

# 1

## **Seven Messages for Parents of Teens and Young Adults on the Spectrum**

This book is written to help you navigate the sometimes bumpy path of raising a child on the autism spectrum. Many books on the market discuss the initial steps of the long journey you will take guiding your child to adulthood, including your child's initial process of being diagnosed with autism and the process of getting services for your young child or school-age child. This book picks up where those books leave off and covers adolescence and the young adult years (ages 11–21 years).

The chapters herein offer guidance for parents with children all along the spectrum and with differing levels of skills. Throughout, *autism spectrum* or *autism spectrum disorder* (ASD) will be used to refer to a group of developmental differences marked by difficulty with social interaction and communication and by repetitive behaviors and restricted interests. The spectrum includes people with autism and what was formerly known as *Asperger's syndrome*. The terms *lower* and *higher functioning* refer to the degree to which a person can speak and the degree to which the person's intelligence can be measured in a conventional manner. These terms are not meant to convey moral judgment, as those with lower functioning forms of autism can also have considerable talents. I also use different pronouns to refer to your child, including *she* and *he*, but this book is also inclusive of teens and young adults who are transgender or gender fluid.

In writing this book, I want to acknowledge how complicated your children's journey to adulthood can be and how confusing,

rewarding, financially staggering, and bewildering it can be for you as the parent. I also want to acknowledge that although this book provides strategies and tools, there is no one right way to raise your child. You also don't need to feel guilty if you can't follow up on these suggestions. I find that a lot of burdens are placed on parents of teens and young adults with autism, and you are often asked—by teachers, doctors, and other members of the community—to do more, while you may also be holding down one or more jobs, caring for other children or parents, and trying to pay the bills. There is always a limit to what you can do, emotionally, practically, and financially. Find the strategies that work for you, and don't burden yourself with the others. The "right" strategies are also the ones that work for you at that moment of your life. Some issues require immediate attention, and others can't be addressed right now. Realize that raising your child is a process, and part of the work involves recognizing your limitations and forgiving yourself for being human. When the time is right, you'll get to the strategies and stages that work for you and your child. In the process, some things may have to slide. For example, if you're facing high medical and other costs for one child, you may not be able to afford braces for your other one. If you're dealing with trying to get your teen to school, you may not be able to teach her to get dressed on her own. Prioritize what seems important and forgive yourself for not getting to the other tasks right now.

There are some messages that I will return to more than once in the following chapters, as I describe the path of your child's development at a more granular level. I hope that you can internalize these messages as you read and as you continue along your parenting journey. Feel free to come back to these pages any time you need encouragement.

## **MESSAGE #1: CHALLENGING YEARS CAN ALSO BE YEARS OF GROWTH**

Kids do not always present with a linear path of development. Although this is true of all kids, it is particularly true of kids on the autism spectrum. As they grow older, kids with autism may

develop a split between their intellectual skills and their life skills. This might be confusing for you as a parent, as you know in your gut that your child is capable of so much more but doesn't seem to be able to thrive in everyday situations. You aren't wrong. The discrepancy between intellectual and practical skills can be frustrating, as your child might be able to carry out amazing tasks such as multiplying three-digit numbers in her head while not being able to tie her shoes. Just because your child still struggles in certain areas, it doesn't mean she isn't growing. Even struggles represent growth, not stasis, or staying the same.

In recognizing what your child continues to need to work on as she progresses through adolescence, note what she is doing well and the ways she has progressed. It can be difficult to recognize progress when children seem to struggle with such basic skills as using money, taking transportation, or dressing themselves. It can also be tempting to compare your children with neurotypical children (children who aren't on the autism spectrum or who don't present with another form of neurodiversity or difference in a way of functioning and thinking), for whom some of these skills can be so easy. However, resist the temptation to equate difficulty with hopelessness or to lose sight of what your kids are good at. You've likely already measured growth for your child by comparing her with the way she was in previous years instead of comparing her with other children, and that's a great skill to continue. Think about your child's growth relative to what he or she did before. There will be growth, even if there are moments when it seems like your child is moving backward.

## **MESSAGE #2: HONOR THE STRUGGLE**

Just because I'm encouraging you to look at your child's growth in a relative way, it doesn't mean that you shouldn't acknowledge the very real struggles that you and your children are going through. Preadolescence, and adolescence in particular, can be times of great struggle for children on the spectrum and their parents (though not necessarily for everyone). By

suggesting that you honor the struggle, I mean that you should acknowledge how hard this time can be for you and your kids.

Be kind to yourself and them as you go through these difficult times. Recognize that while it isn't always easy, your child's struggle may represent growth. Her willingness to embrace new challenges, become more independent, and engage with others represents growth, even though these efforts might also bring complications. For example, many children with autism become more willing to understand social interactions and complications as they grow older. This represents true growth, but it also means that they also might become very frustrated as they come out of their shell and try to make sense of the world. Seeing struggle as progress may help as you go through these times of readjustment with your child.

### **MESSAGE #3: HONOR YOUR INSTINCTS AS A PARENT**

You know more about your child than so-called experts. You are in the best position to know what your child needs and the people he or she should work with. Although you can call on experts, you will be a vital part of the process of helping your child and figuring out what she needs. Trust yourself. If you sense something isn't working, honor your instinct. If a person you're working with isn't taking the time to know your child and her history, consider switching to someone who will acknowledge your perspective as a parent and work with you as a partner. As more and more professionals are trained to work with autism spectrum disorders, you can find someone who understands the particular struggles and triumphs of a child on the spectrum and those of her family.

### **MESSAGE #4: YOU ARE A PERSON, TOO**

It's easier said than done, but if you are fortunate enough to have a partner, spouse, parent, friend, or trusted babysitter who can help you, call on that person. Carve out time for yourself.

And when you're away from your child, don't spend the time making phone calls on his or her behalf or ruminating about his or her future. Instead, spend the time truly relaxing and being a person, whether that means sitting in a hammock reading or (because it's great to keep a bucket list) skydiving. Many parents are tempted to spend their free time writing their son's IEP (individualized education program) or calling their daughter's ABA (applied behavior analysis) therapist. Don't, if you can possibly manage it. This can be difficult for parents who have to work, not to mention parents who have to work multiple jobs, and those who are parenting solo. The chapters that follow will help you identify resources, many of them free, that can help you.

Surround yourself with people who understand. That means you might decide not to be around families who don't "get" your child. Find people who have children on the spectrum or who are sympathetic to its struggles. You'll feel empowered if you do, and you'll have sources of strength and people to call on in moments of crisis. Mindfulness training can also be a way to relish the present and to step back and see your child—and yourself—in a nonjudgmental way. Chapter 8 includes more details about how to help yourself, and in so doing, help your child.

## **MESSAGE #5: THERE ARE PEOPLE WHO CAN HELP**

One of the most difficult things about parenting a child on the spectrum is that it can be very isolating. If you have a child who tends to throw tantrums or who can be aggressive, it can be hard to find social outlets. As a result, parents might feel that they are locked in their house. However, just as parents need to get out of the house when they can, they also need to find people they trust. The world of autism has changed in recent years so that there are doctors, therapists, and even dentists who are knowledgeable about children on the spectrum and who are set up to help them. You don't need to work with people who don't understand, and you can get the help you need.

Each step of the way, you can find people who understand your child and who won't, for example, gasp when your child has a tantrum in the waiting room or can't floss her own teeth. There are more and more children with special needs and professionals who are trained to help them. Don't settle for good enough. There are people who will not only accept your child but also celebrate his or her strengths. These are the people you should work with and who will make you feel less alone. In addition, there are more and more parents like you, eager to find a world in which people who are not neurotypical can feel comfortable. You are not alone.

### **MESSAGE #6: WE'RE DISCOVERING NEW THINGS EVERY DAY—THERE'S HOPE**

One of the most exciting things about the world of autism spectrum disorders is that researchers and those who provide services are making new discoveries every day. In addition, as more and more kids who were diagnosed with autism as young children enter adulthood and are the beneficiaries of proven, validated treatments, we have a better sense of what they are capable of. There are now better services for young adults on the spectrum, including assistance in the transition to independent living, and there are even employers who understand the benefits of employing people at all levels of the autism spectrum. Kids are being educated in what autism is—there is now even a character on *Sesame Street* with autism—and these kids will bring this understanding with them as they get older. Try not to see your child's situation as static. What he is today is not necessarily what he will be over time.

### **MESSAGE #7: EXIST IN THE MOMENT**

At the same time that you plan for your child's future and work as her advocate, try to exist in the moment. Children on the spectrum have a way of seeing things that few other people

do. Relish their perspective, whether it's spelling words backwards or figuring out how to paint their toenails. Your child is refreshing and able to appreciate the world in a unique way. Perhaps, for example, he loves the way trucks sound or can bounce for an hour without stopping on a trampoline. Take snapshots, both visual and mental, as your kids remind you of what it's like to exist in the moment. Mindfulness techniques, including meditation, can help you slow down and quiet your own thoughts so that you are more present for your child.

## **WHAT'S IN THE REST OF THE BOOK**

The chapters that follow will help you understand the different facets of your child's existence as they move through adolescence and young adulthood, and how you can help him at each stage. Chapter 2 provides an overview of the ways in which autism and adolescence intersect and the struggles and triumphs that many adolescents and young adults on the spectrum experience. Chapters 3, 4, and 5 cover the academic, social, and medical aspects of raising teenagers and young adults with autism, respectively, and each chapter contains stories of real parents and teens on the spectrum, as well as practical parenting strategies that are also recapped at the end of each chapter. (Names of individuals have been changed or removed to protect their confidentiality, and some stories are composites of the experiences of real people.) Chapters 6 and 7 include strategies for how to help your child with self-care and independence and how to help them move toward young adulthood. Chapter 8 gives information and strategies about how you can take care of yourself as a parent—because by taking care of yourself, you will be taking care of your child. In each chapter, I discuss the ways in which your child's development may be affecting you as a parent, because your interactions and experience are vital to the life and experience of your child. I also suggest a few practical things you can do to help your child manage the life changes he or she is going through during adolescence and early adulthood.