

New Series / Volume 4 / Number 1 / March 1990

\$

MEDICAL ANTHROPOLOGY QUARTERLY

International Journal for the
Cultural and Social Analysis of Health

UNIVERSITY LIBRARY

MAR 07 1990

University of California
Los Angeles

Living with Difference: Families with Dwarf Children. Joan Ablon. New York: Praeger, 1988. x + 194 pp. \$39.95 (cloth).

THOMAS S. WEISNER

Departments of Psychiatry and Anthropology

University of California, Los Angeles

Living with Difference describes the experiences of American families who have a "different" child, a dwarf. Although being

extremely short is a dramatic and stigmatizing physical condition, it does not usually carry with it other physical disabilities or mental handicaps. The families and dwarfs themselves must nonetheless negotiate normalcy in a society in which physical appearance is important and tall stature is preferred. One dwarf expressed it this way:

We are a contradiction in packaging, for encased in our small bodies are not small minds, nor small needs and desires, not small goals and pleasures, and not small appetites for a full and enriching life. [p. 140]

Definitions of who is a dwarf vary. Ablon cites a definition of 5' 1/2" for men and 4' 8" for women; this figure includes people below three standard deviations of the U.S. mean for height and encompasses some 547,000 individuals in the United States, of whom 208,000 are under 21. Other estimates of the number of "true" dwarfs are about 100,000. Dwarfism has a variety of causes, with most cases arising from disorders affecting skeletal growth or endocrine disorders. Ablon focuses on achondroplastic dwarfs, who have average-size heads and torsos and unusually short arms and legs. Incidence of achondroplasia varies from 1/10,000 to 1/27,100 births. In contrast, "midgets" have a malfunction of the pituitary. Of average proportions, they appear to be simply small people.

Living with Difference is divided into 10 chapters and several appendices. The first chapter introduces the topic and the nature of dwarfism, followed by chapters on family responses to the birth of a dwarf child, logistic and medical issues, school experiences of dwarf children and families, social and family relationships, case studies, and a concluding chapter. Photographs are also included of dwarf children and adults as they get married, ski, play basketball or a violin, and pose with their families.

Ablon includes lengthy interview excerpts with parents, with rich data on family

adjustment and descriptions of the consequences of dwarfism for families. She tells an essentially positive story. Although many examples of suffering and struggle appear in the book, the overall sense is of a group of articulate parents with dwarf children who are integrated reasonably well into the average-sized world around them. The presentation is not driven by theory or an effort to test different models of adaptation, but Ablon implicitly adopts a mixed sociocultural adaptation model and refers to sociological theories of stigma and normalization, along with some family systems and psychological coping theories.

Living with Difference includes many examples of creative, humane efforts to cope. Some poignant matters are involved. Dwarf children may watch their younger siblings begin dating while they remain home. Some relatives never can adjust to their niece or nephew or grandchild being a dwarf, and painful disruptions occur. Some dwarfs need assistance in using the toilet because of their size; most succeeded in finding a friend at school willing to assist, or a parent or school maintenance person to devise a way to help with architecture and heavy doors. The book presents these materials largely in the words of parents, however; words and experience from the dwarf children themselves are surprisingly rare, even when the situations described call out for their own voices to be heard as well as their parents'.

Parents' contacts with the medical profession were sometimes painful and traumatic, and the initial presentation to the parents of the fact that their child was a dwarf was often appallingly handled. *Living with Difference* quotes parents telling about embarrassed and poorly informed doctors; blunt announcements of dwarfism lacking any further emotional or other assistance; a nurse taking a baby away from its mother, saying the mother was not supposed to have it yet, without saying why; a couple being informed of their baby's

dwarfism only as they left the hospital; and a doctor saying, to an achondroplastic father and average-size mother, "I regret to tell you that your child is a dwarf" (p. 17).

Parents reacted in various ways to their child's dwarfism. Some suffered initial depression, avoided social contacts or revealing the child's condition to others, and struggled with the ambiguity and stigma. Ablon discusses four features of families that were able to overcome the initial shock in a positive way: some prior first-hand knowledge of handicap and difference; a "very practical, problem-solving orientation;" a religious or spiritual ideology; and/or membership in an organization of dwarfs, called the Little People of America (LPA).

The LPA is a reference and activist group formed in the late 1950s. One chapter of the book is devoted to this organization, the purpose of which is to assist its members (some 2,000 dwarfs and their families) in adjusting to small stature, and to "focus public attention to the fact that the magnitude of any physical limitation is a function of attitude of both the small and average-size person" (p. 70).

All of the 25 families in Ablon's sample were LPA members. A subsample of six of these families, described as suburban and "middle class," was interviewed repeatedly over six years. Ablon openly advocates LPA and its approach to social support and assistance for dwarfs, and there is no question from her data on LPA that it serves valuable functions for members and their families, perhaps most importantly for dwarfs "to see themselves in the persons of other dwarf children" (p. 87), to gain personal self-acceptance, solidarity, and shared experience with other dwarfs. LPA provides an important referral and information service for medical issues and help which may be needed by families, as well as a potential marriage pool for some dwarfs.

Without in any way minimizing the obvious benefits of LPA, Ablon's exclusive reliance on this group for her sample significantly limits her study. It is unclear how generalizable is the successful coping reported for so many families and dwarf children in the book. In addition, Ablon quotes (with apparent agreement, or certainly without question) "conversations with health personnel who see the general population" of dwarfs and their families. Some disturbing stereotypes of those dwarfs and their families who are *not* LPA members appear in these accounts (pp. 143-144). Non-LPA families are characterized as: in denial (i.e., they "cannot face up to the image of what their child will look like"); ethnic minorities uncomfortable in a white, middle-class organization; people living in small rural areas where they are well ac-

cepted in a more protected world; large families which provide a "cushion of normalcy"; just "not joiners"; or "pathologically maladjusted." Ablon argues implausibly that she could not obtain a non-LPA sample for comparison purposes. Without denying that locating such families would be difficult, one wonders how she and her informants gained such detailed knowledge about types of non-joiners and yet could not recruit them.

Although the sample may be restricted and LPA may figure uncritically large in the book, *Living with Difference* is a very fine qualitative study of the lives of dwarf children and their families, a book that deserves reading for the detailed and sympathetic portrait it gives of the families and lives of a unique group.