

# Contents

<b>Foreword</b> .....	i
<i>Temple Grandin</i>	
<b>Introduction</b> .....	v
<i>Stephen M. Shore</i>	
<b>Chapter 1: Communicating Through Advocacy and Self-Disclosure: Four Ways to Connect</b> .....	1
<i>Ruth Elaine Joyner Hane</i>	
<b>Chapter 2: Help Me Help Myself: Teaching and Learning</b> .....	33
<i>Kassiane Sibley</i>	
<b>Chapter 3: Using the IEP to Build Skills in Self-Advocacy and Disclosure</b> .....	65
<i>Stephen M. Shore</i>	
<b>Chapter 4: Being Your Own Case Manager</b> .....	107
<i>Roger N. Meyer</i>	
<b>Chapter 5: Building Alliances: Community Identity and the Role of Allies in Autistic Self-Advocacy</b> .....	143
<i>Phil Schwarz</i>	
<b>Chapter 6: Disclosure and Self-Advocacy: An Open Door Policy</b> .....	177
<i>Liane Holliday Willey</i>	
<b>Index</b> .....	193

## FOREWORD

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*Temple Grandin*

This book provides an abundance of useful information that will help people with high-functioning autism and Asperger Syndrome navigate their way through the public school system, learn social rules and ultimately advocate for themselves. It also explores the degrees of disclosure and whether or not self-disclosure is a good choice, depending upon the situation and the individual's personality and preferences.

The autism spectrum is broad-ranging, from those who are nonverbal to brilliant scientists. There are also intermediate types such as persons who are fully verbal but have very rigid speech. Others on the spectrum have sensory problems that are so severe that they cannot function in a typical office environment, for example, unless modifications are made in lighting or noise levels.

Whether or not it is appropriate to disclose a diagnosis of autism or Asperger varies, depending upon the severity of the person's problems. Usually, in order to function successfully, people with severe sensory sensitivities, for example, have to disclose that they need an office that is free of fluorescent lights. In some cases, it may be better to tell the employer that fluorescent lights cause headaches instead of attempting to teach the employer about Asperger Syndrome. Individuals with more obvious symptoms such as extremely rigid-sounding speech are probably better off with full disclosure.

However, there are other times when disclosure is not appropriate. I

once visited a small company that employed 28 computer and technical people who made specialized electronic equipment with finely machined parts. It was a little enclave of Aspies. In that situation, I did not think that it was appropriate to tell them about Asperger Syndrome. They were functioning well and successfully selling their products around the world. I decided to leave them in peace in their building in an industrial park somewhere in the United States. It is a nice little Asperger community that does not know they have Asperger Syndrome and for whom contact with the formal autism/Asperger world would not be helpful.

There are two groups in the Asperger community – the ones who know they have Asperger Syndrome and those who do not. In technical fields there are many Asperger people who perform well in their jobs, but many are not doing so well in their personal lives. This book will be immensely helpful for their personal lives because now their spouse or relatives will better understand some of their unique characteristics and challenges.

At autism meetings I am seeing more and more individuals who have mild forms of Asperger Syndrome. In my job designing livestock equipment, I see many similar people employed as draftsmen, welders, research scientists, or computer specialists. There is no black or white dividing line between “computer nerd” and Asperger’s. In many cases these people do not need to disclose that they have Asperger Syndrome. They just need to make themselves so good at their jobs that they are appreciated for their talents. In my own case, I rarely tell clients I am autistic. Equipment I have designed is used by every major meat company in the United States. People thought I was weird, but they appreciated my work. Clients find out about my autism when they have a friend with an autistic child. When this happens, I end up doing autism consulting at a meat packing plant instead of designing equipment. For the first 10 years of my career, I did not do any disclosure until my first book, *Emergence, Labeled Autistic*, was published in 1986.

As mentioned throughout this book, in some cases it is advisable for persons with autism spectrum disorders to find a mentor at work who can help them navigate the social minefields. Also, *The Wall Street Journal* has many good articles to help people deal with mean bosses or sexual harassment.

For those who have mild Asperger Syndrome, the main thing is to develop and sell their talent. Early in my career I was livestock editor for the *Arizona Farmer Ranchman* magazine. When the magazine was sold, the new owner wanted to fire me because he thought I was weird. I saved my job by making a portfolio of all my articles. When the new boss saw my good work, he decided to keep me.

People on the spectrum have to be on the lookout for jealous co-workers who may sabotage them. I have had problems in this area. If the person causing you problems is your boss, you are in trouble, but if it is a co-worker, I have found it best to avoid conflict. Over the years I have learned to be more diplomatic. I learned early in my career that telling others that they were stupid is an almost sure way to lose a job!

I think the best way individuals on the spectrum can advocate for themselves is to sell their strengths. We need to tell the world about the things we are good at, such as being hard workers who can get a specialized job done. People on the spectrum are good at specialized things, and talents need to be developed in the specific areas that others find valuable, such as drafting, accounting, scientific research, and fixing things such as cars or computers. Skills are usually uneven in people on the spectrum – they are good at one thing and not so good at something else.

The emphasis needs to be on the talents, not the deficits. After all, the really social people did not invent the first stone spear – they were too busy chatting around the fire. Throughout history, it has been the Asperger-type people who have given us such things as electricity, for example.

The best advocacy is to work with local businesses, agencies, and schools to sell people on the Asperger person's strengths. Talents such as art, music or science must be encouraged in young children so their skills can turn into rewarding careers. In my own life, I have found that the happiest times have been in construction projects, talking about "cool stuff" we were building. It was "techie"-to-"techie" talk, and to me it provided rewarding social interaction.

I have observed that the people with Asperger Syndrome who have rewarding, fulfilling lives share three common factors: development of talents, mentors at school and at work, and treatment for anxiety and sensory problems. Anxiety would have destroyed me, but antidepressant medication saved me. Some Asperger individuals do not need medication, but others will be miserable without either medical or dietary treatment. This is one area where people on the spectrum need to advocate for services so that they can get the appropriate treatment. There is a great need for more doctors who are knowledgeable about autism spectrum disorders. Another area where people need to advocate is health insurance. Many of the niche jobs where Asperger individuals are hired offer little or no health insurance.

– Temple Grandin  
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# INTRODUCTION

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*Stephen M. Shore*

Leading a fulfilling and productive life involves maximizing control of one's destiny. By focusing on our strengths and what brings us satisfaction to accommodate for challenges we can build a stronger, more positive sense of self that benefits not only ourselves but our community as well. Being productive and fulfilled requires the ability to effectively make our preferences and needs known to others. To do so, in turn, requires a heightened sense of self-awareness – we must come to grips with who we are and what our needs are before we can communicate them to others.

Self-advocacy involves knowing when and how to approach others in order to negotiate desired goals, and to build better mutual understanding, fulfillment, and productivity. In the process, some degree of disclosure about oneself is usually necessary as we have to disclose the reasons why we are requesting a given accommodation, for example. Inevitably, this carries some degree of vulnerability along with the risk of rejection and failure – depending on the individual and the given situation. Yet, without embracing the twin issues of self-advocacy and disclosure, we face an even greater risk: living unfulfilled lives and depriving communities and society as a whole of the potential for people on the autism spectrum to make significant contributions. Despite the importance of effective self-advocacy and disclosure for individuals on

the autism spectrum, for whom these behaviors usually do not develop as a matter of course, to date little attention has been paid towards developing such skills.

There are two compelling aspects that make this work especially relevant to the autistic community, allies, and others. First, all contributions – from the design of the cover, the foreword, and the body of this text – are by people on the autism spectrum. Second, this is the first book entirely devoted to the important twin issues of self-advocacy and disclosure for people with autism spectrum disorders. These two unique attributes combine to create a powerful work created by those who know best what their self-advocacy and disclosure needs are.

Socrates' statement that "the unexamined life is not worth living" encourages a systematic analysis of our lives as a major prerequisite for living fully in all areas of our existence. Given that systematic analysis is something that many people on the autism spectrum do very well, we encourage you to harness that strength by using the hard-earned advice presented by the contributors to this book.

*Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum* opens with a very insightful chapter on how to integrate knowledge of self and learning about others so as to become better communicators. Given the challenges people on the autism spectrum face in reading facial expressions and other nonverbal communication, Ruth Elaine Hane provides a powerful, yet simple template for decoding this mode of communication and, therefore, allowing us to interact more successfully with others. In the following chapter, Kassiane Sibley details a six-step process for helping the young advocate-to-be gradually move toward independent self-advocacy and disclosure. My contribution, Chapter 3, suggests ways to use the individualized education program (IEP) to develop skills in self-advocacy and disclosure by involving students to the fullest extent of their ability in creating their own customized education. Skills learned through meaningful involvement in the IEP can be transferred to life after graduation.

Many of us will have contact with public and private social service agencies at various points in our lives. Roger Meyer provides practical tips on navigating an often Byzantine maze of forms, personnel, and even proper demeanor and dress, when interfacing with these agencies to build one's own "Individual Life Plan." Coming from an Aspie who has been on both sides of the table, the honest, often hard-hitting suggestions in this chapter are particularly helpful. Taking a slightly different slant on self-advocacy and disclosure, Phil Schwarz focuses on the

community level by looking at how we can engage nonautistic people as our allies and together effect positive change in the larger society. Liane Willey wraps up the book by introducing several ways of self-disclosing, offering options that are suitable for most personalities and preferences – from the very subtle to the more direct – along with the importance of self-awareness combined with educating oneself and others about the autism spectrum.

Moving from specific examples and practical steps on the individual level to effecting change at the community level, this book aims to help people on the autism spectrum self-advocate more effectively in their pursuit of independent, productive, and fulfilling lives.

This book is one small effort by six autistic people focused on empowering individuals on the autism spectrum, their community and allies to join hands to achieve more meaningful, productive and fulfilling lives for the greater good of society.



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