

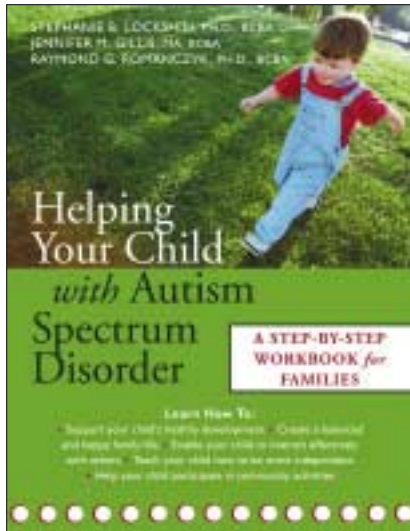
# HELPING YOUR CHILD WITH AUTISM SPECTRUM DISORDER

By Stephanie B. Lockshin, Ph.D., Jennifer M. Gillis, M.A., and  
Raymond Romanczyk, Ph.D.

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## AUTISM IS A FAMILY AFFAIR

*Child development experts help parents of autistic children create a treatment plan that works for the whole family*

Autism spectrum disorders (ASDs) are characterized by severe developmental impairments, including lowered social function and communication skills. In addition to stressing the emotional, financial, and social resources of the family, having a child with autism can create a tug of war between the special needs of the autistic child and the needs of the rest of the family.

With this workbook, parents will learn the latest and most effective ASD management techniques for their children, including the use of the family enhancement treatment model designed by the authors — a program that provides step-by-step guidelines for fostering children’s abilities and enhancing the health of the whole family.

*Helping Your Child With Autism Spectrum Disorder* encourages parents to seek a balance between child-centered and family-centered goals. Parents learn how to assess their children’s needs and create a personalized intervention plan compatible with the family’s resources, goals, and priorities. When accomplished, these behavior goals — like the accomplishment of certain chores or the ability to go with the family on an outing or errands — will benefit both child and family.

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## SUGGESTED INTERVIEW QUESTIONS

- In your book you focus on the needs of children with autism spectrum disorder, but also on the needs of the whole family. Why is that?
- Generally speaking, what are some ASD-specific behaviors or issues that increase stress on families?
- What are some steps that parents can take to minimize the negative effects of ASD on their family?
- You suggest in your book adopting a “family focus on intervention.” Could you explain that term?
- You stress the importance of developing a teamwork mentality. What are the advantages to working this way?
- What suggestion would you make to the parents of a child who complains of feeling ignored in favor of their sibling with ASD?
- Please explain Applied Behavior Analysis, and how it helps teach new skills and reduce problem behaviors in children with ASD.

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## MYTHS & REALITIES

### *The Truth About Raising A Child With ASD*

#### Myth

1. Parents must be perfect.
2. Parents are the only ones who can care for a child with ASD.
3. It is essential to always put the needs of a child with ASD first.
4. All other family members must sacrifice their own needs in order to provide adequate care for a child with ASD.
5. Families in this situation can never approach normal functioning.
6. Superman or Superwoman lives at your address.

#### REALITY

1. Children build tolerance and develop coping skills when their needs are not immediately met.
2. Children can and need to learn to adapt to other caregivers.
3. Well-adjusted families balance the needs of all individuals in the family unit. Not all needs get met all of the time.
4. All family members, including the child with ASD, must compromise in order to ensure that all family members get their needs met much of the time.
5. Despite the emotional, physical, and at times, financial stressors associated with having a family member with a lifelong disability, families can and should strive for normal family life.
6. He or she doesn't.

## **BALANCING CHILD AND FAMILY NEEDS**

**Excerpt from *Helping Your Child With Autism Spectrum Disorder***

At first glance, this chapter might seem to place an added burden on you. You're already doing so much that having to work to keep balance in your family may seem overwhelming. But, if the truth is to be told, your family's efforts to achieve balance are really no different than any other family's efforts to achieve balance. As we've mentioned before, all families must weigh the needs of the many against the needs of the individual. Your family must do this too. You do have a few extra considerations to deal with, but they differ by amount, not type.

Balancing the individual wants and needs of each family member is also critical to the collective health of the family unit. If one family member is unhappy or in distress, all family members will be affected. However, a family that is happy and functioning well does not allow each person to get his or her own way all of the time. Frustration and compromise are a part of belonging to any group, and this reality must be accepted by all family members. As long as the members see the process of compromise as generally consistent, equitable, and fair, they will be willing to give in at least some of the time.

Have any of your children ever complained to you, "You always let . . ."? This complaint usually means that the sibling is feeling frustrated about what he or she sees as the unfairness of different or "special" rules for the child with ASD rather than the extra care required by that child. We all wish children would understand how complex the process of running a family is, but given their age they can only see the world the way they do, and we must be sensitive to their viewpoint (while gently educating them about others' needs and helping them learn to be flexible). As you know, while sibling relations can be difficult in any family, the difficulties can be more complex when one sibling has ASD. You may feel that you are in a position of always defending decisions you believe are in everyone's best interest. Just remember: how a decision is made is just as important as the decision itself.

### **THE NATURE OF CHOICES**

Perhaps there is no greater truism than "Life is all about choices." Choices give us joy and choices give us pain. Because of this, the ability to make good choices is something we all try to instill in our children. We celebrate their good choices and feel pain when they do not choose wisely.

The independence and freedom that make it possible for us to make choices are essential components of well-being and feelings of satisfaction with our life. But for every good thing in life, there is a downside. The adage "Consequences are the children of personal freedom" exemplifies the fact that being free to make choices does not automatically bring happiness, since the consequences of our choices may be unpleasant.

Sometimes we make choices impulsively, based on emotion, need, and immediate circumstance—we simply go with the flow. Impulsive choices can be great fun. Often planned vacations set the stage for such impulsive behavior, and we see no contradiction in planning for the possibility to be spontaneous. Indeed, planned impulsiveness plays an important part in responsible personal

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## BALANCING CHILD AND FAMILY NEEDS

Excerpt from *Helping Your Child With Autism Spectrum Disorder*

(continued)

behavior. We plan to be impulsive, or modulate our impulsiveness, when we go to a party with a designated driver, or buy something we normally wouldn't. We can enjoy the indulgence of treating ourselves to something and acting in a way that is out of character for us. These choices allow us much-needed relief from stress and the constant responsibility of being a mom or dad—of being responsible for inhibiting the impulsive behavior of our children. Although impulsive choices are not necessarily bad choices, they do seem to have a nasty tendency to result in unexpected, and at times unpleasant, consequences. Such negative consequences can be amplified when our decisions affect others. Impulsively buying an expensive outfit for yourself, then feeling guilty and buying toys for your children, and finally agonizing over bill paying at the end of the month because you didn't stick to your budget is just one common example of the unpleasant consequences that can result from impulsive choices.

### MAKING DIFFICULT CHOICES

What are some of the difficult choices and decisions you must make? There are of course the typical choices every family must constantly make about use of resources, work, housing, recreation, schools, and relationships, and the daily mundane choices about what's for dinner and whether there's time to do the laundry, mow the lawn, and help the kids with their homework. In addition to facing this standard set of decisions, parents of children with ASD must deal with some additional issues and problems. Nevertheless, the decision-making tools and processes are the same as they are for other families. Your family needs more complex and specific information than other families do, but the basics remain the same.

No list could encompass all the choices a family will face, but there are core similarities among all families, and we can start there. Some difficult choices your family will face involve the following:

- Social lives of family members.
- Extracurricular activities (amount and type of activities for each child).
- Time allocation among responsibilities. You must come to grips with the concept of “good enough” when you have many responsibilities and limited time. Perfection can be a very harsh goal.
- Family recreation and vacations (who, for how long, where).
- Child care.
- Educational programs for the child with ASD.
- Teaching strategies for the child with ASD.
- Discipline for all children in the family.
- Limit setting for all children in the family.
- Parent involvement in education of all children in the family.
- Organization of day-to-day activities at home (such as schedules, chore assignments, and transportation).

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## BALANCING CHILD AND FAMILY NEEDS

Excerpt from *Helping Your Child With Autism Spectrum Disorder*

(continued)

Because of the number of decisions you need to make every day, you need to have a consistent process for making decisions. If family members view each decision as unique and independent of other decisions, then as a group you will end up painting yourselves into a corner and generate a lot of stress for the whole family. In contrast, the consistent use of guidelines in decision making will help everyone accept the process and get on board. To support this family camaraderie, do what you can to share the process and the rationale, and involve each affected family member.

While not every decision requires a “board meeting,” there are many decisions that will require group effort. These are the decisions that will directly, and potentially negatively, affect another family member—situations where individual needs are in competition.

### COMPETING NEEDS

The problem with trying to consider everyone’s needs is that often the needs of one individual conflict with the needs of another individual. Have you ever had two children playing in ball games scheduled for the same time on opposite sides of town? How do you solve this kind of dilemma? You know that one child or the other will be disappointed; sometimes disappointment is unavoidable. But you can influence how the people involved perceive the disappointment. As we mentioned above, it’s particularly critical for siblings to see your decisions as fair and governed by rules, so you can prevent hurt feelings from carrying over to other situations.

Here’s an example of a worksheet that you can use to give structure to family discussions about difficult decisions. When you use it routinely, all family members soon learn that they have input, that their concerns are heard, and that decisions are complex. It can also pave the way for family members to make concessions about a specific decision because you have a tangible record of the times when each has gotten his or her way. While it may seem strange to keep score like this, it’s actually just a formal way to acknowledge everyone’s past contributions and eliminate a common source of many arguments—the human tendency to remember events selectively.

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