

# COPING WITH AUTISM: families under stress

"You have to be Superman personified."

—a parent in CHILDREN WITH AUTISM, by Michael Powers

While it may indeed seem like a job only Superman could handle, thousands of parents are raising autistic sons and daughters—and thousands of brothers and sisters are living with autistic siblings. New research offers insights into the pressures and stresses these families face, and offers often encouraging news about how well they're doing.

## Siblings: good news

Parents worry about how their other children will cope with an autistic sibling, but researcher Thomas Mates says there may be advantages to growing up with an autistic brother or sister. A 1990 study by Mates found that 33 school-aged siblings of autistic children actually scored higher on tests of self-concept than a control sample. "Thus," he says, "there is some evidence that having an autistic sibling is associated with positive self-concept, interpersonal, and caretaking skills."

Mates' data support an earlier study by E.W. Berger, in which children with autistic siblings "scored significantly better than the normal population" on a self-concept scale, and reported that their friendships and their lives had not been adversely affected by their siblings.

Susan McHale et al. questioned 90 children (30 siblings of autistic children, 30 siblings of retarded children, and 30 siblings of nondisabled children) about their relationships with their siblings. Their conclusions: "First, young children have, on the average, fairly positive things to say about their relationships with their siblings, regardless of whether the siblings are handicapped or nonhandicapped. Second, the sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters look very similar, on the average, at least in terms of the way the children themselves talk about those relationships."

McHale says siblings tend to have a good relationship with their disabled brothers or sisters when parents and peers also have a good attitude; when concerns about the handicapped child's future and parental favoritism are minimized; when the sibling's feelings of rejection toward the handicapped child are handled; and when siblings have enough information to understand the disorder clearly.

Having a disabled sibling can foster increased empathy in adulthood, and may influence the nondisabled sibling—particularly a sister—to select a "helping" career. Gloria Wolpert cites research by F.K. Grossman, who interviewed 83 college students with disabled brothers or sisters and found that "a number of the students appeared to have benefitted from the experience. These students seemed to be more tolerant and more aware of the consequences of prejudice as well as more certain about their own futures

and goals."

On the "down" side, Wolpert says negative effects of having a disabled sibling can include guilt, a sense of isolation, a burdensome feeling of responsibility, and concern about the disability itself.

"Young children especially are concerned with 'catching' the disability," she notes. "As [they] become adolescents, they develop anxiety about becoming parents of handicapped children themselves." She adds that research by Cleveland and Miller "found there was a higher degree of dedication and

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*Siblings of autistic children have a better self-concept than siblings of non-disabled children, according to two studies.*

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self-sacrifice in the goals of siblings as compared to a control group."

There appears to be a slight genetic liability to having an autistic sibling; research hints that siblings are at higher risk for cognitive and language disabilities, and a new study by Nora Gold of Canada indicates that siblings of autistic boys "tended to be more depressed than other siblings, and to show symptoms of clinical depression." Siblings over the age of 11 were particularly likely to show symptoms of depression. However, social adjustment scores were as high for children with autistic siblings as for other children.

In general, recent research tends to be more positive about the effects of an autistic sibling than earlier reports—possibly because early intervention programs, better support services, and family behavior modification training programs (which more and more often include siblings) are making life with an autistic brother or sister easier. In addition, families—including siblings—are less likely to feel ashamed or guilty than they did in recent decades, when psychogenic theories of autism were prevalent.

## Parents: hanging in there

Studies confirm what all parents of autistic children already know: that life with an autistic child can be difficult. A 1990 study by Ruth Bouma and Robert Schweitzer of Australia found that mothers of autistic children actually experience more stress than mothers raising children with cystic fibrosis, a terminal illness. While the mothers shared many stressors—such as limitations to family opportunities, and the need for lifetime care—Bouma and Schweitzer note that mothers of autistic children also must "cope with the additional stress linked to the social isolation and stigma that are associated with psychological disorders."

In *The Effects of Autism on the Family*, Marie Bristol outlines a number of factors that make autism particularly stressful, and that "increase the likelihood of family crisis and the consequent need for family resources." These include:

1. **AMBIGUITY.** Because autistic children appear attractive and have no obvious physical defects, Bristol notes, it often is difficult for parents, relatives and professionals to realize that these children are in fact disabled. "Until the mother understands that the child's deviant behavior stems from an inborn disorder of behavior and communication, she may feel inadequate as a parent," Bristol says, "because the child is obviously not responding the way she imagined well-raised children should." This is especially true in families of high-functioning children who appear "normal."

Mary Konstantareas points out that in addition to making parents feel inadequate, delays in obtaining a diagnosis prevent parents from obtaining early intervention programs, respite care, and other services which could reduce family stress.

2. **SEVERITY.** Autistic children, Bristol notes, have a poorer prognosis than retarded children, poorer prospects for employment and independent living, fewer services, and fewer activities which interest them, and the activities of families with autistic children tend to be limited because of the children's disruptive behaviors.

3. **DURATION.** For many parents, Bristol notes, "the prospect of permanent dependency is overwhelming, especially when the community has made little provision for the child's care when the parent can no longer care for the child." Bouma and Schweitzer were surprised to note in their study that mothers of autistic children scored as high on tests of "terminal illness stress" as mothers of children with cystic fibrosis, apparently because of autism's incurable (although not terminal) nature.

4. **SOCIETAL REACTION.** The negative responses of others to the behaviors of autistic children are highly stressful for parents, and Bristol notes that such reactions "may become particularly acute as the child gets older and the community has less tolerance for deviant behavior in someone who appears to be a normal adult."

Much of the stress of raising an autistic child, a study by James Rodrigue et al. indicates, may come from the tendency of mothers of autistic children to feel less competent than other parents, and to blame themselves for the child's condition (even though autism's biological nature has been well established). While teaching parents behavior modification skills can alleviate feelings of incompetence, Rodrigue says, "parent-training programs that involve altering parenting strategies should clearly indicate that parent changes are necessary because of the child's condition and not because of the parent's deficiencies."

Sandra Harris and Michael Powers note

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