A Parent's View of More Able People with Autism

SUSAN MORENO

INTRODUCTION

I want you to try to see through my eyes for just a little while, so that I can help you understand the experience of parenting a more able autistic child. I will attempt to describe some of the feelings and situations that my husband, Marco, and I experienced both separately and together during the last 17 years, and to delineate some of the basic issues that are part and parcel of raising a more able person with autism. I will try to combine these experiences with those communicated to me by other parents around the country.

In this chapter I give my personal viewpoint about the major issues common to parents of more able autistic people. Then I give advice to nonparents on what to do and what not to do to be supportive of these parents. In the last section, I share what I consider to be the good things in my life that are a direct result of parenting my daughter, Beth, who is a more able person with autism.

Beth is currently a junior in high school who maintains a B average, plays the violin in her high school orchestra, and sings in her high school a cappella choir. She hopes to attend college after high school.

The material at the beginning of the chapter is so serious that it may weigh heavily upon parents of younger people with autism. For those parents, I anticipate that the last part of the chapter will cheer them substantially. A further cheerful note is that I have been dealing with these issues for 17 years, and I regard myself as definitely living a very happy and productive life.

The suggestions to people who are not parents are given in the spirit of cooperation and mutual respect that I share with my extended family, friends,
teachers, and other professionals I have dealt with on behalf of my daughter. I would ask nonparents to please bear with all of the "do not" suggestions and accept them for their positive intent—that of making life a little easier for parents of these rare and wonderful people.

ISSUES IN THE PARENTING PROCESS

The experience of parenting a more able person with autism involves coping with may issues. Some of these issues are dealt with only once or twice in a lifetime. Many occur on a frequent basis. The difficulty or facility of dealing with these issues varies greatly from parent to parent, depending on the individual's personality, available emotional and financial support, availability of appropriate schooling and other services for the person with autism, and the level of difficulties of the autistic loved one.

The first issue that I vividly remember dealing with was that of getting a diagnosis on our daughter. We went through the typical experience of wondering if there was something wrong with our child, but being reassured by family and physicians that she was fine. This, of course, led us to the lovely conclusion that if there was nothing wrong with our child, then we must be the worst parents ever put on earth. After all, she didn't want to be cuddled, wouldn't look at us, screamed inconsolably for hours on end, and slept only about 2 hours in every 24.

When our daughter was 2, we moved to Los Angeles and encountered a pediatrician who said, "You seem like intelligent, caring parents. Therefore, although I don't see anything wrong with this child, your concerns should be addressed by thorough testing." He referred us to a diagnostic clinic in the area, where Beth received an excellent, multidisciplinary workup. We were so very lucky to find a pediatrician who listened to us and respected us as parents!

During this workup, we began to deal with the next issue—how to cope with the medical and psychological bureaucracy. It is, at best, a nightmare. In her book about raising her autistic daughter, Clara Park tells of attending clinics where her observations were disregarded, and another where they did not want even to meet her daughter during the initial diagnostic visit (Park, 1982). My husband and I were made to feel incompetent, unimportant, and a nuisance by many of the medical personnel who tested our daughter. Our suggestions about the best ways to get her cooperation and not upset her were ignored. Luckily, this was not true of the psychology staff that worked with us. Finally, we began to see ourselves as consumers and to speak up for her rights and comforts.

Next, we faced the issue of receiving the diagnosis and the shock and mourning that followed. The staff of the clinic that gave us Beth's diagnosis did so in a compassionate and supportive way. However, I remember that my shock was so great that my ears were ringing and my nose stung as if I had been hit in the head. An odd dialogue continuously raced through my brain: "Don't cry. Don't scream. Don't let these strangers see you crack. Remember to be polite—they are only trying to help." I think my shock was so great because I was one of those parents