Siblings of Autistic Children

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INTRODUCTION

In the usual question-and-answer period after a talk, I am very often asked, "How do your other children react to your autistic child?" There is a natural curiosity, it seems, about the way sisters and brothers of autistic children relate to the strange and pervasive handicap of autism, especially during their growing-up years.

What must it be like when you first realize that other families you know don't have bloodstains or feces on the living room curtains or smeared on the front hall wallpaper (put there by an autistic sibling who likes that medium to finger-paint)? How do you come to terms with the inordinate amount of parental attention, of necessity given to your handicapped sibling, that you wish could go more often to you? What must it tell you about how your community views your family when you see your sibling denied a chance to go to school where all other children go? How must it feel to tell a special friend about your sibling and wonder about his/her reaction? How does it affect the view of your own eligibility for parenthood? Does it leave a lifetime mark?

Although it has not yet, to my knowledge, been studied formally, authorities in the field of language disorders are beginning to wonder out loud if the way language-impaired individuals are perceived might not be considerably different from the way individuals with more obvious handicaps are perceived. There seems to be something particularly stressful about living with a person whose communication skills—which almost always affect social skills—are awry.

I've invited five siblings to write down some of their own experiences for this Parents Speak section. Jesse A. Torisky, from Pittsburgh, is a

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freshman at Penn State and has a 22-year-old brother. Cynthia Bodenheimr, with a new doctorate in psychology, and with professional experience in working with autistic children, is from West Islip, New York. Her autistic brother is 17. Sharon Lettick's brother is Ben, now 24, for whom Benhaven—a school for autistic persons in New Haven, Connecticut—was named. She is 29, an autism professional with an M.A., also in special education. Sandra N. Ochs, 21, of Monroeville, Pennsylvania, is an only sibling of a 15-year-old brother. The fifth author, who requested anonymity, is 14 and has a 19-year-old autistic brother.

Marian K. DeMyer, M.D., a psychiatrist at Indiana University School of Medicine with many years of experience with autistic children and their families, has read what these siblings have to say. Recognizing their intense struggle for a normal family life, she formulates two questions that are basic to each family member and makes some suggestions for professionals and parents.

Professionals who work in programs for autistic persons may see these brothers and sisters occasionally, but it is still mostly from individual families that the information must come—information about long-term crisis living during formative years.

This collection of sibling stories is a modest sample, of course, but it helps to give us some "tone" of what it is like to be the brother or sister of an autistic child and how this handicap manifests itself throughout the family's environment.

It is hoped that this column will help generate some discussion about siblings' role in the "autistic family."

MY BROTHER, EDDIE

Jesse A. Torisky
Monroeville, Pennsylvania

There are two main incidents in my life that give me cause for much thought, specifically in relation to my older brother, Edward, who is autistic. I recall these particular happenings because of their significance in altering my life.

The first event occurred about 2 years ago when I was 16. Eddie had come home from Western State for an overnight on Friday. We were going to take him back Saturday after lunch, stopping first at our grandmother's house for a short visit. Friday evening was fairly uneventful, none of the usual tension in the air that is so characteristic of the times when Eddie comes home. Part of this tension is due to our own anxiety caused by the