

Autism & The Rest of Us

How to Sustain a Healthy, Functional and
Satisfying Relationship with a Person
on the Autism Spectrum

Jeanne Beard

For parents, families, employers, caregivers, teachers and you

www.AutismAndTheRestOfUs.com

AUTISM
&
The Rest of Us

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Satisfying Relationship with a Person
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For Kyle

My life started the day
they put you in my arms.

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Contents

Introduction.....	1
Chapter 1 Ought-ism.....	13
Chapter 2 Life in the Autistic Filing Office	31
Chapter 3 Separating the Person from the “Ism”	45
Chapter 4 The Clash Between Social and Nonsocial Thinking.....	65
Chapter 5 The Seven Hidden Rules of Social Gravity	75
Chapter 6 Funky Social Math: When $1+1=1$	97
Chapter 7 The Big “C” – Communication: Troubles and Tips	111
Chapter 8 What We Don’t Want to Admit About Our Relationships.....	127
Chapter 9 The Feelings We Don’t Dare Express Out Loud.....	155
Chapter 9½ The Hole in My Heart: I Finally Figured Out Why I Am Who I Am	177
Chapter 10 Becoming the Phoenix.....	193
Afterword.....	226

Introduction

Some of the greatest creative minds of all time have been reported to have been autistic. In 2014, *Time Magazine* published a special issue heralding Albert Einstein as a “Person of the Century.” It is believed that Einstein was on the autism spectrum. Other famous notables such as Thomas Jefferson, Charles Darwin, Sir Isaac Newton and Thomas Edison are also believed to have been on the spectrum. Some of the most talented artists who ever lived, the cream of the creative crop—Michelangelo, Mozart, Beethoven, Jane Austen and Hans Christian Andersen—are all thought to have been autistic. Brilliant innovators Jim Henson, Alfred Hitchcock, Bill Gates and Tim Burton also make the list of those with autism.^{1,2} And so does someone I love.

Most people who have not had a reason to learn about autism have no idea what autism is, let alone how to cope effectively. They do not know what to expect when they hear the word *autism*. I see this in the faces of people every time I tell them my son is autistic.

Usually people don’t dare to ask what that means. I think they expect him to be retarded, or nonfunctional, or not able to communicate. The old stereotype of a child sitting in the corner, rocking back and forth, unable to speak, comes to mind. People with no experience with autism often harbor that old stereotype, and that creates an associated stigma. As a result, people on the spectrum often face not only their innate difficulties, but, the stigma that the label evokes in those who are uninformed.

¹ <http://www.asperger-syndrome.me.uk> for a more complete list

² <http://www.babble.com/entertainment/famous-people-with-autism>

People with autism can in many ways look very “typical.” This may be especially true for those over the age of 30 or so, who have always believed they are not on the spectrum, and have learned over the years to act as if they are neurotypical. It may not be until you are in a relationship where the types of challenges that particular individual faces play a role that you begin to see any difficulty at all. This is the more elusive autism of today.

My son is very high functioning; he appears at first to be neurotypical, in spite of the challenges he faces in his own mind and life. He has received extensive, quality intervention, and when he enters a room, no one would detect that he is not just another pain-in-the-butt teenager. My son is bright, talented, good hearted, deeply principled, funny, caring, loving AND autistic. But the world does not always see the remarkable qualities hidden behind the autism. Sometimes, in the fast-paced information onslaught that we experience in the computer age, when his life demands that he perform on cue or to social expectations, the autism shows first, and the rest is lost in translation. That hurts me.

When we are in relationships with people who have autism and we do not know that that they are autistic, we either think

The term **neurotypical** (or NT), an abbreviation of “neurologically typical,” originated in the autistic community as a label for people who are not on the autism spectrum. The term eventually became applied to anyone who does not have atypical neurology.

that they are just “not nice,” or believe they are somehow “screwed up;” we judge or criticize them, feel offended by them, treat them with disdain, or simply avoid them altogether. Understanding more about autism will

help us to recognize more readily when we are dealing with someone on the autism spectrum, and hopefully to develop some compassion. This recognition and compassion will have a two-fold benefit: it will enable us to interact with people on the spectrum more successfully, and it will change the nature of the experience for us.

I can relate to the dilemma of those who are uninformed. Before my son's diagnosis, I was confused and frustrated. I could not make my expectations mesh with my experience. One minute my son seemed like a normal, bright, capable 11-year-old, which led me to expect him to function accordingly, and the next minute he was struggling to tie his shoes! I could not make sense out of these mixed messages; they left me dumbfounded and uncertain about what to do. I did not know what I was experiencing or why, and I certainly did not know how to respond effectively.

As a parent, I did not know when to push through issues and when to back off. I was having little success in accomplishing my parenting goals. To complicate matters, I did not know how to manage my own emotional experience related to these issues. On an emotional level, this struggle created confusion and self-doubt. I did not know where to turn to get my feelings and experiences validated. As a result, sometimes I felt really crazy. I felt emotionally drained and was not sure how to help my son, or how to develop the good, positive, healthy relationship with him that I deeply desired.

The first indication I had that I was dealing with autism in my life was when my son was suddenly diagnosed. It felt as though it had come out of nowhere—I was totally unprepared. My reaction to the doctor's diagnosis of "Asperger's" was fear. I was scared to death and had no idea what to expect for my son's

future. Like any parent, I want the best for my child, but when I heard “on the autistic spectrum,” the future was suddenly in doubt. I did not know if a full life would be possible for him. I freaked out. I promptly set out to find an authority on autism spectrum disorder (ASD).

I looked everywhere for advice on what to do, what to expect, what would happen, and how I could make the most of this new reality to create the best possible outcome for him. The first speaker I ever heard talk about autism said, tongue in cheek,

Beyond being healthy and strong ourselves, the next best strategy for helping those with ASD is to understand autism so that we can develop a relationship that is based on a common language.

that when they diagnose the child, she thought they should also medicate the parent. That gives you an idea of the kind of reaction most parents experience when they find out that their child is on

the spectrum. Because there is still a lot of stigma around the diagnosis, accepting it for your child, spouse or for yourself is often painful and difficult. My hope is that this book will help to reduce the stigma and increase the ease of embracing the diagnosis.

Finally, after several months and failed attempts, I found a therapist who specialized in working with children on the spectrum. He knew what was going on with my child, and that really helped me feel better, because he could help my son cope. Dr. Timothy Wahlberg, clinical director of the Prairie Clinic in Geneva, Illinois, began to explain to me the complicated tangle of issues that those on the spectrum face, the behaviors that arise from those issues, and what these individuals experience.

As I grew in understanding of my child's autism and what he was going through, I began to understand my own experiences as well. But unfortunately, when a family member is diagnosed with autism, all of the focus usually shifts immediately (and often permanently) to that family member, sometimes to the detriment of the other members of the family. There has been very little written on how to cope with our own emotional reaction to the situation, or how it affects those of us who live alongside the individual on the spectrum. This book is intended to fill that gap.

During the process of working with Dr. Wahlberg, I asked him, "Do you have any of this stuff in writing?" because I really wanted to study it. I wanted to understand it, internalize it, and use the knowledge to implement effective changes to improve our situation. He said that he was working on a book, but, as you can imagine, with the demand for therapists with expertise in this area, his time was limited. At that point, I was honored to become part of the writing team for his book, entitled *Finding the Gray: Understanding and Thriving in the Black and White World of Autism and Asperger's*. It is an excellent resource for understanding ASD and the resulting behavior, and for learning some basic behavior modification. After we completed the book, Dr. Wahlberg told me that he felt I had earned a master's degree in autism because of the level of understanding I was able to develop as he shared his knowledge with me during the writing process. I am deeply grateful for the opportunity to be tutored and trained firsthand by someone with his level of clinical experience and expertise. That process has changed my family's lives.

Autism & the Rest of Us is based on my own life experience living with individuals with autism, combined with the information that I learned from Dr. Wahlberg. I hope that

this amalgamation of clinically based expertise and life-long experience will benefit you. My goal is to package this information for parents, therapists, educators, bosses, and coworkers. It is intended for medical professionals, as well as for people on the street; for anybody who desires to understand more completely what is going on with the autistic people in their world so they can create more fulfilling and successful relationships, and develop more peace in their own lives.

I am not a therapist, a diagnostician or a behavior modification specialist (although I often wish I were all three and a magician to boot). I am an experientialist. I have been studying autism 24/7 for 50 years. I am a mother, a daughter, a

Those who are indirectly affected by living with, working with, or relating to someone with ASD—the rest of us—don't have a formal title.

friend and possibly even an ex-wife of someone on the spectrum. I am a veteran of 30 years of family therapy; I have invested those years in study, practice, self-

examination, patience, personal therapy, couples therapy, talking with others and reading countless books to gain the insights I am sharing with you. My understanding has grown over years of painstakingly putting the pieces together.

Today, I can see the thread of having lived with autism all through my life and how that has shaped me as a person. Today, all those pieces fit together to paint a much clearer picture for me of why I am who I am. I hope this book will help you to identify how you may have been influenced by a relationship with someone who has autism, and also provide you some insights and techniques for sustaining healthy, functional and satisfying relationships with those in your life who are on the spectrum.

This book might have been titled *Asperger's & the Rest of Us*, but in May of 2013, when the DSM-V (the diagnostic guideline for medical professionals and therapists) was published, the criteria were changed, and the diagnosis of Asperger disorder was eliminated. Those with Asperger's were moved under the general umbrella of autism spectrum disorder. Anyone who was at one time diagnosed with Asperger syndrome is now simply said to have autism. In addition to being called autistic, those who were diagnosed with what used to be called Asperger syndrome are said to be "on the autism spectrum" (which I take the liberty of shortening to "on the spectrum" in this book), have ASD, or are considered to have "high-functioning autism." Those terms are interchangeable.

Those who are indirectly affected by living with, working with, or relating to someone with ASD—*the rest of us*—don't have a formal title. The family, friends, coworkers, service providers, therapists and professionals who deal with those on the spectrum also face myriad challenges in relationship to autism, many of which impact us emotionally or psychologically. For those closest family and friends, many of these challenges are similar to the dilemmas found in a relationship with someone with an addiction. In the vein of the codependent, maybe we should coin the phrase "co-autistic" as a descriptor because of our similar relationship to someone who is emotionally unavailable. Whatever you call us, this book is about, and for, us.

My heart goes out to the people who are dealing with more severely affected individuals on the spectrum, such as those with limited language abilities, lower IQs, or other issues so devastating that the person can never be left alone and will never function independently. It can be a very desperate, frustrating and difficult situation to face, and in the end, many families

in this situation find that institutionalizing their loved one is the only reasonable method for survival, for both their loved one and themselves. I get it. I am not ignoring the existence of those folks, but this book primarily focuses on where my experience lies, coping with high-functioning autism, coping with individuals with autism who are living, or trying to learn to live, in the mainstream social world.

Many of us want to improve the success of our relationships with these individuals, but we don't know how because our relationship with someone on the spectrum doesn't follow the same rules as our relationship with someone who is neurotypical. It is very complicated, confusing, exhausting and often emotionally painful for the rest of us to deal with the issues experienced in the relationship. We often feel that we are forced to twist ourselves into pretzels in order to work with our autistic loved ones to develop more successful relationships.

This book helps to give the reader a road map for success by addressing the following important questions:

- How does it feel for us to be in the relationship?
- What the heck is going on with them? And why does this upset us?
- Why don't they understand what we are explaining to them?
- Why can't they follow through on things?
- How do we make this relationship more successful at achieving its purpose?
- How do we create a sustainable long-term relationship with someone with ASD?
- What can we do for ourselves to be more effective, happier and more fulfilled?
- Where are the pitfalls that trap us unexpectedly?

- How do we cope with the lack of reciprocity in our relationships?
- How do we go about creating the joy that we seek in all of our relationships?
- What is the value of the relationship in our life?
- What do we have to give up that is important in order to sustain this relationship, and are we willing to make that sacrifice?
- How did we get here to begin with (and possibly, how do we get out of here)?

In order to facilitate the discussion of these topics, generalities have to be identified, but I want to be really careful that I am not over simplifying or making erroneous assumptions. It is always my intention to speak with total respect for every individual. I certainly do not want to generalize or lump people together in careless ways; every person on the spectrum has a unique personality and a unique presentation of the autism spectrum disorder. I have heard it said that, “if you have seen one person with autism, you have seen one person with autism!” This comment implies that no two individuals are alike. However, identifying and describing some characterizations gives us a basis for a conversation, and that is the spirit in which I am making the generalizations.

No matter what I say about the commonalities, the likenesses or the trends, generalizations never apply to everyone; you cannot pigeonhole someone on the spectrum any more than you can pigeonhole someone who is not on the spectrum. If what I say doesn't apply to your loved one in particular, try to look for the principle being described and see if it does play a role in some way. If the person you are thinking of, the person you care about, the person with whom you are trying to

build a better working relationship does not fit something I am describing or does not fit it exactly, that does not disqualify that individual from being autistic. It just means that the attribute does not apply to that person. So take what fits and let go of the rest. There is nothing that applies unilaterally to everyone.

I am also adamant about avoiding blame, criticism or the use of terms like “wrong” or “bad” about someone on the spectrum. I have nothing but respect for people struggling with autism; I know their world is not easy and that they do struggle. Judging, criticizing or blaming them is certainly inappropriate. It is unfair. It is emotionally and spiritually ill-advised. It is just not right.

This book is not a replacement for therapy. Actually, one of its best uses might be as a template for developing therapy,

*Someone needs to talk about “us.”
What is **our** experience, and what
do **we** do with ourselves? What part
do **we** play in our own situation?*

a way to help your therapist understand more about autism and your experience with it. I advocate therapy as an avenue for behavior

modification for those on the spectrum and also for those not on the spectrum—the rest of us. Being emotionally healthy and possessing self-knowledge creates a strong foundation from which to operate in building any relationship, and it is even more crucial when the relationship you seek is with someone on the spectrum. We all need a little bit of therapy now and then.

Beyond being healthy and strong ourselves, the next best strategy is to learn to understand people with autism so that we can develop a relationship that is based on a common language. When we improve our understanding and our communication, we are likely to get better outcomes. I cannot help you magically change your loved one, parent, relative, friend, student,

coworker, patient or other person to behave the way you want, and I am not sure I would want to if I could. That is not what I am here to do. My mission here is to help create some understanding and to keep the focus on *us*. There are already plenty of books about “them.” Someone needs to talk about “us.” What is *our* experience, and what do *we* do with ourselves? What part do *we* play in our own situation?

We need to validate our own and each other’s experience. We need to share and compare notes and build a wiki of experience. Nothing like that is currently available. It is my mission to provide a platform to foster understanding, insight and assistance that will promote healthy relationships and support for the rest of us. At the same time, I hope to encourage the acceptance of people with autism spectrum disorder on their own terms—in a way that honors who they are and how they are different without compromising our own needs in the process. This might be a very delicate balance to achieve.

Relationships with people on the spectrum can be a lot of work. They can be aggravating and frustrating and confusing, especially when you do not understand the autism. All indications are that the occurrence of autism is only going to increase in the future. Let’s work together to help educate the world and find strategies to cope with this ongoing “stuff” — whether it is the challenges we face because of the extra layers of effort, the emotional difficulties, the confusion or whatever else it is we are experiencing. I want to find strategies for living peacefully and building a better world for all of us—those on the spectrum and the rest of us!

This is really a request to begin a dialog. I invite anyone who is interested in this topic to write to me, to communicate with me, and to share with me what is going on in your world. I

welcome the input. How are you feeling about having autism in your life? How are you coping? What are you doing to improve the situation for yourself and for your autistic loved one, coworker, or any person whom you meet? I really want to create a library of success stories. You'll find my email address and website in the *About the Author* page of this book.



In this Chapter

- Learn why everyone needs to recognize and understand autism
- Begin to accept and respond to those who are autistic in a healthy, respectful way
- Appreciate the impact that living with autism has on the rest of us

1

Ought-ism

Autism and the Rest of Us

One out of every 68 children is believed to be on the autism spectrum, a phenomenon that occurs five times more commonly in males than in females.³ Let's do the math: If one out of every 68 children is on the spectrum, it then follows that one in 68 people of all ages is on the spectrum. If we extrapolate that to the total population of the United States, 311 million Americans, we are talking about roughly 4.5 million people who are on the spectrum. This is a new minority, not just a handful of individuals, and the numbers will probably only continue to increase.

An even more staggering fact than the 4.5 million people in the United States with autism today is that there are (at a minimum) an average of three or four others who love each one of those autistic people, who care about them in a personal or intimate way, and a very modest estimate of another five or six

³ Center for Disease Control, 2014

who work with them, and who need to deal with them on a day-to-day basis. That means there are at least ten people who are invested in the lives of every individual on the spectrum. Forty-five million or more Americans deal with autism spectrum disorder on a personal level today. They are the people for whom I write this book—they comprise “the rest of us.”

The rest of us are the people who are in a relationship with someone on the spectrum, whether it’s a family relationship such as a parent, spouse, sibling or child, or a less intimate relationship such as a boss or coworker, or a patient if you are a therapist or doctor, or a student if you are a teacher. Or perhaps, the relationship is a casual interaction, like the one you might have with the kid who bags your groceries at your local supermarket, or the teen who sells French fries at the McDonald’s on the corner. The truth is that we are all probably in relationships with people on the spectrum, whether we know it or not, and as time goes on, we will probably encounter more and more relationships and interactions with people known to have ASD as more individuals discover they are considered on the spectrum. At some point, I would venture to guess that almost everyone in the United States, and probably in mainstream cultures globally, is going to find that someone they love, or want and need to relate to, is autistic.

This means that, as a society, we need to understand more about autism and the experience of the person who has it. We also need to understand how those of us without autism will need to adapt if we are to effectively and happily live and work in a culture that encompasses this growing minority. Embracing this new minority will require more from us than settling for passive coexistence. Creating healthy and sustainable relationships with people on the autism spectrum will require active participation from each of us.

The person on the spectrum faces tremendous challenges in life. Those of us surrounding that person also face significant new challenges related to dealing with autism, an experience that can be very confusing and painful for us, as well. We struggle when they struggle. We hurt when they hurt. We can be on the receiving end of some behaviors that cause us great consternation, worry and pain. The rest of us need to understand why we are experiencing what we are experiencing. We need some clarity about what is happening in our lives and in our relationships. We need our experience validated since our reality can be challenged at times. We need compassion and understanding for the extra challenges we face, and justification for the additional effort we expend. We deserve to have some attention paid to our experience of the relationship, but we also need to learn how to adjust ourselves so we can manage the situation effectively, or, at the very least, minimize our own difficulties. The rest of us are a key factor in the burgeoning autism equation, too!

Sustaining a quality relationship with someone on the spectrum, regardless of whether that relationship is personal, educational or professional, requires conscious, ongoing and intentional effort. Often our social sensibilities are offended by the behaviors, mannerisms, communication, attitudes and choices of those with ASD. These relationships can be extremely frustrating, so much so that the experience can be downright aggravating at times, even when you have the best of intentions and the most loving of hearts. Furthermore, it can be incredibly painful to love people who are relentlessly struggling to find their way in life. This is especially true if you are a parent or spouse of someone on the spectrum.

While there are many books and strategies focusing on behavior modification and/or working with those on the

spectrum to change their behavior, there is very little quality information describing the effect that living and working with autism has on the rest of us. There is also inadequate coping advice available that addresses our emotional situation and needs, and supports us in creating viable, sustainable, productive and even pleasant relationships with people with ASD. Accomplishing just that is the task set before the rest of us. Remember, this book is not about *them*—this book is about *us*.

Accepting Today's Reality

There is so much controversy and debate about autism. What is it? What causes it? How do we treat it? Can we cure it? How do we cure it? The questions are endless. Although the diagnostic criteria are relatively simple, the interpretation of “the spectrum” is so broad that nobody really has a definitive definition of what it looks like; autism exhibits so many different forms in different people. This book intentionally sidesteps all the controversy and the debate about how and why. Regardless of the cause or the curability, living with autism is today's reality for many of us. Focusing on the cause and cure is like trying to identify the source of the fire while the building is still burning down; there is so much more obvious “stuff” to handle to put out today's fires. While others research the cause, this book is focused on building tools for better living and better personal and cultural understanding *today*.

Whether autism is something that really needs to be cured is in doubt. “Curing” is for a disease and autism is not a disease. Autism is a life-long journey—a different way of relating to the world, not a disease, and it is unlikely that there will ever be a magic pill that is going to get rid of it. Autism spectrum disorder needs to be understood, certainly, but incorporating and respecting individuals who are living with it into our society

seems much more appropriate and achievable than finding a magic bullet to obliterate it. Acceptance of the “as is” situation is the beginning of the answer. Our efforts are better spent finding ways to sustain relationships with, and improve the life experience of both our loved ones on the spectrum and ourselves as well. In my estimation, the quest for the cause and cure pales in importance to the task at hand—accepting autism and applying concerted effort to make the most of the reality we are faced with today. Take heart, this reality may not be as bleak as it may at first seem; there is so much hope.

Autism spectrum disorder can basically be defined as another way of processing information, something akin to left-handedness. Autism is a different way of processing incoming data, just like using your non-dominant hand is a different way of holding a fork. The problem is that, unlike forks, our social expectations are not ambidextrous—they cannot be instantly adapted to autistic thinking. That can put people on the spectrum at a disadvantage, and can make them less effective or appear weird compared to those whose automatic response is neurotypical (not autistic). But that does not make them wrong, or bad, or broken, or sick. They are just different than what we consider “typical.”

As the speed of information increases, and survival in the world demands more complicated and increased multitasking, those on the spectrum may look increasingly odd when they struggle to process and mentally perform quickly and nimbly. This new high standard of mental flexibility, agility and speed may enhance the appearance that the number of people affected is skyrocketing.

People who lived in 1900 didn’t face the same processing challenges. The problem is not only about the speed at which

information is delivered, but also about the enormous volume of data that barrages each of us every day via television, the Internet, and hand-held devices like cell phones and tablets. Today, those who struggle with rapid information processing and information delivery (I am referring to general information

The lines can be very blurry between who is and who is not on the spectrum, which can cause us to doubt the presence of autism, or even cause self-doubt if our perception is challenged.

processing, not the savant-like information recall on a special-focus topic that the movie *Rainman* made famous) stand out the same way a left-handed person would stand out if only right-handed gloves

were manufactured. Left-handed people would be required to force fit a right-handed glove in order to use their dominant hand for a task.

I earn my living in sales. When I started working 25 years ago, there were no fax machines. I would write a letter or sales quotation and mail it, and a few days later the letter was received. Then the facsimile machine came into vogue. I could type a quote, then fax it, and my client would receive his quote later that day or maybe the next day, but it was a vast improvement, from a time standpoint, over regular mail. With the advent of email, my client expected to receive the quote within a few hours.

Today, when I am on the phone with clients, they expect the quote to be delivered to their email inboxes before we even hang up the phone. Faster computer speed and the growing demand for immediate information has increased everyone's expectation of how quickly information should be delivered. This trend is causing people who process information differently (slower

or through different avenues) to stand out and look different. Voila! Autism appears to be on the increase.

Whether or not the rise in the actual incidence of autism is occurring, the struggle for the individual on the spectrum to adapt, and thus appear more neurotypical, is much more difficult and more intense today than before the demand for instantaneous information was so prevalent. The world has never put people on the spectrum in a position to be a left-handed person in a right-handed world, so to speak, like it does today. As new technology continues to increase the speed of delivery of information, and (bonus!) we're better at recognizing that difference in people, we are seeing an increase in the diagnosis called autism.

Today's Clearer Picture

Today, in addition to living in an environment that is more dramatically showing autism in contrast to what is neurotypical, we are getting a clearer picture of who is on the spectrum and who is not because diagnosticians are beginning to recognize and diagnose ASD more effectively than ever before. Autism, which in the past may have been misdiagnosed as social anxiety, attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), bipolar disorder, depression, anxiety or some other condition is now being identified and treated appropriately on a more regular basis, although there is still plenty of room for improvement in this area.

People on the spectrum are often still misdiagnosed and treated for some other condition before they are correctly diagnosed with autism. That may change as the general knowledge of, and academic education about autistic spectrum disorder increases. Theoretically, the diagnosis of ASD may encompass a percentage of every other psychological

diagnostic category to create one new, much larger group under the heading ASD.

Unfortunately, as a society we still have a long way to go in terms of providing adequate training for our professionals. I recently spoke to a woman who had just completed her master's degree in psychology; she told me she knew almost nothing about autism. I was astonished, since I thought it would be one of the hottest topics in the psychology world today. She said that there had been so many other topics for them to study that autism spectrum disorder was barely covered.

Clinical therapists aren't the only professionals who lack adequate training about autism. Many special education professionals, social workers, and other individuals who act as the primary contacts for families with special needs children in our school systems probably have little or no training in the area of autism. One expert in the field told me that it is possible to become a certified special education teacher and have had little exposure to autism. Oh, my!

Pretending to Be Normal

Before clinicians began to recognize high-functioning autism effectively, lacking any other explanation for their difficulties, many of those who today would be diagnosed with autism “pretended to be normal.” Liane Holliday Willey coined this important and descriptive phrase in her book, *Pretending to be Normal*, which chronicles the story of her own Asperger journey. These individuals varied in their ability to adapt and function—instead they lived “quirky” lives, or they became anxious and depressed, were misdiagnosed and ineffectively treated, or developed some other psychological (or possibly even physical) malady.

Pretending to be normal is an important concept to understand when dealing with someone on the spectrum

because when it is employed as a survival skill, it can lull the rest of us into a false sense of “normalcy,” and leave us thinking and feeling that the person on the spectrum is on the same page as we are, and that may not be true. This is not a situation where these individuals are intentionally defrauding us; in fact, they are doing the very best they can to manage and fit into the situation they are facing, which is what we want them to do. Developing their ability to pretend to be normal helps those with autism function in our society by allowing them to fly under the radar of the rest of the world. When those with autism pretend to be normal, it contributes to the confusion of the rest of us. The lines can be very blurry between who is and who is not on the spectrum, which can cause us to doubt the presence of autism, or even cause self-doubt if our perception is challenged. Pretending to be normal explains so much behavior that appears to be unaffected by ASD.

When individuals on the spectrum pretend to be normal, they are attempting to force fit themselves into our culture. But, at what cost? Pretending to be normal usually catches up with them, possibly causing more problems in the long run. With more understanding, hopefully in the future, people with ASD can openly be themselves and be understood.

Autism is Elusive and Confusing, Even to Professionals

Autism is confusing. There is no “one size fits all.” There is no pure symptomology. Often there are no outward physical signs, or if there are, they are subtle. In addition to being affected in different ways, every individual with autism also has a personality, and personality is a whole other dimension that impacts every one of the areas of difficulty for someone on the spectrum. Some people with autism struggle with a range of issues from sensory and functional to social; some people only

face a few issues. Some people have intermittent difficulty with a specific issue, struggling at some times and not at other times. Whether or not the individual wrestles with an issue can change from day to day, or may be based on the context of the situation.

When autistic behaviors come and go, it can cause doubt about the validity of autism in the mind of someone who is observing them. The experience is similar to trying to see something in the shadows. One minute you are sure you can see it and the next you wonder if your eyes were playing tricks on you. I frequently felt that I was crazy or making it all up, especially when dealing with an adult who appeared quite neurotypical and functional so much of the time.

The “yes/no” controversy has existed for me in every relationship I have had with someone on the spectrum. I specifically remember when my son was first diagnosed. I must have asked the therapist, who was an expert in treating spectrum disorder, every week for six months, “are you *sure* he is on the spectrum?” I was suspicious that my son’s bad behavior might be a ploy to get away with something, which is the idea my hard-line friends and family were constantly pressuring me to believe, even though I always knew in my gut that something else was going on. I had to fight off my own doubt, which resulted from ignorance, and the pressure from the ignorance of uninformed people around me.

The elusive nature of autism is greatly complicated by the fact that so many people with autism look normal in so many ways. They *are* normal in so many ways. If you lined up 20 kids, three of whom were left-handed and the rest were not, would you be able to tell who was and who was not left-handed? Probably not, unless you ask them to complete a task—the execution of the task would tell the story. The same is true with

autism. In the general population, you may be able to experience many encounters with someone on the spectrum who seems neurotypical, but when you put that person in a certain situation and ask him to complete a certain task, or when you grow into a relationship with the person that requires more complicated inter-dependence such as marriage, you may be able to see the autism that was previously hidden begin to surface.

As relationships become more complicated, the social disability aspect of autism becomes more apparent. One psychiatrist told me that the reason my son's ASD wasn't diagnosed sooner was because it is not until children reach middle school that relationships and social information become complicated enough to be able to see the issues arise. Prior to that, children's relationships are considerably more simple and straightforward, and so they do not provide a background

...there is a distinction between the person and the autism...

against which the autism can be recognized. This is one factor in why so many women marry men on the

spectrum. They don't see the autism until the relationship is more complicated, as it becomes when you get married and now live and work alongside your partner.

Often, extended family members and friends do not see the autism either. Women I interviewed who are married to men on the spectrum frequently report that their parents or siblings think their husbands are simply not nice people. The family does not see the autism. They are not in a daily relationship with the person in a way that the autism becomes clear; all they experience is the social dysfunction or rudeness and they attribute that to the poor character of the individual. These extended family members react badly to the nonsocial behaviors

of the spouse. The family may characterize the situation as feeling that they have to walk on eggshells around the spouse to keep the peace. They may just avoid contact, or they may complain and be critical when they experience the behavior that is offensive, especially if they don't like the way their loved one is being treated. Most of the time, family and close friends do not understand why their daughter, sister or friend entered into the relationship in the first place.

People with children on the spectrum experience something very similar when they go out to a restaurant or a store, and their child, for whatever reason, has a meltdown. I am a veteran of that campaign! I was the target of so many dirty looks since the other patrons in the restaurant were totally unaware that my son was on the spectrum. All they knew was that my child was running around the table, and that was unacceptable. It is hard to be in a situation when you are parenting a child you can't console (or control) and other people do not understand. You can bet you are being sized up as a lousy parent. Even our own families often blame us and accuse us of simply being poor disciplinarians. Something happens that is unacceptable and instantly we are branded bad parents—unable to manage our children.

The Excuse Myth—Seems Like Everybody Has Autism These Days!

One of my most successful friends, a very intelligent, worldly man and an accomplished attorney, quipped that “everyone has autism these days,” implying that he had encountered it in his work as a reason to legitimize and explain socially unacceptable behavior. Our ensuing conversation brought to light the fact that many people do not understand autism and are not sure how it influences behavior. They do not see that there is a distinction between the person and the autism, and they cannot

separate the two. So they question the validity of using the condition as justification for behavior. They struggle with what I have begun to call the “excuse myth.”

Believers in the excuse myth are of the opinion that autism is being used as an excuse not to do the hard work of conforming, fitting in, and following the rules. It is a certain type of prejudice that harbors the belief that people on the spectrum can handle life just like everyone else if they just try hard enough; if they do not try hard enough, they are lazy and they use the autism as an excuse not to make the effort. The ancillary belief to the excuse myth is that tough love is the cure.

Validity of the ASD diagnosis has even made its way into pop culture. In the movie *P.S. I Love You*, Harry Connick, Jr.’s character, who has high-functioning autism, jokes that rudeness is now a “disease” and you can take a pill for it. That may be funny, but it also wrongly minimizes and creates doubt about the legitimate issues of those with ASD.

Resolving the excuse myth, and believing that autism is real and legitimately influences behavior, is an important issue we need to settle for ourselves before we can make progress in embracing the autistic community in our culture. Once the general public understands and believes that autism is real, we can begin to make appropriate accommodations balanced by realistic expectations of someone on the spectrum. We each need to decide for ourselves if we believe in autism or “ought-ism.”

Is it Autism—or *Ought-ism*?

Because they don’t usually display easily visible or recognizable handicaps like someone in a wheelchair, people with ASD are often viewed without recognition of or regard for their legitimate difficulties. In our social world, there is an unconscious and unwritten set of expectations that we

all deal with, but those on the spectrum typically struggle to understand. These are the “oughts” in life. Many people believe the notion that those on the spectrum “ought” to try harder, “ought” to conform more, “ought” to understand the social norms, and “ought” to behave like everyone else. They turn autism into “ought-ism” and deliver tough love and disapproval when those on the spectrum are unable to live within social norms, or don’t perform to popular expectations.

This is especially true in the areas where the autistic person’s lack of social understanding causes an inability to fit in and be “nice,” or to perform to standard social expectations. For

Many believe that those on the spectrum “ought” to try harder, “ought” to conform more, “ought” to understand the social norms, and “ought” to behave like everyone else. They turn autism into “ought-ism.”

example, one family member of mine harshly criticizes my son for not writing thank-you notes, and me for the way I raise him. I have tried to get him to write thank-you

notes, ad nauseam, but it’s a nightmare. Unless you have sat for hours with a child who would rather bite off his finger than use it to write a thank-you note, you have no idea of the difficulty involved. It’s a fight just to get him to fill out a simple multiple-choice work sheet for school! Getting him to draft and produce a handwritten note is, as the saying goes, like trying to nail Jell-O to a tree. I have fought that fight, and the autism won.

At some point, letting go of the battle is a self-preservation strategy for the rest of us—we need to pick our battles so we have the strength to keep fighting in areas that are critical. A more complete discussion of autism as a social disability is the subject of a later chapter in this book.

How Do We Respond Personally/Individually?

So, what is being asked of each of us individually? What can we do on our own to create a healthy, satisfying and sustainable relationship with someone on the spectrum? This is a big call to action, but if we each start with making a decision that there is a reason to educate ourselves, that acts as a good first step. Beyond that, we must truly accept that autism is a legitimate issue, and learn to understand the experience of the person on the spectrum. This goes a long way toward building a better relationship.

We need to make adjustments to our expectations and practice patience. We need to learn to communicate in a way that enables those on the spectrum to really absorb and process the information we present to them. We need to consciously bridge the gap between us, appreciate the positives in the relationship, and tap into our compassion when the autism surfaces or gets in the way.

We also need to work on ourselves. The best relationship partner is an emotionally healthy one. We need to know ourselves and our limitations. We need to practice self-responsibility and self-care. We need to seek out the personal and professional support available to us in areas in which we struggle. Most of all, we need to hold a hopeful vision of a better future for all of us—those with autism, and the rest of us. If that feels too overwhelming, I get it! Boiled down to two paragraphs it appears a daunting task. Take heart—it is not only doable, it is essential, and this book will help you with the journey. We are all in this together.

How Do We Respond as a Society?

In the United States, there are between 1.6 and 2.8 million people who require wheelchairs, depending on which source you

quote. Either way, there are two to three times more people on the spectrum than in wheelchairs—*two to three times more people, and growing*, and look at the accommodations that we make for the wheelchair minority! Every public building you enter, every parking lot you drive into, every bathroom you visit—everywhere you go in the U.S., there are accommodations for people in wheelchairs who have undeniable physical handicaps—undeniable because we can see them.

Currently, any public accommodations for those on the spectrum are limited to the educational environment, and implementing those is a tedious and difficult process at best. Unfortunately, there are still educators who are skeptical about autism and who believe that their autistic students just need to try harder, focus more and conform better. The excuse myth is alive and well in the public school system.

As a society, we need to make some changes. It is up to the population as a whole to create the understanding and the kind of accommodations that people on the spectrum need. Remember, there are three times as many people on the spectrum as those in wheelchairs, and yet there are zero public accommodations for them. Their disability is often invisible, and at present, frequently misunderstood or simply not on the radar of the general population.

So, what can we do? One simple idea is that people on the spectrum, who struggle with sensory overload, would like to find a quiet place to think, a quiet place to collect themselves—a dark room, a room where they would be able to manage their sensory intake. Perhaps a place to do some physical activity that might help them process their day and be able to absorb their experiences and return to a public venue refreshed and ready for new information. Maybe what we need is an environmentally

controlled room in a public building. We can put it right next to the lactation rooms for nursing mothers (a minority I am certain is smaller than those with autism) that are being added to so many public places today. Wouldn't it be great if we could create telephone booth type retreats in public washrooms which feature sensory intake controls so that you can control how light or how dark it is, how loud or how quiet it is, how hot or how cool it is, how stimulating the environment is or is not.

I attended a meeting at which someone from the State of Illinois was discussing the kind of services that are offered to young adults with autism by the Department of Rehabilitation Services (DRS). Since my son will soon be facing the realities of finding a job, I went to see what the state had to offer in support of someone on the spectrum. The speaker gave an excellent example of how the DRS provided support by intervening in the interview process for a young man on the spectrum. He was qualified for a job but did not possess the social skills to interview very well, and he would certainly have been considered awkward or anti-social and therefore unfit for the job if the DRS had not been there to educate the employer on the unique social nature of someone with autistic spectrum disorder. Ultimately, this young man won the position and made a terrific long-term employee.

That one simple act of education changed the outcome of the situation and influenced the future of both that young man's life and that company. Employers need to understand autism to the degree that they can look past the difficulty with the interview and more accurately assess the unique qualities of the potential employee. This response could make a world of difference in the future lives of those with ASD. Given that kind of understanding, someone on the spectrum might not feel

so lost. There is no telling how one small act of this kind can change the destiny of an individual...and the world.

Unfortunately, the speaker also noted that there are simply not enough case managers to oversee the caseload, so counting on the government to provide support and public education won't be the long-term answer. That means that real, meaningful change, understanding, and ultimate acceptance of this new minority into the mainstream world is going to be up to the rest of us. As this minority grows and develops a voice of its own, at some point, the general public will need to get involved in providing accommodations and support. The future is in our hands. Let's take the reins and see how we can help, see how we can contribute to creating a better world for our loved one with autism.

What You See Is Not Necessarily What You Get— the Outside vs. the Inside

People with autism possess many good qualities—the same ratio of good qualities to bad as everybody else. Sometimes, the qualities others choose to see and focus on are just those that appear on the outside. They do not see the daily functional struggles that result from autistic thinking. As a result, they do not understand the perspective of someone who lives in the trenches with autism every day. That leaves the rest of us to feel not only invalidated, but often blamed and/or feeling guilty for our discomfort and dissatisfaction in the relationship, when in reality the issue at the heart of the matter is the autism itself—the internal experience of the individual on the spectrum, or life in the autistic filing office.



In this Chapter

- Develop insight into the perspective of someone on the spectrum
- Understand how autistic brain neurology affects behavior
- Recognize basic behavioral responses of ASD
- Recognize the difference between “can’t” and “won’t”

2

Life in the Autistic Filing Office

Experts believe that the brain neurology of someone with autism is different than that of someone who is neurotypical. This difference in neurology has a far-reaching effect on the autistic person’s experience of life. I want to paint a picture that will help you understand what it might feel like to live with autistic brain neurology, how that might be different from the experience of having a neurotypical brain neurology, and how that can potentially set up the rest of us for a negative experience with someone on the spectrum.

When we refer to the neurology of the brain, we are talking about the way the brain processes information, which happens at an unconscious level. Brain neurology is all about the brain structure and chemistry; not about whether the individual is willing to think about something, how they think about something or whether they have a good attitude. We are not talking about conscious ability, feelings, IQ, or effort, but rather about the physical makeup of the brain, the way the brain is

sending information from one place to another, and the way the brain is accepting, storing and retrieving information when it is needed for reference. Brain neurology is something that is not within the individual's control, any more than the color of your eyes is something you can control.

On the following page I provide a quick comparison between the characteristics of neurotypical brain neurology/processing and autistic brain neurology/processing.⁴

This chart contrasts the characteristic aspects of autistic versus non-autistic brain functions, and highlights the fact that the neurotypical brain is much more flexible and expandable, and possesses important interconnectivity that is not present in the autistic brain. These characteristics affect the way the individual's mind works on a conscious level. The lack of neurological interconnectivity in the brain could result in not being able to generalize information, for example. Neurological inflexibility could give rise to an individual's inability to see things from another point of view besides his own.

This is the critical point at which we encounter the difference between can't and won't. For example, in many situations we may believe that an individual is not willing to be flexible and see our point of view (which is socially offensive and carries with it negative consequences to the relationship), when in fact, the brain neurology of autistic individuals predisposes them to be unable to see our point of view because of the lack of interconnectivity and flexibility. Understanding this concept to the degree that you can incorporate this fact into your daily exchange with an individual with ASD alters the social interpretations, and therefore the ramifications of behaviors, and that changes the relationship.

⁴ Timothy J. Wahlberg. *Finding the Gray: Understanding and Thriving in the Black and White World of Autism and Asperger's*. 2010. Wahlberg & Associates. Geneva, Illinois.

Brain Neurology/Processing Characteristics	
Neurotypical (Not Autistic)	Autistic
Flexible, malleable, global, interconnected.	Inflexible, rigid, linear, compartmentalized.
Always expanding, adding information, updating, building a larger database and allowing new information to revise old.	Not expanding, limiting, attempting to filter out information that does not easily fit, and not revising new data with old.
Always cross-referencing, making new connections.	Not cross-referencing (even avoiding it), not making new connections.
Incorporating new data.	Avoiding incorporating new data because they do not want to disturb the old understanding.
Having the ability to form new cumulative assessments, to see the whole as a sum of the parts.	Having difficulty forming new cumulative assessments because it is focused on the parts instead of the whole.
Ability to see aggregate picture.	Seeing individuals rather than the whole picture.
Ability to see and be comfortable with shades of gray, or abstract concepts, between the concrete black and white.	Attempting to translate data into black and white to make it more easily categorized and understood and thereby eliminating the shades of gray.
Dynamic in that the brain is always seeking, driving to look for new information.	Static in that it has an aversion to and is always resisting new information, trying to limit/avoid new information.

Let's be sure we do not make any value judgments, that we continue to think of autism as different, not as broken, sick, defective, retarded or anything else; there is a huge difference between "can't" and "won't"— and on a neurological level, people with ASD can't easily perform (if they can perform it at all) the types of flexible thinking that comes naturally to most of the rest of us. Remember, we are talking about *processing*, not about *attitude*, not about conscious thinking or what is happening at a conscious level of the mind. Those lines can get very blurry, very quickly. The way the brain's structure and its chemistry process information is not a conscious decision; for all intents and purposes, this processing is as much out of the individual's control as a heartbeat. So, trying to blame someone with ASD for the fact that they do not think "correctly," that they do not have an open mind, is like trying to blame someone with diabetes for not processing sugar correctly.

Hand dominance is similar to autism in that it is not wrong, it is just different, but that difference often presents a functional dilemma. You can pretend to be right-handed. You can do things in a right-handed manner, in spite of the fact that left-handed would be easier or faster or better for you, but you cannot think your way out of left handedness, and you probably cannot act right-handed to the point where you change your left-handed neurology. The same is true with autism. I do not know if anyone is truly positive if brain neurology can be changed, but based on the information I received from the experts I consulted, my understanding is that if brain neurology can be changed at all, it is very, very difficult. Being autistic complicates life like being left-handed in a right-handed world.

Autistic processing difficulties are not just about retrieving data; these issues complicate every other area of life in that

they affect the individuals' ability to utilize and draw upon the resources, the knowledge base and the experience they possess to enable them to do what they need to do, when they need to do it. As such, it touches every area of functionality, making even simple tasks more complicated.

For example, to shower and wash your whole body with soap, and remember to shampoo your hair (with shampoo and not cream rinse),

and remember to put the cream rinse in your hair after that, and then remember to brush your teeth (with toothpaste) and then to use your deodorant after that can be a very complicated series of tasks for someone on the spectrum. The rest of us just call that simply "getting ready to go to school" and do it automatically without thinking.

Trying to blame someone with ASD for the fact that they do not think "correctly," that they do not have an open mind, is like trying to blame someone with diabetes for not processing sugar correctly.

Since autistic brain processing is not the norm, our world is not geared toward it; rather, our world is slanted toward the more common neurotypical processing, a fact that complicates functioning for those with ASD. For example, in our western culture we teach our children in classrooms that are based on social rules and expectations, so much so that the very functioning of the classroom depends upon the students' understanding and adherence to these unwritten rules.

Someone with ASD might be more successful in a one-on-one style education system or one that doesn't rely so heavily on social skills, which can be an area of great challenge for those on the spectrum. Trying to force fit people with ASD into the neurotypical mold can be very painful, if not disastrous!

What Would Autism Feel Like?

What would it feel like to function with an autistic neurology? How can we experience how that feels? Learning to relate on a personal and an emotional level to the experience of those on the spectrum will go a long way toward helping you understand, communicate, and adapt on a day-to-day basis with your ASD loved one. This understanding will change your experience with that person, and thus your relationship.

Here is an analogy called the “Autistic Filing Office,” or AFO for short. Imagine something like the largest Department of Motor Vehicles you have ever seen—a giant room with a very long counter; the customers, each with a unique request, are lined up three deep along this counter. The large number of people and the urgency of the requests create an intense atmosphere in the Autistic Filing Office. The lights are extremely bright, the noise really loud. Irritated customers, each with their own agendas, wait impatiently. They all need different information and they all want it now!

This demanding and fast paced environment puts a lot of pressure on the AFO counter clerk who is responsible for satisfying these varying demands. His job is to search the database and find the specific information that each customer is requesting. This clerk is perfectly capable, smart, hardworking and not autistic. In the AFO, the database is *not* computerized; everything is kept as written records. Behind the counter, there is a doorway that opens into an enormous back storeroom where the information is filed.

In this football field-size storeroom, huge filing cabinets line the 50-foot-high ceilings. The cabinets are dusty and rusted; some are locked, some contain drawers that are stuck or sit ajar where they got jammed the last time someone looked in

them years ago. Some of the information in the cabinets was originally misfiled, possibly lost forever. Everything is very compartmentalized, separated into individual increments of data with no relationship or cross reference. For example, the records for birth months are in one cabinet, for birth date (day of the month) in another, and for birth year in a third location. In spite of its disheveled, segmented and cumbersome filing system, the storeroom is quiet, the lights are dimmer and the atmosphere is a little bit more comfortable; it is peaceful, and definitely a welcome contrast to the pressure-filled waiting area. There is nobody else in there to hassle the clerk, or present any new demands.

Finding what is needed in this giant warehouse of information can be a challenging, tedious and frustrating process. To reach all the files, the clerk may need a ladder or might have to walk a half a block to get to the cabinet where the required information is located. Special tools may be required to open the drawers, or a magnifying glass may be needed to read the information when it is located. Some of the paper on which the information is written is so old and fragile it crumbles when handled. But, all the data, all the information ever needed to answer any request for any customer, is stored in these files somewhere. Just like the birthday example, many of the requests that are made require two or three look-ups and then the synthesis of the information to form the answer the patron requires. In light of the painstaking and exhausting effort required to locate the information, most of the requests seem silly, unnecessary and not meaningful to the clerk, but he must follow through, in spite of his opinion that the requests are ludicrous or don't even make sense to him, just because it is his job. That is the Autistic Filing Office.

Let's contrast that to a different filing office, one we'll call the "Neurotypical Filing Office" (NTFO). Here, even though the room is big, there is no separation between the front and the back rooms. All the data is stored in a single, efficient, well-organized computer database, instead of a giant back warehouse of information where the clerk must laboriously search for and manually retrieve each piece of information separately. The NTFO houses state-of-the-art computer systems that allow the clerk to access any data quickly and easily from one workstation.

The NTFO computer system also has a handy cross-reference feature. When a customer walks in and says, "I need to know about Jeanne Beard," the clerk behind the desk can pull up a dossier of information. He can almost instantly provide the name, address, birth date, Social Security number, family history, educational background, work history, information about where Jeanne Beard grew up, where she was born, and what products she has purchased. With just a few clicks of the mouse, the clerk can access an entire dossier of cross-referenced information to satisfy the request.

The experience of retrieving information in the NTFO is categorically different from the experience of information retrieval in the AFO, where each piece of information requires a painstaking look-up in a separate file, a multitude of steps to gather, and possibly even require some extreme act of gymnastics to access. If a customer comes in and says, "I want to know Jeanne Beard's birth date, and I want to know her address because I want to send her flowers on her birthday," the AFO employee would be required to go back into the warehouse and laboriously locate one piece of information at a time. In the NTFO, this same search would take only a few seconds at the computer.

If the AFO clerk is really experienced and talented and knows where all the birth files are located, he can go to the three separate birth-date files and pull up the birthday in only five minutes. Then he might need to run to the other end of the building because he knows that the address file he needs is going to be far away and high up because it is in the “B” section. He may be working really hard to get this information back to the customer quickly, but meanwhile, the unwitting customer is growing impatient, possibly indignant, and thinking, “Come on! What is taking you so long? Are you stupid? What’s the problem?”

The customer in the AFO does not realize what is happening behind the scenes. He arrived at the AFO with the assumption that this would be the same kind of filing office as any other office he has seen. He had no idea how much effort was going to be required to satisfy his request, what obstacles the clerk may have to overcome, or how frustrating or painful that process might feel to the clerk. The customer’s expectation when he came through the door of the AFO was that every filing office had a computer to help with each request, just like every other filing office. Perhaps this customer was so far out of the loop that he didn’t even know working without a computer was possible.

When the clerk finally returns from the warehouse 10, minutes, 15 minutes, 20 minutes later, and presents the information to the upset and frustrated customer who requested it, it’s easy to see the tension brewing between these individuals; the AFO clerk might even receive a less-than-polite welcome when he returns after all of that hard work. The customer is irritated and angry that the clerk took so long, and the clerk might be thinking, “What do you know anyway,

you jerk!” Is it any wonder why the clerk might question the validity and necessity of each request made, or why he might rebel at some requests?

This tension and anxiety snowballs as the day wears on, and the lines grow longer in the AFO. Customers are increasingly aggravated and demanding, until they are screaming, and the clerk is hanging by a thread of patience, trying to manage a situation that feels ridiculous, out of control and overwhelming. And the customers never stop coming, and there are never any breaks.

The parallel between the processing system of these two offices and the neurological processing of the two brain neurologies is obvious. The customers in our analogy represent

Social and emotional inference is lost on those with ASD, who depend more on logic and reason to create their understanding of the world.

the typical day-to-day demands that are made on all of us. Daily, routine demands might include: take a shower, catch the bus to school, drive to work, answer the phone,

or listen to your mother admonishing “do not fight with your brother” or “eat your green beans.” More complicated demands might include getting married, having a child or facing a serious illness. Each of these requires so much more energy to process in the AFO world.

These difficulties are compounded because life moves at its own pace and unfolds organically. We cannot control the flow of requests into our life, we just have to wing it, minute by minute and take life as it comes. Processing information quickly, on the fly, in the midst of the stream of life can be overwhelming to someone on the spectrum, whose rigid brain

neurology does not lend itself to this type of rolling-with-the-punches way of being in the world.

The warehouse of information in the AFO represents the mind of the person on the spectrum. All the necessary knowledge is available, but retrieving it and using it is not the same experience when you are on the spectrum. From this perspective, it almost seems reasonable to us that those on the spectrum retreat inside, which of course is a classic autistic response to the anxiety of an overwhelming situation.

Given the linear quality of their brain neurology, autistic individuals can be overwhelmed with the unknown. When something happens that is not in the plan, it can stop those with autism in their tracks. Going with the flow, especially when any social contact is involved, is very, very stressful for autistic individuals. When someone with ASD knows in advance what to expect, then he can prepare and be able to deal more easily with the circumstances when they occur. Situations that present a range of possible choices can also be overwhelming. That feeling of overwhelm often elicits some sort of a response that short circuits the conversation or possibly ends with a response of “I don’t know.” I discuss dealing with “I don’t know” in a later chapter.

Social and emotional inference is also lost on those with ASD who depend more on logic and reason to create their understanding of the world. If someone came into the office and said, “I want Jeanne’s address because I want to send her flowers on her birthday,” the individual with ASD might think, “Who cares about flowers on her birthday?” It is very, very difficult for someone on the spectrum to comprehend and understand the value of many typical requests, particularly if they are socially based, which is true of so many requests the world makes of

us. The difficulty with social and emotional comprehension is explored in later chapters.

The information processing system that those on the spectrum are working with cannot support them in being as efficient or as effective at processing information as those of us who have a “computerized” system. People with autism, as a general rule, are not as adaptable, flexible, or able to go with the flow as the rest of us. Their system processes information more methodically. As a result, some people just need time to process the backlog of information, or may desire a quiet, dark place to think. Others demonstrate behaviors that are considered odd by the rest of us but are classic in the world of autism—self stimulating behaviors like flapping their arms, rocking, or chewing their clothing to help them process or to manage the stress of a situation that feels overwhelming. Still others learn to function in a way that appears relatively neurotypical. Those individuals may have found effective adaptations, or they may be “pretending to be normal.”

The Emotional Experience of Someone on the Spectrum

Imagine the emotional experience of the person working in the AFO—put yourself in the position of that clerk working in that Autistic Filing Office. Remember, as the clerk, you are not autistic, it is the system through which you must accomplish your task that is autistic. You possess the same intelligence, effectiveness and feelings as you do in your real life; you have a totally normal range of emotions, abilities, dreams and desires. You are just stuck with an operating system that makes everything so difficult. In spite of that fact, you deeply care about doing a good job, but it just becomes overwhelming.

How frustrating would it be when you know that you are doing your very best and when you know that you are smart and

that you are logical and yet everything is so blasted difficult? How angry would you become if you were continually forced to comply with requests that are illogical or that make no sense?

Do you think you might hate yourself, hate the world, or hate the people or situations that bring you so much discomfort? Do you think it might

Many of us don't understand it when the reaction we receive from someone on the spectrum seems angry, stubborn, demanding, petty, dismissive, uncaring, antisocial or just rude. We frame that behavior from our social and neurotypical context and judge the individual.

make you feel angry or confused, overwhelmed or like you want to avoid the situation all together? And if you felt that way every day, how would it affect your attitude and actions? How would you cope with the peak of the rush in the AFO?

Me? I would jump up on the counter and start screaming, "Everybody be quiet! Get in line! Wait your turn! I am doing the best I can to hurry!" I would begin to act in ways that would probably be considered socially unacceptable controlling behavior, but in my overwhelmed state, screaming and acting crazy would be the best I could do. I would simply try to manage the chaos as best I could with the system available to me, but I wouldn't like it, and it wouldn't feel good. I would absolutely question the necessity of each individual request, and would resist acting on all of those that were not logical to me.

I would be frustrated with the situation and probably with myself for not being able to manage better. If I weren't frustrated with myself, I would be feeling like a victim subjected to this painful situation. I'd be thinking, "Who designed this stupid system anyway?" Anger? You bet. In a life with autism, this frustration

doesn't just last from nine to five o'clock. The difficulties of autism go on 24 hours per day, every day with no breaks—*ever*. If you were that AFO clerk, wouldn't you want to retreat into the warehouse and hide? Unlike many of the brave souls who survive with autism in the real world today, that's probably where you would find me.

Many of us don't understand it when the reaction we receive from someone on the spectrum seems angry, stubborn, demanding, petty, dismissive, uncaring, antisocial or just rude. We frame that behavior from our social and neurotypical context and judge the individual. As the rest of us learn more and more about the characteristic behaviors of people with autistic spectrum disorder, we can begin to understand what is driving their mood and attitude and we can begin to discern the difference between the individual and the autism. This will enable the rest of us to support them by approaching them in ways that are more respectful and effective, thus making the world a better place for both those with autism and the rest of us!



In this Chapter

- Begin to see the distinction between the autism and the individual
- Learn how autism affects the social behavior of the individual
- See how the excuse myth impacts our relationships

3

Separating the Person from the “Ism”

How and Why Theories

The how and why theories about ASD range across the board. There are many different ideas about what causes autism. While I prefer to stay out of that debate, there is one benefit in adopting a particular theory about what causes autism—if that explanation creates a basis for improving the understanding of an individual’s behavior. I learned about the control theory during the writing of Dr. Wahlberg’s book *Finding the Gray*. The premise of the control theory is that the driving force behind characteristic autistic behavior is the individual’s need to control painful, distracting, unintelligible and upsetting stimuli coming from the environment in order to neurologically organize the information so it can be understood or at least endured. The control theory made total sense to me intuitively when I first encountered it, and proved to be an accurate perspective from which I could interpret what was happening on an emotional and behavioral level with my son.

These stimuli are both upsetting on a conscious physical level, and overwhelming on a neurological level. People on the spectrum very often appear to have physical hypersensitivities and feel or experience a forced awareness of sensations and sounds that either don't reach the consciousness of the rest of us, or that we naturally ignore without thought or effort. For example, many of those with ASD can hear the almost silent ticking of the clock across the room, which goes unnoticed by the rest of us. They can smell an odor that has long since dissipated in the awareness of someone without hypersensitivity, or they may be unable to adjust to the sensation of their clothing touching their skin. As a result, these stimuli act as a constant and often upsetting distraction.

According to the control theory, an environment that is experienced as too loud, too bright, too hot, too cold, or too itchy, or extreme in any way, not only causes conscious discomfort and distraction, but overwhelms (or clogs up) the individual's neurological pathways and the resulting reaction is what we call autism—a set of behaviors specifically designed as a survival strategy in response to an otherwise unbearable situation. On a neurological level, these are stimuli that the brains of the rest of us are able to easily process and dismiss, but for those with autism, sensory input like this can randomly engulf and impede one or all of the sensory channels in varying degrees from mild to severe, and it can do so in any combination, or at any time. Regardless of the channel(s) affected for the person with ASD, there is so much data coming in that it is overwhelming on a neurological level, and that has implications in the individual's behavior.

When I fully understood the concepts Dr. Wahlberg described with his control theory, behavior that was once

confusing finally made sense. The more I understood, the more clearly previously disjointed pieces fit together, and I found that my personal years of experience were completely consistent with the explanation and description that the control theory offered.

Using the control theory as a frame of reference helps me recognize the thoughts, actions and words that are driven by the autism, and allows me to project the emotions that those I encounter on the spectrum may be feeling. This perspective enables me to relate to them in a better way; it guides me in my decision making on a day-to-day basis, and helps me distinguish, in the moment, behavior that is driven by the autism and therefore potentially nonnegotiable (you can't negotiate with autism) from behavior that is driven by some other factor like youth, inexperience or stubbornness and can be changed.

The same logic and reason that applies to the rest of us does not apply when I am dealing with autism. By understanding the unique logic and perspective of someone on the spectrum, I am no longer fumbling in a sea of confusion. I now possess the tools and strategies to better understand and manage my interactions with the people in my life with ASD, and that helps me feel like the situation is less out of control. I am no longer lost, confused or feeling like a failure the way I did when I employed traditional parenting or relationship skills unsuccessfully. One of the greatest benefits I received is that as I learned the control theory and my understanding of the inherent issues related to autism grew, I began to discern the difference between my son and his ASD.

How Do We Separate the Person from the *Ism*? And Why Would We Want To?

Identifying autism in an individual through a diagnosis can provide some sense of security to the rest of us in the process of finding solutions to problems, but that is only a first step in providing the most appropriate support and intervention. When working or living with someone on the spectrum, it is important to be able to differentiate which behaviors and characteristics are a result of the autism and which are part of the person's personality, or personal preferences, or even a result of our issue and not theirs. Discerning this difference between the person and the *Ism* changes our experience, our responses, our feelings about the relationship, and even the outcomes we experience.

How do we make the distinction between the person and the autism? The ability to separate the person from the autism will begin to naturally develop as you learn more about the characteristics and qualities that are common among those on the spectrum. With deeper understanding, time and practice, you will be able to identify, in the moment, when your friend or loved one's actions are being influenced by the autism. This book will guide you in the process of learning and identifying the influence of autism on the autistic person(s) in your life, an endeavor that will be ongoing, and must be intentional.

Seeing the individual as separate from the autism is not as easy to do in the moment as you might think. Regardless of your level of education on the subject, concerted effort is required to interrupt the flow of life and to remember on the fly that the person you are relating to sees the world differently. When the phone is ringing, your kids are fighting, and dinner is burning on the stove, it requires concentration and effort to remember why your spouse doesn't come to your aid as

he passes through the kitchen unmoved by what you are experiencing at that moment. The more upset or desperate you feel, the harder it is to remember. I still find myself forgetting at times and treating some of my loved ones as if they are not on the spectrum, and it is not until I get a blank stare, or no reaction, or an undesired reaction that I realize that, once again, I have bowled over my ASD loved one with my neurotypical ways and social expectations. Our social expectations are such an important aspect of the entire picture that several later chapters are devoted to examining their role in our life with ASD.

People on the spectrum can often seem to function normally, and many things about them seem okay, so why even bother to identify the autism? Because it can make a world of difference.

Benefits of Separating the Person from the Autism

There are numerous benefits to identifying autism in someone. Separating the autism from the individual can:

1. *Help us separate the true nature of the person from the Ism and diffuse the excuse myth.* Autism does not define personality; personality traits are separate dynamics that combine to create our experience of the person. Knowing the difference means we will no longer interpret behavior from our socially based perspective as an indicator of personality or as a reflection of the individual’s feelings about us. This understanding helps us manage our negative reactions and feelings and allows us to see how some behaviors that might otherwise be considered offensive are not directed at us personally.
2. *Help us discern the difference between “can’t” and “won’t.”* Until you understand and are aware of the ASD at work influencing the behavior and thinking of the individual

on the spectrum, all behavior is assumed to be intentional and selected by choice. It appears that the individual acts strictly out of conscious willingness and effort (or lack of) and “won’t” do certain things. Once the autism is identified as a separate entity and its inherent limiting qualities are understood, the fact that those on the spectrum are at the mercy of their autism at times and “can’t” do certain things becomes plausible. It remains up to the rest of us to develop the insight to understand this difference. From that perspective, we can begin to appreciate that those on the spectrum are doing the very best they can with the resources available to them. Distinguishing between “can’t” and “won’t” also helps us to strive for achievable goals and fair expectations of our loved ones, and dramatically decreases our negative social experience and emotional reactions.

3. *Give us a solid basis for developing intervention, which is a tricky venture anyway.* Seeing the individual as separate from the autism assists us in building effective intervention strategies, an endeavor that is often based on trial and error. Recognizing that these strategies are not the same, we can develop intervention for both “can’t” and “won’t” issues. Knowing the difference is crucial to determining whether you push through something to conformity or make an exception in deference to the autism. If it is a “won’t” issue, it can probably be worked through, but a “can’t” issue may not be resolved by pressing for conformity, and may require an accommodation.
4. *Help us pick our battles.* Once we can see this landscape more clearly, we establish a basis that empowers us to decide which battles to fight and which to let go. You cannot fight every battle—it is too exhausting!

5. *Give us a basis to understand the social clash we will predictably experience in our life with someone with ASD.* Inevitably this clash between our social thinking and the nonsocial approach of someone with ASD will arise. Being able to see the autism as separate from the person helps to soften the rift, and gives us an alternative way to interpret and cope with the situation. We thus avoid shaming and blaming, which is a nasty habit and damages both parties in any relationship. The ability to avoid blaming the individual for the autistic behavior is welcome relief.
6. *Help us to manage our own reactions and our feelings, and to reduce blame.* It is important for us to consider our own mental health as we work to manage our relationships with our loved ones on the spectrum. Anything that provides clarity, reduces stress, and allows us to be more effective is a powerful tool to improve our own lives.
7. *Provide immediate relief and understanding to the individual who has ASD.* This may be the most important factor of all—true understanding that honors these individuals and their exceptionality, and empowers them to be fully who they were born to be.

In general, separating the person from the autism helps us to untangle the anger, worry, hurt, frustration, fear, concern, blame, etc., caused in a given situation by the issues related to the autism, and to deal with them separately from the regular issues of life—and we all know that there are enough of those. Separating the person from the Ism is like untying a knot that is tied too tight. The individual strands are difficult to discern and so the knot becomes one big complicated mess. By loosening the knot you can begin to see the individual threads unravel, and eventually you can unwind them and increase your chances of

tracking them to their source. Thus, we can much more easily see our part, our loved one's part and the autism's part of the problem (and, yes, there are three of us in the relationship). This diffuses the frustration and negative emotions that are intensified or caused by the autistic qualities of the person, and smoothes out the relationship, giving us a better foundation for building a healthy, mutual and satisfying relationship.

Recently, my son and I visited his new college campus. As we approached the building, my son, a few paces ahead of me, reached the door first. He walked through the doorway, but

By separating the person from the Ism and understanding the drivers behind the behavior, we can create a situation that is far more likely to foster healthy long-term relationships.

did not hold the door for me. I know this act might offend some people's social sensibilities, but it was not offensive to me because I understand him. In this case, I even said, "Most people would hold the door.

Why didn't you do that?" He explained, politely and in a matter of fact tone, "You're perfectly capable of opening the door, and that's just slowing us down."

Since I understand the logic and practicality aspects of his ASD, I know that when my son walks through a door and doesn't hold it open for me, it is not because he is not nice, it is not because he is not a loving person, it is not because he doesn't love me or respect me or care about me. He is just being himself, and the benefit of that social behavior is not on his radar. My life would be so much more complicated, frustrating and painful if I attached a lot of impertinent meaning to the situation.

To highlight the benefits of identifying and understanding ASD, let's view this one small door-holding incident from two different perspectives as illustrated on the following page:

<i>From the “excuse myth” perspective (not separating the person from the autism)</i>	<i>From an acceptance perspective (separating the person from the autism)</i>
The observer sees “won’t” and interprets that as rudeness or an intentional decision to ignore social propriety.	Observer realizes that this incident may not be on their radar and may not be an indicator of their “niceness.” We see “can’t” instead of “won’t.”
The person with ASD is judged as being uncooperative, rude, and when held to traditional social standards, fails miserably.	The person with ASD is not seen as uncooperative, or rude; the social standards are lenient enough to make room for them to still be okay.
Observer doesn’t know how to explain that social norms would dictate a different action. Attempts to appeal to social understanding are ineffective.	If we feel that intervention is required, we are able to explain that social norms would dictate a different action.
The observer feels that this is a social comment or flagrant act of defiance or rudeness directed at them.	We understand that this is not a social comment or deliberate act of defiance or rudeness and that it was not a statement.
Our social sensibility is offended and we experience frustration, anger, irritation or other negative emotions.	We are able to understand the source of (reason for) the behavior; we do not experience negative emotions.
This upset taps into other, deeper issues and all battles become one continuous upset from which the observer experiences negative emotions.	This, and similar, battles are eliminated. Intervention is more efficient.
The autistic person experiences a negative reaction, disapproval, and possibly confusion.	The autistic person experiences acceptance, or possibly does not experience anything at all related to the action.

As we watch the situation unfold from both perspectives, the level of stress that is palpable in the first perspective is almost nonexistent in the second perspective. Over time, the stress level of the excuse myth perspective will not only damage the relationship but may have deleterious effects on the emotional and physical health of both parties. At about number (5) or (6) on this list, we see where our issues enter into the mix and escalate a situation that might otherwise be an isolated incident. Managing our own issues helps to keep them out of the fray. By separating the person from the Ism and understanding the drivers behind the behavior, we can create a situation that is far more likely to foster healthy long-term relationships.

Seeing the person as separate from the autism is a compassionate perspective. When I was truly able to achieve this viewpoint, and began to realize that my son was not the same as

Seeing the person as separate from the autism is a respectful, logical perspective; this perspective diffuses pain and is healthy for the rest of us.

the autism, but rather he was actually trapped inside the autism, it broke my heart. I began to see him as a lost and frightened child living in a world that he didn't understand and

that was overwhelming him, and he was without the tools to decipher the language. I realized that I had to enter his world and let him know I was in it with him and that he was not alone. Otherwise, he would have been left isolated and stranded, alone on a painful island not of his making, and from which he was unable to escape. This changed the way I parented him; correcting him based on social understanding and trying to convince him to understand social expectations did nothing but push him further into his isolation, and frustrate me.

Many times the rest of the world reacted negatively to him as well. He was a magnet for disapproval and disdain because of his ASD, so the child behind the autism was not receiving the kind of reaction, love, affection and attention that he (and every other living creature) deserved from other venues of his life either. When I realized that was happening, I was suddenly painfully and frighteningly aware that I was his lifeline, and I might be his ONLY lifeline until more people around him were able to understand the autism landscape and bridge the gap from the neurotypical world to his world, or until he learned to adapt more effectively and was able to bridge that gap himself. It deeply moves me to think that there are still people who remain stranded and alone, trapped in their autism without understanding and without a lifeline.

Seeing the person as separate from the autism is a respectful perspective. I have spent 30 years in sales and have learned that understanding the person with whom we are attempting to communicate, whether our child or our customer, is the most respectful way to relate. When I build a relationship with a prospective client, I work hard to understand who they are, what they need, and what will fit the situation. That effort is a very important part of a successful relationship formula.

Understanding is something that is even more important when dealing with someone we love. To be able to separate my son from his ASD and see him as a complete, whole, loving, emotional human being who happens to have been born with a different method of neurological processing changed how I approached loving him, caring for him and accepting him for who he is, complete with his autism. It is really about respecting and empowering the entire individual, which is hard to do if you focus on the ASD-related qualities and assume that they reflect the person's nature.

Separating the person from the autism is a logical perspective. Understanding the difference between the person and the autism also allows us to love the person and hate the problem instead of hating the person or being angry with the person because of the problem. The separation allows us to adopt a more logical viewpoint. Let's compare it to the difference between a boat and a car. They are both forms of transportation, they can both get you from one place to another, but you would not put your car in the water. You would get a boat. You would not get mad at your car for not being waterproof! That's not logical. People with autism and people without autism are both people—they are just built differently, like cars and boats.

It is logical and appropriate to tailor our expectations to the individual. For example, let's compare two children. One child is 3 and one is 13, and they both receive a gift from their grandmother. Assuming you are dealing with neurotypical (not autistic) children, you might expect the 13-year-old to write a note to his grandmother, but you do not expect the 3-year-old to do so. Given the developmental level of a typical 3-year-old, you know that he can't do it; that expectation would be unreasonable. Writing a thank-you note is not in his wheelhouse. It wouldn't be logical or appropriate to expect the same behavior from the 3-year-old and the 13-year-old just because they are both children. When you truly understand autism, it is not logical or appropriate to enforce the same expectations on those with ASD as those without ASD.

Separating the person from the autism is a perspective that diffuses pain in our relationships because it helps us discern “can't” from “won't.” Difficulty with this is one of the most common complaints I have heard from women with spouses

on the spectrum. They feel their spouse is just not willing to do something for them, and in reality the truth is that he cannot do what is being asked of him. Either the spouse cannot understand what is being asked because the request is socially based, or he cannot deliver on it. It creates a huge shift when you know that there is a difference between “can’t” and “won’t.”

Separating the person from the autism is a healthy perspective for the rest of us. The clarity, reduced stress and increased effectiveness we gain from this perspective helps us to live a healthier and more peaceful life. Helping ourselves helps them. After all, a relationship is a closed loop where energy recycles; when we improve the situation for one, we improve it for everyone. Besides, you cannot pull somebody out of the pit if you are in the pit with him. Staying emotionally healthy ourselves is a key to providing long-term support in someone else’s life.

Ultimately, separating the person from the autism also helps us to build compassion, and be better people. Underneath the autism lives a person with a very full emotional life – someone who has the same feelings, the same needs, the same desires, and the same need for love and approval as the rest of us, and adopting the most compassionate perspective we can muster means we are expressing the best of ourselves.

Using a Diagnosis to Help Separate the Individual from the *Ism*

A diagnosis is really helpful to the process of separating the person from the autism, because it legitimizes the fact that there is a real, valid, meaningful issue and that justifies the need for reframing, or attaching different meaning to behavior. Without an official diagnosis it is easy to doubt yourself and your belief that your loved one has ASD, which is a common experience for those of us who have very high functioning or adaptable loved ones on the spectrum. A diagnosis helps to defuse the excuse

myth in our minds, and gives us something to hang on to when we doubt our perception.

A diagnosis also provides an opportunity to purposefully intervene with therapy and gives focus to building healthy habits and foundations for the future, especially in children. People with autism are creatures of habit, to say the least. They do what they have always done, because anything else requires too much effort to process. They fight change. That means that teaching children a healthy habit when new information or a new situation is first introduced is the easiest way to help them grow into healthy adults. Rewiring behavior later in life when a pattern has been set can be a huge challenge. If one parent is on the spectrum, which is often the case, this can create an additional challenge because the behavior modeled for the child at home may be less than ideal as well.

Some people may not want to seek a diagnosis because it is difficult to hear the word autism for the first time. I understand that it can feel shocking, terrifying and devastatingly painful to realize that you are now facing what appears to be some horribly debilitating issue that can never be changed. I have been there! If your child is the one who is diagnosed, doubts and fears about her future can be petrifying and overwhelming. I hope that books like this one can begin to change the fear about autism and debunk the myth that autism means lack of success. In the long run, knowing is the first step to maximizing the reality that you face.

Adult/Spouse Diagnosis

Children are not the only ones who are affected—adults are just as likely to struggle with autism. If there is an adult family member in your life, a spouse or significant other, who you think might possibly be on the spectrum, find someone who

can help you clear up your uncertainty. As painful as it may be to hear the diagnosis, not knowing is the worst case scenario. Uncertainty, confusion, issues that seem to have no beginning and no end, and ultimately bearing all of the responsibilities of the relationship is a really tough road. Without a diagnosis in a marriage, it is very likely that one or both of you will have needs that go unmet, and this can eventually damage or destroy the relationship.

I know that territory; I lived there for years trying to figure out why I could never affect any change in my life. Despite all my self-improvement, learning to express healthy boundaries, and asking for what I needed, I still could not effect that change I sought in my relationship. I was blamed for my own dissatisfaction and, lacking any other explanation, and as an expression of humility, I thought maybe it was my problem, so I kept working on myself. After all, I was the one who was unhappy, so I must be the one with the problem, right?

When your spouse is diagnosed, there can be a period of relief and hope because you know that new avenues to pursue are opening up, which may lead to the resolution of problems you have been experiencing that led to the diagnosis. And that may be the case for some families, but if progress is slow or nonexistent because either your spouse is not on board with the diagnosis, or is severely impeded by the autism, hope can evaporate into frustration, and eventually despair. This is especially true if you believe in marriage as an institution and are opposed to divorce, or if your life together has grown in the direction that causes you to feel that your choices are limited because you are no longer in the workforce, and the thought of raising and supporting yourself or your family alone is overwhelming. I have met a number of women who experienced this conundrum.

Other individuals may choose not to pursue a diagnosis because they may not want to rock the boat, they feel too much respect for their spouse, or they fear the possible fallout. There are many reasons why someone may feel uncomfortable seeking a diagnosis, but a diagnosis is the first step to being able to survive in the relationship and to create a sustainable long-term and satisfying relationship. Understanding changes everything, and a diagnosis is definitive understanding—at least for the rest of us.

Your adult loved one may not be willing to accept a diagnosis. Those on the spectrum in my life proved masterful at deflecting responsibility and dismissing their options for

People with autism are creatures of habit...They do what they have always done, because anything else requires too much effort to process.

new behavior all for the sake of avoiding change.

In the past there were times when I felt like I was intentionally being deceived, although today

I believe it was a strong self-preservation drive/survival instinct that precipitated this avoidance behavior rather than any pre-meditated act of meanness.

I have talked to other women who have been in that same situation and the experience is very painful especially when you know in your gut something is not right, yet no matter what you do, or how hard you try, you wind up in the same place. Even a herculean effort doesn't move the situation off the dime, and that has deep ramifications for our self-concept, particularly if it goes on for years or decades.

Here's the difficulty if you are married to a person on the spectrum. The information that is reflected back to us about ourselves in our closest relationship does not portray

an accurate picture of who we are, and that is confusing and unsettling, if not downright frustrating and painful. For example, in spite of the fact that we may act in a very loving and generous manner, we may not receive the thank you or the gratitude that is commensurate with our generosity. When that happens, we can't help but wonder where we went wrong. If we do not blame ourselves, we might feel indignant, wondering, “what did I do to deserve to be treated this way?” Regardless of our other feelings, the situation definitely does not give us any reassurance that we are able to control/manage our own lives effectively; that self-doubt alone can be debilitating.

Remember, the rest of us are operating in a socially based self-assessment system; the world around us influences us and shapes our self-image on an emotional level, whether we want it to or not. The person on the spectrum is disconnected from that social mirroring and interpretation of self. From their perspective, they're not doing anything to you, and they don't get that they are having any effect at all. More than likely, from their point of view, whatever your problem is, it doesn't have anything to do with them. A diagnosis is one of the best paradigm changers available to you in that situation. The clarity is worth the effort and very much worth facing the fear.

Shortlist of Common Character Traits of Autistic Individuals

When endeavoring to see the autism as separate from the individual, it is helpful to be familiar with typical character traits of someone on the spectrum for a number of reasons. First, there are so many variations on the ways that these traits can express themselves that a general understanding of them in their purest form is vital to being able to see their influence underlying the behavior. Second, when we recognize these patterns of thinking and behavior, we are more likely to separate

the person from the autism. Third, if we see these patterns emerging, that may signal us to identify the autism at work in the individual, which in turn may help us determine the most appropriate response.

Below is a summary of traits that can be part and parcel of autism, based on information found in Dr. Wahlberg's writing:

1. ***Black and white thinking:*** This describes the tendency of the individual with ASD to simplify information, and categorize it as black or white in order to process it more easily and effectively. Behaviorally, this is often expressed as “all or none” thinking.
2. ***Rigid thinking:*** This describes the need to control information as a result of the overstimulation. Behaviorally, this expresses itself as a great difficulty forcing them to do anything that they do not want to do, or conversely, not to do something that they want to do.
3. ***Linear thinking:*** This very common trait among those on the spectrum describes the tendency to have difficulty thinking globally, making generalizations or overcoming obstacles. For example, one summer, when school had ended, I folded my son's gym shorts and put them into the stack of folded underwear in his dresser drawer. They were somewhere in the middle. My son took a clean pair of underwear from the pile each a day, but when he hit the gym shorts, he came to me and said he was out of underwear. His linear thinking kept him from digging beneath the gym shorts to find the other ten pairs of underwear below. When the trajectory of their life is stopped, those on the spectrum can get stuck.
4. ***Getting stuck:*** While the underlying reasons may vary, this describes the tendency to be hyper-focused, stubborn, rigid or

unable to change their view or their position on an issue, or their attitude.

5. *Experts in sameness:* When information is hard to process, consistency and familiarity are very comforting. As a result many people on the spectrum like to create “sameness” in their world. “Same” information is familiar and therefore easier to process.
6. *Literal thinking/Difficulty with nonliteral language and concepts:* Most people with autism are very, very literal. Metaphors and slang can be hard to interpret.
7. *Anger:* Dr. Wahlberg states that this is the most highly evolved emotion in those on the spectrum, and anger is the easiest emotion to express.
8. *Commitment to fairness:* Life is not fair, but those on the spectrum believe that fairness is logical, and life should be fair.
9. *Lack of social awareness:* Those on the spectrum do not gather and process social information the way the rest of us do, so their social awareness does not develop in the same way. Lack of social awareness is behind many issues that arise for the individual on the spectrum, so much so that the discussion requires an entire chapter.

Understanding autism in the light of the control theory and being able to see it as separate from the individual demystifies behavior and increases the possibility to see that people with autism are not mentally retarded, they are not mentally ill, they are not sick, they are not crazy—they are different. As a parent of a child on the spectrum, it comforts me to remember that there is really only one thing about my son that is different, in spite of the fact that this difference can have far-reaching effects on his life. People with ASD are just human beings with different

characteristics, albeit some of these characteristics can create challenges for him, particularly in environments where it is necessary to draw on a social database, or when performance is based on social interpretation.



In this Chapter

- Understand the implications of autism as a social disability
- Discover the impact of a missing social database
- Learn the “times 10” rule of thumb
- Appreciate the strengths of those on the spectrum

4

The Clash Between Social and Nonsocial Thinking

Autism as a Social Disability

People on the spectrum are just like everybody else in many ways. They have rich internal lives, they experience a full range of emotions, they display a wide range of personality types, and they are as capable as anyone else. Many are much more intelligent and creative than the average person. Like the rest of us, they possess strengths in some areas and weaknesses in some areas. The degree of difficulty they experience and the areas of functioning that are affected vary from person to person just like everybody else without autism. People with ASD display a rainbow of traits in unique combinations, just like the rest of us, but with one common exception—they process information differently.

If you can only remember one fact about autism, about spectrum disorder, or about the autistic spectrum in general, remember that as a result of this processing difference, autism is a social disability. The term “social” as I am using it here is not

referring to your social calendar, to your social engagements, to your dates, to your friends, or to your socialite activities; I am referring to the ability to form cooperative and interdependent relationships with others. Any event or activity that involves contact between two people can be considered social. For example, buying a video game is a social activity, as is ordering a pizza or driving a car. People with autism often find these situations so painful or confusing that avoiding this type of social contact entirely is preferable to confronting the constant struggle.

The term “social disability” refers to the hampered ability to think and/or operate in a way that is in sync with the rest of the world, taking into account factors that have a social perspective like etiquette, social behavior that is customary or common, or another’s point of view. It implies being unable to see life from a “normal” or neurotypical social perspective instead of the typically-autistic linear, logical or exclusively “me-oriented” perspective. Often those with ASD cannot even fathom the concept that someone else can possess a point of view that differs from theirs, let alone allow that different perspective to influence them.

Social information is the most complicated, subtle and fluid information we process and as such is the first information to go unnoticed or unrecorded when our senses are overwhelmed and our neurological processing capacity is consumed with other input. Imagine a fire alarm screaming at a deafening pitch in the building where you work. Could you do your best work under those conditions? How about make a friend? Even if you weren’t scrambling for the exit, it would be way too much effort to try to relate to someone on a social level. The last thing on your mind would be to think about making small talk to engage a new acquaintance. If you felt compelled to make the effort to

speak at all, it would be brief and to the point. Social propriety (the “oughts”) would not even be a consideration.

Imagining yourself in this situation with the fire alarm screeching might also help you to understand the lack of executive functioning which frequently complicates the lives and experience of our loved ones with autism. In a consuming, highly charged or near-panic situation, how many resources, how much energy and focus, could you spare to plan for the future or to project the consequences of your actions? Probably not much; your focus would be the immediate crisis at hand, centered on managing the painful “now” moment. The social impact of your actions or your long-range consequences would not even be a consideration.

Lost Social Information/The Social Database

When the neurology of someone with ASD is overwhelmed, the person becomes so focused on other data that the social information gets lost in the shuffle, and the data is not gathered or stored at all. Therefore the individual is not building a bank of experience to reference in future similar situations. This lack of a database of social experience is a problem that can compound itself, because the information is not available as a reference later, and a database of social experience is a key element that those of us who are not on the spectrum use to function socially as we develop. Have you ever been so nervous when you talked to someone that, afterward, you didn’t even know what was said? That is a similar experience.

The lack of a database for reference also means that many experiences encountered carry the pressure and trepidation of a brand new experience all over again, rather than feeling comfortably familiar. How hard would life be if you experienced “first day jitters” every day, all day long?

In children, the lack of a social database may mean that they are not developing and socializing at the rate of other children, and that may or may not be evident in their behavior

Imagine a fire alarm screaming at a deafening pitch in the building where you work...Even if you weren't scrambling for the exit, it would be way too much effort to try to relate to someone on a social level. This is the type of distraction that those on the spectrum live with every day.

depending on the depth of the relationship or the difficulty of the task they are being asked to master. These children may experience trouble with other children on the playground, in physical education classes at

school, or in other circumstances such as in the halls or on the bus where relying on social information plays a role in success.

In adults with ASD, the lack of a social database may affect lifestyle choices and it could mean that they may not function well, if at all, in certain jobs or capacities. Although I know there are exceptions, someone on the spectrum would probably not gravitate to a job as an English teacher, occupational therapist, or a driving instructor. As a result of their social struggles, they may experience difficulty in tasks such as going to the grocery store, talking on the phone, handling monetary transactions or driving, all of which require some level of social interaction.

To someone with ASD, the social world can require a great deal of work to decipher, if they can figure it out at all. I talked to one man who was on the spectrum who had a mom, a dad and a sister whom he called the “Bermuda Triangle”—he felt that any communicated between the three of them was lost. He said, “I could never figure out what was going on in the Bermuda Triangle,” which implied that their communication and social understanding of each other was unintelligible to him. This individual is very high functioning and leads a relatively typical

life in the mainstream world, and yet he was unable to interject himself into the circle of relationships with his mother, father and sister; he was unable to understand the communication between them, because it was social in nature. As a result, he always felt on the outside, he always felt blamed and like he was the odd man out, the person who did not fit in. And that made him feel confused, isolated, alone and angry.

You might have heard that people with autism do not “pick up on social cues.” What that really means is that they are either not receiving a great deal of the social information the rest of us incorporate into our thinking automatically, or they do not have the social database to draw upon to interpret the social cues they are receiving. Most of the rest of us receive social data the way a computer receives Wi-Fi at the local coffee shop. It’s just there. When it comes to social thinking, we don’t even need to sign in to receive the data, we live with our receptors open all the time, and we unconsciously and automatically incorporate the data into our understanding. Those on the spectrum typically have their Wi-Fi turned off. Even if they concentrate on receiving the data, they may be unable to take in or process some or all of the data that is available. If the cycle goes unchecked, the social disability can grow and compound, looming larger and larger in the lives of these individual as they develop or mature.

Once the rest of us are familiar with the concept that our loved ones with ASD don’t have a social database, it gives us the background we need to interpret behavior in a new way and to better understand the experience of our loved one on the spectrum.

The Clash Between Social Expectations and Nonsocial Thinking

Inevitably, there is a natural clash between the social expectations in our culture and the nonsocial thinking of someone with ASD. Much of the social conformity that comes

naturally to the rest of us originates from innately knowing and following the social rules without thought—from “ought-ism.” We act, think and do things the way we do because that is just how they are done in our world, no questions asked. But lacking that social behavioral instinct, choosing behavior that is logical would be natural and that is common criteria for many with ASD.

Refusal to do things the rest of us frequently do by rote is a very pronounced and common experience when dealing with those on the spectrum. This behavior can appear belligerent and stubborn and can feel very frustrating and aggravating to cope with, especially on a routine basis. It can also be confusing, since the rest of us naturally care deeply about how we are seen by others and the world around us and we expect everyone else to feel that way, too.

When a certain behavior is difficult or painful to execute, those on the spectrum can’t understand the benefits of how it positions them in the social world, and now it is illogical, too. I can see where my ASD loved ones are coming from when they refuse to do so many things that the rest of us never question. From that perspective, the rest of us blindly following rules we hold subconsciously might look lemming-like to someone on the spectrum.

All of this seeming noncompliance is wrapped up in an additional complication—the difficulty with executive functioning, which makes it unlikely that individuals with ASD will be able to see the big picture well enough to understand their part in it, or, as one psychiatrist said to me, project themselves into the future to see if a certain behavior might result in negative outcomes. Processing data that is not black and white or has many layers to it, like social information, or understanding the consequences of your

actions is difficult for those on the spectrum. I recently heard Temple Grandin speak about cumulative assessments. She showed a picture of a big H on the screen; the big H was made up of little H's. She explained that she would see the little h's but not the big H, and that it is easier for people on the spectrum to see the individual pieces rather than the aggregate picture. They cannot see the forest for the trees, so to speak.

Unable to see the connection between themselves and the consequences (the little h's and the cumulative big H), many of those with ASD habitually blame others or circumstances for their outcomes; it is not uncommon for them to be unaware of their responsibility in a situation. Now, an action that previously seemed like non-compliance, takes on an air of blame, and the rest of us can take it square on the chin at times. Getting blamed for someone else's issues or mistakes is a behavior that feels very antisocial to the rest of us.

Forced conformity to social rules, if it is possible (and it might not be), can lead to anger in someone on the spectrum. Therapists have told me that anger is the most prevalent emotion experienced by those on the spectrum. Dr. Wahlberg said, "Wouldn't it make you angry if nothing in your world ever went your way, EVER?" That is the dilemma of someone on the spectrum whose deepest desire is to control the environment, minimize social contact and narrow their world to make it more manageable and less painful, while the world and the rest of us demand that they interact. We even consider forced interaction therapeutic. Even if it were possible (and it might not be) for all of that energy that is spent avoiding social contact to now get diverted to doing it "right," to "ought-ism," to appropriate social contact, what area of their life gets starved for energy? How painful would that be?

The social difficulties that the difference in neurology can cause often create a giant clash between behavior that is considered mainstream socially acceptable and the social behavior that comes with the package of autism. While a certain level of social conformity is required to function in society (after all you can't go into a bank wielding a gun), that probably still stops short of behavior that most of us who are steeped in social propriety would consider "nice," and "not nice," and really complicates being successful in our socially based economy and society. Individuals with ASD who desire to live independently in the mainstream world will need to find ways to adapt so that they can function successfully and sustain themselves in the right-handed world that is built for the psychological, social, emotional, financial and functional ease of the rest of us neurotypical folks.

The Times 10 Intensity Rule of Thumb

People with a social disability deserve a deep respect and compassion because living in their world requires a great deal of effort—constant and concerted effort. On a regular basis, they must force themselves to participate in painful social contact to survive in our culture. That is like the rest of us asking ourselves to willingly work in an office where the fire alarm sounds every day, all day long. If our world is not easy, their world is not easy by a factor of 10; Dr. Wahlberg would say "times 10." The times 10 factor is a great rule of thumb, a quick trick, if you will, to put yourself in the shoes of someone with ASD and get a sense of their experience.

Anything that is hard for you is 10 times harder for someone on the spectrum. If it is hard for you to approach someone in a social situation, it is 10 times harder for someone on the spectrum to do it. If you get agitated driving in traffic, someone

on the spectrum will be 10 times more agitated. If a situation is confusing to you and you feel awkward and uncomfortable about it, it is going to be 10 times more confusing, more awkward and more uncomfortable for someone on the autism spectrum.

Are there things that irritate you? Does the smell of coffee in the morning make you nauseous? Imagine if it were 10 times worse. When you are trying to watch the news, does it irritate you when the neighbor's dog is barking and you cannot hear the TV easily? It might be 10 times more distracting if you are on the spectrum. Does it upset you when there is lots of commotion around you and you are trying to concentrate? Now imagine these circumstances 10 times worse. Plus, they never let up! There is no respite—ever. That is life on the autism spectrum, and getting our head totally wrapped around that concept changes the way we feel about the behavior we don't like. Think back and remember how you acted the last time you had a really, really bad day. Did you snap at someone, swear, or perhaps even throw something? Imagine how hard life would be if every day were like that day and your anger, frustration, anxiety, and fear compounded daily. That viewpoint puts their behavior in perspective, doesn't it?

Any time I experience some discomfort, if I can manage to stop the rush of life and think about what is going on for me, I can imagine what it would be like to experience the same feeling 10 times worse and get some sort of an idea of what it might be like for those on the spectrum to deal with the same issue. Is it any wonder why they want to be left alone? Why they want to be alone in their room where it is dark and quiet and where they can control the environment and avoid social contact? Any wonder why autism is considered a social disability? Any wonder why new situations, circumstances and interactions are daunting to

face? Some days I want to retreat and hide in my room, too, and that happens without the autism. I can imagine how determined I would be to escape if that feeling were ten times worse. I would work hard for the status quo, too. Makes sense to me!

Meet Them Where They Are

Trying to force someone with autism to do it “right,” or like the rest of us, is like trying to force a left-handed person to function in a right-handed way. It can be done, and some people with autism can learn to look very “right handed,” very socially acceptable, but at what cost? What is the psychological and emotional cost to people on the spectrum when they must force themselves to adapt to the social rules that the rest of us understand and follow naturally. Are we really honoring the best of them if we are trying to force them to be like everyone else? That is a big question, and one without a simple answer, but still a valid question. While I am not advocating letting those on the spectrum do whatever comes naturally and make no effort to follow social convention, perhaps, through deeper and more pervasive understanding on the part of the rest of us, we can meet them at least part way to ease the pressure put on our autistic loved ones to fit into a world that does not suit them.

Really grasping autism as a social disability is a foundational piece of understanding the world of autism and hopefully changes our negative reaction to it. Comprehending this so deeply that it categorically alters our definition of autism is so important that the next chapter discusses it in more detail. The first step toward building better relationships and reducing the clash between our social thinking and the nonsocial thinking of someone on the spectrum is to understand the pervasive implications of our social thinking, and the ways we are socially connected to our loved ones on the spectrum. ■ ■ ■

In this Chapter

- Understand the concept of social gravity
- Learn how the hidden rules behind social gravity create problems
- Discover the social shorthand at work in our world

5

The Seven Hidden Rules of Social Gravity

Social Thinking/Social Gravity

What do I mean by “social” thinking? I mean the awareness of other people—recognizing the presence of others, maybe even possessing a drive to connect with other people, or having a desire to be a part of something that includes other people, and caring enough to live in a way that all of that influences your behavior and your feelings. Social thinking is as common to most of us as gravity. We operate in this world, functioning and making decisions based on our belief that gravity is working because we have always lived with it; it guides how we live our daily lives. We don’t worry when we set down a cup that it will suddenly fly off the table. We know that when we pour milk from the bottle it will fall into the glass below. If gravity was suddenly suspended, everything would be different, and what we do and how we do it would change.

Social thinking operates the same way. Social thinking is something that is so much a part of the rest of us that

it operates as a behavioral gravity and holds us to what is “normal”—to our social and cultural expectations. Social thinking affects how we relate with, live amongst and connect with other people. Our social thinking tethers us to a certain set of rules, behaviors, and a certain way of doing things, and it forms our expectations of the responses we will receive from others who we presume operate under the same laws of social gravity. Based on social gravity, we believe that if we do “X,” the appropriate behavioral response from someone else operating under social gravity will be “Y.”

There is also a more subtle cultural aspect to social gravity whereby we almost instinctively harbor beliefs about what a good life should include, and those beliefs shape our expectations of people and our ideas of what success should look like. For many of us, that belief about success may include a fulfilling career, financial independence and security, family and good health. These may not be realistic or desirable goals for someone on the spectrum, and the rest of us who surround those individuals who do not hold these same goals for themselves may find it very disconcerting or disturbing, even to the point of considering them unsuccessful.

The power of social gravity to bind us to behavioral and lifestyle expectations is so automatic that we are not even aware of it, and our assumption is that everyone is operating from the same base of information. After all, everyone is bound by the earth’s gravity, right? Social gravity’s influence is based on the ability and desire to recognize the need to reference, process and apply the information in our social database.

The nature of the largest part of our communication is unspoken and subtle—emotionally and socially based information rather than written, fact based or sensory based.

This information exchange can be very complex, occurring on multiple levels at the same time. The same phrase can reflect two different meanings depending on the body language that accompanies it. For example, if someone says “I love my neighbor” with a smile on his face, that is a very different meaning than if someone says “I love my neighbor,” while making a gesture of choking the person.

The differences can be even subtler than that. Emphasis on a certain word can change meaning. “I *love* my neighbor,” which implies that you love your neighbor as opposed to hating them is very different in meaning from “I love *my* neighbor,” which connotes that you love your neighbor as opposed to how someone else feels about their neighbor. For those of us not on the spectrum, much of the subtle social data and meaning we capture stays below the surface of our awareness, but it is there for retrieval at some later time. For those on the spectrum, that subtle information will probably be lost forever.

In Chapter 4 we discussed the fact that those on the spectrum do not develop a social database to reference in order to understand, interpret and operate socially like the rest of us. The net result of not developing a social database is that people on the spectrum do not always have a reference point for behavior. At the very least, they do not use the same frame of reference or reference point that the rest of us use. For example, in preschool, young children may participate in circle time, where they are expected to sit down and talk or read a book as a group. A child on the spectrum might not sit down when the teacher calls for “circle time” even though all the other kids do gather to sit in the circle. Socially based kids who missed the direction will see the others sitting down and follow suit because their social gravity tells them that doing what others are

doing is safe, acceptable and appropriate behavior. They do this because of their innate social awareness—social gravity. A kid on the spectrum may totally miss both the teacher’s direct request and the social flow of the group and end up still wandering around the room playing with the other toys. Children on the spectrum typically do not possess that internal social reference mechanism, or social gravity, that tells them that if everybody else is sitting down, they should sit down, too. Social gravity is either suspended or spotty in their world.

Part of social gravity’s power feeds our expectation that everyone has the same frame of reference that we do. When we suddenly run into an individual who is not operating under the same social gravity, it can blindside us, sometimes coming as a real shock. Even worse, we can live for years thinking that the person we are in a relationship with is operating under the same socially influenced thinking as we are, and upon understanding that they are not, realize that we misinterpreted years of social data. Operating under the erroneous belief that the individual with whom you are trying to sustain a long-term relationship has the same social gravity at work in their world that you do is a really frustrating and confusing experience. The fallout in our lives and the damage to our opinions of our self can be immense.

Rule #1: Comprehending Differences in Thought

Researchers and psychologists have identified that theory of mind can be an issue for people on the spectrum. Theory of mind is about understanding that someone else has a different perspective. It means knowing that your perspective is only your perspective, not the one, single, definitive truth about something, and that someone else might legitimately feel or think differently about the same subject.

This belief that we know the absolute truth can be a real stumbling block. For example, when my son and I disagree on something that we are discussing, it will often sound like this:

“Mom, you are not listening to me.”

“Yes, I am listening to you.”

“But, that is blue.”

“No, it is green.”

“No, mom, you are not listening to me. It is blue.”

“I am listening to you. I just do not agree. I think it is green.”

His feeling is that if I do not agree with him, I must not be listening to him because, from his perspective, there is only absolute truth and he knows what that is. In his black and white thinking, all other possibilities for truth are eliminated in the gray areas. How can I disagree with him? I must be hearing him incorrectly or not listening. He has a difficult time understanding that we could be looking at the same thing and that my perspective could be real at the same time that his perspective is real. That recognition would require theory of mind. The possible social difficulties that might arise as a result of lack of theory of mind are obvious.

Rule #2: Social Information as a Motivator

Social information is also a motivator to those of us without ASD. We don't want to feel awkward about how we look, so we dress like everyone else. That is not usually true for someone on the spectrum; social information does not usually provide motivation. I have seen some pretty strange looking outfits over the years! The rest of us don't want to stand out as weird so we pay attention to our appearance and wear what is considered appropriate (if not stylish) instead of wearing our shirts inside out and backwards and our pants three inches too short, revealing

mismatched shoes. It would be a very rare individual who would wear a suit and tie with a felt hat to a picnic in today's world—that level of formality isn't stylish anymore and would look odd, so we are motivated by social gravity not to do it.

What do you think would happen if an individual with ASD is having a nice dinner at a fancy restaurant and he suddenly needed to fart really badly? He might fart very loudly in the middle of the dining room. You and I would not do that. Those of us who live socially based lives would be motivated by our social gravity to excuse ourselves and go to the bathroom to fart instead of farting in the middle of the restaurant and then excusing the behavior by saying ... “that is what the body does, it is natural, it is normal, it happened, my body just did it. It is not my fault. Why would you say that is a problem? I do not see why that is a problem!” For someone with ASD, because that social database is lacking, there is typically not a social filter or reference, or social motivation to do what is “socially acceptable.”

Rule #3: Social Thinking Shorthand

Social thinking not only shapes our expectations in a relationship, it acts as a kind of shorthand because it has embedded within it commonly accepted wisdom/knowledge which is so widely believed that it is neither questioned nor challenged. Thinking socially is the difference between saying “that is how it is done” and having that be sufficient explanation, versus explaining all the reasons why that is how it is done. For example, simply saying “we pay our bills on time” and having that understood versus a conversation that might sound like this:

“We pay our bills on time.”

“Why?” will be the invariable response.

“So that our credit rating stays high.”

“Why?”

“So that we can buy something on credit when we need it.”

“Why?”

“So that we can achieve our goals and dreams that require money.”

To which they might respond “Why?” or “Who cares about goals and dreams?” But, eventually, the response will be some form of dismissal of our socially based logic.

Being required to explain the common understandings that comprise social shorthand is frustrating, sometimes even exasperating. Being required to justify their validity is like trying to trap a bubble with a spoon! At some point we fall back on our social gravity as a bedrock foundation, which goes without stating and the rest of us accept as a common basis for understanding.

As an experiment, create a conversation where one party always answers with “Why?” At some point you will find yourself relying on social understanding and either defending or debating its validity to make your point. Even an argument that comes down to “If you do not do this, you will die” can result in the response, “So what if I die?” It is a socially based assumption that we do not want to die. This lack of a common bottom line creates a loophole through which one can always escape agreement, and thus be unaccountable to respond to the socially logical requests of the rest of us.

This difference in the understanding and acceptance of social shorthand’s common base of knowledge can drive a huge wedge between people who view individuals with autism as ignorant, uncooperative, argumentative or just wrong when

they do not recognize or respect the social gravity that the rest of us follow without even being aware of it. The lack of a shared base of understanding on the part of those with autism renders every meaningful conversation the rest of us engage in with them exponentially more difficult, frustrating and possibly even contentious.

Rule #4: Social Air Buffer

When we learn to drive, we are taught to keep an empty air buffer around our vehicle while in traffic to help prevent accidents. Interestingly, this same principle may be at work in people with ASD when it comes to social interaction. Avoiding social contact by keeping a distance serves the purpose of eliminating conflict, and reducing the demands on their energy.

My son and his friends recently started college. When I asked him how a particular friend was doing at school, I expected to hear that his friend liked being away at school, didn't like it or some other detail about the friend's experience. Instead, what my son said was "I don't know, I didn't ask him because it's none of my business. It's his private business." By the same token my son feels that no one else should ask him how he feels or how he is doing with his new school experience.

To the rest of us, asking these questions shows interest in someone and shows that we care. To my son, this inquiry is an unwelcome intrusion on his privacy because it requires a lot of effort to respond. He prefers to remain distant which acts as a social buffer, a "free zone" around him, and I can see how, from his perspective, he might feel that not engaging will help him avoid accidents socially. Not everyone on the spectrum desires to stay distant from others, but many find solitude much more preferable, peaceful and relaxing than social contact.

Rule #5: The Social Exchange

Let's define "social exchange" as any exchange that is based on social gravity or includes social context which is innate, unwritten, or unspoken behavioral information surrounding the social interaction between two people. For example, when I go into McDonald's and I want French fries, I tell the clerk what I want, I give him the money, and he gives me French fries. That is a social exchange and it has a context. Purchasing with an accepted legal tender is a very deeply understood piece of social shorthand in our world.

Purchasing French fries may not be a very deep exchange, but nonetheless, it is a social exchange. If you were an alien from another planet and did not know our culture or you did not know the social context, you might think that you could just go in and demand French fries and when the guy came to the counter, you could grab the fries and hand him some meaningless rock in exchange, or perhaps punch him in the nose and run off. Neither would be social exchanges in keeping with the social context that is prevalent in our world today.

In every relationship there are certain criteria that define the relationship. There is the customer and the French fry guy at McDonald's. I don't need to tell you what the social context of their relationship looks like; you already know—it's everything that is appropriate in a relationship where the sale/procurement of French fries is the goal. There is the doctor and the patient in the office. There is the mother and the child. There are spouses. There is the customer and the lady who hands you your dry cleaning. There is the policeman directing traffic on the corner and the person driving the car. Every relationship has two people, and there are certain social expectations, rules, and roles that are ingrained in the effective working of that

relationship. We learned these as part of the development of our social database, which included learning the unspoken rules and appropriateness of social contact.

Usually a social exchange goes smoothly because the social context (all that unwritten information) is understood automatically. Using our social gravity to motivate us to draw upon our social database helps the relationship function without stating everything explicitly. This is not always crystal clear to someone with ASD.

One of my favorite stories (and one of the most beautiful) illustrating how a social exchange can go awry when social context is misunderstood, misinterpreted or absent happened on a Halloween night the first year my son, then 2½, went trick-or-treating. Dressed in his costume, he was ready to leave the house with his empty plastic pumpkin bucket to go door to door and collect treats. But we couldn't get him out of the house; he had a meltdown at the door! We thought maybe he was afraid so we tried to carry him; that didn't work. He wanted the candy we had at *our* door. We pointed out the other children already out on the street, but he continued to insist that he wanted candy from our house. Finally, I put a big handful of our candy in his bucket and he left content.

I watched as my husband walked him next door. When the door opened, he reached in his bucket, took out some candy and dropped it into the dish that the neighbor held and turned to leave. He did not understand that the social context of trick-or-treating meant that he *received* candy. His only experience of trick-or-treating was watching me give candy to those who came to our door, so giving candy was what he thought was the "right" thing to do. That misconception was not only at the root of his meltdown, it caused him to behave inappropriately

(although beautifully) in the situation. I love this story, because it is innocent and shows the beautiful and giving nature of my son's heart, but when you scale that type of misunderstanding up to adulthood, the issues might not be deemed so innocent, beautiful or easily brushed off. What if that same type of misunderstanding happened to an adult over money? The consequences could be severe.

The social exchange between a husband and wife is based on an ingrained, unspoken, understood social context of marriage that defines the expectations and the understanding of the relationship. It is something that everybody knows. It is so widely spread that most of the sitcoms of the 1950s and '60s were written about it. When Lucy and Ricky of *I Love Lucy* fame fought over money, we all laughed and thought it was funny because we understood the context of their relationship. We understood that there was a financial connection between Ricky and Lucy, and that is what made it funny when Lucy was trying to sit on her hat to hide it because she did not want Ricky to know she had spent the grocery money to buy the hat at the department store. If we did not understand the context, we would not laugh. It is possible that someone on the autism spectrum would not understand why this was funny.

Those on the spectrum often experience a great deal of anxiety around social interaction, which may cause them to avoid any contact with others. Even if those with ASD are not trying to avoid social interaction, they may miss our intention when we approach them. A good friend of mine, whom I talk with several times a week, has recently moved in with her boyfriend, who has ASD. Everything is going well for them, and we often compare notes. Because of her understanding of autism, theirs is a real success story. Recently she recounted an

incident to me in which she approached her boyfriend while he was deeply engaged in building a complicated homemade electronic weather station. (This is the type of activity many people with ASD like to do.) It was late at night and she wanted him to spend some time with her. She asked him what he was doing and he told her the name of the weather gauge he was building. She asked several more questions in an attempt to gain access into his world, and he answered them with some very technological data, which of course she had no interest in knowing at that time.

To his nonsocial way of thinking, her questions were just questions that required an answer and no more. She asked and he answered believing that the information is what she wanted. After all, why would she ask otherwise, right? In reality, she wanted to connect with him and to engage him socially. He did not realize that her line of questions was actually a way to get his attention; she wasn't interested in the technical details of his project. Fortunately, because my friend understands autism, she can manage her reactions and her needs to keep the situation from escalating. Eventually, to truly gain his attention, she will probably have to ask for it clearly and directly, and even then, he may or may not be willing to give it to her.

The fluidity with which social context is absorbed, understood and obeyed by the rest of us often does not happen for those on the spectrum. They lack the social database that the rest of us use as a reference. We innately refer to our social database and extrapolate meaning from previous social exchanges and contexts we have experienced to apply to current situations. While many of those with ASD may know the context of buying French fries, these individuals may appear odd on a job interview or at a first meeting of a friend's parents,

or in some other unique situation where the social context may not be so apparent and the ability to reference similar situations may be hampered by the autism. Many social exchanges are so painful or confusing for those on the spectrum that they actually work hard to avoid them, which only perpetuates their lack of a social database to reference.

Rule #6: Social and Emotional Connectedness

Social and emotional connectedness is another important dimension to any relationship; it is also the one that is most disturbing when it is out of kilter. Social connectedness is a continuum, ranging from zero acknowledgement of someone in the room to close relationships that require deeply recognizing and allowing the other person to influence you, as in a marriage. At some point on that continuum, the individuals become emotionally connected as well. So, on one end there is the kind of exchange that you might experience in an elevator—a grunt, a nod of your head or a tiny smile—something very minimal, or even no acknowledgement at all.

On the other end of the gamut would be a relationship where the connection between the two people is so deep and so important that one feels motivated or moved to make a difficult, painful, or important adjustment just because he cares about the other person, and he cares about how the other person feels.

Connectedness is what happens in our hearts and in our minds when we consciously or unconsciously decide to let someone matter to us, and the more they matter, the more connected we are. Connectedness is not about agreeing with one another, or even seeing things the same way; it is not even about truly understanding each other.

Connectedness is about the level that you will allow that person to influence you. At some point on the continuum, the connection

becomes an emotional connection as well. If the French fry guy said to you, “Your shoes are ugly” or “You are ugly and I do not like you,” it would probably not affect you in the same way as if your sister or your spouse said those same words to you. In the end, connectedness is really about how willing you are to allow the information coming from that other person to register in your mind in some meaningful way and be motivated to respond to that. This deep social/emotional connectedness answers the question, “Why would I do that for you?” with “Because I love you and your happiness is important enough to me to go out of my way or experience discomfort to please you.”

For example, a wife might say to her husband, “Honey, I want ice cream,” and the husband might reply, “I do not really feel like going out to get ice cream.” She looks at him with questioning eyes, and he says, “Well, if it makes you happy, I will go for ice cream.” Although a very inconsequential request, she

When you are repeatedly left emotionally hanging, it feels like the connection in the relationship is somehow unnameably incomplete.

relied on her emotional connection with him to motivate him to action. This could also happen on a very deep and important issue such as “I love you

and I want to have children with you,” to which the response might be, “I love you, too, and because it is important to you, that is what I want, too.”

The emotional impact and the depth and the importance of the topic can vary greatly depending on the relationship, but the fact remains that every relationship requires an appropriate level of social and emotional connectedness or place on the continuum.

Rule #6 (Part A): Too Little Connectedness

What happens when that social/emotional connectedness is not appropriate, especially when the connection is not enough? You would not walk up to the French fry guy and say, “I would like an order of French fries. By the way, I want you to quit this job and get a better one,” and likewise the French fry guy would not say, “Here is your change,” and proceed to also give you a kiss. Those types of casual relationships are much lower on the scale of social connectedness. By the same token, you would not step into an elevator and give an almost imperceptible nod to your best friend. If you did, your friend would either respond by getting really angry or think you were nuts!

In a marriage, if you feel that your spouse is not willing to change for you at all, is not willing to listen to you, or does not respond to you, eventually you will probably feel that what you say does not matter, and that you are unable to influence your spouse at all. When that happens, it feels like the connectedness gets lost. When you lose that connectedness, you may feel as if the relationship is somehow incomplete, as if you are the only one in the relationship, which can be very painful, especially in a long-term relationship like a marriage.

I spoke to one woman whose husband is on the spectrum. She lost her parents within months of one another. She was quite close to her parents, and when her mother died, the second of the two parents to pass away, she came home from the hospital heartbroken. She was devastated and felt very alone. When she walked in the door from the hospital and said to her husband, “My mom died,” he looked at her and then looked out the window and said, “Did you see that the bluebirds are in the nest again?” She was crushed by that response. He did not have that connectedness to her and if he did, he was not able to

express it; he was unable to be there for her in one of her darkest moments, and she was left feeling like “... what the F#@*?” Given the pain she was experiencing about the loss of her mother, the discovery that he was not emotionally connected to her was like salt in her wounds.

For the rest of us, this lack of connection is a very dissatisfying emotional experience that really misses the mark and leaves us with an itch that never gets scratched. When you are repeatedly left emotionally hanging, it feels like the connection in the relationship is somehow unnameably incomplete. That can be very sad and lonely, and we can have the sense that we are the only one in the relationship, even if that is not the case.

The experience has the sensation of being on the wrong side of a one-way mirror jumping around screaming and hollering, and feeling like you can't even be seen. If they cannot even see you, certainly they cannot experience what you are experiencing, share your pain, or comfort you. When emotional needs go unmet in this way it can have all sorts of negative emotional implications on the rest of us, including creating self-doubt and anger among other feelings.

In a marriage situation, this social difficulty can feel like there is no sense of partnership. Communication, joint decision making and negotiation are very social acts, and they require a certain social connectedness. In order to be willing to even engage in negotiation, you must be on the connected end of the social connectedness scale to a certain point. You need to care about the other person and want to work toward a compromise in order to even begin to negotiate.

Lack of connectedness and cooperation is accentuated by the demands of any relationship where the two individuals rely on

each other deeply, whether that is a business relationship or a personal relationship.

Over time, repeated experiences of missing the social/emotional connection target create a deep need in the neurotypical partner that keeps growing until it becomes very painful to feel unconnected. If you continue to give of yourself from this one-sided, unconnected state, living with too little emotional connection becomes draining.

Rule #6 (Part B): Too Much Connectedness

On the flip side, when the connection is too much, like the French fry guy who wanted to give you a kiss, it can be very awkward, weird or even be perceived as criminal in some situations. The stories of autistic teenage boys who fall in love with the most popular girl at school but are inappropriate in their approach are classic. I have also heard descriptions of individuals who have casually befriended someone with ASD who misreads the level of connectedness and interprets the casual friendship as a new best friend scenario.

Being connected does not come naturally and easily to most people on the spectrum. Sometimes, they consciously decide if they are going to be connected. In his book, *The Journal of Best Practices: A Memoir of Marriage, Asperger Syndrome and One Man's Quest to be a Better Husband*, David Finch talks about becoming aware of his social disability and about making a conscious decision to let his wife guide him. He let her in at the deepest level and let her advice, opinions, and social input guide him and guide his decisions. He made a conscious decision to adopt a social connectedness perspective even though it did not come automatically for him. He had to work at it. In order to do something like that, David had to possess the capacity to care about his wife and the willingness to overcome his own internal

stressors to act on the commitment and to trust her enough to change himself. Not only was that an important message, but, it was really very beautiful. David also writes about empathy. He uses the word “empathy” in terms of being able to let the other person reach you in a way that influences you. I just want to share one quote from his book, which I adored, and highly recommend. He says, “Engaging the social world without empathy is like going to the mall without pants on. It can be done, but you are bound to have problems.” *Amen!*

Rule #7: “If You Love Me” Messages

The “if you love me” message is a very subtle form of communication. It is emotionally or socially based, and is not implicit, so it is not on the radar of someone on the spectrum. Let me give you an example: A wife might say to her husband, “I am not feeling well. Will you make me soup?” She says those words out loud, but the underlying message is, “If you love me, you will make me soup.” Her husband might respond with “I do not do soup,” or “I am not going to make soup today” or “I am making turkey today.” He misses the real message about her needs, but the wife’s expectation is that he will be able to hear that message and deliver on it. If he doesn’t, then the wife feels like he doesn’t love her. Guess what? “If you love me” messages probably do not register in the mind of someone on the spectrum.

“If you love me” messages can take different forms. In the workplace, they might translate to “if you respect me.” If the relationship is more professional, such as one with a doctor or an accountant, the message might be “if you trust me.” These messages: if you love me, if you respect me, if you trust me all share a similar flavor because their meaning is below the surface of the words. The emotional meaning is implied by the

statement coupled with the nature of the relationship and that is the first reason that they may not resonate with someone who is autistic. There are so many pitfalls in the “if you love me” message that they are probably doomed to failure before they are uttered. Here’s why:

- The first piece is the communication itself. That is such an important topic that it warrants its own chapter, but for now, let’s just say that the subtle, implied message is not typically effective with someone on the spectrum.
- The next piece is the connectedness that happens when someone decides to let someone else in. Often those with ASD don’t connect, or appear to connect, as deeply as we expect in our socially based thinking about relationships.
- Thirdly, the ability to execute behavior at an appropriate level on the connectedness continuum can often be a challenge. Even if those on the spectrum know what they should do, it may be difficult or impossible for them to clearly or effectively communicate their level of connectedness through their actions.
- Finally, there is the motivation to respond. Those with autism may be confused about your request that they do not know how to react, it may be so painful to fulfill the request that it is the lesser of two evils to disappoint you than to force themselves to act, or they may simply not see taking action as important because it is not perceived as logical or necessary from their point of view.

To respond appropriately, first the individual needs to recognize the message as an “if you love me” message. Since these messages are built on certain social expectations that just do not translate into *autism-ease*, someone on the spectrum can easily miss the underlying social context. Then the individual

must experience being connected at a deep enough level that he would allow himself, or more accurately push himself or force himself through his discomfort, to respond to that message. Thirdly, the person would need the executive functioning and ability to organize and follow through and actually execute appropriate action. Underlying all of this would have to be the motivation to do it.

Motivation is a key element because the “if you love me” messages are meant to be motivators in our social minds. So, someone with ASD would need to connect pleasing you with the message, and then he would need to understand that pleasing you is an important consideration to warrant action.

What feelings do the rest of us experience when someone ignores these messages or does not respond to them? In our social minds, we assume that the other person is intentionally ignoring them, but maybe, as I mentioned before, that person is not even hearing the messages. Either way, when you do not receive the response that you expect you suddenly feel uncomfortable with the level of social connectedness. All of a sudden, the person whom you thought really loved you is not acting like he loves you. The person who you thought respected you is not acting like he respects you. The person who you thought trusted you is not responding as if he trusts you, and it is confusing. These hidden messages are an important part of our communication.

Hidden Social Rules in Conclusion

For those of us not on the spectrum, our social gravity database starts to build when we are born, beginning with our connection to our mother and father, and growing from there as we build an experiential database of social information. For example, nobody tells a baby that her mother’s touch is

comforting or that if she cries a certain way, her mother will feed her; the infant gathers that knowledge from experience automatically. It is as if we were born with Wi-Fi, and our Wi-Fi is turned on, so we pick up the available signals naturally and add them to our growing database of social information. We communicate and then we judge our success based on the reaction. Then we adapt accordingly. Thus, ever since we arrived on the planet, our database has been increasing with layer upon layer upon layer of new information gleaned from every connection and interaction with every person we meet. As neurotypical individuals, all of that information is available to us to retrieve and consult for every future situation we encounter.

Not so for individuals on the spectrum. Their neurology is consumed with dealing with other types of input—their channels are too busy processing other information. In their world, social information tends to get lost because it takes a back seat to the sensory data that is presented—the lights, the sounds, the sensations, etc., causing subtle social information to be drowned out and not recorded. Since there is simply not enough bandwidth to process all the information at one time, those with ASD just get the tip of the iceberg, and the rest falls away. As a result of that neurological style, unlike the rest of us, people on the spectrum are not building the same broad, deep and multilayered social database from the time they are born. Instead, those with autism develop a limited social database, which does not grow and update on a regular basis, so when they enter into a relationship it can often feel out of balance, one sided, or as if $1+1$ doesn't equal 2.



In this Chapter

- Validate your feelings without blame; accept yourself
- Cooperative versus logical behavior
- Attraction to someone on the spectrum
- The “Nice” factor and how it shapes our lives

6

Funky Social Math: When $1+1=1$

Responsibility for the Relationship

Imagine two neighboring countries separated by a small sea. Each can be seen from the other’s shore, but there is no real connection between the two nations. They are separate countries living their own lives independently of one another.

Country A is a social country that has, by its very nature, a drive to develop relationships that enrich its people by attracting new people and new ideas. The people of this country have a desire to explore, discover new lands and share those experiences at home. Country A wants to engage and connect with other countries, and to share and grow and find the kind of satisfaction that is only derived from connecting with others in a meaningful way.

This country is confident that its ships can traverse the ocean safely and land on the other side; it does so with the hope and expectation of building bridges that will promote long-term additional richness in its life. As a result of the innate ambition

in this country, its people begin to build ships and send them out to explore and to find other worlds.

Eventually, this country stumbles across Country B, which is totally different. Life is really tough there. Country B is facing pestilence and famine, disease and poverty, crime, hatred and all kinds of other internal issues that are consuming the country's energy. This country has its hands full, focusing inward on itself and its struggles. The citizens of country B are so bogged down with survival that they cannot conceptualize traveling to the other country even if they wanted to expand and connect; they are maxed out with other demands. Their resources are totally tapped, and they do not possess any extra initiative to even begin to consider connecting socially with another country. The residents of Country B are so totally engrossed in survival mode that they are unaware that Country A even exists.

The citizens of Country B are not wrong or bad or broken or even antisocial. They are good, kind, loving, warm, wonderful people who need love and who need assistance, but they are not reaching out for some very valid reasons.

Once the people of Country A discover Country B, they realize that they are not all that far apart, although they are different and that is intriguing. The social country decides that they really care about this new country and they imagine a bridge to facilitate regular, easy access. However, if there is ever going to be a bridge between these two countries, all the work for its conception, creation, design, funding, building, labor, and maintenance is going to fall to the country that has the drive to form a social connection. The other country simply does not possess the resources.

In this example, the bridge represents the relationships we build with those with ASD. In the same way as in the analogy,

it is going to be up to the rest of us to build and maintain the connectedness with people on the spectrum. They are probably not going to have the resources, or the drive, to build a relationship with anyone. That one-sidedness can be offensive to our social expectations; when we find ourselves in this situation we are experiencing the funky social math in which $1+1=1$.

Reciprocity

Reciprocity in a relationship refers to mutual give and take in all areas of life: giving gifts, time, energy, attention, help, support, compromise, love, etc. When reciprocity exists, the flow of energy back and forth may not be equivalent, but it is at least satisfying enough for both parties to stay in the relationship. When reciprocity is occasionally missing, it may go unnoticed, but over time, the predominant or complete lack of reciprocity in a relationship can become painful, especially to the party who is doing all the giving. That person can feel angry, used, or resentful and those experiences can escalate to feeling empty, unloved, or even unloveable!

When an electrical circuit is broken, the energy never recycles; it becomes depleted. Energy goes out and goes out and goes out, and nothing ever returns back to recharge the source. Therefore, maintaining the relationship becomes a lot more work. In spite of the fact that a non-reciprocal relationship can be satisfying for a while, it is not easily sustained; too much energy is expended with nothing to replenish it, and at some point the giver burns out. We may not be consciously aware of the lack of reciprocity, but our social nature usually experiences the offensiveness of the situation on some level. Whether consciously or not, our assumption (based on social gravity and assuming that this is a personal relationship and not a mission on the part of the giving party) in entering the relationship was

that it should be reciprocal, and not having the reciprocity can seem very unfair.

Awareness of the difficulties the other person is facing and consciously choosing to bridge the gap because it's what we want to do can go a long way toward comforting our social nature. For example, my son is into Pokemon, Anime, and video games of all sorts. If I really want to be with him and connect with him, I need to get into his world. He cannot get into my world. I make the effort to join him in his world because I want to, because he is my son, and as the parent in the relationship I want to step up even if he does not reciprocate at all.

I know someone else whose husband with ASD is into sports, and if she really wants to share his world, she needs to grab a beer and sit down at the TV on Saturday afternoon and watch sports with him. Watching football or basketball games together is one way she can connect with him. He might be able to come into her world, but that would require a serious motivator.

This experience may feel different in different types of relationships. A marriage builds on a different social context and I would not necessarily feel as inclined to do all the giving if it were my spouse rather than my son. I would expect more reciprocity in a relationship with another adult such as a marriage. Our expectations of reciprocity can change from relationship to relationship but no matter what, we will probably need to be more flexible when the person we are attempting to relate to is on the spectrum.

Attraction to Someone on the Spectrum

If you are thinking “Why would you want to bother with a relationship with someone who doesn't care enough about building a relationship with you to make any effort?” then

maybe you never loved someone on the spectrum. For strong independent people, the differences in personality can be very engaging at first—opposites do attract. Often, they balance each other out and the two opposites can equal a whole. If you are a strong, driven person on your own, and you are not looking for someone to take care of you, but rather looking for someone who shows that softer side, someone who is creative, someone who is talented, someone who is smart and innocent in a certain way, or someone who does not ask so much of you that you feel smothered, you may be very likely to find a good partner in someone on the spectrum.

Not all reciprocity looks totally balanced or like equality. Sometimes the very act of balancing out dominant characteristics with their counterpart can be a form of reciprocity that leaves the whole better. Each relationship equation is unique, with each individual deriving his or her own special benefits from the relationship, so it is hard to judge from the outside. Lack of reciprocity can also be something that isn't experienced in the early stages of a relationship, and so may not be evident until the relationship becomes complicated enough in the areas that require true interdependence.

Cooperative (Social) vs. Logical (Nonsocial) Behaviors

There is a distinct difference in the behavior associated with the cooperative (social) perspective common among neurotypicals and the logical (nonsocial) perspective that comes most naturally to many people with autism. I don't mean to use the term nonsocial as a criticism, just as a counterpoint to social. We might also make this comparison by using the terms inwardly focused and outwardly focused, but inwardly focused also carries an unintended implication. In socially based thinkers there is a spirit of cooperation and they are motivated

by social gravity to help just because it is the right thing to do, or “the way it’s done” in an environment whether or not it is logical, or what they desire. When you think socially, your thinking includes a spirit of cooperation and of being part of something larger.

In contrast, people on the spectrum typically have a logical or nonsocially based perspective. They make decisions based on what is logical and meaningful to them. If I made a mess, it’s my mess. That’s logical. It’s not as though they intend to be not helpful or self-centered, but usually they lack the types of social understanding and motivation the rest of us feel; social gravity is suspended in their world, and does not hold them to the same cooperative behavior that the majority of us expect as part of social shorthand.

Let me give you a few examples of the differences between the behavior that results from social and nonsocial thinking in a family situation:

Nonsocially Based Thinking	Socially Based Thinking
“I did not make the mess. Why should I clean it up?” <i>or</i> “I don’t care if the mess gets cleaned up. If it bothers you, then you clean it up.”	“I will do it because my mother told me to, and not doing it will bring consequences.” <i>or</i> “As a family member I am expected to help out around the house.”

From outward appearances, it is easy to assume that people with this nonsocial perspective are just not giving, not nice, not helpful, etc., but those assumptions may be categorically untrue. Not judging this perspective changes our emotional reaction to

it, but in order to suspend our judgment, we probably need to understand autistic brain functioning and how that leads to the lack of a social perspective, and consciously choose not to blame the individual with ASD.

In a similar example, if you are married and want help washing the windows, you might ask your spouse, “Will you please help me wash the windows,” and the response might be as follows:

Nonsocially Based Thinking	Socially Based Thinking
<p>“Windows are not my job. If you want the windows washed, then do them yourself.”</p> <p style="text-align: center;"><i>or</i></p> <p>“I do not care if the windows are dirty. If you want them clean, wash them, or otherwise leave them dirty.”</p>	<p>“I will help you because you asked me to, and if it is important to you, I will make the effort.”</p> <p style="text-align: center;"><i>or</i></p> <p>“As one of the adults in the household, I need to participate in taking care of the house, so I will do what needs to be done.”</p>

Intuitively, many of us in a family setting realize that “working cooperatively is what families do.” It is what makes a family a family. In those cases, family members might just pitch in without being asked when they perceive that a task is burdensome or difficult on another family member. If we see our spouse with 10 bags of groceries, we automatically jump in and help to bring them into the house. After all, that’s what families do, right? Someone on the spectrum may not intuitively understand that concept. Each request might need to be processed separately, and each request requires a valid reason

behind it. The idea that “we do it just because we do it” is not going to register in the mind of someone on the spectrum, and it is probably not going to act as a motivator.

Here’s a workplace example: a supervisor makes a request of an employee: “I have a meeting tomorrow and I need XYZ report.”

Nonsocially Based Thinking	Socially Based Thinking
<p>“I have to complete 10 other reports, so I will add that to the bottom of the list. When I finish the other 10, I will get that one done.”</p>	<p>“My boss asked me to do it and he must have a good reason, so I will do it because he asked and I don’t want to get fired.”</p>
<p><i>or</i></p>	<p><i>or</i></p>
<p>“Why do you need that report? I gave you 10 other reports and that report is useless anyway. I don’t see any reason to do that report”</p>	<p>“Sure, Boss, I will be glad to do whatever you ask of me. When do you need it?”</p>

In the workplace, social cooperation might also translate into wearing long pants or a shirt and tie because “that is what we do at company ABC.” People on the spectrum might think, “I am not comfortable in a tie. I do not want to wear a tie,” and they behave accordingly. They do not necessarily want to respond to “we do it just because that is the way we do it here.”

When we are on the receiving end of behavior that is so self-focused that it flies in the face of our social expectations or the social context, and/or the appropriate level of connectedness for that social exchange, we can feel offended, our feelings can be hurt, or it can leave us really angry.

The Nice Factor

Underlying our relationships, there is this whole “nice factor” at work in our social environment. The rest of us feel a natural urge to be nice or to follow the rules so that we appear to be nice. Here are some examples of nice:

- Nice people do not fart loudly in the restaurant.
- Nice people do not hang up without saying goodbye.
- Nice people do not tell their mothers-in-law they are fat.
- Nice people do not leave dog poop on their neighbor’s lawns.
- Nice people don’t take things out of others’ shopping carts in the store.
- Nice people don’t cut in line in front of others who are waiting.

You get the idea. We do what we do because it is nice to do it, because then we are nice people; social gravity holds us to that behavior.

We judge people as not nice when they do not follow common rules of niceness: it’s not nice to key someone’s car. It’s not nice to ignore your neighbor when they say hello in the front yard, it’s not nice to walk into someone’s house with mud on your shoes. People who are not nice leave their garbage on the table at the food court in the mall for others to pick up. They take all of the doggie waste receptacles at the park instead of taking just what they need. They slam the door in someone’s face if they don’t want to talk to him.

People like “nice,” but people on the spectrum often seem “not nice,” because they behave in ways that the rest of us would consider not nice. It’s not necessarily because they are not nice people. Some of those social contexts are just lost on people

with ASD. That is part of what therapists are attempting to teach those on the spectrum through therapy—to get along with the world on the world’s terms, but typically the nice factor is not a motivator for people who are on the spectrum; the “nice” rules are not even on their radar.

As I have mentioned, I have two sons—my older one is on the spectrum and my younger son is not. We were leaving for school the other day, and my autistic son was in a hurry. He was already in the car. My socially based, 15-year-old son came out carrying a cup of tea, walked through the garage and reached the garage door when my son with ASD hit the button to close the door. That action scared my younger son, who spilled his cup of tea all over the front of his clothes. This upset him because now he had to change his outfit. He became angry because he said it took him a long time to pick out this outfit, and he didn’t want to go to school with tea stains on his sweatshirt.

Such a clash between the social and nonsocial people in my family! There were so many clashes between them in this scenario, it was almost funny. First, my son who is on the spectrum did not feel that he was in any way responsible for spilling the tea. After all, he was not holding the cup, nor did he tell his brother to bring the tea with him in the car, nor was he responsible for the fact that his brother jumped in reaction to the door’s movement over his head. My ASD son even went so far as to blame his brother, saying, “This is your fault. You are the one who threw the tea on yourself. All I did was press the garage door button.” He sincerely did not see himself as responsible for the mishap.

Furthermore, he could not understand why his brother would bother to spend the time picking out an outfit, why he cared about looking good, and what difference it made if he had

tea stains on his clothes at school. All of that seemed ridiculous from an ASD point of view, especially since the immediate task at hand was to get to school quickly.

My younger son not only felt angry but also hurt because he said his brother “was not being nice.” His social sensibilities were offended, especially by the lack of connectedness he felt his brother displayed.

Not only did he cause the spill, and did not apologize or take responsibility for it, but he criticized his

People like “nice,” but people on the spectrum often seem “not nice,” because they behave in ways that the rest of us would consider not nice.

brother for caring about his appearance—double whammy. The “not nice” factor played a big role in that situation; my younger son ended up on the receiving end of his autistic brother’s logical and nonsocial thinking in more ways than one.

Because I watched the whole incident, and I understood both perspectives, I know that my autistic son did not hit the garage door button to be not nice. But, that just did not register in the mind of my socially based son, nor did simply being told that his older brother did not mean to scare him into spilling his tea soothe his ruffled feathers. Lacking the executive functioning to see his role, my older son did not possess the social thinking (and certainly not the connectedness) that his younger sibling wanted from his brother. Ultimately, my younger son came away with a great deal of sadness that his brother “doesn’t care” about him because he is “not nice.”

Over time, incident after incident like this without any positive emotional resolution can create very deep feelings of pain and separation between the rest of us and our autistic loved ones. This downward spiral can be slowed or reversed when we

gain a deep understanding and acceptance of autism, and make the effort to reframe what we interpret from incidents like these.

I did take the time to explain the social perspective to my son with autism, and how his actions impacted his brother. He heard me, and still thought his brother was being illogical!

The Rest of Us Are Social Chameleons

Part of being social is being chameleon-like when it comes to mannerisms, behaviors, styles, beliefs, customs, habits, etc. Adapting happens naturally to those of us whose social antenna is always up. We continually receive and adapt to social information in all its forms, and on all levels. This happens both unconsciously and consciously. For example, we can unconsciously be absorbing and responding verbally when we match inflection, tone of voice, speed of language, volume or word choices of someone with whom we are having a conversation. Making ourselves blend in can be visual when we dress like those around us, or we can even go as far as changing our beliefs as we do when we join a church, club, or other group. On an unconscious level, we may mirror body language, lean in to talk with someone who is leaning in towards us, or if we are in a different part of the country we may change our inflections and accent to reflect the local dialect.

Much of this is unconscious, but we also choose to mimic those around us on purpose at times. If you attend college, you might buy spirit wear—some article of clothing that reflects your connection to the school where you are attempting to fit in. Dressing like those around us is often a conscious choice for the socially literate. Both men and women decide to change their hairstyles and their wardrobe to stay current with popular styles, and to avoid looking odd.

As social chameleons, when we live surrounded by autistic loved ones, we can pick up on their traits. For example, we might adopt the habit of blurting out at inappropriate times, ignoring certain social etiquette such as saying please and thank you, or not looking someone in the eye.

I used to be confused when I saw traits that I attributed to my loved ones on the spectrum in myself or my non-autistic son, and wonder if we, too, were on the spectrum. But when you think about it, it is easy to understand how this happens. If our parent is on the spectrum, it follows that we would naturally assume some of their qualities and behaviors even though we are not on the spectrum. It's what was modeled for us, so reflecting those traits can happen unconsciously—people who live together tend to grow to look alike, and also act alike.

Perhaps your child seems to display some of his father's ASD traits, but doesn't diagnostically qualify to be on the spectrum. The degree to which we mimic those traits may be a measure of our sensitivity, rather than an indicator that we are on the spectrum. Some of the rest of us are so sensitive to nonverbal information that this can go one step further and we can actually become like psychic sponges, instantly aware of what someone else is experiencing or what kind of mood he is in.

I especially want you to take note of this if you have ever thought "Maybe it's me who is on the spectrum," as I have thought on occasion. If you are reading this book, looking for ways to improve your life or the life of someone else, I would be willing to bet that it's probably not you who is on the spectrum.



In this Chapter

- Discover 17 tips for better communication
- Become aware of the role of the rest of us
- Prepare for “I don’t know” or “I don’t care” responses
- Learn to reframe behavior from a new perspective

7

The Big “C” Communication: Troubles and Tips

Difficulty with Words

Difficulty with language is integral to autism. It is a classic feature of more severe autism in children where language does not develop at all or begins to develop and then disappears again. Even high-functioning people on the spectrum can struggle with language, trying to find the right thing to say and, barring finding the perfect words, they may not find any words at all. They may not say anything, or they may respond with “I don’t know,” or “I don’t care,” two dismissive responses that can be a very frustrating to hear all the time. Communication difficulties can be based on a number of other issues that are part and parcel of autism such as processing speed, cognitive flexibility, black and white thinking, the inability to find the words to describe an emotional experience, or one of the other social difficulties we discussed in previous chapters. Communication struggles can stem from an intricate combination of any of these issues, and result in the inability

for those with ASD to communicate their thoughts and feelings effectively in the moment.

Communication with those with ASD can be socially awkward because the filters of someone on the spectrum are different. For example, if I just cut my hair and I asked someone on the spectrum, “Do you like my haircut?” she might say, “No, I do not like your haircut.” In the social world that the rest of us live in, most would not say “No.” Even if you do not like it, social convention dictates that one might say, “It’s nice,” or one might mumble some other evasive comment to avoid the negative social repercussions. An individual on the spectrum might say in a matter of fact way, “No,” and then be confused by the potential negative reaction. “If you did not want to know how I really felt, why did you even ask me? I told the truth, why are you upset?” When you encounter this response, it is difficult to remember that the person with whom you are communicating really believes he responded with the appropriate answer. The whole social piece, cognizance of the nice factor that is designed to smooth out social interactions can be missing, and that can quickly offend the social part of the rest of us.

When the communication becomes nonverbal, intent can easily be misconstrued by those on the spectrum, or even entirely missed if the nonverbal information is subtle. I know of two little boys who used to play together, both on the spectrum. One little boy loved the other one very much, but he would poke, poke, poke at him all the time until the other one got mad. That was the only way he knew how to engage. He did not know how to engage in a socially acceptable way. He did not know how to use his words; he did not know how to say, “Come on, let’s play.” He only knew that if he poked his friend, he gained his attention. It is very common for those with ASD

to struggle with both verbal and nonverbal communication, especially in regards to anything that is social in nature.

Neurotypical Communication is Like a Journey

A conversation between two people who are not on the spectrum is like a shared journey. It starts out with a topic, and the conversation builds as both parties gather information through a variety of channels. These channels can provide both verbal information and nonverbal information, like facial expressions or body languages or gestures, which are a big part of communication and can dramatically influence meaning. Information can be transmitted by intonation or innuendo or specific word choice. There are a lot of different ways that we glean information from a conversation with someone when we are not on the spectrum, and they all work together to create the shared journey between the people involved in the conversation.

As the conversation develops, the two people travel together from where they started conceptually on some sort of a common trip. That does not mean that they are necessarily in agreement about whatever they were discussing, but at least they have a common understanding of each other's opinion and a shared experience of the conversation that they come away with, even if they do not agree on the subject. This shared experience is especially important if nonverbal communication accounts for a large part of the conversation, and is therefore critical to accurate interpretation of the words.

In contrast, communication with an individual on the spectrum can be complicated and filled with pitfalls. Much of that subtle communication, the nonverbal information such as facial expression or body language, may not even be captured by the person on the spectrum or it may be lost before it is processed. Emotional information can be completely absent,

both in terms of what the individual with autism receives and delivers back to the neurotypical person. When this happens, the person sounds like Mr. Spock on “Star Trek.” Everything is fact-based and logical; devoid of emotion and human warmth. When no emotional information transfers whatsoever, the individual appears very cold, hard and unaware of our social sensitivities. Spock totally lacked social shorthand; even if he understood the words, part of the meaning was lost.

One of the most frustrating and disconcerting aspects of communicating with people with ASD is that they can get sidetracked in their own minds, making associations that the rest of us are not making, and end up conversing about a completely different topic than the one that was initiated at the beginning of the conversation. For example, if I want to discuss homework with my son, I might ask him if he has his math book. He might respond by saying “My math book is blue,” and then launch into a dissertation about why blue is a great color for the sky. Math homework? He forgot I even mentioned it! Unlike taking the average communication journey with someone who is not on the spectrum, communication with someone with ASD can be a real trip!

Successful Communication with Someone on the Spectrum

Truly successful communication with anyone takes effort, but it takes more effort when you are communicating with someone on the spectrum. We must allow our understanding of ASD guide the pace and the depth of detail delivered in the message. If the ASD individuals are not clearly and correctly interpreting our meaning, we need to employ special techniques to package the information in a manner that helps them grasp it more readily. There are certain approaches that you can adopt to help improve communication with those on the spectrum:

1. *Slow down.* Learn to speak at a pace that is comfortable for them to process the information. Do not try to deliver more than one message at a time; this is rarely successful (especially if you communicate by text message). Take one thing at a time.
2. *Ask if they understand.* Take a deep breath, come up for air and check on their progress in following the conversation. Are they with you? Be aware that sometimes they will say that they understand just to get rid of you and end the painful experience of conversing with you, so it is important to know if they really do comprehend what you are saying.
3. *Write a list.* Sometimes it is beneficial to eliminate the detail and fluff that is required to form a complete sentence. Short, concise, and to the point works better.
4. *Use pictures.* Pictures often help the person on the spectrum grasp meaning more easily than words.
5. *Remember social shorthand.* Fill in areas where information may be missing for someone on the spectrum because they are not proficient with social shorthand. Remember social shorthand is a common basis of information that we accept, for the most part, and so the embedded knowledge or wisdom goes unchallenged and explanation is not necessary to ensure that we are on the same page as the person we are communicating with.

The benefits of social shorthand may be totally absent in your communication with someone on the spectrum and you can wind up describing, or even debating, information that goes without saying in your communication with a neurotypical individual. This probably detracts from the original purpose of the conversation.

6. *Give details in writing.* Especially complicated instructions. Written communication can be helpful for the person on the spectrum to use as a reference later. Remembering a multitude of steps can be difficult for any of us, and ten times more challenging for those on the spectrum. Take the memory requirement out of the equation to assist the individual in focusing on executing the steps required instead of being distracted by the effort required to remember the list. They may not be able to do both at the same time.
7. *Detail changes in routine carefully.* When changing methods from an old way to a new way, write a list or a sketch a chart showing the old way and the new way side by side so they can compare and contrast to easily see the differences. Providing both old and new is important to help solidify understanding.
8. *Be patient and handle one thing at a time.* I cannot tell you how many times someone on the spectrum has said to me, “Just one thing at a time.” I am always trying to do 12 things at once, and I forget that my pace overwhelms them.
9. *Avoid emotional language.* Statements like, “I would love it if you would rub my feet” may be less effective than saying, “Would you please rub my feet.” I have been told many times that I should just say what I want, and not couch it in a more subtle message.
10. *Avoid analogies and slang.* Phrases like, “What’s up?” or my son’s personal favorite, “That is right up his alley,” are bound to bring interesting results from a literal thinker. While analogies certainly make the conversation more entertaining, they are not necessarily more effective in communicating with someone with ASD.

11. *Be prepared for "I don't know" and "I don't care" responses.* If they don't understand what you are asking, make a quick decision about how important it is to pursue the question at this time, and if it is important, be ready to help them figure out what you are asking and how to answer the question. If you are convinced that "I don't know" really means that they really don't care (and often they don't), be prepared to move ahead without their input
12. *Give specific options rather than open-ended choices.* For example, instead of saying "Where do you want to go on vacation?" ask, "Would you like to go to Disney World or SeaWorld for our vacation this year?" This type of question increases your chances of getting a response. When I ask my son an open-ended question, his first response is always "What are my options?" So listing them up front is a way to simplify the conversation.
13. *If at all possible, point out a way that this communication will benefit them.* I know this makes a person on the spectrum sound very self-serving, and that is not my intention in saying it. Because of how those on the spectrum are motivated, understanding and expressing the benefit to them is important in getting the message heard. Remember this little trick: the world's largest radio station is W.I.F.M. (what's in it for me?). Detailing that benefit helps motivate the person with autism to push through the communication difficulties in order to achieve understanding.
14. *Provide details and consequences.* Detail what you want, and more importantly, the consequences if they don't comply. Again, showing both sides of the equation is a critical component to the autistic person's full understanding of the situation. Just sharing what you want done without the

consequence of noncompliance is expecting these individuals to understand ought-ism. In many cases, they may not have the executive functioning to project themselves into the future, or the social database to allow them to fill in that blank on their own and assess future consequences.

15. *Stay calm/Avoid emotional pleas.* The upset and aggravation that we express to motivate a social thinker to act or react will probably produce little or no movement on the part of the person with ASD. Often, if your request is not being heard or processed, it is better to fall back, regroup and try again at a later point than to express anger or frustration as a tool to move the individual to action.
16. *Check to confirm that you are on the same page.* Ask them to explain to you what you just said. Be aware that some of those on the spectrum parrot back language without any understanding. Ask them a question that requires that they process what you said before they can answer. It is a classic blow off (used by those not on the spectrum equally well) to just say, “Yep, OK,” without having any real understanding. And those on the spectrum would like nothing more than to dispense with this conversation and get rid of you.
17. *Double check.* Fill in any missing details and ask again.

I want to emphasize one aspect of the communication tips just listed. I can tell you as a parent that when I told my son, “You need to study so you get good grades,” I had to add, “Poor grades mean you will not get into college.” I have no doubt that if he did not get into college, he would have said to me, “You never told me that not getting good grades would keep me out of college.” The rest of us inferred that information from the original statement, but those with ASD usually don’t think with that flexibility. Detailing the negative consequences is often as

important as communicating the positive outcomes if you are trying to motivate the person to take action. It is automatic for the rest of us to rely on social shorthand and assume that the person we are communicating with understands all the underlying social information the same way we do.

After hundreds of opportunities to test this approach, I know for a fact that detailing both the positive and negative consequences surrounding your request is imperative for someone on the spectrum to achieve the full understanding of your message. Usually without help, they cannot see the forest for the trees. They cannot put together the pieces and project themselves into the future in a way that will allow them to realize that bad grades may mean not being accepted into college.

Although this list of communication dos and don'ts sounds complicated, it is less stressful to use these tips than to ignore them and approach your autistic loved ones as if they are neurotypical, and you will meet with greater success. The deeper your understanding of their experience, the more naturally you will employ these strategies for communication success.

Dealing with “I Do Not Know” and “I Do Not Care”

When the person on the spectrum with whom we are communicating cannot come up with an answer fast enough, the answer is often “I do not know” or “I do not care.” This is an area of personal challenge for me. Dealing with “I don't know” is very difficult because my ideas and thoughts are so clear that it is hard for me to understand the difficulty for the person with ASD. Here are some tips on how to deal with that.

First, try to be patient. The person with whom you are trying to communicate probably does have an answer and may very well care, so “I don't know” may be either a blow off to get rid of you or a filler response while they formulate an answer. You

can ask, “Do you need more time to think about it?” “Would you consider A or B?” or “Would it help you to decide if I gave you some options?” List the options. Ask if more information is needed to make a decision. Ask if he understands the question. Perhaps, agree to step back with, “I will let you think about that answer, and I will come back and ask you again in an hour. Is that okay?”

If the response is “I don’t care,” one strategy is to try proposing an answer that you are pretty sure they will NOT like, and see if that gets a reaction. That may very well stimulate them to provide an alternative to the objectionable suggestion you made. For example, if you ask, “What do you want for lunch,” and the answer is “I don’t care,” then you might respond with, “Okay, then we will eat a big bowl of peas for lunch!” If they hate peas, you will probably get a reaction, and this may stimulate an answer.

Most of all, try to be patient and realize that that the “I do not know” and “I do not care” answers may very well be an escape strategy to avoid having to push through the pain of dealing with you and whatever you are asking and to get you off their back.

Remember most of all that we must meet them where they are because they *cannot* meet us where we are, through no fault of their own. It is not that they do not want to. It is not that they think that they are better than us. It is not that they are selfish or self-centered or self-focused or anything else. They simply lack the neurological processing required to build the social database that would allow them to meet us where we are, and that realization can be shocking and painful for us.

Reframing Behavior

While I realize that humans are not dogs, I learned a terrific lesson in reframing behavior from my dog, Cary Grant, a

120-pound Bouvier des Flandres. Bouviers are large herding dogs with a strong personalities. They protect their turf. When Cary was just under a year old, he started to get aggressive at the door. When that happened, I would respond by patting him and say, "It's okay, it's okay, everything is fine." I would try to calm him the way I would try to calm a human with quiet, soothing tones and words. In spite of the amount of time and energy I spent calming him, soothing him, and reassuring him that everything was all right before I opened the door, he still lunged at the door when I opened it. I couldn't understand why he was getting so upset.

After months of trying to manage him at the door, we hired a dog therapist who explained the problem. In dog pack behavior, when no one else is taking charge, someone has to take control, and as a dog bred for protection, Cary thought he should step up. So she told me to stop being gentle with him and to get in his face and growl at him and say, "I am in charge of the door. You leave it alone. That is my company, and I am in charge."

I did this and as soon as I started behaving in a different way, my dog stopped biting people at the door. Cary and I did not experience the same social understanding. I was getting the wrong reaction because I was giving him the wrong signal; we were living in alternate social realities. I needed an expert in dog behavior to reframe the situation for me so I could understand his perspective and communicate with him effectively.

We can experience the same kind of positive results in our relationships when we learn to understand where people on the spectrum are coming from, reframe situations and communicate in a language that translates into their world more effectively.

The Big “C”

My mother always talks about the “Big C” being, not cancer, but communication. Communication is a fundamental building block of our relationships and our experience of life. Knowing that the person you are communicating with is autistic categorically changes the approach to healthy, effective and satisfying communication. Some of the pain, anxiety and contention can be alleviated as you grow in understanding, knowledge and compassion for those with ASD. Let’s try a little exercise. Let’s see how a conversation between a husband and wife might sound with differing levels of understanding of autism. This is a wife talking to her husband. She has an agenda: she wants to make some plans for a family holiday function, plans for her birthday, and dinner tonight.

A wife who knows nothing about autism speaking to a husband who knows nothing about autism (this couple is totally in the dark):

*“What is wrong with you? What do you mean you don’t care if you see your mom and dad at Christmas this year? What about the kids? Can you not see how your actions are hurting the rest of the family? You never keep your promises. Don’t you care about me? You are just being a jerk. You’re not even listening—look at me! Stop being such a self-centered a\$#*hole!!! You never think about anyone but yourself and my birthday is always proof of that. This year you better think of something nice for my birthday because last year you blew it off. You’re ordering Chinese for dinner tonight because I have done everything around here today and I am tired.”*

Sounds like she is feeling angry and frustrated, and feels taken for granted. I am sure she feels like she is in the relationship alone, given the one-sided nature of her complaints.

If this has been going on for some time, she may also be feeling hopeless, desperate and at the end of her rope. With no understanding of autism, she has no idea how difficult the requests she is making are for her husband to comprehend and execute. And it pisses her off that he won't just do it. The angrier she becomes, the more the situation will deteriorate as her spouse's ability to respond becomes more remote.

A wife who knows nothing about autism speaking to her husband who has been told he is on the spectrum:

"I know you are trying to fix your problem, whatever that is, but you are not making any progress. Nothing ever changes. You are going to force me to deal with your family to make the plans for Christmas, again, aren't you? It drives me crazy that you never think about anyone but yourself. (volume increases) You ignore my needs, and it seems like you just don't give a s@#t! Last year you forgot my birthday, and so we didn't do anything. This year you better think of something great. I just do not get where you are coming from. Why don't you get some help? See a therapist. Do something!" "You figure out what we are doing for dinner. I did it last night."

Sounds like this woman is in a similar state to the first. She has no idea how difficult change is for her spouse on the spectrum, regardless of the fact that he is aware of the autism. She has no idea how to get her own needs met other than screaming louder. Again, this situation is likely to deteriorate if both parties don't get on the same page in regards to the autism. The husband alone will probably not have the strength to swim upstream and fight both his issues related to autism and his wife. Even if he did, until she gets on board and develops some real understanding about his situation, she will likely continue to feel very dissatisfied.

A wife who knows about autism speaking to her husband who does not know (or who is in denial) about his autism:

“I know change is hard for you, so let’s take small steps, but we need to take some steps, because I can’t keep on going this way. I need to know that you care enough to make an effort. I know you have a problem with following up on your commitments, but what can we do to make the situation easier for you? Let’s write a list and keep it here on the bulletin board as a reminder. Right now we have three things to discuss. First, we need to let the family know if we are coming for Christmas. Will you please send them an email? Second, next week is my birthday, and I really want to go out this year for dinner, okay? And third, would you please order Chinese for dinner tonight? When you complete each item, then cross it off the list.”

It sounds like this woman is feeling frustrated and irritated but in spite of that, she wants to be understanding. It can be very frustrating to deal with a spouse who is in denial about their autism. She is making an effort to get her own needs met by making suggestions that will help her not to be disappointed, and asking him to take action. She is trying to help her spouse affect some changes and since he is not willing to look at the autism, she can only keep trying different approaches until one works. Once the person on the spectrum acknowledges his autism, there may be a shift in his willingness to be coached or supported in order to create more functionality in their life together.

Being married to a spouse who is not willing to acknowledge the autism is not an easy spot to be in. When the partner is in denial or refuses to make an effort to change, that leaves the NT partner at a dead end with only one alternative to get any

movement—to end the relationship. One therapist described this challenge as being backed toward a cliff, unable to move forward and with the only escape being a less than desirable and painful jump off the cliff. I have spoken with a number of women with husbands on the spectrum who fell into this category. One woman told me that her husband laughed at her and told her it was her problem. After all, she was the one who was upset; he was fine! For the rest of us, that can create a scenario fraught with anxiety and fears about the future, or a sense of being helpless or trapped with no control over the situation.

A wife who is aware of autism and has a spouse who knows he is on the spectrum might say:

“Honey, because of your autism, you are having a hard time seeing how what you do affects everyone else. Can we sit down and discuss the situation? Then we can figure out what makes sense for you to be more effective. When we don’t respond to our family’s invitations, they think we don’t like them. We need to let the family know if we are coming for Christmas this year. Have you decided if you want to do that? It is okay that you need some more time to decide. I made a note on the calendar to remind you to please call your mom before the end of the week. Also, my birthday is next week and I would like to go to Luann’s restaurant for dinner, can you please make the reservation? I am tired and don’t want to cook tonight. Would you prefer to order Chinese or go out for Italian for dinner?”

Over the course of these four examples, the situation steadily improves as behavior is reframed in the light of understanding autism. The intensity of the wife’s frustration and resulting anger is abated as she grows in her knowledge of the difference between can’t and won’t. Her husband’s lack of response is no longer interpreted as lack of caring about her or about

the relationship. When she feels that she is being heard and her desires and feelings are being considered, or worth being considered, she feels validated and understood, so it takes a lot of pressure out of the situation.

As she becomes more aware of how to communicate with someone with ASD, there is a better chance that her needs, desires and feelings are both heard and understood by the person on the spectrum. This happens increasingly effectively when she learns how to ask for what she needs in a way that her spouse with ASD can understand and follow through. She helps to set her autistic loved one up to succeed. As she improves her ability to reframe his response to her needs and his behavior in light of the autism, the entire situation de-escalates and emotions level off.

Understanding on the part of the rest of us is a pivotal factor in the ease, effectiveness and peace in a relationship with someone on the autism spectrum. However, regardless of our level of understanding, there can be an emotional undercurrent that leaves us with feelings that we do not feel good about admitting.



In this Chapter

- Learn how to build a healthy relationship with someone on the spectrum
- Understand how each relationship is a value proposition
- Learn how to motivate someone on the spectrum
- Understand that you can't negotiate with autism

8

What We Don't Want to Admit about Our Relationships

Life Is about Our Connections

Like a mobile, we are all connected, we maintain a certain balance, and we are all related to each other in a certain way. We don't have any choice in this matter—it is the nature of life. When one moves, the equilibrium changes, the balance changes, everything changes, and all the parts move in synchronicity; when one moves dramatically, the whole system rocks.

By the same token, when we heal one, we heal all. When we help one, we help all. Nobody goes through life without touching others; all of us live in interdependence. By improving our relationships, we make everyone's world a better place. In life, we develop relationships, each of which brings something unique to our lives.

Every relationship is designed to accomplish a specific purpose. The degree to which that purpose is served, the importance of the purpose in our life, and our satisfaction

about how the relationship meets that purpose all determine the value of the relationship to us. *For example:*

- A doctor/patient relationship works toward good health.
- A teacher/student relationship focuses on education.
- A policeman/civilian relationship centers around protection and respect for the law.
- A store clerk/customer relationship is about assisting the customer in the purchase of products.
- A parent/child relationship is more complex. It is about raising a child, but also about loving, nurturing and self-satisfaction, among other benefits for the parent, including leaving a legacy for the future so that you are remembered in generations to come. There may be other types of satisfaction for parents, but let us say primarily a parent/child relationship is about parenting and about giving or receiving love.

Some of these examples may be more complex than I describe, but for the most part I think you understand my intention. Every relationship should work toward a mutually beneficial purpose.

Boundaries

The relationship equation can be divided into two parts. The first is to take care of ourselves and to know how we feel about the relationship—our side. The second is to give to the other person and to acknowledge his feelings about the relationship—the other person’s side. Between these two parts there are boundaries that we establish and maintain.

Boundaries are the guidelines that we use to define our limits in relation to someone else; they are the psychological lines between us and the other person in the relationship. As the recipient of actions, these boundaries help us to determine

what behavior we deem acceptable when it is directed toward us, and what behavior we deem not acceptable. When we are on the receiving end of behavior that is unacceptable we feel that our boundaries have been crossed, and we typically experience a negative reaction and become angry, frustrated, hurt, or upset; we may feel violated or taken advantage of, offended, or we may feel some other negative reaction. When our boundaries are crossed it never feels good.

While society dictates certain boundaries, such as between a doctor and patient, or between a student and teacher, for the most part we are each free to define our own relationship boundaries based on how they feel to us. Most often we establish them unconsciously, and only recognize them when an issue concerning them arises, and by then it may be too late to change the course of the relationship.

In a relationship with someone on the spectrum, verbalizing and clarifying boundaries may be very helpful, since intuitively knowing where the boundaries lie would require social thinking.

It is important to maintain boundaries that feel comfortable and easily sustained. Boundaries that are too lenient will leave us feeling used, and boundaries that are too stringent can leave us feeling angry, cheated, or isolated. Boundaries that require too much maintenance or are hard to keep in place are exhausting and frustrating. Appropriate and healthy boundaries are an important part of creating a sustainable equilibrium in a relationship. This doesn't mean that boundaries need to be rigid—boundaries can be either fluid or static, but they do need to be operating within a comfortable range for both parties.

Regardless of the level of flexibility in the boundaries, a healthy relationship has a unique equilibrium and has comfortable boundaries.

A Relationship Is a Value Proposition

This probably sounds very cold, but at the base of every relationship, working in conjunction with the boundaries, there is a *value proposition*. We could also call the value proposition the “give-and-take equation.” That sounds nicer. But whatever you call it, there must be a reasonable balance between effort and reward, between what an individual gives in a relationship and what one receives back, and the give and take has to feel fair—that is to say, it cannot be so extraordinarily or persistently out of balance that it can’t be sustained.

The balance may look like “I give to you financially and I receive your love and appreciation—when I feel your love and gratitude, I feel good about myself” or, in a marriage, the balance may be “I take care of the home and children, which allows you to go out into the workplace and earn a living that supports both of us” or, between girlfriends it might sound like “I support you in your struggles with your relationship with your boyfriend, and you bring a lot of fun into my life.” The exact nature of the value equation in a relationship is different for each of us and different in every relationship; no two value propositions are the same.

The value of a relationship may depend on the purpose of the relationship. If you are a man in a relationship with your girlfriend, and your girlfriend spends all your money and does not leave you feeling good about yourself, then that is not a very good value proposition.

If you are in a marriage and your spouse takes care of you financially, but you are starving to death emotionally, that may not be a satisfying value proposition. How good or bad the value proposition is will depend on how you feel about a myriad of other factors in your life, such as how difficult it might be to

find a new relationship partner, how old you are, or what you believe a spouse should provide.

If you are a psychologist and your patient is frustrating to work with, but in working with that person you are satisfying your love of helping people to make a living, then it might be a good value proposition. As long as the relationship includes sustainable satisfaction it can be a good value proposition.

The balance between give and take in any relationship isn't static or perfect. Some days the equilibrium might be better or worse, but in spite of the fluctuation, there is an underlying balance based on a give and take at the root of every relationship. If the equation is too lopsided, with one person's contribution to the relationship disproportionately large, the relationship will not work over a long period of time because it will become very draining for that partner. When a relationship is healthy, it feels satisfying to both parties, and staying in the relationship comes more easily; the relationship is more sustainable.

Examining the value proposition of a relationship can be a healthy way to stay conscious about your life choices. Stepping outside the emotion of the situation and focusing on identifying and appreciating the practical, psychological, emotional, physical, spiritual, or other benefits from an intellectual perspective can be a fruitful exercise. Stated in such black and white terms, that may sound a bit calculating, but this exercise can help you determine if you should remain in the relationship during a difficult time, or it can flag a relationship that is not healthy or mutual and that can help you decide if it might be better to leave before it has dragged on for 10 years.

Recognizing that the value proposition isn't working for you doesn't necessarily sound the death knell for the relationship.

Actually, the conscious recognition that the value proposition isn't working can create an opportunity to implement a myriad of other smaller changes before you reach the last straw (the proverbial one that breaks the camel's back). If the value proposition is not working for us, whether or not we are aware of that fact does not change the reality, and the truth usually

Every relationship has a certain give and take that you must evaluate for yourself in order to decide if what you receive from the relationship is worth the energy you devote to it.

surfaces eventually.

Proactively identifying the plusses and minuses of a relationship may eliminate years of uncertainty, denial or wasted time.

How many of us have felt dissatisfaction with our

relationship creeping up long before we were able to verbalize it? Early recognition of an insufficient value proposition might even save the relationship by providing opportunities to correct the imbalance that has developed before it is too late and we discover we have unwittingly been backed into a corner by life choices from which there is no escape.

In the video games that my son loves so much, there are "hit-points" or "life-points," which are a unique combination of time and energy that you expend performing different tasks, or lose when you are injured. You receive a certain limited number, and when you have used up all your life-points, your life is over. I like that concept—it is a unique way of seeing what something costs you in the currency of your time, energy, effort, health, commitment, drive, etc. Does your relationship provide a good value in terms of the life-points it consumes? Are there things in your life that you know consume too many life-points? How many of us have quipped at one time or another, "Life is too

short.” That is an expression of determining that too many life-points are being consumed for this activity to be worthwhile, and so we deem that it is not a good value proposition for us.

Identifying your own personal value proposition does not need to be a complicated and cumbersome process. There are a wide variety of influences that could affect your particular value proposition, but if you step back and take the 30,000-foot view, I'll bet you can boil it down to a few key factors relatively easily.

To create your value proposition, write down your relationship's primary benefits. What do you receive from the relationship in question? Then write down the costs to you in terms of the expenditures of time, energy, frustration, and or whatever other cost is involved, including money. What does it cost you to stay in the relationship? What are the negatives about the relationship?

Examining your own values, goals, and “must haves” in life is a key component to examining your satisfaction with your value proposition. Look at it from a daily perspective, but also consider your life as a whole. Can you pursue your own dreams, and the goals you want and need to accomplish in your life, while participating in this relationship? When you compare what you give with what you must give up, or with what you get in return, how do you fare? Voila! You have a value proposition.

Every relationship has a certain give and take that you must evaluate for yourself in order to decide if what you receive from the relationship is worth the energy you devote to it. When the value proposition doesn't work for you, either the relationship is in jeopardy, or you will begin to feel dissatisfied or drained by the relationship.

Understanding your value proposition in a relationship with someone on the spectrum gives you an incredibly powerful tool

to help monitor and manage your relationship. It is like creating a dashboard to help you consciously visualize your readings in certain areas—without it you are flying blind.

The Challenges of Change

Relationships and their value propositions change. If they are being sustained for any length of time they must by their nature change and evolve in response to life's experiences as they occur. Both the relationship and the value proposition need to develop to allow the participants to mature, grow and incorporate new information and experiences. Because of the rigidity in their thinking, people on the spectrum may find it difficult to adapt in a relationship over its duration, especially one that is complicated and multi-layered such as a marriage.

Those of us who are neurotypical naturally continue to grow through new stages in life, incorporating new levels of maturity and functionality. In contrast, part of the ASD way is to find a comfortable track and then to stay on it. This is not a character defect, but rather a result of their neurology, which is predisposed to reduce incoming data to manageable terms—to black and white, to familiarity, to similarity and to consistency.

In other words, those on the spectrum fight to stay the same, avoiding painful change as much as possible. Major life events can be very hard for them to process and incorporate, and can even stop them in their tracks. One psychiatrist described to me how an individual with ASD can sometimes get stuck at the point of a major life change such as marriage. He explained that an event of this magnitude could be so overwhelming that the individual freezes at the point of the change, unable to adequately process and incorporate all the new data presented by the event. The rest of us are flexible enough to almost automatically adjust, change, and rebalance ourselves in the

face of such major events in our lives, even if that adjustment requires effort or pain. This difference in our ability to adapt and incorporate new phases of life and growth might be minimal and go unnoticed in some areas of life, or the difference can be so extreme that we no longer enjoy the common ground on which we originally based our relationship.

Imagine for a moment that you and your autistic spouse were married when you were both at the developmental age of 16 years old. As you grew up and became more mature, you (the neurotypical partner) took on new challenges, new responsibilities, and were changed by life. Each struggle, success or failure you faced and overcame changed your perspective and approach to life as you grew.

Your autistic partner on the other hand, stayed mentally, emotionally, developmentally and functionally exactly where he was on the day that you were married. This wasn't by accident. He made an effort to stay constant. He approached life the same familiar way, thought about things the way he had always thought about them, and kept the same interests he had at the developmental age of 16, and he did it on purpose in order to manage the stress and discomfort that is part and parcel of dealing with enormous change for someone with autism. This is not a value judgment of his choice. His response was necessary for his survival.

With one partner growing, changing, and adapting, and the other partner staying stagnant, the gap between the two would more than likely grow progressively larger and more distinct.

Life moves fast, and this type of natural growth (or lack of growth) is so integral to the process of living that it can be almost undetectable unless you really look for it. To do that, you need some opportunity to step back, reflect and adopt a fresh

perspective. Both positive life events, such as marriage or a baby or negative events that bring you to your knees emotionally, like the loss of a loved one or a job, provide the needed opportunity to alter your perspective. Those are the times when you might look to your partner for input or support or comfort, and find that he is no longer there! Stunned that your partner has not grown with you, you may be suddenly aware that you are married to a spouse who, at least developmentally, froze in time on your wedding day, and suddenly you realize that you are married to an individual who is operating from an entirely different perspective. It's like getting blindsided by a ton of bricks... "*What?!*"

You have the dreams and desires commensurate with your stage in life and your spouse on the spectrum is still in the same place he was 20 years ago. That may mean that you are preparing for your children to leave home and marry, and your spouse's biggest priority is still getting tickets to the next rock concert he wants to attend. With your focus so disparate, your spouse with ASD might begin to feel like your child instead of your partner. The sensation that we are parenting our spouses is one of the things that can be hard to accept about our relationships.

Given our ability to change and acclimate, some of us end up adapting all around the person on the spectrum so that we can continue to include them in our lives. We morph our lifestyles, our world, and ourselves in order to accommodate this immovable object that autism becomes in our life, and we work around it.

While it may seem inappropriate or unfair for all the compromise and change to come from one person, I can't help being reminded of how a pearl is formed. The irritation

experienced because of the foreign object in the oyster causes the oyster to surround the object with a substance to protect itself, which eventually results in something really beautiful—a pearl! With enough knowledge, patience, willingness and love, the irritants in our life surrounding those on the spectrum can produce pearls, too. The choice is up to us.

Be Flexible—You Cannot Negotiate with Autism

If we are too demanding and rigid, life will be very hard for all of us. A rigid partner and a pedantic partner are a recipe for relationship stress. Autism is stubborn like a bulldozer. It just comes at you, and it is going to keep coming. Autism does not know that there is difficulty or danger or hurt—it doesn't possess social awareness; autism does not care, so negotiation is out. It does not realize, nor would it care, that it is making it hard for the other person in the relationship. Autism has no concept that it impacts others in any way. You cannot talk rationally to autism. You must go up, go over, go around or retreat; you must find some way to live with it on its terms. That means that the rest of us are required to be big enough people to be willing and flexible, to change our approach to relationships. This is true for a parent, a spouse, a coworker or any other type of relationship. Demanding that the relationship go our way is pointless.

The bottom line is that, in so many areas of life, it is going to be incumbent on us to be flexible and adaptable enough to meet our autistic loved ones, coworkers, friends and acquaintances *where they are* because, due to the neurology over which they can exercise no control, they *cannot* meet us where we are (assuming they can even see or conceive that we are in a different place). We need to get in touch with our compassion, remembering that we desire to be in a relationship with someone who, through no fault of his own has a social disability that creates work

and maybe even pain for us. When we find peace with this, it becomes very matter-of-fact on some level, just like the rain in the spring. It is what it is.

In a relationship with someone on the spectrum, we can't let every little nuance upset us—we need to be flexible, easy going, and forgiving, and take these irritations in stride or they will take way too much out of us (i.e., cost us too many life-points). I realize that flexibility can also demand determination and strength, if not sheer guts, but at the same time, it offers us the opportunity to put the power back in our hands so we don't feel victimized by the situation.

Motivating Someone with ASD

Do you think you have the ability to motivate the individual in your life who is on the spectrum? This is a sticky wicket for anybody, but is especially difficult with someone who is autistic. People on the spectrum tend to do only what is required of them, and usually nothing more. So, unless there is an immediate means to an end—an action that is required in order to gain something that they want—they may do nothing at all. When it comes to taking action, they are stalwart and stingy; they only take the action that is absolutely required of them to get by in the circumstances with which they are faced and achieve the outcome they desire, and that is usually only about achievement of short-term goals. This immediate-means-to-an-end perspective, among other reasons, makes long-term goals or larger goals with many steps a real struggle, if not impossible.

Motivation for people on the spectrum is not socially based like it is for the rest of us; they are not inclined to be motivated to act “just because it is done that way” (that would be social thinking) or because of other lofty and spiritual goals such as “being a good person” (that would be ought-ism). Typically, they

are pragmatic and immediate in their drives and desires. While this may sound like a very offensive description of someone with ASD, it is not meant as a criticism or value judgment about who they are or how they live their lives. Remember, this is an approach dictated by their neurology.

Understanding the motivation, or lack of motivation, of someone on the spectrum is a vitally important tool if you are going to create a strategy for a healthy, satisfying and sustainable relationship because almost all relationships require that both parties are motivated to cooperate to fulfill the purpose of the relationship.

One social worker described the motivation of those on the spectrum as appearing to be “living out of their pleasure centers.” Our social perspective, which includes doing things to please others, staying conscious of our impact on others and being aware of long-term consequences, can make it seem by contrast as if those on the spectrum are totally self-focused and moving from one “feel good moment” to another as they grasp for psychological sanctuary from their autism without any regard for others, social expectations or consequences.

To motivate them to action, either we need to know how to get out of the way and allow circumstances to push them to move, or we need to create conditions that provide our ASD loved ones with the type of circumstances required to elicit a response. But, this can be painful and difficult to do, and can also feel dissatisfying and offensive to our social minds. “He’s an adult, why should I have to tell him to (*fill in the blank*)?” Fill in the blank with: *pay the bills, feed the kids, go to work, take a shower, etc., etc.* When we are required to find specific ways to motivate our loved ones to do something that we believe they should already be doing, it may trigger our “if you love me” button, and

we can feel hurt, angry or unloved. We can also feel like we are parenting or worse yet, manipulating and controlling.

An example where their lack of motivation can cause pain for the rest of us in a relationship is in gift giving. In order to elicit any response, we may need to ask specifically for what we want. To our social nature, it may feel that the act of requesting the gift negates the value of the gift, especially

Motivation for someone on the spectrum is one of the true challenges of autism.

if you believe the giver didn't really care enough to give the gift freely, but a specific request is often the

requirement to raise their awareness about your needs. The same principle can apply to other aspects of life. For example, if you feel your spouse should be caring for the children once a week to give you a break, but you need to ask him, or motivate him to do it by offering a "reward" in exchange, then it may feel as if he doesn't care enough about the family, or doesn't care enough about you to attend to his children on his own volition, and that probably isn't true!

Motivation for someone on the spectrum is one of the true challenges of autism. I used to always say that *m*otivation, *i*nspiration and *a*mbition were M.I.A. (missing in action) in my loved ones on the spectrum. It is not their fault, but it is their challenge. If you are going to create any type of sustainable relationship, chances are you will need to motivate your loved one at some time or another in order to continue to co-exist peacefully. Otherwise, the inevitable clash between your socially based needs and your loved one's nonsocial thinking will create a very dubious value proposition. Someday, some psychologist may find a formula that helps to motivate those with ASD to act in a more socially typical way, but today, for all of the reasons

we have covered in our discussions about their social nature, the best we can do is try to find something that they want, and attempt to use that as leverage to move them to action. Ughh!

The Fine Line Between Helping and Hurting

This brings us directly to the doorstep of one of the most difficult aspects of relating to someone on the spectrum—finding the fine line between helping them and hurting them. There are several dimensions to this, and they all pivot around the fact that the natural tendency of those on the spectrum is to reduce, limit, and narrow their world. If their world is not constantly being forced to expand, people with autism will probably opt to make their world smaller and smaller by reducing the activities that require social contact or other discomfort; most would become less functional and possibly even reclusive if given the opportunity. Left to their own devices, they would probably do things like eat the same foods all the time, wear the same clothes, and generally shut off options as they move in the direction of more similarity, familiarity and consistency.

The first dimension to this puzzle we face is whether or not our help is enabling in some fashion. Both extremes—overprotecting, and pushing too hard, can easily slip into enabling, which is sheltering them in a way that makes it possible for them to continue to live without coming face to face with the natural consequences of their choices. For example, over protecting can become enabling when we continue to replace money when it is lost so that they do not experience the pain or consequences of losing it. How will they ever learn not to lose it, if they don't experience the negative consequence? Remember, they need that circumstance to motivate them.

We can also enable our loved ones to continue to narrow their world by pushing so hard and so consistently that it becomes us (i.e., our energy) driving their actions, not them. We may do this by making so many accommodations in the name of protecting them from the world that they never see the consequences of their actions, or we might just manage them so completely that the results they see are results we produced through them, rather than results they can claim as their own. For example, a parent might appear to be helping his child through constant, daily communication with the school to manage homework, but then the child doesn't need to develop the organizational skills needed to succeed on his own. If the ASD individual is an adult, over accommodating might include constantly monitoring their checkbook to make sure that they never bounce a check. When we over-manage the situations our loved ones face, we steal their opportunity to experience their own consequences. On the other hand, making no accommodation doesn't necessarily feel right either.

So, what do we do? Of course, there are a number of important considerations such as safety, legality, health or how an action might impact their social functioning. Would they be ostracized by their peers? Can they interact with the authorities in an emergency? Is this an area of critical importance to their long-term independent functioning? We may not press as hard to teach them to ride a bike as we might to teach them to learn to drive or ride the bus so they can get to work independently.

As tough as it is, try not to do for them what they can do for themselves, and maybe do just a little bit less, so that your loved ones on the spectrum always have at least a little room to reach, stretch and grow. Too many demands may push them into overwhelm, but too few demands sets up the vicious cycle

that causes their world to shrink. Finding this balance is one of the most challenging aspects of a relationship with someone who is autistic, and can be very psychologically and emotionally demanding on the rest of us.

The second dimension is how much we push those on the spectrum. At what point does not pushing your loved one into participating in a certain activity change from helping them to grow, into not respecting who they are and the challenges they face, especially if you are dealing with an adult. How hard do you push? When do you push, and when do you let it go? How much painful pushing can they tolerate from you without rebelling against you or resenting you? And how much pain on their part can you tolerate witnessing before you buckle under the torture of watching them suffer and make an accommodation? This is a black-belt balancing act and is probably different for every person, in every relationship, at every stage in life. But, it is the fragile balance we must manage when we relate to someone on the spectrum, whether that person is an adult or a child.

When we love someone, it is very tempting to provide a sheltered life for our loved ones who often seem innocent and unable to fend for themselves. We long to ease their burden and make the road less difficult for them. I get it. It is very difficult to push people beyond their comfort zone at all—and even tougher to do it all the time. It's tougher still when the person you are pushing has a legitimate handicap to overcome. After all, you wouldn't try to force someone with no legs, who depends on a wheelchair, to walk just because walking is what everyone else does, right? As a parent, this falls into the category of "this hurts me more than it hurts you," and requires tons of effort and even more intestinal fortitude.

Unfortunately, this dynamic is also like a tug of war—each inch of ground is hard won, and can be recaptured by the other side any time we lighten up. You can never let the tension in the rope slacken. There is never a day off when you can take it easy. There are also no downhill rolls or favorable bounces. You must earn each inch of ground.

The need to effectively manage the boundary between accepting those with ASD as they are and pushing them to reach their potential puts the rest of us in a very difficult position, especially if the individual is an adult. We must find the fine line between honoring our loved one as he is and not pushing, versus pushing him and risking becoming (or at least feeling like we are becoming) a parental figure to our spouse by trying to motivate and force him into healthier behavior.

Ironically, those on the spectrum actually perceive some of the things we do to help them as hurting them and resist, argue, or ignore us. That alone is often enough to make you want to throw your hands up in the air and surrender, especially if he or she is an adult.

This boundary is very different than the typical boundaries experienced between most adults. This boundary requires constant attention, monitoring, and rebalancing of both functional and emotional aspects of our relationship in order to be effective, and maintain a successful relationship. We are asking ourselves to interject with the right combination of support, encouragement, and accommodation while staying out of the situation enough so that those on the spectrum both feel respected, and also experience the consequences and circumstances they need to continue to motivate them. AND, in addition to that, we need to find a way to get our own needs met. Tall order!

Therapists who tell you that you must hold the line and keep pushing rarely point out the incredible effort it requires from the rest of us. Still, therapists well trained in autism may offer a beneficial point of view because they can step outside of the emotion and assess more clearly if a particular issue is “ism-driven” or not, and so can provide some guidance on how critical it is to push in certain circumstances.

Finding the right balance is not only important to the life of the autistic individual, it is a factor in the quality of our lives and in our satisfaction with the value proposition, too. It is complicated to navigate the muddy waters surrounding motivation in those on the spectrum, especially with adults. The emotional fall out for the rest of us can be enormous, and can cast us in roles that we do not wish to be in, such as parent or manager. In addition, our success can be limited. We need to find the right balance so that our loved ones are the most prepared for the world, since in many respects, the world will probably not accommodate our autistic loved ones; they will need to find it in themselves to fit in to the “way it is”—the “one-size-fits-all” world on so many levels.

It's ALL You!

I do not want to gloss over the truth that it can be a lot of work to be in a relationship with someone on the spectrum. Just as with those two countries where one had to build and maintain the bridge, the neurotypical partner will probably carry the lion's share of the effort required to sustain the connection in the relationship. In addition, more than likely, that person will become the driver behind many other aspects of life such as making decisions, initiating change, providing energy and motivation in all areas of life, and contributing the necessary discipline to keep life moving ahead, or at least to keep it functioning.

On top of the effort required by the interpersonal and day-to-day operational aspects of the relationship, sometimes those who are married to someone with ASD become the functional “right brain” for the partnership or family, and that position requires a lot of extra organizational work. I remember one

If their world is not constantly being forced to expand, people with autism will probably opt to make their world smaller and smaller by reducing the activities that require social contact or other discomfort.

time when I was scheduling future dates with my son’s therapist. As she listed off every two weeks for the next four months, I checked them off in

my phone calendar—yes, yes, yes, looking up at the ceiling and thinking, mentally scanning the family’s long-term calendars and looking for conflicts. My thought process was so visually obvious that the therapist laughed and said, “Oh, I forgot. You are the right brain for the whole family!” She was right—I was managing the organizational pieces for all of us, and that requires a great deal of effort.

This imbalance of responsibility can also transform the rest of us into the social filter for the whole family. Here’s an example of how we act as a social filter: If your family is invited to a birthday party and you know that your husband, who is on the spectrum, will want to leave immediately after dinner and not stay for opening presents and cake, you may call the hostess and explain, “We may need to leave a little bit early, so if we do not stay, I hope you understand,” thus making an effort to pave the way for a smoother, more socially acceptable departure. Beneath this gesture, the rest of us could be experiencing a number of different emotions including shame, guilt, sadness or

anger. It can feel like we always get stuck making excuses for our loved one with ASD. This is especially true if your loved one is in denial about the autism.

It would not be uncommon for the neurotypical partner to be the one who reaches out to family and friends to plan for holidays, buy birthday gifts, remember dentist appointments, contact repairmen, order the Chinese food for dinner and generally maintain relations with the outside world that require any social contact. In addition, planning is not a great skill for those on the spectrum, but a full and good life requires planning.

One woman put it this way: “When I was married, my husband used to complain that I was no fun. I worked very hard to manage the many aspects of our lives, from the kids to finances and investments, from household chores to our social engagements, all the while building a full-time career. There was no time for fun! As the responsibilities for our life shifted to my shoulders, I remember thinking that the reason I was no fun was because he “used up” all the fun. In our lives, there was only so much leisure and play time and energy, and because the responsibility quotas were out of balance, there was never enough left of me in terms of time and energy to expend having fun.”

All of this work may land in the lap of the neurotypical partner and with it comes all the “stuff”—the criticism, negotiation, dissatisfaction and angst that happens even in so-called normal families. The rest of us typically end up doing all the extra legwork to keep life running smoothly. In describing this, one therapist said to me, “It’s ALL you!” (Can I hear an Amen?)

Worry

The rest of us may be inspired to take action because we worry that our loved one will wind up in a painful situation. Whether the pain is in the form of embarrassment, humiliation, fear, or some other negative feeling, at some point we will probably experience pain on behalf of our autistic loved ones. This can occur spontaneously, but we can also worry preemptively, experiencing emotions because, with our social minds and ability to project into the future, we know that the person we care about is heading for a socially awkward situation or a painful collision with life. We may even go to the extreme of trying to arrange situations so that our loved one experiences the least amount of pain.

For example, as a parent, I know I have expended tons of extra effort to insure that my son fit in (or at least stood out less) in certain situations. He recently graduated from high school, and a couple of days before commencement he told me he did not order a cap and gown, in spite of the fact that he very much wanted to walk in the graduation ceremony. The thought of him being unprepared or unable to participate was very painful for me. I am sure parents of kids without ASD feel the same thing, but remember the times 10 factor.

In my imagination, my son showed up at the commencement staging area with the other 600 students and was turned away without a real understanding of why. I had visions of him leaving the staging area dejected and confused because he did not have a cap and gown. That vision haunted me, and I fought to ensure that it didn't become reality. I went to great lengths to guarantee that he would be dressed in the proper attire on graduation day. I made phone calls and sent emails to school and expended several hours of vigorous

effort to assuage my fear about the sadness I knew he would experience if he could not participate on graduation day.

As it turned out, the worry was all for naught, because he had, in fact, been measured for a cap and gown with the rest of his class, but he either did not remember it, or did not know what it was all about when he was measured. All the extra stress and effort that I expended was unnecessary, and the woman at school thought I was an overbearing nut case! In this instance, I was relieved, but I could have also felt angry, frustrated or even stupid.

These types of incidents pop up in our lives if we are in a relationship with someone on the spectrum whom we care about. Some of these incidents can be funny, but some can be terribly frightening. I know that, like me, you will do what you need to do when these situations occur, but amongst ourselves, let's at least acknowledge the fact that it is sometimes a lot of extra work, strained emotion, and maybe even aggravation heaped on top of our already demanding lives. My advice is to stay in the present. Don't project gloom and doom. If we can learn to handle what is, rather than manufacturing trouble in the future, life will be more manageable. Talking about our experiences to each other and occasionally laughing about ourselves is the great first step in handling the bulls**t in a healthy and productive way, instead of letting it get you down!

Case Study: A Marriage Dissolves

If you are married to someone with ASD, you may be inadvertently contributing to the deterioration of your spouse's independence, functionality and long-term relationship with the world if you do not allow circumstances to push him or her to action. This can be particularly true if you entered your marriage with the autism unidentified, and have always

taken action based on the belief that you were being a good, supportive partner to a socially based thinker.

Finding the right balance between pushing and not pushing can be even more complicated in a marriage than with a child. Standing back, doing nothing and allowing your own life to be negatively affected while waiting for your spouse to act can be a difficult tightrope walk. Can you imagine letting your mortgage go unpaid so that your partner will learn the consequences of not managing that responsibility properly? I can't. That can be a painful and confusing road, doubly so if you do not understand autism.

I know many of you might be thinking "well, let them experience the consequences of their own actions in less important areas of life..." Which are those? The kids? The house? The job? Where do you draw the line? When is it important enough to warrant the effort to keep your hands off and honor their process, but not so important that the damage to your life is minimal? The choices seem to be to either assume the responsibility yourself, or live with the negative consequences of letting the situation lie. The third option is to cajole, remind, beg, oversee, and generally become the nagging fishwife you swore you would never be, which really sucks!

I know of one woman who feels she made the mistake of handling too much of the responsibility and realized after it was too late that she had actually contributed to the destruction of her marriage by providing too much of a safety zone for her spouse. She was ambitious, energetic, and hardworking, and she loved her husband, but unbeknownst to either of them, he was autistic. She worked hard to make their life nice, and to support her husband in his areas of difficulty. She just thought that is what a good wife did.

When he struggled with a responsibility, she helped him; if a chore overwhelmed him, she would work alongside him. But, eventually, as she did more, he did less, and so she picked up the slack and did more still, and he did less yet. She continued to compensate for his difficulties because she felt that was the natural thing to do when trying to raise a family and build a life together.

She was operating with socially based thinking; her natural tendency was to pitch in and help instead of complain.

Rising to the challenge of dealing with autism in our world may be one of the most rewarding and fruitful endeavors of our lives, taking us down a path we could experience in no other way.

She worked hard to keep their lives working and growing in a healthy direction. This created a pattern that ultimately resulted in his becoming less and less functional and her carrying more and more of the weight of responsibility and at the same time becoming more frustrated and more deeply desiring a true partner.

Ultimately, she felt alone in the relationship; there was no longer any value left in the marriage for her because she was doing everything on her own, and he was doing nothing. Over the 20 years of their marriage, the shift was so subtle that the violation of her boundaries never seemed like an issue. Because change in a relationship with someone on the spectrum is grueling and difficult once the damage is done, her numerous efforts to rebalance the weight of the responsibility ended in failure. The marriage finally crumbled because both parties felt that their needs were not being met.

In retrospect, the match was a perfect mismatch—one strong partner and one who is willing to let the other use that strength.

The result was that the husband's ASD overtook him as his world and his ability to function in life shrank. Eventually, he wound up watching television in the basement all day long. The wife in this story told me that she used to feel that she was the only one in the marriage, and that she had three children instead of two children and a spouse. When you compound that type of functional difficulty in a marriage with the lack of emotional connection, it is a recipe for divorce.

A Special Note to Spouses

I want to include one special note for those who believe (or know) that their spouse is on the spectrum. It really ups the ante when you attach your life to someone on the spectrum in the way you do when you marry. You are then bound to this person functionally, physically, emotionally, socially, sexually, financially and in every other way. The dynamics of a marriage with someone on the spectrum are difficult to negotiate, and are influenced by many factors including: sex (which can be a very loaded subject for many people anyway); your hopes and dreams; who you want to be in your life; what you want to accomplish; where you want to go; the things you want to do; the myriad issues revolving around children; and most importantly, whether or not your spouse is willing to accept the diagnosis and the ramifications that go with it.

Not only is life with an autistic partner not easy, it may even be a conundrum, not to be solved, only navigated as best as possible. If you are a strong, compassionate and forgiving person, this is a word of caution for you. You may find yourself attracted to someone on the spectrum, but for your marriage to succeed, you will need to manage your personal power carefully so as not to steamroll your partner or assume the responsibility for your loved one. This can be a huge challenge when it feels

that by doing so, your life is falling apart. If you truly love the person and are able to find healthy ways to meet your own needs (and you must do this consciously), it is possible to find a successful value proposition. Finding the balance between your approach to life and the autistic approach to life is a challenge, no doubt, but with knowledge, it is doable. I think our optimistic battle cry must become, “Remember the pearl!”

A Relationship with Someone on the Spectrum Can Be Rich and Fruitful

One psychiatrist I interviewed often reminds me that people on the spectrum are incredibly loyal—they are stable, they are faithful, they are honest, they are direct, they are dependable, and they are consistent. This is her experience of the people whom she has treated in her practice and whose lives she has witnessed as they developed over the years.

She’s right—those on the spectrum embody many fine qualities that can be wonderful aspects of a good relationship, provided that the relationship is an equitable and sustainable value proposition. That is why consciously knowing the value proposition of a relationship is very beneficial.

During times of stress or difficulty in the relationship, as happens in every relationship, it helps to remind yourself that, “I am here because I appreciate the loyalty, stability, faithfulness, honesty, dependability, consistency, trustworthiness” (or whatever the benefit may be for you), and to know that the lack of social functioning and emotional connection is not intentional, nor a reflection on you, nor a measure of how much you are loved.

If your relationship is not a marriage partnership or a parent/child relationship, you are in a prime position to focus on the positives and accept the rest of the package as it is.

What parent among us would be willing to give up their bright, talented and wonderful child who also happens to be on the spectrum? Not me and not any parent I have ever met. No individual is perfect; we each come with a unique set of features and benefits, as well as challenges and issues. Every one of us has been given a measure of both positives and negatives to enjoy and overcome respectively. Rising to the challenge of dealing with autism in our world may be one of the most rewarding and fruitful endeavors of our lives, taking us down a path we could experience in no other way. I know that has been true for me.



Dear Reader,

Have I said thank you for taking the time to understand how autism is affecting your life? I know you are a fine person, and care very deeply, or you wouldn't be sitting here reading this book. I just wanted to take a minute to encourage you and applaud you for the effort you give and your willingness to grow. This is not easy stuff we are talking about, and I appreciate your hanging in there with me to the end! Take heart, my friend, Chapter 10 is full of comforting thoughts and suggestions on how to cope.

—Jeanne

In this Chapter

- Learn to cope with emotional negativity in healthy ways
- Come to terms with the reality of living with autism
- Overcome the self-doubt and confusion and manage frustration

9

The Feelings We Don't Dare Express Out Loud

Emotional Negativity

There are as many different reactions to the reality of living with someone on the spectrum as there are people. We are all individuals. Our emotional experience can be all over the map, ranging from anger to frustration to sadness. We can feel lonely or frightened, or we can wind up feeling bad about ourselves. We can interpret the lack of reaction or negative reaction we receive from the individual with ASD as a reflection on us—an indicator that we are not accomplishing our goals, that we are doing poorly, missing the mark or failing in our relationships or in our family. We can harbor an anger that builds below the surface and erupts at the drop of a hat, exploding disproportionately to the real issue at hand. We can even feel that our loved ones on the spectrum simply do not care about us or anything else. We may experience dull, aching and lingering unhappiness or dissatisfaction, maybe even a sense that we are damaged goods, feeling like we don't fit anywhere, or feeling out of control.

In spite of the variety of emotions the rest of us may experience, I do believe that there are common threads that run through our emotional lives, regardless of our level of understanding about autism. These feelings don't always happen in sharp spurts nor are they necessarily accompanied by understanding. Between points of clarity in our lives, an undercurrent of emotions can develop such as a general sense of being upset or angry, vague fear about the future, distrust in God, distrust in the universe or divine unfolding, distrust in ourselves and in our ability to evaluate and decipher what is going on around us, and self-doubt. These feelings can sneak up on us, come and go, and even hide in a general sense of confusion. I know there were times when I just felt crappy, and didn't know why.

Even when life is going well and you are enjoying some serenity and clarity (and in every relationship, there are times when life seems to go well), you may spend time looking over your shoulder wondering when things will fall apart again. We can develop a general negativity about life, which can be blatant and worn on our sleeves, or that we bury, but which surfaces sideways, expressing itself in indirect and covert ways.

A steady diet of negative emotional fare coupled with the lack of connection we often experience in our relationships with our ASD loved ones can leave us feeling discouraged, frustrated, alone and overwhelmed by a life we cannot seem to budge off the starting blocks. Effecting change in a relationship with someone on the spectrum is often a slow and arduous process, so even if we identify the need for change, we may struggle to make change happen. Hopelessness and despair can ensue. Pursuing happiness and peace requires sustained effort and time, as well as thoughtful, conscious decisions about how to proceed, but it is doable.

Energy and Autism

Unlike the energy you invest in other relationships with socially based thinkers, whose social natures tend to instinctively respond with mutuality, autism, by its very nature, will never return energy back to you. Autism creates an energy black hole, and will swallow as much energy as you will give it. Since that does not seem logical to our socially reciprocal mindset, we tend to not believe it's true until it's too late and we are experiencing painful repercussions from giving too much.

Part of our social gravity is to think that we should be receiving in proportion to what we give; we enter into relationships expecting reciprocity in terms of energy (i.e., time, attention, support, help, and giving of all varieties), and typically don't receive much, if any, in return from our ASD relationships. Those of us with a giving nature or who are very tolerant or patient may keep giving until we are exhausted. I remember thinking that I would eventually give enough that it would overflow and my energy would return to me by default, but that didn't happen.

If our autistic loved one is a child, the lack of reciprocity may not be a big deal—it may even resemble the plight of every parent who ever parented a teenager, but if it is your spouse, parent, close friend, business associate, or someone else with whom you expected to share a mutual relationship, it feels different. It can feel like you are pouring yourself into a big black hole, and no matter how much energy you invest in that relationship, it may never come back.

As time passes, the rest of us who face this painful dilemma can become disgusted, bitter, angry, resentful and tired. This is especially true in the moments when our strength and resolve wear out, which they do from time to time when we are

overwhelmed by life. Education and self-care are important steps to help combat the fatigue in our relationships. We need to learn to pace ourselves emotionally and stay in touch with and advocate for our own limits and needs, seeking appropriate support outside of our relationships when necessary.

How the Rest of Us Feel about Our Selves/Self Esteem

I had the opportunity to be part of a group of women, all of whom had husbands on the spectrum. This was a group of talented women. There were several who were highly educated, with multiple postgraduate degrees. Everyone in the group was successful in her career, confident, and hardworking—a group of talented and driven women. Why, then, did many of us feel so insecure about ourselves? I postulate that to some degree, we drove ourselves because of our need to create better self-esteem. This may be in part because we were not getting an appropriate, or at least accurate, response from our primary relationship and that affected our experience of the world. The fact that we all had such a drive professionally may also be, at least in part, a result of the fact that we invested more energy into an area of our lives that was receptive and responsive to our input, unlike our marriages to men on the spectrum.

It was common among us to feel that our lives and relationships were not working—that is the reason we all sought help in the group. I felt that way often. The feeling was unnamable, but I felt like I was just somehow missing the mark all the time. I was interpreting the fact that the emotional satisfaction that was missing for me was a reflection on me. I believed that the fact that I was not creating the results I sought meant that I wasn't "doing it right." This feeling of being off kilter and out of sync affected me on a social level, too; I felt like I was a round peg in a square hole. I knew that my family

was different than other families. Somehow, because I could not find any other explanation that made sense, I thought my dissatisfaction was entirely my fault. I believed my faults and my issues were the cause of my problems, and sometimes I just felt uncomfortable in my own skin.

It's easy to doubt yourself and feel badly about yourself when your efforts don't seem to be producing the results you expected. As I learned more about autism, I began to see the whole picture and I realized that my self-esteem was often founded on the inaccurate feedback I received as a result of the influence of autism on my life.

Confusion

This clarity did not come until I had suffered through a great deal of confusion. Confusion is a regular companion to autism, as much for the person on the spectrum as for those surrounding that individual. Before I recognized the autism, there were so many times when I just felt confused. Have you ever thought:

“I don't understand why you do not ever see it my way!”

“I cannot figure out why you always leave the dishes lined up on the counter.”

“Why do you always say, ‘I do not know?’ Who should I ask?”

“Do all couples suffer from this much trouble while resolving issues? I don't think so. Therefore it must be something about us.”

All of these statements reflect unanswerable questions; they are simply an expression of our confusion over why things are the way they are.

In reality, confusion may actually be a signal that you are dealing with someone on the spectrum. The contradiction

between what appears on the outside to be a normal, healthy, functioning human being (after all, we can't see any autism, right?) and the lack of accountability, reciprocity and absence of social gravity on the part of the person with ASD can leave us feeling very confused, even to the point of feeling crazy, when our gut doesn't line up with our experience. If you can suspend your instant social judgment of right and wrong long enough to try to figure out why the individual is acting as he is acting, and you still can't make sense out of it, you might have pinpointed the difference between social and nonsocial thinking and that can be an indicator that you are dealing with someone on the spectrum.

The pieces often don't fit together in any way that makes sense until you recognize the presence of the autism, which finally makes the disparate, disjointed parts fit together into one cohesive picture. Do you find yourself coming away from an interaction scratching your head and asking yourself, "What just happened here?" You might be experiencing the confusion that often accompanies autism.

Self-Doubt

Confusion can become such a tangled, knotted perversion of the reality about who we are and what is happening around us that we may give up trying to understand and just continue to feel uncomfortable. When that energy is turned inward, it becomes self-doubt. Self-doubt is a confusion that has ricocheted back to us as feelings of being wrong, bad, or at fault, unloved or unlovable. You may often wonder:

"What did I do to cause you so much anger?"

"Why do you care so little about my feelings?"

"I must be the worst cook in the world if my spouse will only eat a few foods that I prepare."

“If he really loves me, he would buy me a birthday present.”

You might even secretly fear that he doesn't love you because there is something wrong with you.

I know for myself that time and again there was so little acknowledgement of me, my concerns and my issues that even when I mustered the energy and nerve to raise them, the conflict would usually end with me holding all the emotional marbles. He would be unaccountable, I would be blamed and the issue would be pushed back on me. He would leave the conversation content—after all, it was my issue, right? Nothing was bothering him. I was left standing there emotionally empty-handed, wondering once again, “How did my feelings and needs evaporate into thin air without any resolution? How is it that my feelings and opinions are always inaccurate, off base or wrong? What's wrong with me? I must be the problem.” When the responsibility for every disconnect we experience ends up on our doorstep, repeatedly, it develops into self-doubt. In my heart of hearts, I knew it wasn't just me, but the self-doubt was more easily understood than the autism.

Given our assumptions about social gravity, we expect to be heard and understood, and to receive a socially appropriate response. To add insult to injury, when his feedback was full of blame and he accused me of being too controlling, expecting too much, or being too demanding, I started to wonder if maybe he was right—maybe I am the problem. The stakes doubled-down when I worked to be humble, focused on managing my own behavior, and really made an effort to listen and respond to his feelings. The harder I tried, the “behinder” I got.

Frustration/Exhaustion/Depletion

Frustration is a common experience for the rest of us. Ironically, the harder we try to force the relationship to work

Trying to manage the situation so that they conform, or trying to persuade, cajole, or demand that they rigidly live and act by the standards of the rest of us is a recipe for frustration.

by using familiar socially based tools, the more frustrated we can become. This is especially true if we are operating in the dark about autism, which makes it exponentially more difficult to understand why our loved ones on the spectrum can't "get with the program." We simply have no idea the forces at work in their brain. (The truth is they are with the program, it's just that the program in their head is different than the one the rest of us embrace.) Trying to manage the situation so that they conform, or trying to persuade, cajole, or demand that they rigidly live and act by the standards of the rest of us is a recipe for frustration.

In the heart of fall color, I saw a beautiful, neatly planted row of maple trees that had all turned autumn red, except for one tree which remained very green. I pointed it out to my ASD son, thinking how similar that tree was to him—proud and healthy, but different. And his beautiful response to me was one of total acceptance. He said simply, "It is doing what it is programmed to do." Yes, but if that tree was a small child on the spectrum who refused to wear a coat in zero degree weather, "doing what he was programmed to do" would be a huge source of frustration and worry to the parent who loved him.

In a relationship with someone with ASD, change may take a long time (if it happens at all—remember times 10!). Sometimes we reach the end of our rope and lose our patience. Do any of these lines sound familiar?

"I am done with this!"

"I feel like I live in the movie *Groundhog Day*."

“Nothing ever changes!”

“Haven't we discussed this a dozen times before?”

“When will you take action?”

When we have reached our limit, frustration turns to exhaustion. Even simple communication can be frustrating, given the processing speed and the special communication requirements of someone on the spectrum. The patient and metered communication required to succeed takes deliberate effort, and life can lose some of its spontaneity and ease. It can be frustrating to try to engage, to accomplish a task, or to feel like we connect in a meaningful way.

In a relationship with a business associate, spouse or other adult, we may feel that all of the responsibility for leadership, motivation, and decision making winds up in our laps. We take the lead because someone has to step up to keep life moving, but this role requires additional effort. Migrating ducks fly in a **V** formation because it reduces the load on the ducks in the back of the formation. The duck at the point of the **V**, in the front, absorbs more of the friction while the other ducks draft behind it. During long flights, the ducks rotate in turn, so that no single duck is required to be in the lead for too long. Nature taught ducks to take this teamwork approach automatically because it is exhausting to always be the lead duck, and rotation allows them to fly for longer periods of time.

When we are in a relationship with someone on the spectrum who is our spouse or partner, we may feel exhausted from our role as the perpetual lead duck, always providing the motivation and initial energy for every joint endeavor. Remember, this isn't a trait to judge, this is an example of “can't,” not “won't,” and understanding and preparing for that makes the likelihood that we can sustain a successful relationship much greater.

There are times when we feel frustrated, exhausted, alone and stuck there. If we continue to operate when emotionally exhausted, we can develop a state of emotional depletion in which we may experience perpetual exhaustion, despair, and resignation to suffering in a painful situation without escape. It is overwhelming when you feel that you are swimming upstream, holding everything together that is designed by its very nature to fall apart. Couple that with the missing emotional nurturing in your life, and you have created a recipe for depletion.

Other Feelings

Of course there are a multitude of other emotions that the rest of us can experience as a direct result of living with autism. Here are a few of my most prevalent:

1. *Trapped.* If we feel stuck in a situation that we experience as difficult, confusing, challenging and never ending, we can feel trapped. Thoughts like, “I said for better or worse, and I meant it. Now I am stuck with you,” or “You are my child and I will always love you,” or “I have no idea how to get control here and create a life for myself” may become commonplace. There are times when we can feel tied to the whipping post by life. Remind yourself that no matter what the situation in which you find yourself, there are always choices available can relieve the sense of being trapped.
2. *Bored.* The repetition, or sameness, that is comforting for those on the spectrum may leave us feeling under-stimulated or bored. There is a scene in the movie *Adam* depicting the main character’s dinner routine. He opens the freezer, which is full of boxes of frozen macaroni and cheese all lined up perfectly in a row next to bags of frozen green beans stacked on top of each other. Adam sits at the table eating his mac

and cheese and green beans. As the days progress, the movie shows the number of boxes of mac and cheese and bags of green beans diminishing, graphically indicating that these comprise his one and only choice of dinner entre. Then the movie cuts to a scene in the morning that shows him again opening the cupboard, where 12 boxes of his favorite breakfast cereal are all lined up perfectly in a row. These scenes are a vivid portrayal of the rigid and limited routine that some people with autism find comforting, if not necessary. The rest of us might find this routine annoying, aggravating or even crazy making. Therefore it is important that we continue to pursue independent hobbies, activities and endeavors over which we have control, and where we can express our need for variety.

3. *Unheard/Disregarded.* It's not unusual for the rest of us to feel unheard or disregarded, and if you have ever experienced this when you are upset or trying to communicate on an important topic, it can cause you to become frustrated and angry. When something is important to us and we are trying to get a point across and it is not going over very well, we can begin to think, "Why can he not just listen to me?" or "Why can't he just be nice to his brother?" or "Why can't you answer my question. I really deserve an answer," or "When is it my turn to get what I need?" Talking to a therapist or close friend (or both) with whom you can safely share your thoughts and feelings and receive validation becomes an invaluable lifeline.
4. *Unloved/Unlovable/Disrespected.* Feeling disregarded and unheard may quickly become feeling unloved. Our social expectation is that if someone loves us and cares about us, he will care about our feelings and listen to us. If you expect

to feel closeness, warm fuzzies, warmth and acceptance, or to receive generous praise from someone on the spectrum, you will probably be disappointed. These outward indications of loving approval are not typically part of the natural emotional expression of those on the spectrum, and the lack of that can leave us feeling unloved. Interestingly, we can know in our hearts and minds that this person loves us deeply and still experience the lack of expected social warmth and outward signs of appreciation as an emotional disconnect or distance-maker in the relationship. I know that this has been true for me in certain relationships. Again, relying on other relationships for validation and support is a key to diffusing this issue

5. *Walking on Eggshells.* Those on the spectrum can be quick tempered or may appear angry all the time. As a result, we can feel like we must walk on eggshells to avoid arousing the anger of our loved ones with ASD.

“Do not say that. You know how it upsets your father.”

“Do not touch your brother’s movies. He will go ballistic!”

“Do not tell our son ‘...just because I am the parent and say so’ or he will lose it.”

With anger such a prevalent and easily ignited emotion for those with autism, we might twist ourselves into a pretzel trying to keep the peace with our autistic loved ones. When we accept that anger is part and parcel of autism, it is easier to remember that the anger of our ASD loved one may not reflect their feelings towards us in this specific instance, and therefore it is easier to avoid walking on eggshells in their presence.

Living Without the Emotional Connection

Loving someone and being emotionally connected are not the same. You can experience very strong feelings of love, and know in your heart and mind that the person also loves you, but if you do not experience the warmth, acceptance and attachment, you are probably not feeling an emotional connection. When someone responds to your emotions because they are your emotions, and they feel them with you because they love you, then that is a sign of emotional connection; emotional connection feels like someone is “in it with you.”

The lack of emotional connection in our lives can be difficult to manage especially if it has been a theme running across many relationships. It isn't always possible within the bounds of certain relationships to find a substitute for meeting our emotional connection needs. For example, we may be able to find someone to replace the loving emotional connection that our mother could not give us, but we probably cannot achieve an emotional attachment that can replace the one that we might experience with our spouse through sex. The need for emotional connection is very subtle, akin to the need for unconditional love and acceptance. The relationship may look fine empirically, but if you feel something missing in your relationship, check how you feel about the emotional connection. It was a big insight for me when I realized that I was missing this connection.

Anger

Anger is an important topic. For those on the spectrum, anger eruptions are common and immediate. The rest of us deal with our anger in many different ways; some of us have no problem expressing it, with varying degrees of decorum and effectiveness, and others of us stuff our anger, pushing it

down emotionally. Some cope by overeating, or overspending, obsessing about something or in some other way. Healthy, direct approaches to negotiating our anger with our autistic loved ones are often unsuccessful in providing resolution. My experience was that confronting my loved one with autism only served to trigger his anger, and in the battle of angry attitudes, he always won. I used to say that there was not enough room in our relationship for my anger—his always squeezed mine out.

If we are going to manage a healthy long-term, sustainable relationship, we need to find ways to effectively express our anger, as well as other feelings, within the relationship. Regardless of how good we get at it, chances are, we will not be able to resolve all of our anger-producing issues directly with our autistic loved ones, so we also need to find an appropriate forum for our anger outside the relationship where we can vent, learn to resolve our anger in healthy ways that do not depend on our loved ones, and also deal with the emotions related to the inability to find resolution of the anger within the relationship.

When it comes to issue resolution in general with someone with ASD, mastering it is not always about getting it all resolved. At times, it's about learning to live with an issue and stay healthy while the issue is still unresolved.

We may need to resolve issues strictly for ourselves, in our own minds, rather than between our self and the individual with ASD. Issues, including anger, that are not dealt with effectively are very unhealthy physically and emotionally and can eventually blossom into larger issues such as anger with God, or with “the way it is.” We need to work diligently to manage negative feelings when they arise so that they don't build up and create a toxic emotional and/or physical state in our lives.

Blaming and Shaming

It is very tempting to indulge in blaming and shaming when we are angry, especially when we are in the dark about autism. We may have blamed our loved one on the spectrum and found fault with them, thinking or making such statements as:

“It is your fault our marriage does not work—you just don’t care!”

“If you would only be nice to your boss, you could hold a job.”

“You are so inconsiderate! You always make the family wait for you.”

Blaming and shaming is a counter-productive activity. It rarely produces the movement we hope for in those who are not on the spectrum, who naturally respond to social pressure, and as a motivational method will probably be even less fruitful when applied to someone with ASD. Social pressure does not usually act as leverage in those on the spectrum.

Hopefully, once we understand how autism affects our relationships, we can be more accepting of less-than-ideal-behavior in a given situation and we can find alternative ways to get our needs met without resorting to shaming and blaming tactics. Our understanding will help us take the pressure off the individual with autism in the areas over which he has no control, and help us to be more at peace with the autism and ourselves.

Today, I could no more blame my son for his autism and the behavior that comes with it, than I could for the fact that he was born with red hair. The idea of causing him any further pain, isolating him by pelting him with shame, or abandoning him emotionally is contemptible to me.

Mirroring

Psychologists use the term “mirroring” to describe how our environment gives us feedback about who we are, how we compare to the world, how we fit in (or don’t fit in) and how we are doing. We learn who we are by seeing ourselves in relationship to other people. This is part of how we learn and grow. Feedback is the means by which we evaluate ourselves, adjust our behavior to move in our desired direction, and create our self-image.

Ineffective mirroring amounts to the fact that we are erroneously accepting information that is not accurate as a literal and factual reflection of ourselves. When we receive information that is being mirrored back to us that is not representative of what we are presenting, it feels confusing, painful, odd, and disconcerting, and gives us an inaccurate picture of who we are, and how we are behaving and performing. Imagine looking in the mirror and moving your left hand, but the reflection doesn’t move. How weird would that feel?

If you are in a relationship with someone on the spectrum and that person does not give you a birthday gift for 20 years, that does not mean you do not deserve a birthday gift. If you are in a workplace with someone with ASD who never accepts

Ineffective mirroring means that we are erroneously accepting information that is not accurate as a literal and factual reflection of ourselves.

your invitation to go to lunch, that does not mean that she does not like you. If you are parenting a child on the

spectrum and the child does not respond to your discipline, it does not necessarily mean that you are not a good parent. It is so important that we filter the feedback we allow to influence

our self-esteem and to affect our beliefs about ourselves, remembering that this person with autism is probably not accurately reflecting who we are, at least not based on typical social assumptions.

The blind expectation that my partner was a social thinker and was responding to me from the same social database that I used to respond to him caused me to believe that the information that I was receiving was an accurate reflection of what I put out. In other words, I thought I got what I deserved. I thought the mirror couldn't lie. That left me feeling like I was unlovable, undesirable, and ineffective, when actually his response had nothing to do with me at all. He was absorbed in his own world and I was face-to-face with the autism, but I didn't know it. Today, I can disconnect my feelings about myself from the responses I get from my autistic loved ones. This is a tender balance to maintain because I don't want to shut them out. I still want to be receptive and be able to be influenced by these individuals, and also to respond appropriately to their input in my life.

Psychologist Maxine Aston gave a name to the issues related to being the spouse of someone with Asperger syndrome; she called it the Cassandra syndrome, or affective deprivation disorder (AfDD). The mythological character Cassandra was said to suffer from the condition of speaking the truth, but no one believed it. How would that be for crazy making? Aston likens Cassandra syndrome to seasonal affective disorder because they have similar symptoms including: sleep problems, overeating, depression, social problems, anxiety, loss of libido and mood changes.

Self-Talk/Getting Triggered

For the rest of us, one of the biggest question marks is how we interpret the types of responses we receive when we

express our needs, our feelings and our requests. What do we tell ourselves about the feedback, or lack of feedback, we receive from the world? What do we add, edit and forget in our own minds? No doubt the responses we receive can be confusing, hurtful, irritating, aggravating, and often very hard to understand.

But, what do we do with all that stuff when it rattles around inside our heads? This is an important point of power for the rest of us; we can't change them, but we can change our own self-talk and the interpretation of the information we receive. All of these negative feelings we have discussed can be managed more effectively if we understand what is going on with the person on the spectrum, and adjust our perspective and our self-talk accordingly.

Our expectation of socially and emotionally steeped feedback happens so automatically that it is difficult to avoid, but just knowing that this happens doesn't necessarily solve our problem. It is a great challenge to remember that the response

It is a great challenge to remember that the response or feedback that we receive from the people in our lives who are on the spectrum is filtered through their autistic thinking...

or feedback that we receive from the people in our lives who are on the spectrum is filtered through their autistic thinking—their own

perspective or difficulties—and therefore may not be flavored by the emotional and social influences that we, as social thinkers, assume have gone into it. It is very hard to stop yourself in the heat of the moment, in the middle of an argument, in the middle of something that is painful, when you feel like you want to scream or cry, and then say to yourself, “Oh, wait a minute.

This really is not about me. It is about the autism. This feedback is not accurate.”

Even as focused as I am on understanding as much as there is to know about autism, it is very easy for me to slip back into my typical social expectations of the world and to be upset with my son for not holding the door open for me. Some events, comments, and behaviors just trigger us. To accomplish this detachment and to avoid reacting to the trigger takes a momentary suspension of all the rules of social gravity. We have to step outside of our own thoughts, just long enough to remember that we live in the reality of autism. This act may feel very uncomfortable at first, but once you practice it a few times, it does become easier.

For example, one trigger I need to work on constantly is the battle in my head for my mother's approval. This is not about her, it's about how much I love her, respect her opinions, and want to earn her approval, and what goes on in my head surrounding those feelings of wanting to please her. I need to work hard to quiet my mother's voice that I can clearly hear in the back of my mind saying, “Manners count—a young man should open a door out of respect for a woman.” She is right. But in the moment, there is a split second to decide if I want to take up the fight for socially expected manners “just because,” or be cognizant of what is going on with my son, accept him as he is, and save my energy to fight for something else that is critical for his well-being such as eating vegetables instead of chicken nuggets from McDonald's, or the value of going to college versus playing video games 24/7.

Many conflicting emotions can get hooked in to these momentary decisions when we are triggered. The infamous ought-ism will certainly weigh in. Other factors such as how you

were raised and how you feel this behavior reflects on you in the eyes of those who do harbor social expectations that they cannot suspend, and are therefore judging you, will play a role in your feelings. What this says about the autistic person's respect for you, or his feelings for you, and a myriad of other influences, all need to be processed to come to a decision about how to handle the situation in the moment. Is your head spinning yet? Mine is!

Giving Up Our Dreams/Grieving

One of the most deeply painful aspects of living in a close relationship with someone on the spectrum is that we may need to give up some of the dreams, expectations, and wishes that surrounded that individual. The dream of the ideal coworker, boss, brother, child, parent, lover or spouse we always wanted may be unrealistic with this individual. We have the one we have; we have the one providence gave us, and it can be a bitter pill to swallow to give up hope and realize that this is never going to be

Take heart, my friend, there is acceptance of life, appreciation of the good things, happiness, contentment, peace and fullness of joy on the other side of grief. Yes, even if your loved one is still autistic, you can be happy!

the relationship of our dreams, nor is it ever going to fulfill the deep emotional need that was at the root of that dream.

My younger son is very social, and

desperately wants closeness and love with his older brother. He wants them to be best friends, and he wants to share all the closeness and companionship that he sees his friends enjoying with their siblings—the love, acceptance, and camaraderie that brothers share in his ideal world. When we discussed his feelings about his brother, my youngest son described one of his friend's relationship with his brother, and poignantly added, “like a

brother should be with a brother.” Unfortunately for him, achieving that kind of intimacy and relationship will probably never happen the way it happens in the movies or in other families, and that is a huge loss. Maybe movies set unrealistic expectations for anybody, but those unrealistic ideals border on painfully impossible when you have an autistic relative, and that hurts.

We may also need to let go of other dreams in our life because of the additional work that a relationship with someone on the spectrum entails, work that utilizes resources other people have available to accomplish and enjoy varying life endeavors. For example, as a parent we may have had dreams of starting our own business, and that may end up on life’s back burner when autism enters our family picture. We may have dreamed of running the Boston Marathon, writing a book, or learning to play an instrument, but autism has sapped the resources we need to accomplish goals like these. Some of the rest of us may experience feelings like:

“I experience so much other stress in my life, I will never muster the energy to reach my goals.”

“I will be forced to give up hoping my child will live a full and independent life.”

“I must give up my dreams of finding a soul mate.”

We may be forced to make painful choices between our dreams and our reality in order to maintain these relationships.

Giving up the dreams of what we wanted in our life from or with this person with autism, and accepting the impact that this unplanned occurrence has on our world can be very painful, even heartbreaking. Our lifelong goals can be shattered, and we can be left trying to pick up the pieces and patching together a life that pales in comparison to the one we have always dreamed

of. This is an important consideration when assessing your relationship's value proposition if your relationship is one that can be exited, such as a marriage.

Letting go of those hopes and dreams, accepting what is, and facing a lifetime with certain unfulfilled needs is spiritually big stuff, but Chapter 10 is filled with ideas about how to cope. Maintaining a healthy spiritual life is a huge advantage when living in a relationship with someone with autism.

We need to allow ourselves to grieve these losses. Grieving is an important step in coming to terms with the presence of autism in our life. Like any other grief, as we grieve, we adjust ourselves to the new reality we face. Some of the losses can be huge life-long losses and may take time to work through, but we need to be careful not to get stuck in the grief. There is so much good literature available on coping with grief that I am not going to delve into it too deeply, but be aware that some of your emotional distress can be part of the grieving process and is worth working through on a conscious level.

In spite of the magnitude of the pain I have been describing, I know from personal experience that there is a way to move through these difficulties and find peace and joy. Take heart, my friend, there is acceptance of life, appreciation of the good things, happiness, contentment, peace and fullness of joy on the other side of grief. Yes, even if your loved one is still autistic, you can be happy!



In this Chapter

- My story
- Autism in families—
discovering the family
connection
- Facing denial
- Benefits of a spiritual life

9^{1/2}

The Hole in My Heart

I Finally Figured Out Why I Am Who I Am

**Remember,
as far as everyone knows,
“We are a Nice Normal Family.”**

This sign hangs by the back door in my house. In many respects, we *are* a nice normal family. We are a nice normal family with some members who have autism. Other families are nice normal families with a family history of high cholesterol, or heart disease, or diabetes, but we are all still “Nice Normal Families.” When I found this sign, I related to the concept that we are a normal family, but we need reminding...because I often feel that we are not very normal. I was drawn to the tongue-in-cheek humor that by hanging the sign in our house, we acknowledged that we are not a normal family, but we recognize that these families might exist, and we can pretend to be one. When it comes to families, what you see is not always what you

get. This isn't a value judgment against my family or any others, but it is difficult to accurately assess any family by its outward appearance. That may be even more true if the family includes members who are on the spectrum "pretending to be normal."

I grew up in a wonderful home, with wonderful parents who loved me very much and worked hard to make my life "just so." We lived in a very nice part of the suburbs where people had what they needed and there wasn't much material lack. But I also grew up knowing in my gut that something was always missing for me. I searched many places for it, but had very little success feeling like I found the right explanation until my story completely unfolded in the spring of 2014.

During my search to fill the empty hole in my heart, I tried psychology, philosophy, new age theories, traditional religion, multiple brands of therapy, dozens of self-help books, and I learned a lot about 12-step programs, the latter of which was a very helpful philosophy, but it still didn't quite scratch the itch. As much as I related to many of the emotional experiences that people shared, they never quite hit the nail on the head. I felt that I was different.

I never quite understood why I didn't feel like I fit anywhere. Why, in spite of knowing that I was loved in my family of origin, I felt like I wasn't quite connected the way others were with their families. Why I felt that I wasn't quite good enough, that I wasn't like everyone else, that I lacked the full acceptance of me for who I am and who I am not. I saw the relationships my cousins enjoyed with their parents and noticed the closeness. I watched my friends with their brothers and sisters and always knew I didn't experience the same kinds of relationships that they had. Sometimes that feeling made me uncomfortable in my own skin, like there was something wrong with me. I lived with a vague and continual sense of loneliness.

When I graduated from college and launched my career, I worked with great gusto and passion, trying to derive from my job that sense of completeness I longed for. Guess what, not there either! But that did not stop me from working to excel in my career and trying to find some self-esteem from feeling good about my own efforts. For a while, focusing on work helped me feel okay about myself, especially because I worked in sales and had a very clear measurement of my productivity. Besides, as a successful salesperson, I certainly had to be connecting with people on some level, right?

When work alone wasn't enough, I focused on a house, on building a life for myself and for my spouse. I started a family and focused on making them happy. I have never been afraid of hard work, and I put myself to work trying everything I could think of so that I would feel complete. I was a human doing instead of a human being.

All the while, I searched on an emotional level through therapy, endless conversations with people, and self-help books. When the ACOA movement really became popular in the late 1980s, I related to most of the literature and concepts published about adult children of alcoholics. But, the problem was, I didn't grow up in a home with alcoholism. I didn't relate to living with drinking, but what I did relate to was the difficulty with the emotional connection—the struggle for intimacy that adult children of alcoholics experience as a result of growing up in an alcoholic home, and all of the emotional baggage that goes with that experience.

I found some peace in that philosophy. I kept my focus on changing myself and accepting those around me who I could not change. As my family grew, struggles with my son began to arise and I discovered the presence of autism in my life. When I

learned more about autism, I realized that my son and his father were similar in many ways. Understanding more about autism finally shed some light on my frustrations in my marriage. Prior to that time, the only words I found to describe my frustration with my spouse was, “I hate the way you relate to the world.”

It wasn't until after my dad passed away in March of 2014 that the final pieces of the puzzle were revealed and true understanding began to dawn on me. My relationship with my father was an important part of my life. We loved each other deeply. Anyone who knew either of us would attest to that fact. I quoted his wisdom often, and bragged about his accomplishments, his strengths and his insights into life. He was an amazing man who lived a wonderful and full life. He loved me, too, and those who knew him, knew I was the apple of his eye. There were many wonderful aspects to our relationship, yet I never felt that warm fuzzy of deep emotional connection. Those of us who knew him well, knew that he was not an “easy” person when it came to more intimate relationships.

I remember as a child, I envied my cousin who was quite obviously close to her dad in a way that allowed her to share all of who she really was and be accepted. They were emotionally connected; my dad and I were not. By nature, emotional connection is deep, complete, secure, and mutual. It's what we refer to when the chips are down and we comment “but I still have you” as in “have you in my corner, have you to love, have you to help my life feel complete, have you to love me, have you to be my companion, soul mate, best friend, have you!” It includes a feeling of transparency, in which you can be totally yourself and still receive unconditional acceptance and unconditional love, as if this other person loves us even when we are unloveable, and is entrenched in our life with us, come what may.

In spite of the missing pieces, my relationship with my father was very successful. I used the strategy and tips I am sharing with you to create a strong, healthy relationship with him. I used the tools in this book to accept him for who he was and to enjoy the many gifts he brought to my life; we were able to compensate for what we did not have and appreciate and enjoy what we did share, and to find a way to let that be enough. For me, the value proposition was clear, and the good far outweighed the difficulties—by a long stretch.

My father died at the age of 96. He was loved by people of all ages and his memorial service was packed with hundreds of people—there was a swarm of boy scouts in uniform, college athletes (even a whole team of Northwestern University Lacrosse players) and people ranging in age from young cub scouts to seniors nearly his age; even our local congressman was in attendance and spoke. At 96, there aren't many peers still around to attend a funeral, yet his service was packed. I knew my father was deeply loved by all of these people, because he purposefully cared for people, and he intentionally made an effort to show it. Somewhere, during his life he learned that skill. The people I spoke to at his memorial service confirmed for me how much he meant to them.

When I thought about the wide range of love, admiration and respect he garnered from all those who were there, it was confusing. In my own experience, I found it hard to totally let my guard down and be the real me with Dad. Intellectually, I knew he loved me, but when it came to talking, he talked at me, more than with me. Always as lovingly as possible, he often lectured me on various subjects of life that he felt were important. To me, he was the quintessential iron fist in the velvet glove. There were few, if any, warm fuzzies in his delivery.

He saw it as his job to help make me the best person I could be, and that was not through warm fuzzies. His messages were always delivered straight up and emphatically, and without opportunity for me to respond. The communication was somewhat one-sided. This is very much like my Asperger son, who shows his deepest caring in very similar and serious ways, which can come across hard, matter-of-fact, and lacking any emotion.

One day, on a pilgrimage to my parent's house, I drove the hour-long drive with a family friend who lived near me. He was the son of my dad's best friend (so he happened to be my age). He loved my dad like his own father, and communicated with him often. As we drove, he commented on how my dad always focused on the positive about other people and pointed that out to them, which he did intentionally, but didn't ever seem to do the same with my brother and myself. That was when one of the first lights went on in my head.

My relationship with my dad was different from everyone else's. He was my dad, not my grandfather, not my kindly wise

A child with ASD runs into an issue when he tries to connect with peers in situations where social mutuality and reciprocity are required.

old neighbor, not the booster at the college campus cheering on the team. He was my father, and our needs and expectations of

our parents are different than those of other relationships. In spite of how amazing he was with people (and he was), and how much we loved each other, we lacked that emotional connection that I have looked for all my life and could never name until now.

At first, the discrepancy between my experience and the experience others had didn't make sense to me intuitively, until

I remembered something Dr. Wahlberg had told me years ago about people on the spectrum: he explained that a child on the spectrum can go out to the ballpark and play well with the older boys—after all, they will allow accommodations or exceptions in the rules for him because he is just a little kid. That same child can go out to the park and play with the children younger than he is because he can be the authority, the boss of them, and make or change the rules at his own liking. A child with ASD runs into an issue when he tries to connect with peers in situations where social mutuality and reciprocity are required.

My dad could be an authority figure, the wise older man, and the grandfather everyone wanted; he could manage good grandfatherly relationships and be loved, respected, and cherished by all those people who came to say good bye after his death, and still struggle with his relationship with me. The intimacy and emotional connectedness piece were the difficulty, and today I believe that stemmed from autism. As an adult, my relationship with him fell into the category where the person on the spectrum struggles—direct, open, mutual, and reciprocal.

As part of my research for this book, I attended a talk by Temple Grandin and her mother, Eustacia Cutler, which was held shortly after my father's passing at, of all places, the high school in my hometown. My mother, still a very active and engaged woman at 88, wanted to attend with me since I was going to be in her neighborhood.

Together, we listened to Temple and her mother speak about life with Asperger's syndrome. In one of the very beautiful ways that the universe unfolds, my mother said to me as we drove home, very simply and lovingly, "I think your father was on the spectrum." Bingo. In an instant, the whole picture became clear.

I am sure it's not hard to fill in the blanks from here forward. I had met and married a man who I loved and whose

There is so much hope for your relationship when you understand the realities of the situation you face.

love felt familiar; it lacked the same emotional connection as my relationship with my father. No

surprise there, I don't think there is much argument about the fact that many women seek out men like their fathers. When my son was diagnosed with ASD at the age of 12—he was finishing up fifth grade and preparing for junior high school—I began to learn about autism and what it looks like and how it works. As I became more fluent in the subtleties of the Ism, I began to understand my relationship with my spouse much better.

My ex-husband is a wonderful person in his own right, and he has many fine qualities. He doesn't think he is on the spectrum, and it doesn't really matter at this point. All I know is that there is a genetic component to autism, and I have found that if I apply the same principals to my relationship with him as I apply to my autistic son, my life is a great deal less frustrating. I have adapted the expectations I hold for him. I no longer expect him to operate in his life as neurotypical, and that means that I am better prepared for reality and less frustrated by having expectations that are not appropriate. I feel that I understand him much better. Today, our relationship is peaceful and pleasant.

For the 20 years of our marriage I worked on myself, thinking I was the problem and that somehow I needed to fix my receptors that made me unable to feel loved in a relationship. I tried innumerable different approaches in my marriage to make it work. Managing my own needs and taking care of myself was my mainstay strategy, but I also tried couples therapy, individual therapy, starting a business, building a

home, looking for common hobbies, etc. In the end, nothing ever hit the mark, so I made do without that connection as long and as best I could.

Ultimately, when I could not hold it together any longer, my marriage crumbled, and my therapist declared me “depleted.” I was depleted from 20 years of trying to create an emotional connection that didn’t exist in my marriage. If I had tried for another 20 years, I still wouldn’t have been able to make it happen. That is not a criticism; he was doing the best he could, too, but it’s crazy to try to extract from someone something they do not have to give.

There is so much hope for your relationship when you understand the realities of the situation you face. Now that I know and understand what was missing and why, new chances to find the emotional connections I need are opening up for me. It’s too late for my marriage, but it may not be too late for yours. In spite of the fact that there are many difficulties in marriage with someone on the spectrum, they are not insurmountable. That is the story for another book.

The Hole in our Hearts/Lack of Emotional Connection

It’s difficult to describe what it feels like when the emotional connection is missing. The relationship feels incomplete. Like a donut, there can be substance all around it, and it can even be good, but the very best, the heart of it, is inexplicably absent. I remember calling it the emotional bull’s-eye. With autism, it feels as if the arrow never quite hits the target solidly. Like trying to put two magnets together, the negative and positive sides never allow them to connect squarely; they force the connection to one side or the other. The feeling is similar to hitting a golf ball, but never hitting the sweet spot so that the ball zings off the end of the club with its full-blast, beautiful, easy power. As

a golfer, when you connect with the ball's sweet spot you feel satisfied in a way that you can't experience in any other way. It doesn't mean that there can't be thousands of other effective, even exciting shots, but they are not the same as hitting the sweet spot and feeling that perfect connection.

Living without the emotional connection that the neurotypical majority naturally enjoys, the rest of us may feel that hole, that gap, that something missing. This hole is the lack of emotional connection, and it can impart far-ranging effects on our personalities, our relationships and our lives. The longer we live with this hole unrecognized, the more devastating the situation can be to us. Those of us who grew up with a parent, or have lived with someone who is unable to emotionally connect for a long period of time may experience a very deep need for an emotional connection.

Individuals with ASD need and want emotional connection just as much as those without autism, but there are a couple of factors that contribute to their inability to connect on this emotional level. First, those with autism are not typically wired to make the social connection at all (see chapter on social difficulty). The neurological processing difficulties they experience do not pre-dispose them to emotional connection because of their tendency to become overwhelmed and miss the social data entirely. The resulting lack of social connection snowballs, creating a downward spiral in intimacy that takes the person in a direction that is farther and farther away from emotional connection.

If those with autism are able to connect at all, other issues such as anxiety, previous bad experiences, or their inability to express the emotions that they do feel may become barriers to their success in creating emotional connections. Someone

with ASD may simply not be able to fashion the language that is effective in communicating his emotion and completing the connection. Dr. Wahlberg shared a story of a young man on the spectrum who was extremely infatuated with a girl, and when asked how much he liked this girl, this young man's solemn response was "as much as potato chips." When an individual with ASD feels deeply and strongly, they may simply have difficulty in executing the words or behaviors that effectively reflect the connection.

So what happens to the rest of us over a period of time when relating to those on the spectrum with whom we do not experience an emotional connection? As a result, we might develop emotional difficulties of our own due to our long unanswered need. These difficulties might include:

- Low self-esteem
- Self-doubt
- Feeling that you must earn love, that you do not innately deserve it
- Feeling like defective goods
- Confusion/uncertainty, particularly in relationships, but this spreads to other aspects of life as well
- The sense that you never give enough
- Feeling that love is conditional
- Inability to trust your emotions
- Exaggerated sense of responsibility
- Over achievement
- Role reversals
- Development of codependent traits
- Mistrust of God or the universe

The Benefit of a Spiritual Life

Although it is not for everyone, for me, there has been a tremendous benefit in having a spiritual life—it influenced my thinking and my self-talk in a way that helped me to fill the hole in my heart, counteract the negativity and stay connected to my hope. This topic could be a book by itself; there are many fine resources available to assist you in your spiritual walk.

Many of us face constant challenges, frustrations and doubts, often from numerous fronts simultaneously. These trials can threaten to overwhelm us at times and it can be a challenge to stay positive. A solid spiritual life can be a great way to maintain peace, which is invaluable for surviving in a close relationship with someone on the spectrum where we often feel alone, without choices, confused and trapped.

At those dark moments, I needed the spiritual, psychological, emotional and practical assistance of a higher power (or God) to face questions about the future for which there were no immediate answers. I have heard other people say of the questions for which they do not know the answers, that they are going to “put that on the list of questions” they will ask God when it is their turn to meet him. This kind of thinking acts as a pressure valve to relieve the stress when the situation is out of our control and we feel like we might otherwise implode.

Another important way a spiritual life has helped me appeared in my life one day as I struggled with the weight of my marriage. A close friend of mine shared with me her secret behind sustaining her marriage. She said that there were three in her marriage—her husband, herself and her God. This is a really beautiful way of taking the pressure off our spouse, and is equally applicable to every relationship in our lives. If everything we do is done for “an audience of one,” it releases

the energy that is otherwise being tied up in keeping score, and opens up the possibility that our return will come from some other source. Suddenly, giving is once again filled with hope and therefore less draining and feels less like there is a giant abacus in the sky tallying the points.

My spiritual life has led me to believe that no matter what you are going through you are not alone. You are protected by the care of a loving God who has a good plan for you personally. Trusting God, the universe, divine order or the divine unfolding of events is just so much easier than the alternative fight against life. That strategy, can help us keep a positive outlook, look for the good, and remember to trust that “All things work together for good.”

Yes, even autism can work for the good. Maybe this challenge was placed in our lives for a very specific purpose. What can we learn from it? How can we use this challenge in our life to grow into the best version of ourselves? Take heart, my friend, God loves you and has a good plan for you, and that plan includes your happiness!

Codependency and the ACOA Connection

People in relationships with alcoholics are often referred to as codependents. Codependency has certain qualities that are common to most individuals such as low self-esteem, people pleasing, poor boundaries, and being controlling, among others (refer to www.allaboutcounseling.com/codependency.htm for a complete definition of codependency). If you tend toward codependency as I do, the boundaries between yourself and anyone else are not easy and natural. I find that my boundaries close in on me, and I end up giving too much for a whole host of reasons, including love, compassion, generosity, the belief that giving is good, and because I see myself as the stronger of

the partners, to name a few. Codependents often experience an exaggerated sense of responsibility for their relationships, and this can spread to all areas of our life. Codependents may also end up looking outside of themselves to find a way to feel complete and whole, because they have been unable to make themselves feel complete and whole on their own.

Whether our tendency to codependency draws us toward relationships with those on the spectrum, or we develop codependent qualities as a result of living in these relationships is unclear. Either way, I have found that understanding codependency and the issues that surround it has given me a deep and meaningful foundation for understanding the issues and struggles of someone with a loved one on the spectrum, particularly a spouse. Our situation has the flavor of codependency.

The groundbreaking book *The Struggle for Intimacy* by Janet Woititz details characteristics of people who are adult children of alcoholics (ACOA). I know when I first read this book many years ago, I totally related to the characteristics of an ACOA, in spite of the fact that I had not been raised in an alcoholic family. The fact that I related so completely was a puzzle to me until I realized that those of us with family members on the spectrum also struggle for intimacy. Just like ACOAs, we find that the target of our love is typically emotionally unavailable.

I believe that this connection between autism and alcoholism is worth touching on. Lacking any other explanation, I can see where a diagnosis of alcoholism would be a solution and philosophy that someone on the spectrum could adopt to help find peace. When you step back and think about it, drinking kills two birds with one stone for those on

the spectrum. It is a socially acceptable way to numb pain, plus it has the added benefit of making you look like you fit in. Do you ever wonder where all the people who are on the spectrum, but who are older than 20, are? I think that this may be part of the answer—some of them may have ended up finding relief in a (socially acceptable) bottle of alcohol and then when trouble ensued, found true understanding and connection through the simple, yet rigid guidelines of Alcoholics Anonymous. Without further study, there is no way to know for certain if people with ASD tend to actually be alcoholic or if they just identify with alcoholics, and I am not sure that it really matters. Let's just leave it at this—based on my experience, my best guess is that there is a connection.

Breaking through Denial

Realizing that we are facing autism in our life and understanding what that means to us is tough. The first layer we need to sift through is determining exactly how our loved one on the spectrum is affected by the autism. That alone can be devastating and frightening. Most of us stop there. If we are diligent about our search, we can probably find the paths that led us to these relationships with people on the spectrum, like I did when I realized that my dad must have been autistic. If we continue to seek healing in our lives, eventually the realization that we are facing a lifetime without the social reciprocity we might have expected in this relationship will come to the surface. The lack of social reciprocity impacts so much of our life, both functionally and emotionally, that it may be one good reason to seek professional therapy.

I know it's hard to face our fears and break through denial, but our problems exist regardless of our level of consciousness about them. Sticking our head in the sand does not solve

anything. If you have come this far in learning about autism, I invite you to go on to the next chapter to find salve for your wounds. There I give you my very best coping advice, derived from twenty years of recovery from living with the effects of autism in my life.



In this Chapter

Learn strategies and helpful tips for:

- Living more peacefully with the “as is”
- Taking healthy action
- Developing a healthy outlook

10

Becoming the Phoenix

So, here we are—the last chapter. We have walked a fairly lengthy road together during the course of this book. We started by discussing why we even needed to have this conversation at all. If people with ASD are the puzzle piece, we are the rest of the puzzle; given the statistics, the rest of us, by default, whether we plan to be or not, will probably be living alongside, working with, or loving someone with autism spectrum disorder in the near future—if we don’t already.

We examined the high level view of what life might be like in the shoes of someone on the autism spectrum, and began to build some empathy. We learned more about the challenges those with autism face, and how that changes their ability to fit into our society; we discussed autism as a social disability and we scrutinized our own reaction to that dilemma. We outlined some tips to improve our success at communication. We candidly examined how living with an individual with autism can affect the rest of us emotionally, and discussed a strategy of

how we can manage the challenges by creating and using our own value proposition. Then we had a real heart-to-heart about the deepest hurts and struggles that many of us face when we love someone who is on the spectrum. We have covered quite a lot of ground.

The real crux of the matter, the real bottom line, lies here in Chapter 10. In order to create the most functional, healthy, productive, and satisfying relationship possible with someone on the spectrum, the rest of us must rely on our own logic, intellect, spiritual life, spiritual values, emotional good health and hard work to manage ourselves. We must learn to take care of ourselves, because our autistic loved one probably cannot take care of us in the ways that our social thinking may have previously led us to believe, hope and dream they should. Self-care is an important life skill for everyone, but it is essential to sustaining a relationship with someone with autism. With this one skill, we can compensate for the biggest portion of the lack we experience in pivotal areas of our relationship with someone on the spectrum. But it won't happen by coincidence; it requires intent and purpose. When we successfully embrace self-care as a strategy for wholeness, we become like the Phoenix, able to rise from the ashes with new power and strength.

One crucial element in the type of self-care we need is to seek and secure validation for our experience. Overruling our natural social/emotional reactions and responding from the best, most understanding part of ourselves is not always easy, especially when that requires us to operate outside the social gravity that comes instinctually to us. We need someone whom we can, on a regular basis, rely on to help us maintain our perspective, sort out our part of the equation in relation to the autism, and distinguish the autism from our autistic loved one. This

person needs to be savvy in the ways of autism, and aware of the type of support we need to cope with the issues we encounter. That is why it is so critical that we talk amongst ourselves or with properly trained professionals for emotional validation and to sustain our own mental health. There are far too many people who do not understand the nature of the dilemma we face, including much of the therapeutic community, the general public, and insurance companies. I would ask that all of you lobby your insurance company to cover ongoing mental healthcare and therapy not just for our ASD loved ones, but also for the rest of us. They just don't get it.

The rest of this chapter contains a broad-based formula for taking care of ourselves, and for building the inner strength we need to sustain our relationship. Here, I provide a general outline of the skills and tools that will help us the most. Even as you read, I am developing additional tools and resources to give you tips that will help you accomplish the goals outlined here. In the end, this really boils down to you becoming your best version of yourself: These tips, which build on one another, are organized in the following five categories:

1. Know the Truth
2. Know Yourself
3. Be Responsible for Yourself
4. Think Healthy Thoughts and Nurture a Healthy Attitude
5. Take Healthy Actions

Know the Truth

Know that, without a doubt, relationships with people on the spectrum require a lot of work

We can all find a relationship that is good for a day or two or three, but to create any long-term meaningful relationship

Self-care is an important life skill for everyone, but it is essential to sustaining a relationship with someone with autism. With this one skill, we can compensate for the biggest portion of the lack we experience in pivotal areas of our relationship with someone on the spectrum.

requires that, as a foundation, we must know the other person and accept that person for who he is by nature. After all you have read, I am sure you have concluded that

a relationship with someone with ASD can require effort, discipline, persistence, flexibility and a great deal of love—you are right! And all of this can be a lot of work.

I just want to reassure you once again that the fact that this relationship requires extra effort does not mean that you are doing it wrong. On the contrary, if your relationship with someone on the spectrum is a lot of work, you are probably doing it right. Entering the relationship knowing that it requires such effort helps to eliminate the self-doubt and the frustration that can go hand-in-hand with any endeavor that requires sustained effort. It is so easy to slip back into our social thinking and begin asking ourselves why we must do the lion's share of the relationship work. I just want to remind you one more time. We have to do it because they cannot—not will not, cannot.

Believe your own eyes, ears and experience

Trust yourself. Trust your own experience and do not expect the person on the spectrum to validate your experience—it is very likely that will not happen. Remember, in all likelihood your loved one sees life from a totally different, nonsocial perspective. Your truth and their truth may be totally different, in spite of the fact that you are viewing the same situation.

As a matter of fact, they may be clueless about what you are experiencing, and it often feels like they don't even care. Asking for what you need is a healthy skill, but asking them to validate your feelings is a losing proposition, and is likely to backfire in your face; you may wind up feeling even more aggravated and upset than you were before you asked. If you need validation, find a trusted source outside of the relationship. Whenever possible, trust your own experience!

Accept the “as is” for yourself and for them

One of the first strategies I learned in taking care of myself was to accept myself exactly where I was, and with the feelings I had. Whatever you are feeling is valid and acceptable. There are no wrong feelings. Your truth is your truth, and you are entitled to it. Be aware that if you reach out to someone who does not understand the fallout surrounding life with autism, you may feel blamed or that your feelings are being minimized. Find the right source that can help you ferret out your feelings, express them and make peace with them. Accepting yourself “as is” is just as important as accepting your autistic loved one for who he is.

Avoid self-doubt, especially about your needs

Trust your gut and don't fall victim to self-doubt, particularly where your own needs are concerned. If you feel like you are not getting what you need, then you are not getting what you need. Period. End of conversation. This is not something to debate. There is no need to blame the other person or deny your truth—trust yourself. Work to develop ways to get what you need, and do not let someone else blame you for having those needs. It is not your fault that you have needs. Fulfilling your needs may require seeking satisfaction from a source other than your loved one on the spectrum where ethically and morally acceptable. Beware, it is easy to fall victim

to people whose sympathy and social thinking can be very alluring. Look for healthy and appropriate ways to meet your needs, and remember, your needs and feelings are valid, whatever they may be—there is no reason to doubt them.

Know Yourself

Know yourself and know your feelings

Knowing feelings is the first step toward being able to express them clearly and concisely. The more definitively you can express your feelings and needs, the more likely it will be that the person on the spectrum can understand them. They may or may not respond (or be able to respond) to you, but you are going to experience a much higher likelihood of getting some response if you can clearly and simply state what you need and how you are feeling.

Remember, do not expect them to fill in the blanks with social shorthand—rather, use this three-step formula:

1. Spell out your feelings
2. Detail what happens if your needs are met
3. Clearly delineate the consequences if your needs go unmet

Each ingredient in this communication recipe is important, because very often those on the spectrum will not be able to project the negative outcome of not responding, and knowing that consequence may be a crucial component required before they take action.

Know your weaknesses

Know your weaknesses—your Achilles heel. For instance, my Achilles heel is the way I react when I am too tired. When I am exhausted it is much more difficult to articulate my thoughts and cope with frustration. I also become overwhelmed very

quickly. I know this about myself—if I feel confused and cannot easily make a choice or do not know what to do, I am too tired to do anything; I need to rest.

It is important to my emotional health to rest sufficiently and regularly, and when that does not happen, I need to be savvy enough to recognize I am tired before it sabotages my day. Knowing that fact about myself and being aware when it is at work helps to ensure that I do not end up in pitfalls due to being over-tired. Other people have different weaknesses to which they fall prey, such as being hungry, being in unfamiliar surroundings, feeling overwhelmed, etc. Knowing which of these can create a pitfall in your life is invaluable.

Know your triggers

Along the same line, know the things in life that flip the switch on negative emotions for you, sometimes tapping into a wellspring of pain and hurt that can be overwhelming. For example, paying bills is one of my triggers. When I sit down and pay bills, you do not want to talk to me. You want to give me at least an hour to finish up and give me 15 minutes to decompress because sometimes the act of paying the bills triggers me and I experience a variety of feelings like anger, frustration, and worry. If you approach me with something you need or want during that time, I am liable to snap back with a less-than-desirable response.

So when one of my kids asks me something while I am paying the bills, I simply ask him to give me an hour or two. Sometimes I plan to do this activity when they are at school to avoid a conflict. Knowing your triggers and managing them appropriately allows you to achieve the best possible relationship experience.

Know your “nonnegotiables”

It is important to know the issues that are not negotiable for you. For example, if you are a young married couple and you will never feel that you have lived a full life unless you parent children, and there is no way you can see your life without kids, but your spouse on the spectrum is absolutely not willing to go there with you, that may be a deal breaker—it is not negotiable.

When we don’t consciously know our limits and nonnegotiable issues, they can often act as underlying disturbances that aggravate other areas of our life. As painful as that may be, and as brutally honest as it requires us to be with ourselves, in the long run knowing which items are nonnegotiable keeps the relationship healthier. This may also be an important piece of our value proposition.

Taking time to identify and verbalize these items does not obligate us to end the relationship if we can’t resolve the issue to our satisfaction right now. Putting words to the problem may help us to contain the related emotion and keep it from polluting every area of our life together, and thus give us a better chance for a good outcome. There is always a benefit to airing out your feelings in a healthy way. Feelings that are buried are like landmines, waiting to be detonated.

Know your limits

When you have asked for change in the areas that are not negotiable, and change has not happened, at some point, you will reach your limit. When you have done all you can and exhausted all your possibilities, you need to know when to take action to change the situation. If it is an option, such as in a marriage, that may mean leaving the relationship and moving on. Limits aren’t just about ending relationships. They may also develop related to specific issues. For example, if your child is not doing her

homework well enough, you might set a limit such as “if you get another D in math, I will hire a tutor for you.”

You may believe that your limit is in one place, but you don't truly hit your limit until you are finally moved to action. The time between when you experience a psychological limit and when you actually take action can be very painful, so trying to reduce living in that state of duality can ease the tension. Many of us live in this space of discontent for long periods of time—I know I did. If the pain is not great enough to move you to action, it is helpful to be consciously aware that you have chosen to live in limbo because it is less painful than the action required to move you forward—acknowledge that you have a limit, but haven't reached it yet. Being aware that you are making a choice helps to satiate the feeling of being a victim.

Know that you are remarkable

This is a really important point. You probably won't find too many places where you will be earnestly praised for your willingness, effort and diligence in your relationship with someone on the spectrum. As a matter of fact, people who don't understand autism might tell you the opposite; they may feel that you are crazy or wasting your time, or that you are accepting behavior you shouldn't tolerate.

So listen up! You are special. Not everybody will recognize the need to make the effort, or take on the challenges and extra responsibility. There are far too many people who will neither recognize, nor be willing to extend themselves if they do recognize the need to accommodate someone on the spectrum. They will not exert the effort to remember that inside every person with autism there is an amazing human being struggling and trying and doing his best. Your recognition of that fact makes you special.

Those of us who work to develop a good relationship with someone with autism will find immense benefits in our own development. To be the best relationship partner, you need to be the best person you can be. You can derive peace of mind from knowing that you are carrying out a giving lifestyle and you are loving someone else the best way you know how. Kudos to you!

Whether you are a family member, a friend, a coworker, a teacher, or a spouse, if you are making the effort to work on this relationship, then you are remarkable. I am saying this with tears in my eyes because the people who are willing to make the effort to care and love and help the people on the spectrum to lead their fullest lives truly are blessings to the world. You should feel really good about yourself, and on behalf of those who surround you but cannot say it, I acknowledge you, and I thank you!

Be Responsible for Yourself

Seek your own emotional good health independent of the person on the spectrum

A healthy you is the best relationship partner that you can be for anybody, whether on the spectrum or not. If you suffer from issues that you brought into the relationship, resolving them will help to untangle the mess that might develop when your issues are further complicated by the difficulty of relating to someone on the spectrum. Keeping your side of the street clean can go a long way toward smoothing the path for a sustainable relationship. For example, if you come into the relationship very needy and require boatloads of attention from your partner, the lack of social understanding you will find in an individual with ASD will complicate the issue of your neediness.

Resolving your neediness independently will help to facilitate the resolution of your relationship issue as well. The less needy you become, the less taxing it will be on the

relationship. In general, one of the best first steps you can take if you are having trouble with your relationship is to identify and deal with your own issues—the ones that exist independently of your partner, and will undoubtedly be triggered or intensified by a relationship with a nonsocial thinker.

Eliminate waffling, insecurity and self-doubt

Is it me? Is it you? Try to eliminate that waffling, back-and-forth, flip-flop type of uncertainty in your thinking. When the top is already spinning, this uncertainty just spins it harder and harder, and we may wind up more confused than ever. Perhaps this is an opportunity to sit down and draft a list of pros and cons, or reach out to someone else and lay out all of the pieces of a situation and ask for an opinion—especially elderly people, who often have a wonderful perspective on life. If all else fails, try to just stop thinking about it, and focus on something else—sometimes we over analyze issues that are unclear, much to our own detriment. In due time, all is clear.

One effective strategy I use to cope with uncertainty surrounding decisions is to give myself permission to “sit on the fence” and find peace in not knowing. If the question is important, the answer will become clear at some point. If it is not important, the question will become irrelevant. For example if you are struggling with whether to stay in your marriage and you flip flop from one extreme to the other, work on becoming peaceful with the thought “it is too early to tell.” There is no shame in being unsure, and by acknowledging that you do not know, you give yourself permission to be in that space. Otherwise, you are pressuring yourself to make a choice that you may not be ready to make. Remind yourself that “all is well,” and remember:

*It's not about getting it all together,
it's about learning to live with it while it's all apart.*

Maintain healthy and well-defined boundaries

Healthy and well-defined boundaries are often challenging for the rest of us. Healthy boundaries are part of an individual's healthy self-esteem and healthy relationship skills in general. This is as true in the workplace as it is at home. None of us are mind readers, so when boundaries are clear and stable, each individual has a better chance of success in respecting the boundaries. Maintaining a consistent boundary is not always easy, but when your boundaries waffle around and change all the time, it is very confusing to those around you.

When communicating boundaries to someone on the spectrum, it might be helpful to them if you can articulate exactly when the boundary gets crossed. For example, it might be more effective to calmly explain, "I will wash your laundry if you put it in the hamper, but I will not pick it up off the floor and wash it." This is more effective than shouting "I am not picking up your dirty laundry anymore." Either way, once the boundary is stated, sticking to it is important. I know that this has made me much more careful about what I say, especially in the heat of the moment. Responding with idle threats and knee-jerk reactions has backfired on me because enforcing those boundaries created such a challenge for me later.

I struggle in this area; for me, this is another one of those "talk's easy, work's hard" situations, in spite of the knowledge that healthy and well-defined boundaries will improve my relationships. Unhealthy boundaries set you up both to develop resentments and feel taken advantage of when those boundaries are crossed.

Express your needs clearly

Being able to clearly and precisely articulate your needs helps someone on the spectrum to understand those needs.

Do not rely on the social shorthand, the unwritten book of general social knowledge. Do not assume that “because you love me, you are going to buy me a birthday present.” If you need a birthday present, say, “When I do not get a gift from you on my birthday, I really feel bad. This year, will you please acknowledge my birthday with a gift, no matter how small? It is important to me. Here is a list of four things that would make good birthday presents if you need help thinking of something. Maybe one of those would work out for you, but if you would like more ideas, just let me know. Thank you.”

I know that takes some of the romance, charm and surprise out of the situation for you, but being clear and precisely articulating your needs is an effective way to ask for what you require, and it is an effective relationship strategy with someone on the spectrum. The end justifies the means here; employing a tactic that results in your needs being met justifies the loss of the surprise factor. When you ask for what you need, as time goes on, you will avoid layer upon layer of pain and hurt that stems from having your needs continually going unmet. You will become accustomed to asking for what you need, and this will, more than likely, be the shortest route to peace.

Understand caregiver exhaustion/fatigue/burnout

Caregiver exhaustion is a phrase that psychologists use to describe what happens to people who act as caregivers for a long period of time. Caregiver exhaustion is characterized by a state of physical, emotional, and mental exhaustion and/or a change of attitude. This type of burnout can happen if caregivers don't seek help when they need it, or if they try to do too much for too long. This happens regardless of whether the help they are providing is physical, financial, emotional, or in some other form. Caregivers may experience a variety of symptoms

including fatigue, stress, anxiety, depression or guilt. Many also feel uncomfortable if they spend time on themselves rather than helping the recipient of their care. Being the person who is always giving, always taking care of the other person in the relationship, takes a toll.

It is imperative for a sustainable relationship that you continue to take care of yourself and your own needs in a healthy way. That may be through exercise and diet, through spiritual or psychological support, or by pacing the giving and taking care of yourself. I have one friend who is a huge proponent of “treats” as a method of self-care. Her advice to me is always to treat myself by rewarding the difficult tasks I accomplish with something that pleases me. This helps me to meet my own needs, so that I don’t end up feeling cheated or overburdened. By understanding that caregiver exhaustion exists, and that we often act in a role similar to caregivers, you can be more aware of your own needs and you can plan to refresh yourself before it is too late.

Think Healthy Thoughts and Nurture a Healthy Attitude

Exit crisis mode

When my son was first diagnosed, it felt like a crisis. If you feel that way, I get it. There is an initial shock and a grieving period that goes along with the discovery that someone you love is on the spectrum, and you need to experience those feelings and grieve appropriately. But by its nature, grieving brings us to the acceptance of a new “normal.” We need to allow ourselves to move all the way through the grief and exit crisis mode on the other side when we achieve this new normal.

Exiting crisis mode doesn’t mean deciding to like the situation, or even figuring out how to handle it, but it does

mean making peace with the fact that you don't like it; giving up the struggle with the existence of the issue, and coming to terms with life as it is, in spite of the fact that it is not as you want it to be. When you exit crisis mode you will find a new, peaceful, stable baseline from which to operate going forward. Acceptance is the antithesis of crisis mode. I know, easy to say and complicated to accomplish. Take the time you need to come to acceptance, arriving there when the time is right for you—just know that is your destination.

Abandon beliefs that don't work

Be willing to re-evaluate, change or abandon old beliefs that are no longer working and adopt new ones in their place. For example, if you always believed that the man should be responsible for locking the doors at night, and your spouse isn't doing it, then maybe you should abandon that belief instead of being angry that he is not the kind of man you hoped or expected he would be.

If you always believed in marriage and thought that divorce was just the lazy way out, maybe you want to reconsider that. The new belief I adopted on marriage is that marriages that are not healthy for one or both of the partners are not good marriages and if you have exhausted your options for making the relationship work, those marriages are better exited than using up all your life points trying to fix something that is beyond repair. After all, nothing lasts forever; change is the only constant.

Detach with love

Detach with love is a concept borrowed from our friends in Al Anon who are learning to deal with the difficulties of being in a relationship with someone with alcoholism. It is really

good advice. Detach with love means to continue to love the individual but to step out of the struggle and let the individual work through the problem for himself.

When you detach with love, you step aside from the emotionally charged nature of the situation and let the chips fall where they may. Done properly, the angry, retaliating, fearful and vindictive quality that sometimes accompanies creating distance from an individual dissolves, and we lovingly release the person to their own devices or to God's care if you have an active spiritual life. You can still love the person and care about the person, but you do not need to struggle so hard, or stay enmeshed with the autism. This was a mainstay in my toolbox for years, and is best attempted with a healthy dose of acceptance of the "as is" situation!

Don't take yourself too seriously/be less touchy

If you are anything like me, you may find that you take yourself too seriously. Occasionally stop focusing on the problem and have some fun. Go to a movie, take a drive or a walk. Eat outside, have a picnic. Listen to the birds sing. Daydream. Play games with your kids, take turns reading jokes off the Internet; laughter is an incredible salve for psychological wounds. Relax, break out of the serious routine and do nothing (there's a novel concept)! It's important not to take yourself or your situation too seriously all the time. Remember, the world will keep on turning while you are at the movies.

When we take ourselves less seriously, it increases the likelihood that we will not take everything said to us so literally or personally—there's probably enough of that in your household as it is. Even when it feels like the negativity is directed at us, often the irritation at its root has nothing to do with us. When you can learn to recognize "that's the autism

talking,” you are one step closer to focusing on the important issues in life and making real progress. This advice takes some sensitivity and experience to apply. I am not suggesting that we categorically dismiss the negativity as something that is only driven by autism and therefore should always be ignored. I am suggesting that we can learn to discern the times when the autism presents us with feedback that is not a reflection on us at all. Then we can just let those negative comments or actions roll off of us like water off a duck’s back. That affords us a better chance to live in peace.

Knowing ourselves well and understanding our triggers will also help us to become less touchy. As we admit our foibles and weaknesses to ourselves, we diminish the power others command when attempting to push our emotional buttons by pointing out and using our faults as a weapon against us.

Be flexible

Dealing with someone on the spectrum is where the rubber meets the road on the old adage “would you rather be right or be happy?” You can stick to your high ideals, your way of doing things, your “perfect world” approaches, but if you insist on rigidly applying them and inflexibly demanding the person on the spectrum live up to them, you are bound to end up in a battle of wits with autism, and you will lose. Your “social-ness” is a chink in your armor when in battle with autism’s rigid and unfeeling façade.

Releasing your stubborn grip a bit will pay huge dividends in terms of the level of peace and positivity in your relationship with someone on the spectrum, and it will create the opportunity for you to be more serene. Besides, being flexible is a good, healthy spiritual quality. Go with the flow!

Pick your battles

This is really important. With someone on the spectrum, you cannot fight every difficulty. You need to pick and choose. This is true whether the person on the spectrum is your child, your spouse, or your coworker. Take a stand when you need to take a stand, but be flexible where you can because if you meet autism's bulldozer-like inflexibility with your own inflexibility, a collision is inevitable. Let the smaller issues go so that you have the energy and emotional resources to take a stand on the important issues, and so you don't drive yourself crazy. Nothing will ever be perfect, so it is okay to back off on occasion and settle for less than one hundred percent.

Turn down the volume on the perfectionistic voice

Soften your perfectionistic stance both in regards to yourself and others wherever possible. Lighten up a little bit and don't let that nagging voice in your head force you to push too hard. Weed out the critically important from the inconsequential areas of your life when it comes to high ideals. Which of your daily activities can you afford a "C" on today instead of an "A+?" Where will lowering your standards a little create more peace in your world? That perfectionistic voice can be the impetus for unrealistic expectations as well as for nagging dissatisfaction due to the less-than-perfect outcomes you are bound to experience in life (with or without autism). Perfectionism is the yellow brick road to unhappiness.

Live in today and avoid useless worries

Here is another strategy borrowed from our 12-step friends: "Live one day at a time." Dale Carnegie used to say, "Live in day-tight compartments." Live in today and avoid useless worries about the future and the past—especially the past. You can do

nothing about what is already done. Worries about the future are, for the most part, fruitless as well. Obviously, we need to plan for the future, but to worry for the sake of worry is not a very effective use of your time and energy. Joyce Meyer says worry is like a rocking chair, it keeps you busy all day long, but you don't go anywhere. Most of what we worry about never comes to pass anyway. If worrying is a big issue for you, pursue help in that area because worry may be costing you valuable energy you need for other endeavors. It may also be harming your physical health!

Adjust your expectations or let go of your expectations

This can be a real toughie for people because it can feel like they are selling out. If at all possible, accept without surrender. That means adjusting expectations without giving up hope and without giving up trying to affect change, especially if you are a parent. It is unthinkable to give up wanting your autistic loved one to do well, and live a full and satisfying life, but expecting them to be perfect by social standards or expecting them to respond the same way an individual who is not on the spectrum responds sets you up for disappointment. A full and satisfying life may look very different from an autistic point of view than it does from your socially based perspective. If I expect my son on the spectrum to live up to the same standards as my neighbor's child who is making straight A's and is the captain of the football team, I am setting my son up to be a failure in my eyes, and I will surely be disappointed.

When I first learned I was going to be a mom, one of my best friends gave me a very good piece of advice: "You need to lower your standards." At first I scratched my head and thought "huh?" She meant that if I held myself to the high standard of requirement to which I was accustomed when I had this huge

new responsibility, I would set myself up for disappointment, frustration, failure and misery. She suggested that I lower my standards a little bit in some of the other areas of my life, such as work, so that I could open up room and energy in my life to focus on my child.

It was very good advice, and that advice applies to dealing with autism. Autism requires energy, so lowering our standards in other areas of life may free energy that is needed for experiencing a successful relationship with someone on the spectrum. It is also a healthy way of being gentle with yourself. If you are a therapist, that advice may translate into lowering your expectations on how quickly you can provide help, and accepting that autism takes some extra time and energy to address. If you are a doctor, it may mean realizing that this individual does not have the ability to change his ways abruptly and may need more or different types of support. If you are a spouse, that advice means focusing on one or two areas that are important and letting the rest go. For example, focus on paying the bills and taking care of the children, and let go of your high expectations that your spouse will repair everything in the house that is broken. You can hire a handyman for that.

Keep the focus on yourself

In the introduction to this book, I wrote that sometimes when a family member is diagnosed with autism the focus shifts immediately and, much to the detriment of the rest of us, often permanently to the individual who receives the diagnosis. It can be a great challenge for us to pull our attention away from our “problems” and focus on ourselves; we think that we will get around to dealing with our own issues later, when the person on the spectrum is doing better, or no longer needs so much of our attention. As a result, our needs and wants can get lost

in the shuffle, or pathologically pushed to the back burner. It is a classic sign of codependency to be constantly focused on someone else as the problem, or the solution to a problem. Shifting the focus to ourselves and our own needs helps us to balance the requirements of every party in the situation, and to refrain from giving away our power by basing our sense of well-being on someone or something else. When our primary focus is outside of ourselves, we often end up blaming either the autistic individual or the autism itself for our troubles.

A healthy dose of self-focus keeps our attention on the only thing we truly can control— ourselves. We cannot control others no matter how hard we try, or how much focus we apply. By keeping the focus on our selves, we are applying the most energy to areas we can control. None of us is perfect, so if we focus on improving ourselves, there should be plenty of areas for development to keep us busy.

Learn to like yourself, honor yourself, be gentle with yourself, and be good to yourself

These four concepts are closely related. If we like ourselves, then it is much easier to be good to ourselves and take care of ourselves. Plus, when we like ourselves, it is far less important if others like us. I don't mean to sound antisocial or stuck up, but it is important that we like ourselves because when we do, the approval of others is far less important, which is a good thing in a relationship with someone who is probably not going to spend a great deal of time and energy validating you.

Liking yourself is a good first step toward honoring and being gentle with yourself. As a result of living with the frustration and difficulties from which we have not yet found escape, many of us are so self-critical, so hard on ourselves, that we heap additional pressure, if not self-loathing, on top of our

already painful experiences. Remember, you are doing the best you can do. If you could do better, you would already be doing it!

When we honor ourselves, treat ourselves with gentleness, and listen to our own needs, we build a healthy foundation to be good to ourselves and to respect and respond to our own feelings. Self-care in the form of liking, honoring and treating ourselves gently is life-giving water in the parched desert of our emotional soul when we live with someone on the autistic spectrum.

Be open to the possibilities/give up trying to control

Give up trying to control your loved one on the spectrum by force; it cannot be done. It is an exercise in frustration and futility, which will surely become painful to us. The old adage “you can lead a horse to water, but you cannot make him drink” applies here. You can even pump the water into his mouth, but you cannot force him to swallow. Your best bet is to put salt in his oats! When social gravity kicks in and we believe that we have the ultimate understanding of what is best for this individual and are therefore obligated to enforce what is “right” in their lives, we are harboring an attitude that keeps us on dangerous ground.

It is a conundrum for a parent, but as already discussed, logic may be a better use of your energy than edicts which are impossible to enforce. Of course, the age of the child and specific issues they face temper this advice, but trying to control and trying to employ discipline by being demanding is not usually a very effective strategy with someone on the spectrum once the person crosses a certain age and maturity level. Giving up control and working more effectively with the “as is” situation becomes an increasingly worthwhile endeavor in order to achieve the emotional benefits you will experience when you

relax and take life as it comes. You might possibly even become more effective.

Life takes a very different route than what we expect, so be open to the possibilities and the process as it reveals itself. To accomplish your goals with someone on the spectrum, you probably will not go from point A to point B in a straight line. Sometimes you zig-zag or stagger all around—two steps forward, three steps back, four steps forward and one step back. Be flexible and open-minded; appreciate the ride as life unfolds—those detours may take you through some of the best scenery on the trip, and if you fight the route with your controlling attitude you may miss out on both the beauty and the innate gifts in the situation, as well as making the trip more stressful!

Grow where you are planted

When we struggle with life, fight circumstances, and find dissatisfaction in the current situations and conditions in our lives, we have slammed the door in the face of the possibility that we are heading through the wilderness to the most beautiful new place imaginable, one that we could not reach in any other way. By accepting life as it unfolds, we can operate from a position of calm power. When we intentionally grow where we are planted, it is more likely that we will capitalize on the positive aspects that do exist in our world, as well as experience more peace in our lives.

I know that I have not always wanted to be where I am, especially at the painful times in my life, but the decision to be positive on purpose sends a powerful message to our own psyche, to those around us, and to our higher power, whatever we conceive that to be. Deciding to grow where we are planted is an indicator of healthy spiritual humility, and yields results unavailable to those who fight against the circumstances of their lives.

Compare notes in a loving way—validate each other

Reaching out to other family members or to coworkers to share your feelings and to meet each other's needs is really beneficial. This is not about ganging up on our autistic loved one or coworker, but it is important that we validate each other's experience, since the person with ASD will probably not validate us or our experience, which can leave us confused and guessing about what is going on with them.

Sharing openly with other family members or people close to the situation can be done in a respectful, nonjudgmental manner, without criticizing, or complaining about our ASD love ones. An important ingredient is that we take responsibility for our own feelings, and not place blame. We can compare notes and encourage each other without slamming the person whom we love so much. Healthy and productive sharing is all a matter of attitude and if you continue to remind yourself that your ASD loved one is not to blame, that will naturally surface in your thoughts and behavior.

Be prepared for the long haul

There are no quick fixes, or as Dr. Wahlberg would say, "no magic bullet." So, many of us need ongoing validation in the form of therapy and support groups. Coping with autism in your life is not a one-time event that you accomplish and then move on. Coping is an ongoing, life-long effort that is demanding on many levels and is best accomplished through healthy long-term support. If you don't know anywhere else to look for support, perhaps you can start a support group, or take advantage of some of the other resources on my website.

Finding a long-term strategy is the key, because, I assure you, there will be moments when you are painfully aware of the fact that living with autism is a long haul. In spite of that, there is so

much hope and beauty and goodness inherent in the situation and by developing healthy attitudes and thoughts, you increase the possibilities that you will enhance, see and enjoy those positive sides of life.

Take Healthy Actions

Review your value proposition

Reviewing your value proposition is a very valuable exercise to reflect on the reasons why you entered into this relationship, and the benefits that you derive from it. Some of us find enough value in our relationship that it is well worth the effort we put in. Others find that they need to make adjustments in their relationship to achieve more value, and still others realize that the scales are so severely tipped toward the “no value” end of the range that they are left feeling “What’s in it for me?” Your value proposition will help you to figure out where you stand.

There are many wonderful people on the spectrum—talented, creative, intelligent, amazing people, and if you are in a relationship with one, take the time to appreciate his or her good qualities. After all, nobody is perfect, and we tend to focus on the negatives and overlook the positives. Besides, you may find that you garner a much higher value from the relationship than you realized. Knowing this and using it as a counterpoint to balance the scales lightens the burden of the inevitable tough day, and that helps make the bad times easier to survive.

Don't let your troubles steal your joy

When life becomes very demanding and it takes a great deal of energy to push through a day, it is easy to let the things that we care about slip away. Identify those activities in life that bring you joy and are important to you. What makes you you? Some of these endeavors may also be part of your value

proposition. You don't want to miss out on the joy in life, so make participating in the activities you enjoy a priority. One of the most difficult acts of self-care can be to put yourself on your own priority list. As they say in the standard airline safety message, "put on your own oxygen mask before helping those around you." You can't help anyone else if you're spent, so don't let the difficulties in life drown out your joy.

If you love scrapbooking, find a way to enjoy scrapbooking an hour or two a week. If you love to knit, put your knitting in the bathroom and knit for five minutes before your shower. If you like to run, run around the block a couple of times a week. I like to do jigsaw puzzles, so I often keep one set up so I can lose myself in it for a few minutes each day. Life is short, and you don't want to wake up one day and realize that it was the you that got squeezed out of your life.

Find strategies and commit at least a little time each day to pursue your joy. I have a friend who uses blocks of time as small as 10 minutes for these activities when her life is full of demands. Any amount of time is better than nothing. It is a signal to your inner child that she is not forgotten and her needs are being recognized and acted upon. Fun is a grossly underrated form of therapy.

This is not just about the activities you enjoy on a daily basis, but also about protecting yourself from future regret. For example, with the hustle and bustle of life when my boys were young, back in the days before phones had integrated cameras, I was so absorbed in shuffling everyone from here to there that the camera was usually forgotten. As a consequence, we shot very few photos of our children being children. This is a huge regret for me. If I were to do it all again, I would buy a camera and keep it in the diaper bag so that it was always handy. At

the time, I didn't possess the conscious awareness that I was missing something—I was just scrambling. As part of your value proposition, create a list of what is important to you, and develop plans to ensure that these activities aren't wiped out by the presence of autism in your life, or by any other circumstance for that matter. This type of strategy will help you mitigate regrets in the future and avoid allowing the difficulties of dealing with autism steal your joy in a bigger life-long arena.

Develop independent projects/do what you do because you love to do it—not for the response you will get

If what you are doing pleases you, then regardless of what response you get, at least someone is happy! Be sure that you do what you do for reasons that make you happy, not for the response you will get from the person on the spectrum. For example, I love to cook, and I love to cook for the people that I love, because it is deeply satisfying to me when I see them enjoy the food I have prepared. But, if I didn't love to cook just for the sheer joy of it and was counting on the reaction of my loved ones on the spectrum to fulfill me, I would be angry, frustrated and disillusioned most of the time. I would have set myself up for disappointment because my loved ones are very picky eaters and turn their noses up at so many of the foods I prepare.

Expecting them to react in a way that pleases me is an unrealistic expectation—an expectation that puts the power over my happiness in their hands. Not good! When I really need appreciation for my cooking to make it rewarding, I invite some friends over who I know will enjoy the food I have prepared so that I get the response I need. That is taking care of myself.

Maintaining some areas of independence is important in any relationship, but takes on a new meaning when someone in your life is on the spectrum. Develop some projects in your life

that you can control and goals that you can achieve no matter how your ASD loved one behaves. This allows you to have some area of your life over which you feel you have control instead of feeling that the autism has taken control. Choose areas of endeavor that cannot be negatively affected by the issues or actions of someone else.

This concept becomes really valuable in the workplace, where some projects may require relying on the performance of someone on the spectrum. Projects that are independent of the person who is on the spectrum allow you a sense of total control, which helps to waylay feelings of being victimized, stuck, or carrying the other individual because you are relying on someone who may not be motivated in the same way you are. By maintaining some independent projects, you have a place to focus where you can feel effective when the frustration of coping with autism threatens to be overwhelming and which acts as a release valve for any pressure that might build.

Slow down

I know that the presence of autism in our lives creates more things to do, more responsibility and often more chaos as we try to catch up with life and manage someone else's responsibilities as well as our own. Slowing down can help us get in touch with our feelings, set better priorities, and live a more purposeful and less chaotically out-of-control life. It may not be practical to do it all the time, but carve out at least a little space in your life to slow down and be intentional and purposeful. It will help to offset the sense that you are scrambling all the time.

Jigsaw puzzles are part of my slow-down strategy, along with hot baths. My friend uses needlepoint to focus herself and slow herself down. Physical exercise may also be an effective way to get your mind off the psychological hamster wheel and to slow down.

Substitute if possible

It's okay to allow other people, places and things to give you some of what you need but can't get from your relationship with someone on the spectrum. For example, if your autistic spouse doesn't acknowledge your feelings, you need to find another way to feel understood and loved. Maybe a sister, brother, parent or a close friend can acknowledge and validate you. We all need safe places to vent, and if your loved one on the spectrum is not the best place to do it, then find an appropriate substitute. Be aware that there will be some situations where substitution is not a good idea, possibly even reaching the point of being immoral, unethical or illegal, so this recommendation must be applied carefully.

When you consciously make the decision to locate a substitute outside your relationship to meet your needs, it can be very empowering and satisfying. If you need someone to support an endeavor, hire the support you need. If you are upset because your spouse with ASD is no longer helping you sufficiently with the yard work and it is becoming a source of aggravation for you, consider hiring a landscape maintenance company. I needed someone to support me in writing this book, so rather than "going to the hardware store for milk" as they say, I hired both an author's coach for encouragement and a consultant to help with book cover copy and marketing. Sometimes hiring expert support is more effective anyway; certainly it is less emotionally charged than feeling angry, disappointed and alone all the time. It's okay to find substitute avenues to get your needs met, but for substitution to work effectively, you must be sure you are not harboring resentment for what you did not receive from your desired source.

Develop plans for self-preservation, strategies for recuperation and tactical contingency plans

Autism is not an excuse for physical violence. If your loved one on the spectrum becomes physically violent, take the necessary steps to protect yourself. Do not accept unacceptable behavior. Self-preservation is not only about your safety, but also about your emotional and psychological state. Make time for yourself, take breaks, and make plans independently of the person on the spectrum. Taking a break and getting away is huge in terms of creating the space we may need to rejuvenate ourselves.

A girlfriend of mine who lives in another state, and whose husband is on the spectrum, occasionally hops on a plane and comes to visit me just to take a breather. There's nothing like a change of scenery to refresh the spirit. If you can't travel, then add a special break for yourself in the middle of the day. Take your shoes off at the office, or lie down at lunchtime, eat an ice cream cone for breakfast, or do something out of the ordinary to give your spirit a lift. In what indulgence would you partake specifically to treat yourself if it was your birthday? Do that. Those breaks are incredibly valuable as a self-preservation tool. Even when the actions are very small, they send a signal to your psyche that your needs are on your radar too, and that's huge!

To keep yourself refreshed, create a specific list of recuperation strategies that you can draw upon when you need to recharge your battery. Maybe you would feel better if you got a massage, took a hot bath, called a friend, bought yourself flowers, walked around the block, went to bed early, played with the puppies at the local pet store, or took a nap—whatever makes you feel good. Develop a quick-fix recuperation strategy that is doable for you quickly, independently, and frequently

to regenerate your sagging emotional state or to recharge your energy level. I like to sing at the top of my lungs in my car, it just leaves me feeling better!

Another important strategy is to develop tactical contingency plans. If you are going out for the evening and you think that maybe your autistic loved one will cancel at the last minute (which happens all the time in my world), then consciously create a plan B. This goes a long way to disengaging the frustration, anger and disappointment that can come with feeling let down, especially at the last minute. Maybe plan B is to be prepared to go by yourself, or possibly to give someone else a heads up that you might need a last minute companion to go with you to a certain event. Either way, be prepared with a plan B so that your needs are met and you are not disappointed regardless of your loved ones behavior.

Giving is never in vain

Despite my earlier comments about pouring energy into a black hole, I believe that giving is never in vain. It requires a more philosophical or spiritual mindset to see giving in this way, but I believe with all my heart that “as you give to the world, so it will give to you.” When we are open to allowing the source of our repayment to be other than the specific one in which we invested, and trust that we will be repaid, we have a greater chance of finding satisfaction.

I know that seems counterintuitive, because when you invest you try to do it prudently and wisely, making sure that you get a return from your investment. But, by believing that the good that you put into the world returns to you, it opens up the possibility that your repayment could come from anywhere. This type of belief transforms the act of giving to your loved on the spectrum from what may sometimes feel like a fruitless

investment, to one of the most powerful and loving gifts that can be given.

“Speak your truth quietly and clearly”

I love the line from the poem *Desiderata* by Max Ehrmann, “Speak your truth quietly and clearly.” Simply good life advice, there are three aspects of this suggestion to consider. The first is the ability to formulate and verbalize your feelings—your truth. Sometimes it is hard to put your truth into words that really capture the essence of your experience. I hope that this book will help you to do that more effectively.

The second aspect to this suggestion is developing and maintaining an appropriate venue to express those thoughts. It is important to find a way to speak your truth and be heard, or at least feel that you have been heard. Then, finally, you must exercise the discipline to take the risk to actually share your feelings. When you do this in a quiet and clear way, you are acting from the best part of yourself, and will probably receive the best response possible. Overcoming the fear of intimacy is often the most difficult part.

Speaking your truth directly to your loved one on the spectrum may not leave you feeling heard (and for many of us it doesn't), and if you do not relate to another family member who can give you the air time you need, seek professional help. Go to a therapist, tell him that you are dealing with autism and tell him the struggles that you are having. If at all possible, find someone who specializes in treating autistic spectrum disorder because a specialist will offer a much better understanding of the challenges you face.

Whatever else you do to move forward, find ways to “speak your truth quietly and clearly.”



Afterword

Healing by Appreciating

Those of us who are parents, family members or friends of someone on the spectrum have many things in common, but first and foremost is our love of someone who is on the spectrum. These are talented creative, warm, funny sensitive people with issues that are not of their own making. Expressing our compassion and appreciation for their many gifts is one of the most healing things we can do. I love this piece of writing from Brenda Boyd. I read it several years ago. It is very uplifting and helps to remind me that there are many great qualities about my son—his rhythm with the world is just a bit syncopated, and my job is to help him learn to be “comfortably” syncopated so that he can feel good and accomplish his goals in life. Hope you like it, too.

Report from Planet Asperger

On Planet Asperger humanity has evolved quite differently and some of the scourges of our world which result from human cruelty and deceit are completely unknown. People highly value individuality, space, privacy and freedom from coercion. The phenomenon of group behavior, such as the tendency to organize into social groups and follow a leader, is virtually absent. This has had very far-reaching implications. War, for example is completely unknown.

The inhabitants tend to have a keen sense of fair play. Their laws are based on clear moral standards, although specific regulations can be unduly complicated. Highly developed computer technology facilitates much of the communication. When people come together socially it is usually for specific reasons, such as when they have a special interest in common. On such occasions, small talk is not an important feature.

Visitors to the planet sometimes feel uncomfortable at the

characteristically blunt and direct manner of the natives, but if they can get used to it, they often find it refreshing. For on this planet there is nothing hidden and no pretence. No one is treated in any way differently purely on account of his status. Compliments and insults alike are doled out with complete sincerity and openness and everyone knows exactly where he stands.

Emotions are expressed with equal openness, which allows them no time to fester. In consequence, there is no room at all for grudges, bitterness, resentment, hypocrisy or psychological “game playing.”

Humour on this planet falls into two very distinct categories, neither of which is ever decadent or cruel. The first is an obvious and uncomplicated slapstick humour, the second a very sophisticated humour based on clever word play.

In every home and on every street corner, special distressing capsules are to be found that help deal with the exceptional sensitivities which are so common. These capsules work by allowing the user complete control over a simulated sensory environment—choosing his own level of light, colour, pressure, noise, and so on.

But perhaps the most special feature of all on Planet Asperger is the great respect given to children and their values. All its inhabitants grow up to adulthood without losing some of the more beautiful qualities of childhood—the sense of wonder, uncensored honesty and ability to see moral issues with uncompromising clarity.

By Brenda Boyd

*Parenting a Child with Asperger Syndrome:
200 Tips and Strategies*

Carry on the Dialog

My book is not the end of the discussion; it is just the beginning. So, please, talk amongst yourselves. Talk to me. I would love to hear from you.

Take this book with you to your therapist—it can be a great tool for helping him or her to understand you. As awareness grows, I am hopeful that the rest of us will start support groups. I am also working to develop additional tools that you can use to support yourself in reaching a new level of understanding, comfort and peace, so please visit my website for more helpful information.

Thank you for your time, allowing me to share my thoughts, and for the privilege of including me on your journey. I hold the highest hope for peace, joy, health, satisfaction, comfort and love for all of those individuals on the spectrum, for you personally, and for the rest of us, too!

*Many blessings,
Jeanne*

For further resources and information please visit:

www.AutismAndTheRestOfUs.com

or email me at:

info@AutismAndTheRestOfUs.com



Encourage • Educate • Support

The Mission of the National Autism Academy is threefold:

- Encourage, educate and support parents, families and caregivers who live, love and work with those on the autism spectrum to increase understanding and effectiveness
- Create greater awareness, acceptance, understanding and accommodation in the general public
- Address and create solutions to resolve future long term issues facing families

Empower Your Thinking about Autism

- Get the answer to the question “Why does he/she do that?”
- Increase your compassion for your loved one with ASD
- Shift your parenting paradigm for effectiveness and ease
- Learn to balance accommodations with conformity to “norms”
- Relieve the out-of-control feeling and begin to feel better!
- Make powerful parenting a part of your life with autism
- Discover new hope for the future!

Assessment

Take a 4-minute parent assessment here:

www.naa-assessment.com

www.nationalautismacademy.com

Suggested Reading List

- *Finding The Gray: Understanding and Thriving in the Black and White World of Autism and Asperger's*, Timothy J. Wahlberg, Ph.D. 2010. Wahlberg & Associates, Geneva, IL.
- *Pretending to be Normal: Living with Asperger's Syndrome*, Liane Holliday Willey. 1999. Jessica Kingsley Publishers, London, UK.
- *The Journal of Best Practices: A Memoir of Marriage, Asperger Syndrome, and One Man's Quest to Be a Better Husband*, David Finch. 2012. Scribner, New York, NY.
- *Struggle for Intimacy*, Janet Geringer Woititz, Ed.D. 1990. Health Communications, Inc., Deerfield Beach, FL.
- *Courage to Change: one day at a time in Al-Anon II*. 1992. Al-Anon Family Group Headquarters, Inc. Virginia Beach, VA.
- *Parenting a Child with Asperger Syndrome: 200 Tips and Strategies*, Brenda Boyd. 2003. Jessica Kingsley Publishers, London, UK.

