s symptoms of ASD.


A second important tool for you is the “100 Day Kit.” You can download the kit for free at www.autismspeaks.org/family-services/tool-kits/100-day-kit. This kit, which is available in Spanish, gives information on ASD diagnosis and causes, your child’s educational rights, different therapies and treatments, and 10 things your child wishes you knew, as well as safety tips, useful forms, and a

glossary. The kit will provide you with a detailed plan for what to do in the next 100 days. Knowledge is power, and the 100 Day Kit will help you feel better prepared for the start of your journey down the new road that has opened up in front of you as a parent of a child with ASD.

The strategies that you will learn starting in Chapter 4 will help you work with your child at home right now, while you are waiting for intervention to begin. They will continue to be helpful once your child is enrolled in an intervention program. That is, they will ensure that your child is learning not only while with teachers and therapists, but also throughout the day-to-day moments with you. You are, after

all, your child’s most valuable teacher—just as parents of children without an ASD diagnosis are—because you know your child best and you’re the person with whom your child spends the most time. Those daily activities with you are the most important and most frequent learning opportunities your child has, and you are there and ready to make the most of them.

²If you have trouble accessing this information on a computer, you can call 888-AUTISM2 (888-288-4762) and speak with an Autism Response Team Coordinator. The 100 Day Kit will be sent to your home for free.



Helpful Tip

The 100 Day Kit from Autism Speaks provides these things:

- General diagnostic and medical information
- Help with family issues
- Guidance for finding services
- Descriptions of different types of treatments
- An action plan for getting started
- A glossary and resources

Finding the Best Intervention Program

In 2001, the National Research Council,³ an organization that advises the U.S. Congress on policy, made a set of recommendations about **best practices** for early intervention with young children with ASD. These straightforward recommendations can serve as a basic guide and yardstick by which to assess the effectiveness of an intervention program you're considering. The criteria are as follows:

- ✓ Intervention should begin as soon as possible.
- ✓ The intervention program should be individualized for each child, taking into account each child's unique characteristics, strengths, and challenges.
- ✓ The intervention program should be designed and overseen by a trained, professional, interdisciplinary team.
- ✓ A curriculum that focuses on the specific areas of challenges in ASD should be used.
- ✓ The program should provide for ongoing data collection on the progress the child is making in each skill area, and adjustments to the program should be made when progress is not evident.
- ✓ The child should be actively engaged in the intervention activities and should receive at least 25 hours of structured intervention each week.
- ✓ Parents should be closely involved in the intervention, as well as in setting goals and priorities, and should be taught how to implement the intervention strategies at home.

We would add another criterion to this list: The intervention provided for your child should be based on **evidence-based practices (EBPs)**. You may run into this phrase often as you read about autism interventions. It means that the intervention has been tested in scientific studies and published in scientific journals, and that the results showed those intervention practices to be more helpful for young children with ASD than no intervention. With all the claims and all the hype about autism treatment these days, you will want to be sure that your child is receiving interventions that have been tested and found to be effective.

How will you know? You can ask the providers if their intervention is based on EBPs, and if you want, you can ask them to share with you the research articles that demonstrated its success. You can find trustworthy information about EBPs on the National Standards Project website (www.nationalautismcenter.org/

³Committee on Educational Interventions for Children with Autism, National Research Council. *Educating children with autism*. Washington, DC: National Academy Press, 2001.

affiliates) and on the website for the National Professional Development Center on ASD (<http://autismpdc.fpg.unc.edu>).

Receiving appropriate early intervention based on best practices is not just a goal. It is a legal right of your child's, thanks to a law called the ***Individuals with Disabilities Education Improvement Act (IDEA)***, which was enacted in 1975 and revised in 2004. This law guarantees the rights of all children, including those with ASD, to a free and appropriate education that meets their unique and individual needs. This means your child with ASD is eligible for free education that addresses her specific needs (even as a toddler).

How do you find an early intervention provider? The professional who provided you with the diagnosis may also have provided you with a name and phone number to call to begin the process of starting early intervention services. If this did not happen, your child's doctor may well know the agency and phone number to call. Another route is to call your school district's special education department, say your child has just received a diagnosis of ASD, and ask whom you should speak to. You can also find information on how to find and access early intervention services in your state on the Autism Speaks website (www.autismspeaks.org/family-services/resource-guide) and the Autism Society's website (www.autism-society.org).

A good early intervention program can be provided in different ways:

- **If your child is under age 3**, you will work with the early intervention provider to develop an ***individualized family service plan (IFSP)***. This is a document that you and others will write together. It will describe your child's specific intervention needs and goals, and the types of services your child and family will receive to reach those goals.
- **If your child is 3 years old or older**, he will receive an evaluation, and you and the preschool services agency staff members will develop an ***individualized education program (IEP)*** for your child, usually under the direction of your local school district. Your child's intervention will move from "early intervention" to "preschool" services at age 3, even if you started out with an IFSP.



Helpful Tip

You can locate early intervention services in your community by calling your school district's special education department. Even if your child is much younger than school age, your school district can help you. Your child's doctor is another source of information about services. There is also information on the Autism Speaks website (www.autismspeaks.org/family-services/resource-guide) and on the Autism Society of America's website (www.autism-society.org).

Choosing a Birth-to-3 Program or Preschool Program

Because the needs of each child with ASD are unique, there are many ways to construct an early intervention program that can help your child, and many types of intervention models to draw from. Some children receive all of their services at a specialized clinic- or school-based program, whereas others receive most of their interventions from people who work with the children at home. It is common for young children with autism to receive their intervention from a combination of school-, clinic-, and/or home-based intervention programs. In some places, services are delivered by people working for the public agency. In other places, the public agency contracts with private groups to serve children.

As we have said above, high-quality programs use EBPs. Most EBPs have come from the field of *applied behavior analysis (ABA)*. What is ABA? ABA is the use of teaching practices that come from the scientific study of learning to teach or change behavior. The principles of ABA can be used to teach new skills, shape existing behaviors into new ones, and reduce the frequency of problem behaviors. Later in this book (Chapter 9), we describe the principles of ABA in more detail. For now, the important thing is to look for early intervention programs that use EBPs in their approach. As noted earlier, you can ask any early intervention provider directly whether the program uses EBPs in its teaching approach. If the answer is no, look for additional options.

Providers of early intervention programs and services may include early educators, speech-language therapists, behavior analysts, occupational therapists, or other professionals, along with educational or therapy assistants. Although the amount of intervention for preschoolers recommended by the National Research Council (see the checklist on page 13) is 25 hours per week, we don't know what the best number of hours is for children under 3, and public services in many places may provide only a few hours per week of intervention. You can use the intervention strategies described later in this book, and those you learn from your intervention team, at home to increase the number of hours of high-quality learning experiences your child receives. This will also help your child learn to bring (*generalize*) the skills learned in other settings into daily life at home and in your family activities.

If you have a choice of intervention programs, try to visit and observe different programs in action, meet with the director and teachers, and talk with other parents of children participating in the program. As you observe the program and talk with the teachers and parents, imagine your child in this program. Is the intervention approach based on EBPs? Does it seem right for your child? Is this the kind of approach you think will work best for your child? Programs differ in their degree of structure and routine, how they work with parents, how they teach language, how quiet or noisy they are, whether they are delivered at home or in a group, and so on. How do these qualities match your child's individual

personality, learning style, and abilities? How do they match your preferences, values, and expectations for how others should interact with your child? The National Research Council recommendations mentioned earlier can be broken down into more specific criteria that you can use to evaluate an early intervention program.⁴ You may not be able to determine whether all of the criteria in the checklists in the box on pages 18–19 are being met without delving into a lot of detail with the providers, but you can get a fairly good idea of whether many of them are being met by observing the program closely and asking questions as they arise.

Use of Additional Therapists

Public agency intervention programs will have speech–language therapists, occupational therapists, psychologists, and physical therapists on staff. If you go through your public agency for services, your child is likely to receive an evaluation by a speech–language therapist, and perhaps an occupational therapist as well. Their information is typically used to build the goals and service plans that appear on your child’s IFSP or IEP. Sometimes these therapists work directly with children separately from other children; sometimes they work with a small group of children, or children and parents; and sometimes they consult with those who are providing the ongoing intervention, rather than working directly with children. Some families also use these types of therapists privately, using their children’s medical insurance to cover the costs, if possible. If your child is not making enough progress in developing spoken language, discuss this with your team members and ask them whether additional therapy from a speech–language therapist might be helpful. You can ask them for referral sources, and your child’s physician should also be able to refer you to a speech–language pathologist whose services are covered by your child’s health care insurance. Their treatment may focus on general communication, including use of gesture and developing word use, articulation and speech development, and even social interaction and play.

If your child’s motor coordination or responses to sensory stimuli are very concerning to you, you can follow the same process just described to find an occupational therapist. Discuss this with your team and your child’s physician; ask whether additional occupational therapy or physical therapy may be helpful to your child; ask for a referral to a professional whose services are covered by your child’s health care insurance; and seek additional treatment. A list of therapists who have experience working with young children with autism in your area is also provided in the “Resource Guide” section of the Autism Speaks website.

⁴Adapted from Librera, W. L., et al. *Autism program quality indicators: A self-review and quality improvement guide for programs serving young students with autism spectrum disorders*. Trenton: New Jersey Department of Education, 2004. Available at www.eric.ed.gov.

Therapists in the Home Setting

When an intervention is delivered at home, typically a professional person acts as a *program manager* or supervisor of the program. The program manager has expertise in early intervention and supervises a team of *therapists*, who may be paraprofessionals who should receive training and ongoing close supervision by the program manager. These paraprofessionals (sometimes also referred to as *tutors, aides, interventionists, or home therapists*) come to the home regularly to work with the child. In some areas, these services are paid for by the public early intervention service agency. In other areas, health insurance will pay for these early intervention services. Sometimes parents pay out of pocket. Reforming insurance coverage practices to cover such services is an important goal for advocacy organizations. If you have home-based therapy, it is important to ensure that the program manager is professionally trained and credentialed, will see your child frequently, will observe and supervise the others working with your child frequently, and is using EBPs. Use the checklist in the box on page 21 to determine whether a home-delivered intervention you are considering will be effective for your child.

The Role of Your Child's Physician in Early Intervention

Only recently has the impact of your child's medical health on her ability to learn and benefit from early intervention been fully recognized. We have learned that



Helpful Tip

If your diagnosis came from a medical center team, your child probably had a medical workup as part of the process, including a blood draw, urinalysis, and other tests. If your diagnosis came from an independent professional, you may not have had a complete medical workup for your child's autism yet. If you have not, ask your child's doctor to carry out a full medical workup for autism. It is quite important, because in some cases there is a known medical reason that is contributing to autism, and it may affect your child's treatment.

ASD not only affects the brain and behavior, but can also affect the whole body. Thus your child's physician will play an ongoing role in your child's treatment. Common medical issues that children with ASD may experience include sleep disturbances, such as difficulty falling asleep and frequent awakening; eating difficulties, such as finicky eating and food aversions; gastrointestinal problems, such as constipation and diarrhea; and seizures. Less common medical problems include rare inborn problems with metabolism. A physician should screen for these metabolic conditions as part of the diagnostic workup.

Not all physicians are familiar

Criteria for Measuring the Quality of an Early Intervention Program

1. Does the program engage the children sufficiently?

- ✓ Are all children involved in the classroom activities? Or are some children wandering or isolated?
- ✓ Does the program give your child at least 25 hours a week of structured intervention when added to other interventions the child is receiving?
- ✓ Is each teacher or other adult staff member in charge of only two to three students?
- ✓ Is the program offered year-round?
- ✓ Are the educational activities planned systematically and appropriate for the developmental age of the children?
- ✓ Does the program track daily progress so that the methods can be assessed for effectiveness?

2. Are staff members well qualified?

- ✓ Do they know how to develop an IEP to meet the unique needs of a child with ASD?
- ✓ Do they know how to use a comprehensive curriculum specifically for ASD?
- ✓ Can they adapt the learning environment and use instructional methods known to help children with ASD learn?
- ✓ Do they use strategies to promote communication and social interaction?
- ✓ Can they implement behavior management techniques based on ABA?
- ✓ Are they able to appropriately handle a crisis?
- ✓ Do they have appropriate credentials in their profession?
- ✓ Do the teaching and therapy assistants receive direct instruction and supervision?
- ✓ Are staff members provided with regular inservice training on educating young children with ASD?
- ✓ Are consultants available to the program?

3. Is the curriculum appropriate for children with ASD?

- ✓ Are educational objectives, methods, and activities based on a written curriculum?
- ✓ Do staff members adapt the curriculum to meet children's unique abilities, challenges, ages, and learning styles?

- ✓ Does the curriculum focus on important areas for learning, including communication and language, fine and gross motor skills, toy play, imaginative play, and social skills?
- ✓ Do children have opportunities to interact with typically developing peers?

4. Are the teaching methods effective?

- ✓ Are the methods EBPs?
- ✓ Do the methods help children participate in appropriate activities?
- ✓ Do the instructional methods take advantage of naturally occurring rewards?
- ✓ Do they encourage children to use learned skills spontaneously in different environments?
- ✓ Does the staff analyze data collected on each child's challenging behaviors, use a functional behavioral assessment,* and support positive behavior to reduce challenging behaviors?

5. Does the program involve the family?

- ✓ Does the program involve parents and family members as active participants in all aspects of the child's evaluation and education?
- ✓ Does the program give parents information about the educational philosophy, curriculum, and instructional strategies?
- ✓ Does the program staff respect differences in culture, language, values, and parenting styles among families?
- ✓ Does the program help parents understand child development and support parents' efforts to apply the teaching methods at home? Does the staff meet regularly with parents and inform them about their child's progress?
- ✓ Does the program work with families to find family support services?
- ✓ Does the program help the family transition the child into the next phase of education?

***Functional behavioral assessment** is an EBP, a technical procedure for identifying the functions of challenging behaviors such as aggression. It involves collecting data about the frequency and severity of the problem behavior and identifying the immediate factors that preceded and followed each occurrence of the behavior. It leads to an intervention approach designed to minimize contributing factors; make environmental accommodations to prevent or reduce the challenging behavior; and build alternative, appropriate skills that address the identified function of the behavior.

with how to assess and treat the medical issues that your child may be facing. If your child is uncomfortable, tired, or in pain because of a medical issue, your child may start to become aggressive, have a tantrum, or become lethargic. These “problem behaviors” may be viewed by the physician as “just part of the autism.” If you suspect that your child has an underlying medical condition, work closely with your child’s physician to find the answers. Your child’s doctor may need to refer your child to a physician who specializes in autism for appropriate medical assessment and treatment. Such specialty physicians are typically available at university medical centers and children’s hospitals, which often have entire autism clinics. Ask your child’s doctor if this type of referral is needed for your child. You can also look for a physician in your area by visiting the “Family Services” section of the Autism Speaks website.

Common medical issues that children with ASD experience include sleep disturbances, such as difficulty falling asleep and frequent waking; eating difficulties, such as finicky eating and food aversions; gastrointestinal problems, such as constipation and diarrhea; and seizures.

Sleep Difficulties

Sleep problems are extremely common among children with ASD. In fact, it is estimated that over half of children have at least one frequent sleep problem. This means that over half of parents of children with ASD have sleep disruption, since parents’ sleep is inevitably disrupted when their child has a sleep difficulty! Among the sleep problems that parents report are delayed sleep onset, night waking, early awakening, obstructive sleep apnea (difficulty breathing when asleep), and reduced need for sleep. Research suggests that ASD may be associated with differences in genes that regulate the sleep cycle and the production of

Fact: Over half of children with ASD have sleep difficulties, with insomnia the most common problem reported by parents.

melatonin. Melatonin is a chemical secreted by the pineal gland in the brain that helps regulate the circadian (daily) rhythms, including the sleep cycle. Occasionally, sleep problems are caused by seizure activity that is occurring during the night.

If your child is struggling with a sleep problem, he will not be able to take full advantage of early intervention. Studies have shown that sleep disruption in children, including children with ASD, is associated with poor attention, memory difficulties, and behavior problems, such as tantrums and aggression. The most common sleep problem parents of children with ASD report is insomnia. Often insomnia in a child with ASD can be helped substantially by establishing a more consistent bedtime routine (this is often referred to as good *sleep hygiene*). In an

Criteria for Measuring the Quality of a Home-Based Intervention Program

If the answer is yes to each of the following questions, you can be confident of the quality and experience of the intervention group.

- ✓ Does the program manager have an educational background appropriate for working with young children with ASD, including a graduate degree (master's degree or PhD) in a field like behavior analysis, special education, or psychology?
- ✓ Have the program manager and therapists been trained and certified in an intervention method with scientific evidence to support it? What is it?
- ✓ Have the program manager and all home therapists passed a criminal and educational background check?
- ✓ Does the program manager spend time regularly supervising the home therapists, observing them at work with your child, reviewing your child's progress and working with your child directly, and adjusting teaching strategies to improve progress?
- ✓ Do the home therapists you have met appear well trained, competent, professional, and motivated?
- ✓ Do the program manager and home therapists encourage you to observe and join their treatment sessions with your child and explain what they are doing?
- ✓ Does the program manager consult with professionals in other disciplines (such as occupational therapy, speech–language therapy, and pediatrics), when needed?
- ✓ Does the intervention program use a curriculum that identifies the specific objectives your child is working to achieve?
- ✓ Do the home therapists collect data on your child's progress daily and review the data regularly with the program manager?
- ✓ Does the program manager meet regularly with you and other professionals who are part of your child's intervention team?
- ✓ Do you feel that you are a respected part of the intervention team, and that your program manager listens to you?
- ✓ Does the manager help you prioritize what to focus on with your child? Does he or she show you how to help your child make progress on his or her objectives in your interactions with your child at home?

article on sleep hygiene for children with developmental disabilities published by the American Academy of Pediatrics, the following recommendations⁵ were offered for helping children with developmental disabilities sleep better:

1. Provide a sleep environment that is comfortable for the child, in terms of temperature, lighting, mattress, textures of blankets, and so on.
2. Provide a relatively dark sleep environment, because even low levels of light inhibit melatonin production (a night light is okay if necessary).
3. Establish a regular sleep–wake schedule, including regular times for naps, going to sleep, and awakening. In general, there should not be more than an hour’s difference in bedtimes and wake-up times during the week and weekends.
4. Plan bedtime activities carefully to help calm your child before sleep, because children with ASD can easily be overstimulated. Avoid new and unexpected activities, excessive noise, vigorous play, and large meals close to bedtime. Bathing, lullabies, presence of a familiar toy or blanket, and looking at books together are usually calming. Other calming activities include light massage, brushing hair, and soft music.
5. Do not have a TV in your child’s room. Do not play movies or TV as a way to help your child fall asleep.

If your child has a sleep problem, the first person to consult is the psychologist on your child’s early intervention team. There are excellent behavioral methods for parents to use that can improve children’s sleep enormously. V. Mark Durand has written two excellent books to help parents improve their child’s sleep based on good science: One is called *Sleep Better* (1998), and the other is *When Children Don’t Sleep Well: Interventions for Pediatric Sleep Disorders: Parent Workbook* (2008). Full details on both are listed in the Resources section at the back of this book. If these techniques are not effective, check with your pediatrician, who can provide more information about help for sleep. Melatonin is sometimes given orally to assist in establishing a regular sleep–wake cycle, but this should be done under the supervision of your family pediatrician.

Gastrointestinal and Feeding Problems

Another common medical problem experienced by many children with ASD is gastrointestinal (GI) distress. Parents frequently report that their child with ASD has abdominal pain, diarrhea, gas, and constipation. The most common problems reported by parents are diarrhea and constipation, which can alternate in the same child. Although these problems are fairly common in all children, there

⁵James, E. J., et al. (2008). Sleep hygiene for children with neurodevelopmental disabilities. *Pediatrics*, 122, 1343–1350, 2008.

is some evidence that they occur more frequently in children with ASD. Such GI problems cause pain and discomfort and, like sleep problems, can result in problem behaviors and difficulty paying attention. These problems in turn can result in failure to benefit fully from the intervention program.

Because children with ASD have difficulty communicating, it may be challenging to know whether or not your child is experiencing abdominal or other types of pain. Be observant of abrupt changes in your child's behavior, excessive crying or whining, self-injurious behavior, holding her stomach, and other nonverbal indicators of pain. If you are suspicious, take your child to the pediatrician to have her evaluated. GI problems are treatable. Depending on the type and severity of the GI problem, treatments can include dietary interventions, nutritional supplements, and medications. There currently is no scientific evidence that special diets, including elimination of casein and gluten, improve the behavior of children with ASD; however, some parents have anecdotally reported significant benefit from such diets, including improved attention and fewer behavior problems.

Fact: Feeding problems are common in children with ASD and can show up during infancy.

Eating problems are also common among children with ASD. A recent study published by the American Academy of Pediatrics⁶ found that children with ASD often start to have feeding difficulties as infants. They are more likely than typical infants to start eating solid food at a later date, for example. By 1 year of age, children with ASD are more likely to be described as "difficult to feed" and "very choosy." As toddlers, children with ASD have a less varied diet. Although this study did not find any differences between children with ASD and typically developing children in terms of nutrition, other studies have found that children with ASD sometimes have deficiencies in certain nutrients, perhaps because of their picky eating or the use of special diets.

If you have concerns about your child's eating patterns, bring this up at your next pediatrician visit. Also, discuss this with your case manager, your behaviorist, or the psychologist on your child's early intervention team. There are many ways you can help your child eat a wider range of foods, and your therapists should be able to help you a great deal. If your doctor is concerned about your child's nutrition, he or she may refer you to a nutritionist. Sometimes at university or hospital clinics, there is a nutritionist on the team who can provide specific suggestions regarding how to help your child eat better or how you can make sure your child is getting the nourishment he needs. There are different reasons a child may have eating difficulties, including having trouble chewing and swallowing, sensory sensitivities related to different food textures, food intolerances

⁶Emond, A., et al. Feeding symptoms, dietary patterns, and growth in young children with autism spectrum disorders. *Pediatrics*, 126(2), e337–e342.

or allergies, and avoidance of novelty. Your early intervention team and doctor, working together, can help you determine whether you should worry about your child's nutrition, help you understand why your child is having eating difficulties, and help you improve your child's eating habits.

Seizures

Although seizures are not usually a problem in early childhood, approximately one out of every four individuals with ASD will develop seizures at some point in life. Seizures typically develop for the first time in adolescence or even adulthood in ASD, though occasionally they appear early in life. It is important to have seizures treated, because the seizure activity can affect how the brain functions and develops. Thus, if your child has a seizure or has symptoms (described below) that suggest seizure activity, seek medical attention as soon as possible.

There are many types of seizures: seizures that involve staring spells (absence seizures), seizures that involve repetitive movements (partial complex seizures), and seizures that involve convulsions (grand mal seizures). Mild symptoms may be difficult to detect because some of the symptoms, such as staring into space and not responding when called, are also typical symptoms of ASD. Symptoms of an absence seizure may include “blinking out” or becoming unresponsive to sounds and sights for 10–20 seconds, blinking repetitively, eyes rolling up a bit, mouth movements, muscle stiffness, jerking movements, rubbing fingers together, and staring spells. If you have concerns about possible seizure activity, check with your pediatrician, who may refer your child to a child neurologist for an evaluation.

Putting It All Together

As you can see, there are many different parts to early intervention, including the basic intervention program (either group or one-on-one), and sometimes additional therapy from a speech–language pathologist, occupational therapist, and/or physician. Over time you will learn about the choices that are available in your community, decide what you feel is best for your child, and voice your preferences so that your child gets the best services available in your community. You will need to encourage the different people working with your child to talk to each other and share information. These things need to happen, but they don't happen automatically or all at once. They happen step by step because parents make them happen.

Many parents find it helpful to have regular “team meetings” with all the professionals involved in their child's care. The team meetings help keep all the team members on the same wavelength—focusing on similar goals, handling behavior problems in similar ways, learning from and listening to each other.

You have the right to ask for a team meeting at any time, to review your child's IFSP or IEP, and to discuss progress. Other ways to help your team work together include these:

1. Have a notebook that stays with your child throughout the day, so that teachers, therapists, and family members can make notes about your child's behavior and progress.
2. Ask your child's intervention team to send you information about your child's progress each week.
3. Some "tech-oriented" families even set up a blog or website on which different team members as well as the parents can communicate what they are working on, describe what has been effective (or not), and offer tips that can be helpful for the other providers. This is a place to share problems and victories as your child begins to develop new skills.

In this chapter we have provided basic information on setting up an intervention program for your child. For further reading, we have provided lists of excellent websites and books on the topics covered in this book (see the Resources section at the back of this book). Up to this point we've been focusing on your child. But what about you? Like your child, you and your family need special attention as you meet the challenges ahead. By doing so, you will be less likely to experience "burnout" and will be better able to meet the needs of your child with ASD and the rest of your family. The next chapter provides strategies for making sure that you and your family stay healthy and balanced, in spite of the stresses that come with raising a young child with ASD.

2

Taking Care of Yourself and Your Family

As Carmen and Roberto scrambled to put together the best intervention plan for Teresa, their 3-year-old with autism, several weeks flew by in a flurry of phone calls and appointments. Luckily, Carmen worked the afternoon shift, 3:00 to 11:00 p.m., so she was home during the morning and could make phone calls. All the focus was now on Teresa. Roberto worked the early shift, 6:00 a.m. to 2:00 p.m. The parents saw little of each other except on the weekends. When they had any time together, Carmen tried to tell her husband what was happening with Teresa—all the appointments, all the new people, the advice others were giving her about how to handle Teresa's tantrums and how to help her communicate. It seemed as if Teresa was all they were talking about now, and Roberto felt distant from it. He wished this would all pass, like a bad dream, and life would go back to when he had a happy wife, a close marriage, and a life that was smooth and easy. He worried about his ability to take care of his wife, son, and daughter in the face of this new, unknown, and scary future.

Carmen was living this new life, every waking moment. There was little time to talk about anything else, even 5-year-old Justino, who had just started school. Carmen soon started to have trouble sleeping. She lay in bed worrying about Teresa. Would the intervention program they had found really help her? Would their health insurance cover the expenses? Would she need to quit her job to focus on Teresa and Justino? How could they afford that? Her mind was swimming with questions and worries, and her eyes filled with tears. She looked over at Roberto and felt far away from him. He had become quieter and quieter. They rarely laughed and had fun together any more. He was staying late at work more often. She couldn't blame him for wanting to avoid the challenges they were facing, but she needed him more than ever now.

And what about Justino? He went to kindergarten in the morning, and

Grandma picked him up afterward, since Teresa had therapy until noon far away from Justino's school. Grandma brought him home at 1:00 P.M. and stayed with the children until Roberto arrived home at 3:00 or so. Carmen felt as if she hardly saw Justino any more except to send him off in the morning.

"I completely relate to this. Even though I worked in the special education field and had colleagues, no one understood what I was feeling, and I felt completely helpless and alone. It's a devastating feeling."

She pulled the covers over her head and buried her face in the pillow. She wished she had someone to talk to about all this, but it was difficult to talk to her family and friends. They told her that she was overreacting, that the doctors were wrong, that she was spending too much time with Teresa. No one knew what she was going through. She needed advice from her mother, help from her family, and love from her husband. She needed all the

energy she could muster. For the first time, she was going to have to draw a lot more people into her family circle. Would she be able to find people who understood what they were going through—people who could help with Teresa and even give them a break now and then?

Adjusting to Caring for a Child with ASD

The feelings that Carmen and Roberto were experiencing are the feelings of many parents who are adjusting to having a child with ASD. Research has shown what families of children with ASD have been telling us for years: Caring for a child with ASD can be very stressful! But many parents have also told us that it can be rewarding and fulfilling—not in the first few worried, hectic months, perhaps, but after that, as new routines get set, as children start to progress, and as the future becomes brighter.

During the first several months or even years after learning that your child has ASD, it is tempting to put aside your own needs and those of other family members while you focus on your child with ASD. It is, however, very important to take some time to consider the needs of your whole family, including yourself. It's tempting to put yourself at the bottom of the priority list. Don't do it! Taking care of yourself is the only way you'll be able to take care of everyone else. Therefore, it's important that you frequently take stock of how you are doing and take steps to ensure that you are healthy, both physically and mentally.

The prospect of taking care of yourself, your spouse or partner, and your other children may seem overwhelming when you feel that you're devoting every minute of the day to your child with ASD. We won't pretend it will be easy, but our experiences with numerous parents who have faced the same challenges

have taught us some tips for adjusting to having a child with ASD. In every way we can, we try in this chapter to describe some strategies that may make it a little easier to handle all that's on your plate: from the daily management hassles, to the tough balancing act of staying close as a family, to finding some of the rewards and fulfillment that lie along this new path you are taking.

Taking Care of Your Family

Everyone in your family will be affected by the new path that ASD has carved out for you, but the impact does not have to be negative, especially after you've gotten through the initial adjustment period. For most parents, especially during that adjustment period, the biggest impediment to maintaining healthy relationships and keeping the family strong and united seems to be time—time to spend with each other and time to communicate. Of course, finding the same amount of time for your other family members now that you're trying to help a child with ASD is challenging. Fortunately, parents who have been through it have shared ideas that can help.

Fostering Your Marital Relationship¹

Does the challenge of raising a child with ASD have a negative effect on marriage (above and beyond the effects of having a child without special needs)? Not necessarily! In fact, research² based on hundreds of families of children with ASD from early childhood until young adulthood showed that there was *no* difference in divorce rates of couples with and without a young child with ASD. (As the children reached late adolescence and adulthood, couples of children with ASD were somewhat more likely to divorce, but it is unclear why this was the case.)

The added pressures of taking care of a child with ASD often result in less time for your primary (marital or long-term) relationship—time that has already been reduced by the needs of young children. You may feel as if you have no choice here. The needs of your child with ASD may have to come first right now, but if you leave your partner on the sidelines, you're denying yourself a critical member of your social support network. Additionally, managing this huge new challenge outside of the partnership can start to distance the two of you at one of the most significant points in your relationship. A few guidelines are particularly important to follow at this early stage after your child's diagnosis.

¹"Marital relationship" in this chapter refers broadly to your relationship with your partner or significant other, whether you are officially married or not.

²Hartley, S. L., et al. The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449–457, 2010.

Communicate!

Talk to each other. Because you are so caught up in the issues involving your young child with ASD, it is hard to think about, or talk about, anything else.

Roberto felt as if Carmen was living the new life that had been thrust upon them and had completely left the old one. He himself felt caught between two lives. The old one was gone, and a new one, seemingly much less satisfying, was on the horizon—unknown, stressful, and scary. While Carmen was living it, he was only hearing about it—and not much else from his wife. For Carmen, this was all she could think about. She wanted to share it with her husband, but he didn't seem very interested. It made her angry that he was not joining her in all the decision making and stress she now faced, and she felt distant from him in a new way.

It's important to share other parts of your lives in your communications. When you see each other after your separate daily routines, make a point of asking about the other things that matter to each of you: “How was work today?” “What do you think we could do for fun this weekend?” “Do you still have a cold?” “Did you talk to your mother on the phone today? What's new with her?” Really listen, and try to join your partner in his or her life when you talk. Try hard to spend just a few minutes each day together, focused on each other, before launching into the subject of the children.

“Spending a little time focused on each other is crucial! As I reflect on the past, we never did this. Everything was about the kids and their disabilities and therapies. Nothing about us any more, like we didn't matter. At the time I felt that we didn't—nothing was more important than the kids—but in retrospect, you always need to find time for yourself and your relationships with your other children, spouse, and family members. Everyone is important to the family dynamic, and happiness is key.”

Listen

When your partner is talking, listen quietly. Don't interrupt or judge. Try restating what your partner has said to make sure you've understood his or her perspective and feelings. For example, if your partner tells you about a problem he or she experienced that day, refrain from criticizing and telling your partner what to do. Instead, it's more helpful to restate the highlights of your partner's message and offer support, saying something like this: “It sounds like you really had a rough day. You sound tired and upset. How can I help?”

It's very common for parents to have disagreements about their child with ASD. They may have different opinions about the diagnosis, what type of intervention to use, discipline, and expectations. For these kinds of disagreements, the first step is choosing a good time to talk them through, so you can really hear what your partner is thinking. The second step is really listening to the other's point of view and taking it seriously, rather than thinking that your partner doesn't know or understand. For example, if your partner makes a suggestion about a new treatment that you disagree with, try to respond by eliciting more about why your partner thinks it's a good idea, rather than dismissing the idea or criticizing your partner. Listen closely to hear each other's reasoning, and search for a midpoint or convergence between your two views, or another solution that works for both of you. If coming to a decision requires information about your child that one or both of you need, see if you can find a time to sit down together with your service coordinator or a team member to ask questions and gather the information you need. If you are having trouble hearing each other or finding a common ground, see if you can meet with a psychologist or social worker on your child's team to come to a more shared point of view. But before you seek others' help, try hard to hear each other out openly and respectfully.



Helpful Tip

Avoid placing blame at all costs.

It's human nature to try to find someone to blame for your child's diagnosis, for the dreams that you may feel have been dashed, for the sadness you feel right after a diagnosis. *But there is no blame. No one caused this. There was nothing anyone could have done to prevent this. You and your family are the solution, not the problem.* Blaming yourself is destructive and unproductive. Blaming your partner will undermine his or her self-confidence, weaken your shared trust, and lead to feelings of estrangement. You need each other more than ever now. Your partner can be the most helpful person of all in this new challenge. When you start to feel blame or guilt, recognize the feelings and remind yourself that *no one is to blame for autism.*

Show Your Partner That You Care

Showing acceptance of and empathy for your partner's feelings, and expressing interest in what's going on in his or her life, are important ways to show that you care. Dr. John Gottman, a renowned marriage expert, stresses the importance of the small day-to-day interactions that we have with our partners. These everyday exchanges are the foundation on which strong marital relationships are built. See

**Helpful Tip**

If you need reminders of how to communicate in positive ways and show your partner you care in the midst of the stress of this new path, try a simple device we'll be offering at the end of each chapter in Part II (Chapters 4–13). That is, write reminders to yourself to help you remember the importance of nurturing your relationship in these hard times. Write whatever reminders are particularly helpful for you, whether it's "Don't say, 'YOU ALWAYS . . .'" or "Remember to tell her 'I love you' before hanging up the phone" or "Remember to greet him when he first gets home, no matter what." We call these reminders "refrigerator lists," but you can post them wherever you'll see them regularly: on your phone, in a drawer you open every morning to get dressed, in your closet near your clothes, or any other place that works for you.

if you can find some way to do or say things that are thoughtful, caring, and supportive daily. Dr. Gottman's research has shown that these ordinary but loving gestures act as deposits in your "emotional bank account." Having a full emotional bank account can help each of you now, during this ongoing stress, and when inevitable conflicts arise. You have something to draw upon. Take what you need, and deposit as much as you can.

Keep Your Sense of Humor

Marriage experts have long recognized the benefits of maintaining a healthy sense of humor. Laughter reduces stress, feels good, and increases a sense of intimacy. Especially during an argument, humor (as long as it doesn't attack or put the other

person down) can relieve tension and lighten the situation. As silly as it might sound, even watching funny movies together helps bring people together and relieve stress. Seek out ways to laugh. Consider a "Friday Family Comedy Night," when you take turns picking out a comedy film to watch together.

"I personally have found it really easy to find humor in situations that others can find scary or weird about autism with other parents who are going through it with me. Networking with fellow caregivers about the trials and tribulations can often bring not only comfort but much needed humor, and these people are empathetic and not judgmental. (For example, if I want to talk about how my daughter smeared poop on the dog, I think a fellow autism mommy may get that a lot more than a neurotypical mom.)"

Make Time for Your Relationship

Is making time for your relationship easier said than done? Definitely—but it's not impossible. Try to carve out some regular time that is devoted specifically to being (1) together with your partner, (2) free of the distractions of children, and (3) enjoyable for you both. Spending just a few minutes each day involved with each other can really help connect you after a tough day and open you to hearing about each other's lives—both the joys and the sorrows—in a caring, nonjudgmental, and honest way. When friends or family members ask what they can do to help, ask them to come over to give you a little “couple time,” or ask if you can drop the children over for a little while with them. Making time for your relationship involves finding help with the kids that you trust. If there is no one to help, ask your service coordinator or a team member for ideas. In some places, respite care is available for children with ASD, and there are a number of resources you can turn to. We describe these next.

Use Respite Care

Respite care is a term for babysitting or other short-term care provided to an individual with a developmental disability (or other chronic medical condition), so that the family members can get some time away from the daily routines of caring for the individual. Respite care can be very helpful in relieving stress and providing an opportunity to take a break and spend time by yourself, with your partner, or with other family members. It's a time to recharge your batteries, relax, and take care of yourself and the rest of your family. You can find a respite care provider through the National Respite Network and Resource Center (see www.archrespice.org). The website offers a National Respite Locator Service that will help you locate respite care services in your state. Services are provided by trained, sometimes licensed, employees of these agencies. Many programs are provided by local organizations such as churches, school, and other nonprofit organizations. Respite care can be provided in or out of the home. Respite care programs often offer training for friends and family members in how to care for a child with ASD, so you can call upon a friend or relative to care for your child.

In addition to respite care, there are resources to turn to for the occasional night out. Ask people at the local autism association or parent group for references. Ask other parents that you meet about child care. Many parents have experienced, skilled people working with their children with ASD who might provide babysitting for you. If you have no other leads, call a college near you; ask for the psychology, social work, or child development department; and ask if there are students who would be willing to babysit for a child with ASD. Have a prospective sitter come over to play and meet your child ahead of time. See how the student interacts with your child. Ask for references. Then slowly let the student provide some care while you and your partner get some time together.

Leaving your young child with ASD with someone else for a little bit is not neglecting your role as a parent. It provides something positive for your child. First, it gives your son or daughter a refreshed parent. Second, it provides benefits on its own. It is quite important that all children learn to accept care from other adults. It helps them learn that the world is a place to be trusted. It helps them get ready for preschool. It is a growing experience for children and for parents, and it is a superb learning experience for the students involved. Two of us (S. J. R. and G. D.) got into this field through babysitting experiences we had as teenagers. Help others learn about ASD by sharing your child with them.

What about Your Other Children?

Carmen was losing a lot of sleep worrying about whether she was neglecting her other child, Justino. And she missed the time they used to have together before Teresa was born, just the two of them. She had so much fun playing with Justino. He made parenting so rewarding. Now everything she had to give—all her energy and all her time—seemed to go to Teresa. She missed time with Justino, and he was talking about missing time with her. She didn't want him to suffer because of his sister's diagnosis.

Brothers and sisters of children with ASD have special needs. Being sensitive to these needs will help all your children make a positive adjustment. Many studies have documented the concerns of brothers and sisters of children with ASD. Often they feel a sense of loss and loneliness when their parents' attention is consumed by their sibling with ASD. They may also experience feelings of resentment toward their sibling with ASD, and older children will feel guilty about feeling resentful.

Schedule Time to Spend Exclusively with Each of Your Other Children

It helps a sibling to spend some time alone with parents. This special time can be as simple as going to the store, washing the car, having a bath, or reading a book together. Use the time to listen to this child—to hear about friends, school, interests, problems, feelings. Let the sibling know how special he is to you and how much you enjoy time with him. Also, let him know that you know the child with ASD takes a lot of your time and attention, and that the sibling can tell you if he needs some time with you. Younger siblings may not be able to ask for time and attention, but they express it through their behavior or misbehavior (e.g., crying, clinging, developing fears, or misbehaving to get attention). The important thing during these times is for a sibling to feel that this is his special time, when your attention is focused on him.

Teach Skills That Will Help Siblings Interact in Pleasurable Ways with Their Sibling with ASD

Siblings may feel bad or rejected and unloved when their sibling with ASD won't play with them. Fortunately, research has shown that siblings can be taught skills that will help their relationship with the child with ASD. This can be helpful for all of the children. Help each sibling understand that ASD makes it very hard for children to learn to play, and that the sibling with ASD does not know how to play now, but that over time the child will learn. Teach siblings how to give simple instructions that their sibling will follow, how to engage in simple games, and how to reward the child with ASD for appropriate play. Be sure to help the child with ASD follow through. These simple interactions help promote a bond and social relationship between siblings. "Parallel play" activities where the siblings are all playing with similar materials—at the kitchen table with art materials, or puzzles, or snacks, should be encouraged. Be sure to include activities such as swinging outside on swings, playing chase, or watching a DVD together. These activities don't require the child with ASD to share or to engage in complex, back-and-forth interactions.

Talk about It!

Studies have shown that siblings benefit from talking openly and frequently about a child's ASD. A sibling may not understand why the child with ASD does not play and talk with her. When you explain what ASD is and how it affects social and language development and other behavior, the sibling will be less likely to interpret the child's behavior as dislike. As the sibling gets older, her understanding and perspective will become more like yours, with more and more questions and worries, so it is important to have an open line of communication about ASD with your children. Use words and concepts that your children can understand. Provide simple explanations and phrases that a sibling can use to explain ASD to her friends, so she has ways to deal with other people over the ASD-related differences that take the "sting" out of teasing or questions. Model this by letting the sibling hear you explain ASD to others.

Explaining ASD to a sibling will take different forms, depending on the age of the sibling. A preschool-age child won't be able to understand what ASD is, but will notice that a sibling is behaving differently. Elementary-school-age children are likely to be very aware that their sibling is different and to be embarrassed about their sibling's behavior around friends. Talking openly about these differences with your children from the time they are little will enable them to voice their feelings instead of being ashamed of them. If a sibling doesn't want to have friends come over, ask about it. See if there are ways you can help this sibling be more comfortable. Siblings may also worry that ASD is contagious or that they too may develop ASD. Siblings may feel guilty about their negative feelings

toward the child with autism. They can even feel guilty that they don't have autism! Some wonder if they somehow caused their sibling's ASD. Talk openly with your child about these fears and worries so you can provide facts and reassure your child. You will probably have these conversations many times, because it is unlikely that your child will understand everything that you say the first time you explain it. Different questions and concerns will arise over time. Make ASD an open subject in your household. If your child never asks about ASD, it's most likely because it seems to be an unacceptable topic. Bring it up yourself, the sooner the better, and the more frequently the better. Ask your child what scares him about his sibling's ASD, what worries him, what makes him angry, what he thinks about, and how it affects his life.

Some siblings feel they must try to be "perfect" to make up for the child with ASD; they may feel pressure to achieve in academic or sports activities. The pressure may come from inside them, or it might be coming from you. Have your expectations increased for your other children because they do not have a disability? Not having autism does not make them "super-children." Help your child voice these feelings, and listen quietly, as you do with your partner. Acknowledge and restate the feelings rather than rejecting them, interrupting them, or denying them. (Some of them will be hard to hear, so be prepared.)

Your child may have some painful observations about you—about your absorption in the sibling with ASD; about the lack of family time; about your increased expectations for your child for greater maturity, responsibility, child care, household care, or emotional support. Listen! Take it in. Try hard not to deny, not to become defensive, and not to get angry. Listen to what your child is saying; provide the information your child is asking for; correct any misconceptions; and reassure your child of your love, your acceptance of the child's feelings, and your appreciation for the child's honesty and trust in you.

If your child's behavior has changed significantly (acting out, not seeming like herself for a long period, withdrawing from activities and relationships); if your efforts to talk to your child or provide more support are not helping; and if your child's functioning at school, at home, or with friends is suffering—talk to your child's doctor. Signs that a sibling may be having difficulty include these:

- Needing to be perfect
- Eating too little or too much
- Frequent complaints of headaches or stomachaches
- Loss of interest in everyday activities
- Frequent crying or worrying
- Withdrawing from social activities
- Increased aggression
- New problems at school
- Signs of anxiety or depression (see page 41)

Take Advantage of Books and Other Resources Specifically for Siblings

Increasingly, the special needs of siblings of children with ASD and other developmental disabilities are being recognized. Numerous books written about and by siblings, including those with ASD, are available. We've listed some of these at the back of the book (see the "Further Reading" list in the Resources). Also, look for special programs, websites, and workshops for siblings of children with ASD. These programs offer siblings an opportunity to talk with other children who have a sibling with ASD, and especially to share their feelings and concerns with other children who understand the challenges and rewards of having a sibling with ASD. The Sibling Support Project (www.siblingsupport.org) is a national program dedicated to the brothers and sisters of people who have developmental disabilities and other special needs. The project's website offers information about workshops, conferences, publications, and opportunities for siblings to connect with one another. Autism Speaks (www.autismspeaks.org) also lists resources for siblings in the "Family Services" section.

Studies have shown that being a sibling of a child with ASD can have benefits! Siblings often grow up to be people who have insight, empathy, and compassion; are mature, accepting, and self-sufficient; and are loyal toward their siblings with ASD and their families.

Dealing with Your Extended Family: Help or Hindrance?

Extended family members can be among the greatest parts of a support system for a family with a newly diagnosed child with ASD, and they can also be one of the biggest challenges for young parents. If both your and your partner's families are there for you, supporting your concerns, aware of the evaluation process, sharing all the emotions that occur after diagnosis, providing comfort and reassurance—then rejoice! They are a strong part of your support system and will help immensely in the adjustment process. Provide them with all the information that they want and you have. Let them help you. Let them care for your child. Let them join you in appointments, meetings, evaluations, as you and they wish. The more the extended family shares the challenge of autism, provides ongoing love, support, and encouragement for you, and appropriate optimism for your child, the better the adjustment process goes.

However, extended family members go through all the same emotional processes that parents do. They may not want to see the problems your child has and may deny your observations. They may tell you that you're worrying too much, you expect too much, boys don't talk until later, an uncle didn't talk until age 3, or you're spoiling your child and doing too much for him. This makes it harder for you to move ahead, and young parents sometimes move away emotionally from their families during this period to get through it.

If this is happening to you, there are several things you can do. First of all, trust yourself and your partner. You live with your child every day. You are not crazy, you love your child, and your worries are real. Proceed as we have suggested, by calling your doctor. Don't feel guilty about distancing yourselves a little from your family members if you need to get through this. Tell them as much as you can about each step in the process so they know what is going on, but make the decisions you know in your heart are right for you and your family and child.

Second, turn to other people in your support system. Talk to friends and others who are sharing your concern and providing you with emotional support. Lean on them right now, so you don't feel so alone. You need support to get through this period, and the more support a young couple has, the easier the process can be. Third, ask others who are part of the process to talk to members of your extended family. Your service coordinator, a parent from the autism advocacy group, one of your child's therapists or evaluators, or your child's doctor may be very willing to have a family meeting and answer members' questions. It is much easier to have another person providing the information than to do it alone when your family is not "ready" for the diagnosis. Take others up on their offers of help!

Finally, continue as you need to for your partner and your children. Keep your extended family members aware of what is happening. You might provide them with copies of reports that people give to you, treatment plans, home programs. If they sometimes take care of your child, show them how to implement basic treatment routines that help your child. At some point, your family *will* come around to accepting the diagnosis and supporting you. However, family members all have their own timetables of acceptance and have to move at their own pace. Families come around, and seeing a child they love making progress is a big part of what brings them around. Occasionally some family member will not adjust to your child's special needs and may even undermine what you are trying to do. If this happens, it's okay to limit the time your child spends with this person until he or she comes around.

Taking Care of Yourself

Now it's time to talk about you! No time to take care of yourself now that you're devoted to helping your child with ASD? Ask yourself this: If you are tired, preoccupied, and stressed, how can you optimally care for your child—and the rest of your family? Even though you may feel like your needs come last, they can't, or all will suffer. Your needs are as important as your children's and your partner's, and you need to monitor and care for yourself—your physical well-being and your emotional well-being—daily, just as you monitor and care for everyone else, so that you can continue to do so.

Physical Health

We don't have to tell you what you've heard a thousand times before: Physical and emotional health are built upon adequate nutrition, sleep, and exercise, and these are even more important when you are faced with stresses, such as learning that you have a child with ASD. When you're caught up in caring for a child with autism, it's easy to make these fundamental healthy behaviors a low priority. It's easy to forget to eat until going through a fast-food drive-through seems like your only option. It's easy to pretend you can maintain your energy on 5 or 6 hours of sleep a night. And it's easy to forget how good you used to feel after a walk, bike ride, or trip to the gym.

So let's review the fundamentals. You know the importance of good nutrition—whole grains, lots of fruits and vegetables, low-fat milk products, lean meats, poultry, and fish, as well as nuts, seeds, and beans—for protecting you from illness, maximizing energy, and enhancing your mental capacities. How can you manage that for you and your family, when fast food, soda, and snack foods are quick when time is short? Try these ideas:

- Buy and put fresh fruit and ready-to-eat veggies out on a table or counter, to help you and your family learn to turn to fruit instead of rooting around in a cabinet for high-calorie snacks. Substituting fruit and veggies for some of the snacks and cookies doesn't cost any more.
- Try to eat home-cooked meals (not necessarily cooked by you!) as often as you can. Try to find a weekly time to cook, and when you do, make a big stew, or soup, or a big platter of grilled chicken to go in the fridge so you can use it for dinners for a few days. Buy salad ingredients and veggies that are already washed, cut, and ready to use. It may seem more expensive, but you will eat more veggies and end up with less waste (the most expensive food is the food that gets thrown out!).
- When others ask what they can do to help, ask them to make and freeze a healthy dinner for your family. It will make them feel better to be able to contribute, and it will help you with a big and important task—feeding yourself and your family well.

Are you uncomfortable accepting or seeking help from others? Asking for a cooked meal is a good way for you to get used to accepting the help that is offered to you and identifying the sources of support among the people outside your immediate family that you're going to need.

Sleep can feel like a rarer commodity than ever if you're occupied with your child all day and then kept awake by worries at night. Here are a few ideas for better sleep that you probably already know but might need help remembering:

- Consider your bedtime sacred. Go to bed at a reasonable hour, even if you feel that your to-do list is endless.
- Help yourself ease into sleep with things that make you sleepy, not stressed. Don't watch the news in bed, use your computer or phone right before retiring, or try to plan tomorrow's agenda in your head while you lie there. Take a hot bath or shower, read something innocuous, listen to relaxing music, or imagine the most restful moments of your life as you ease yourself into sleep.
- If you're suffering from insomnia, don't wait for weeks to see if it will pass. Talk to your doctor soon! There is much he or she can do to help.
- If your children are sleeping with you and you wish they were not, move them into their own beds. If you need help with this, consult your pediatrician or your child's team. There are also excellent books for parents on helping their children sleep independently and through the night.
- There are excellent self-help books available to you on improving adult sleep.

Consider your own nutrition, sleep, and exercise as part of the treatment for a family with ASD, rather than a luxury for you that you can't afford right now. Not convinced? Check out the list of benefits in the sidebar on the next page. Getting 20–30 minutes of exercise a day can improve your heart, your lungs, your sleep, and your mood. Here are some exercise opportunities that can work for parents with young children at home:

- Regular walks around the neighborhood with your child in a stroller
- Regular trips to the park with two adults—one watching the children and the other getting in a good walk, then switching
- Trading off times and days with your spouse to go for a walk or ride or to a gym or dance class
- Trading child care with friends so you can get in exercise time, maybe even as a couple

"I know I hated taking my daughter to the park. I was so worried about all the stares and questions about her behaviors or peculiar sounds. So I took baby steps to that point. I started with 5-minute stroller walks, then 10, then 15; then we found a nature trail; and finally we could end at the park for a few minutes at the end of our walk. The fresh air was good for all of us, even on days I didn't feel any energy to leave the house."

According to medical research, regular exercise can . . .

- Improve your mood
- Reduce stress
- Boost your confidence
- Prevent heart disease
- Increase your energy level
- Help manage your weight
- Promote better sleep

Research has shown that exercise can also ease depressive feelings and anxiety. One study showed that people reported feeling less tense and had improved energy after only a 10-minute brisk walk!

Emotional Health

Because you now have more responsibilities and challenges, paying attention to your emotional health is more important than ever. Emotional health has many facets: giving yourself time to deal with the emotional impact of your child's diagnosis; cultivating your supports; spirituality; and problem solving. We touch on a few key points here.

Dealing with Grief, Sadness, and Anxiety

Even when you are doing all you can to cope with the challenges of raising a child with ASD, you're likely to find yourself feeling waves of grief and sadness, depression and anxiety.

Grief. During the period after first learning that your child has ASD (or any other chronic medical condition, for that matter), it is not uncommon to experience a period of grieving. All parents form an image of their "imagined" child (often even before birth). But part of the typical parenting process is gradually coming to know and love our children as they are, rather than as we imagined or hoped them to be. The athletic father who imagined playing baseball with his son comes to accept and appreciate the child's emerging preference for music, and the musical mother who dreamed of singing in the choir with her daughter learns to play basketball with her when she shows no interest in music. However, when parents find out that their child has a long-term medical condition, such as ASD, their "imagined child" is changed very suddenly.

As with any other grieving process, it may take time to feel better. And even when the strong feelings of sadness subside over weeks or months, they may

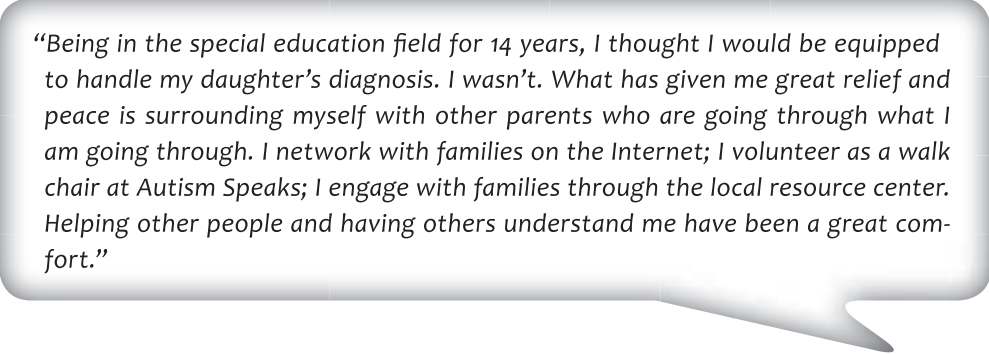
resurface temporarily, especially during events such as birthdays and holidays. Fortunately, these feelings don't supplant the love you feel for your living, breathing child. This is still the same child you loved and treasured before the diagnosis, with unknown potential and a future that has yet to unfold. Your child's learning, success, and happiness in life are as much in your hands as they were before the diagnosis. The future may look different than you had imagined it because your path is a new path, but there is still an unwritten future for your child.

Depression and Anxiety. Grief is a normal condition, and feelings of anger, sadness, depression, and low self-esteem are all part of the grief process. However, for some people, these feelings do not resolve but deepen into chronic depression. According to the National Institute of Mental Health, symptoms of depression can include difficulty concentrating, fatigue, feelings of guilt and hopelessness, insomnia or excessive sleeping, irritability, loss of interest in pleasurable activities, overeating or appetite loss, persistent aches and pains, chronic sadness, and suicidal thoughts. Temporary, mild to moderate depressive symptoms can feel debilitating for the short term while you are adjusting, and you will need the help of friends and family as you go through these first few weeks or months after your child's diagnosis. If, however, you find that your feelings of sadness, irritability, or anxiety are so intense that you cannot cope with daily life—can't get out of bed, do the basics, care for the children, eat or sleep, stop crying, or have images of hurting yourself—tell your partner and your closest friends or family members, and call your doctor and let him or her know what you are experiencing. Your family doctor will be able to help you by providing medication and/or a referral for counseling. These are *very helpful* for dealing with depressive and anxious feelings. Don't resist getting help. It is not a sign of weakness or being crazy. Everyone in your family needs you, and you need to be able to use your own personal resources to cope with your new path. Depression and anxiety can block you from using your own strengths and talents. If your chronic sadness or anxiety has lasted over 6 months, or if you have had thoughts of suicide at any point, we urge you to call your doctor and get help now.

Parents of children with ASD are more likely than other parents to experience anxiety, perhaps because of the worries and the unknowns that come with parenting a child who has this diagnosis. Anxiety has several faces. It may include constant feelings of worry and fear (generalized anxiety); it may trigger repetitive, irrational, upsetting thoughts (obsessions); it may trigger repetitive actions linked to coping with irrational anxiety (compulsions); and it may take the form of panic attacks, which to some people feel like a heart attack. If you find that one or more of these symptoms is becoming part of your life, call your doctor. Anxiety disorders are very treatable with medication and behavioral strategies. Again, both anxiety and depression can prevent you from having the energy and creativity to do what is needed for yourself and your family. By voicing these

feelings to your partner and others closest to you, and getting help from your doctor, you will be much more able to help your child and family.

Building a Strong Social Support Network. Decades of research have shown that one of the most helpful things you can do to combat stress is to build up a strong social network. Building and using a network of family and friends *who genuinely care about you* will help buffer you from the negative effects of stress and give you people to turn to for help and support.



“Being in the special education field for 14 years, I thought I would be equipped to handle my daughter’s diagnosis. I wasn’t. What has given me great relief and peace is surrounding myself with other parents who are going through what I am going through. I network with families on the Internet; I volunteer as a walk chair at Autism Speaks; I engage with families through the local resource center. Helping other people and having others understand me have been a great comfort.”

Ironically, sometimes when a big challenge arises in our lives, we avoid turning toward our friends and family for support. We feel that others may not understand our problems, that they will be judgmental, that we are weak and should be able to take care of our problems by ourselves, or that we will become a burden on others. However, people who love you want to help you. It gives them an opportunity to show you that they love you. They will feel honored that you trust them enough to tell them about your feelings, fears, and problems and to ask for their help. It is a gift to a loved one to confide in him or her and ask for help. Give close friends and family the gift of being included. Few things feel worse than to learn that a person you love dearly has gone through a difficult time and you did not know and did not help. Give those closest to you the opportunity to be part of this new aspect of your life and your feelings. You will not feel so alone, and they will cherish being included.

Cultivate and nurture your circle of friends and family by staying in touch however it works best for you: phone calls, emails, Facebook, or social gatherings. If you find that someone in your inner circle is adding to your stress by being negative, critical, or judgmental, or by refusing to accept the reality of the situation, avoid spending so much time with that person. Turn to the people who help you feel better—by listening and really hearing you without denying or rationalizing, by boosting your confidence, by providing sound advice, by accepting you for who you are, by being trustworthy, and by encouraging you to engage in healthy behavior.

Do you have a strong social support network? Here are some questions

adapted from the RAND Corporation Medical Outcomes Social Support Survey³ that can help you assess your resources. For each question, consider whether this is true all or most of the time, true some of the time, or never true.

- Do you have someone you can count on to listen to you when you need to talk?
- Can you turn to someone to give you good advice in your current situation?
- Do you have someone to confide in or talk to about yourself and your problems?
- Do you have someone with whom you can share your worries and fears?
- Can you turn to someone who shows you love and affection?
- Do you have someone who hugs you?

If the answer was yes, all or most of the time, for many of these questions, then you have a strong social support network. If the answer indicates that you could use more support, keep reading.


Parents of children with ASD often find it extremely helpful to talk to other parents of such children. Other parents who are more experienced can help mentor you and provide invaluable advice and information. Most U.S. states have an

organization called Parent to Parent USA (www.p2pusa.org), which is a national non-profit organization that provides parent-to-parent support and training. Parent to Parent USA is committed to providing emotional and informational support to families of children who have special needs by matching each parent seeking support with an experienced, trained “support parent.”

Another way of finding a support group of parents who are in the same place you are is to visit the Autism Speaks website. Click on the “Resource Guide” section under “Family Services.” Then click on the state you live in on the map that is

provided, and you will find a list of community and support networks, including support groups in your area. Support groups for parents of children with ASD and other special needs are often sponsored by local schools, intervention programs, churches or other religious institutions, and medical institutions. These

³Based on the RAND Medical Outcomes Study Social Support Survey. Available at www.rand.org/health/surveys_tools/mos/mos_socialsupport_survey.html.



Helpful Tip
Building and relying on a network of family, friends, peers, and acquaintances *who genuinely care about you* will help buffer you from the negative effects of stress. If you don't currently have a strong support network or find it is difficult to turn to friends and family at this time, build up a social support network.

are often listed in the newspaper and on the web. Try a computer search with “autism,” “parents,” and the name of your city as keywords; local parent groups are very likely to come up.

If you can't find a support group close to where you live, you can also consider joining an online social network. Autism Speaks offers the Ning Community, which hosts groups and discussion forums, as well as the ability for members to share information with one another within an active community of other parents of children with ASD. Another site sponsored by Autism Speaks is FriendFeed, which sponsors discussions and sharing of information about autism among parents and others concerned about ASD. To get information on both, click on the “About Us” tab on the Autism Speaks home page, and then on “Social Networks.”

The bottom line is this: However you do it, cultivate and nurture a strong social network where you experience a sense of belonging, self-worth, and security, and where you can ask for and get help and support. Don't hesitate to lean on the people who care about you during your time of need. You, your family, and your child with ASD will reap the benefits both now and in the future.



Helpful Tip
The Autism Speaks website offers opportunities for forming a social network with other parents of children with ASD, including the Ning Community and FriendFeed.

Spirituality. Spirituality also improves emotional health and can help people cope with difficult circumstances. In fact, spirituality is now considered by many doctors to be an essential part of medical care. In 2001, it was reported that nearly 50 medical schools offer courses in spirituality and medicine⁴ to new doctors in training. Spiritual practice can take many forms, including attending religious services, praying, meditating, doing yoga, taking a nature walk, singing, reading inspirational books, and listening to music. Because spirituality has been found to improve physical and emotional health, we encourage you to take a moment to identify things or activities in your life that give your life meaning and that provide you with inner strength and comfort. Then consider including spiritual activities with your partner as a regular part of your new journey.

In this chapter, we discussed some of the stresses and strains that come with parenting a child with special needs. We also want to emphasize that recent studies have shown that many families adjust quite well to having a child with special needs. Families are often very resilient and respond with strength and

⁴Anandarajah, G., et al. Spirituality and medical practice: Using HOPE questions as a practical tool for spiritual assessment. *American Family Physician*, 63, 81–89, 2001.

determination. They don't just survive the challenge but actually thrive. A review of studies on family adjustment by Hastings and Taunt⁵ found that parents often had very positive attitudes about their child and the new situation they were facing. Parents reported that they derived pleasure from parenting their child and saw their child with special needs as a great source of joy. Learning to help their child gave them a sense of accomplishment and purpose in life. Parents sometimes reported that their marriage was strengthened. Finally, they said that having a child with special needs had led to a deeper awareness of spirituality and greater perspective on what is important in life. We hope that some of the suggestions in this book will promote resilience in you and your family.

To conclude this section, let's review the suggestions for taking care of your emotional health. These suggestions are based on studies⁶ of parents of children with special needs who have developed effective strategies for coping with stress and have continued to thrive and experience happiness:

- ✓ Identify a specific goal or challenge and start working to achieve it. Research has shown that addressing stress by defining specific challenges and developing a plan for addressing those challenges helps reduce stress and create a sense of confidence and self-esteem. The goal could be as simple as spending 10 minutes of interactive time with each person in your family most days, or getting your child into an intervention program in the next 12 weeks, or finding a babysitter who can give you a night out once or twice a month.
- ✓ Take control. Studies have shown that stress results when you feel your life is unpredictable. You may feel that you have no control over your life right now—that everything depends on someone else—but that's not true. Recognize that you have some control over your life right now. Figuring out what you have control over, setting goals in those areas, and acting on them will not only solve some problems, but will also prevent you from feeling powerless. What if you make a mistake? It's not the end of the world. You can make a different decision. Think it through, look at the results, get some advice from people you trust, and if you made a mistake, then undo it and make a different decision. Mistakes are fixable. Action feels much better than doing nothing, and action leads to outcomes.
- ✓ Take a break. You may feel that you must spend every waking minute focused on your child and others in the family, but taking a moment to

⁵Hastings, R. P., & Taunt, H. M. Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation*, 107(2), 116–127, 2002.

⁶Murphy, N. A., et al. The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, 33, 180–187, 2007. Raina, P., et al. Care-giving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, 4, 1–14, 2004.

focus solely on yourself will help recharge your energy and help you keep perspective. Even if only for a short period, taking time to do the things that give you pleasure and are restorative will reap benefits not only for your emotional health, but for that of others in your family as well.

- ✓ Share caregiving responsibilities with others. Find others who can help with these responsibilities, whether these persons are family members, day care providers, other parents, or friends. Studies have shown that parents whose children participated in a day program that the parents trusted and had confidence in felt happier and were less stressed.
- ✓ Reach out to others. As we have discussed earlier in this chapter, establishing a reliable, loving, accepting group of people who care about you and are willing to listen and offer support is a key to maintaining emotional health. Research has shown that forming relationships with other parents who are experiencing similar stressful situations improves the emotional health of those parents.
- ✓ Pat yourself on the back frequently. Take a moment now and then to think about all you are accomplishing, and give yourself some positive feedback! Pride yourself on reading this book, seeking an evaluation for your child, balancing the needs of your family, and so much more you are doing. You will learn about inner strengths that you and your partner have that you had never seen before. You will experience joys that you never would have shared. You are on a different road from the one you expected, but it is taking you to new opportunities for learning, sharing, and building relationships. Jot down some of the things you are learning from time to time—to see where you have come and how you have grown in the face of stress.

Of course, you will need some new skills to build your sense of control and competence in your new role as a parent of a young child with ASD. We have written this book to provide you with skills that should help you in your new role. We hope the strategies you'll learn in Chapters 4–13 of this book will help you see what a difference you can make to your child with autism by building on the ways you already interact with your child during your typical routines, without having to add hours of work for yourself. Combining this with the experience-backed advice of the professionals who help you with your child's intervention program will give you the skills and confidence you need for the challenges of your daily life.