

**briefly stated**

## Seeking Strengths in Families of Developmentally Disabled Children

Lynn Wikler, Mona Wasow, and Elaine Hatfield

ON Mother's Day, 1980, Erna Bombeck included a supportive poem for mothers of handicapped children in her syndicated newspaper column.<sup>1</sup> In later commenting on the reactions of readers, Bombeck indicated that "never in the sixteen years of [the column's] existence, had there been such a reader response." Most of the letters were written by mothers of handicapped children, who stated a determination to be strong and to feel good about themselves. In contrast to these was a letter from a social worker, which said, "Sure, some gain the strength you talked about. *But tell about the ones who drown.*" (Italics added.) This statement exemplifies the perspective that many helping professionals have toward the parents of developmentally disabled children. This article is a plea to professionals to look instead for families' strengths when working with the families of children who are developmentally disabled.

Clinical intervention and research with the families of developmentally disabled children have consistently focused on the problems, stresses, and inadequacies of these families.<sup>2</sup> There are at least two reasons why this approach may be detrimental. First, it may be mistaken. Families may have more successes than failures in dealing with their children, and by looking for problems within the families of the developmentally disabled, the clinician or researcher may unknowingly direct attention away from potential positive out-

comes. Second, the clinician or researcher may create the milieu that he or she assumed existed. This could come about as a result of insufficient reinforcement being provided to families for exhibiting coping behaviors and because of a focus directed exclusively on the negative.

In the past, when parents insisted on mentioning their strengths, such as by pointing out that they had benefited from the challenges presented by caring for a developmentally disabled child, experts would often interpret these reactions as defensive. Parents' statements of satisfaction or pride were therefore frequently considered to be evidence of denial, sublimation, or overcompensation. In 1981, the authors conducted a study that examined reports of "chronic sorrow"—sadness that did not disappear over time—experienced by par-

<sup>1</sup> R. Brooke Jacobsen and Ruth A. Humphry, "Families in Crisis: Research and Theory in Child Mental Retardation," *Social Casework*, 60 (December 1979), pp. 597-601; S. Price-Bonham and S. Addison, "Families and Mentally Retarded Children: Emphasis on the Father," *Family Coordinator*, 3 (July 1978), pp. 221-230; and M. Berger and M. Foster, "Family-Level Intervention for Retarded Children: A Multivariate Approach to Issues and Strategies," *Journal of Child Psychology and Psychiatry*, 22 (1981), pp. 1-12.

<sup>2</sup> See Lynn Wikler, Mona Wasow, and Elaine Hatfield, "Chronic Sorrow Revisited: Parent vs. Professional Depiction of the Adjustment of Parents of Mentally Retarded Children," *American Journal of Orthopsychiatry*, 51 (1981), pp. 63-70. Sample sizes given in the present article are based on responses to a second questionnaire used in the 1981 study that were not reported originally.

ents of mentally retarded children.<sup>3</sup> In part of the study previously unreported, parents were asked whether raising a developmentally disabled child had made them stronger or weaker. The response to the query was surprising. As expected, most parents acknowledged that they felt chronic sorrow, but, remarkably, most of them also indicated they had become stronger people because of their experience.

At the time of the study, the authors discounted these findings. (However, they did not discount the data from the rest of the questionnaire.) They decided that methodological reasons accounted for many subjects' apparent conviction that being the parent of a retarded child had been a strengthening rather than a debilitating experience. They now consider this initial dismissal to be another example of a pervasive stance adopted among professionals, in which problems instead of strength and instances of coping are concentrated on in dealing with families of developmentally disabled children. They therefore wish to share their earlier findings with others and to discuss the pertinent clinical implications.

### SUBJECTS' RESPONSES

When asked directly, 75 percent of the parents studied ( $N = 27$ ) reported feeling that being a parent of a developmentally disabled child had made them stronger. Forty-six percent felt that the experience had made them much stronger. Although most parents indicated that they experienced chronic sorrow, they also stated that they tried to keep their feelings of sadness under control. They were divided on whether it was better to express their sadness or to control it, but they knew clearly what they wanted professionals to do for them—they wanted to be encouraged to be strong.

The authors also asked workers in a social service agency ( $N = 43$ ) about their perceptions of how parents of mentally retarded children adjusted to their children's illness. The workers' descriptions were in keeping with

<sup>1</sup> Erna Bombeck, "God Carefully Selects Handicapped Child's Mom," *Wisconsin State Journal*, May 11, 1980, Sec. 5, p. 7.

the parents' responses in several instances. For example, they were aware that parents experience chronic sorrow, that is, that parents' feelings of grief fluctuate over time rather than move in stages from despair to mature adjustment. Specifically, 63 percent of the workers felt that parents experience chronic sorrow, and 65 percent of the parents reported experiencing it.

However, the workers underestimated the extent to which parents felt they had been made much stronger by the experience of caring for a mentally retarded child. Forty-six percent of the parents felt they had been made much stronger, but only 9 percent of the workers believed that parents would feel this way. They also underestimated the extent to which parents wished to be encouraged to be strong and to cope: 67 percent of the parents wished to be encouraged to be strong, and 26 percent of the workers believed that parents wanted this.

Parents shared their feelings to a greater extent than they were asked to as part of the study. A curious combination of sadness and strength appeared in their remarks. Subjects

stated that "Yes, we experience a sorrow that does not disappear with time," but "We feel stronger from and even grateful for that experience." The following are typical comments made by the parents in the study:

As the parent of a retarded child, I believe that it has made me stronger. It has made me much more patient than I was. Even emotionally you get an inner strength to deal with everyday care and problems of the child.

I don't really know if I am any stronger emotionally or not. I think you learn to accept what you cannot change, and you have to learn to cope and live with it. I comfort myself with the belief that God gives these children to special people. I'm honored He chose me as one He didn't want to lose contact with.

When I first realized my son was lagging, I felt very guilty and wondered if I had somehow caused it. Then I began to tell myself that I

can't handle it, I'm too inept to cope with a retarded child—but all the while I was coping with him.

It has caused us to be more sympathetic toward people with such problems. Our love for this child seems deeper as we realize her need for greater understanding.

Having a retarded child causes you to ask certain questions that perhaps you would never ask and to develop certain values.

We hit many peaks and valleys. I would say that there is some sorrow, but our happy moments overshadow the sad times. Our daughter has been a joy and a sorrow.

### CLINICAL AND RESEARCH IMPLICATIONS

Clearly, no one elects to have a developmentally disabled child; the events that have such a permanent impact on the course of one's family life seem to strike at random. As indicated earlier, the literature on the adjustment of families of developmentally dis-



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abled children focuses on the detrimental impact that such children have on the family. Study after study has been done to determine whether the presence of a mentally retarded child in a family is associated with increased rates of alcoholism, depression, physical illness, or divorce. In each instance, when social class has been held constant, the answer has been no.<sup>4</sup> The only repeatedly observed effects reported in the literature can be summarized as the following: (1) increased risk of social isolation for the family, (2) increased stress experienced by the primary caregiver, usually the mother, and (3) an increased tendency for adolescent siblings who share the burden of care to develop problems.<sup>5</sup>

Intervening variables related to family resources, such as supportiveness between marital partners, religion, and regular contacts with extended family, have been found to reduce the risk of stress.<sup>6</sup> However, even

findings such as these have been presented in the literature in a less-than-positive way, for the variables have been regarded as nothing more than mediators of stress rather than as factors contributing to a family's well-being. Overall, the possibility that families who raise a developmentally disabled child might derive some unexpected benefits from their experience is rarely considered.<sup>7</sup>

New perceptions of these families, in which they are seen not as the odd few who somehow survive a calamity but as successful family systems whose strength has been augmented by raising a child with developmental disabilities, call for a new program of research. General understanding of these families' success would be enhanced by detailed studies concentrating on various family relationships and on such questions as these: Are the spouses especially open and intimate, and do they share tasks and attitudes? What is the special nature of the parents' relationship to the handicapped child—are they more nurturing and less judgmental than other parents? Do these families have exceptionally warm and supportive extended families, and do they have unusually frequent contact with them? Although families who have been successful in caring for a developmentally disabled child may not excel in all the areas relating to these questions, surely their strengths derive from or are reflected in more than the individual resources of each family member. Findings from the research proposed here might help clinicians to focus on strengthening certain family relationships and thereby enable the families to profit from raising a child with developmental disabilities. Social policy, too, might be advantageously revised as a result of studies based on this positive new perception. In the present era of retrenchment, the knowledge of which family support services such as respite care, counseling, or medical care are most effective may prove essential to increasing the number of success stories among families of developmentally disabled children.

Given the bias reflected in the clinical literature, it is not surprising that most of the helping professionals in

the authors' study underestimated parental reports of the positive effects related to raising a handicapped child. On the basis of their study and their own work as professionals, the authors have derived several clinical recommendations intended to help workers determine and emphasize a family's strengths. They are the following:

1. In general, workers should be aware that although parents of developmentally disabled children are under stress and are grieved, they may benefit and grow in many ways from having an exceptional child.

2. During the initial interview, workers should ask parents about their child's unique traits that have given them pleasure.

3. Workers should assess parents' strengths by asking for stories of familial successes in coping. Parents can also be asked what they have learned from their experience and whether friends or family have come through for them in unexpected ways. They should be praised for their creative parenting and be given an opportunity to cite examples.

4. Workers should help parents who have been successful in coping to meet parents whose children have recently been diagnosed as developmentally disabled. During this process, a model of successful familial managing can be provided.

The authors' experiences as clinicians and researchers lead them to believe that chronic sorrow and increased emotional strength are by no means incompatible. Parents of developmentally disabled children experience recurring sadness as a natural response to a tragic reality. However, at the same time, most of them also develop increased strength and coping abilities. Social workers should be paying more attention to the latter.

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<sup>4</sup> M. Davis and D. MacKay, "Mentally Subnormal Children and Their Families," *Lancet*, October 27, 1973; S. J. Korn, S. Chess, and P. Fernandez, "Impact of Children's Physical Handicaps on Marital Quality and Family Interaction," in Richard M. Lerner and Graham B. Spanier, eds., *Child Influences on Marital and Family Interaction* (New York: Academic Press, 1978), pp. 299-325; R. Roesel and G. F. Lawlis, "Divorce in Families of Genetically Handicapped/Mentally Retarded Individuals," *American Journal of Family Therapy*, 11 (1983), pp. 45-50; and L. J. Shufelt and S. R. Wurster, "Frequency of Divorce Among Parents of Handicapped Children," *Resources in Education*, 11 (1976), pp. 71-78.

<sup>5</sup> Lynn Wtkler, "Chronic Stresses of Families of Mentally Retarded Children," *Family Relations*, 30 (1981), pp. 281-288; and Berger and Foster, "Family-Level Interventions for Retarded Children."

<sup>6</sup> B. Farber, "Family Adaptations to Severely Mentally Retarded Children," in M. Begab and S. A. Richardson, eds., *The Mentally Retarded and Society: A Social Science Perspective* (Baltimore, Md.: University Park Press, 1975), pp. 247-266; R. Levinson, "Family Crisis and Adaptation: Coping with a Mentally Retarded Child," unpublished Ph.D. thesis, Department of Sociology, University of Wisconsin-Madison, 1975; and P. Petersen, "Stressors, Outcome Dysfunction, and Resources in Mothers of Children with Handicaps," unpublished Ph.D. thesis, Department of Psychology, University of Nebraska, Lincoln, 1981.

<sup>7</sup> Berger and Foster, "Family-Level Interventions for Retarded Children."