



CHILDREN WHO ARE DIFFERENT

MEETING THE
CHALLENGES OF
BIRTH DEFECTS
IN SOCIETY

ROSALYN BENJAMIN DARLING
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CHILDREN WHO ARE DIFFERENT meeting the challenges of birth defects in society

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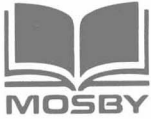
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meeting the challenges of
birth defects in society

For
Eric and Seth

FOREWORD

Two decades ago I bore our eagerly awaited first son. The delivery was a “natural,” unusual in those days, and punctuated by people sticking their heads through the open door to express interest and wish me well. After Jeff was virtually caught and handed off to a nurse flanking the doctor’s right side, the mood of easy camaraderie, cooperative venture, and exhilaration changed abruptly. At first I did not notice. I was satisfied with the pronouncement that “We have us a boy.” The baby was on my abdomen face up being aspirated with a small, bulb-type syringe, and the doctor was slicing through a tortuous, purple umbilical cord and catching its blood in a test tube in a manner rather more reminiscent of swashbuckling than my visions of an operating arena. Somewhere in the midst of this frenetic activity, Jeff was whisked away—before I could hold or examine him, before I could realize that something was terribly wrong. Suddenly everyone was gone, with the heavy door slowly and ominously closing me away from human contact and information.

Oh, there had been clues. But they were lost on me as I allowed myself to be carried along with the excitement and joy. Then suddenly, I had the sense of having done something wrong, of being abandoned. As I lay there alone, I searched my mind frantically for the meaning of what was happening. I had asked what was wrong with Jeff’s feet; the doctor had replied that it could be fixed. Then, shortly after Jeff had been taken away, the chief of obstetrics had come in asking if we knew the baby had a “spot” on his back. The doctor had replied, “No.” My queries of “What spot?” and later, “What does she mean by a spot?” had been answered with silence as if I did not exist anymore, and I heard myself ruminating aloud, “A birthmark? Do you think she meant a birthmark? That must be it. Why would I care about a birthmark?” They did not answer. The time of joy and creative powerfulness had turned into a barren wasteland.

In the intervening years, little has changed. I have heard the stories of hundreds of parents—in workshops I conduct, in response to questionnaires, in telephone calls at strange hours interrupting me from all manner of activity, in personal and always moving letters that appear in my box, and in hotel rooms in cities I never see save from the air. With rare exceptions they are all the same in essence, even today. The pain, frustration, and anxiety of professionals result in curtness to the point of rudeness, technical jargon to the point of insensibility, and other well-known behaviors that aid them in distancing themselves from us just when we need human contact the most.

One time I mentioned that no one ever seemed to examine professionals' reactions, especially the "denial" and distancing behaviors practiced by professionals when they are discomforted. Instead *parents* are turned into patients and are endlessly analyzed, scrutinized, and finally packaged into neat stages as if they were one-celled animals going through mitosis. I ventured that much of the subsequent anger parents often feel and direct at professionals might stem from our having to subvert our own needs to protect professionals when we are so very needy ourselves. For example, I felt distraught by the pain I saw in the eyes of the people charged with helping me in that delivery room. I could not press them because I could see that they could not handle the situation, and they physically took flight as soon as possible. A family therapist in the session where I put forth this interpretation exclaimed, "The Parentized Child! Of course."

"What?" I asked.

"Well, of course. I see. What you are describing is well known in therapy. It's like a child in a family going through divorce. He often plays the parent and nurtures and protects the actual parents because he sees they can't handle any more stress. So he doesn't ask questions or depend upon them for support. He knows they are too hurt themselves to function competently in their former role."

I was amused and heartened. Heartened because she definitely got the idea and amused because it seems that we often have to put a label on something before we can talk about it or figure out what is happening. And talk about it we do. Many parents and people who have grown up with disabilities have developed a strange type of gallows humor. For example, one parent, a ranking professional in human service herself, told me of her initial clinic visit where the social worker assured her that guilt in a parent was natural and that she shouldn't feel bad about it. (Think for a moment about that as a contradiction in terms.) Stunned, she allowed the social worker to go on at some length before informing her that the child, in fact, was adopted. Less than a week ago, a parent told me that she did not like the assumptions a professional made in giving her bedside counseling. When the worker suggested that perhaps they ought to consider finding "a home" for the child, this mother replied, "We already thought of that," and then gave the street address of their house. Sometimes we laugh in order not to cry. The suggestions the Darlings make for early counseling and referral to other parents could go far toward alleviating such experiences.

One of the wonders of the Darlings' book is that they refuse to cast parents in precut molds, and yet they have accurately captured the essence of what's going on—in and between parents and professionals. More importantly, they illustrate how the larger society impacts on families of children with disabilities. It seems to me they are saying that although, in fact, parents and people with disabilities do have obligations and responsibilities, they must not be victimized by their status. They should not be plunged from active, cooperative control of their own lives to become dependent, stigmatized outcasts of a persecuting or a patronizing system because of a mere moment in time when their baby issued forth a bit different from what was expected.

Another profound insight the Darlings offer is how the historical attitude of stigma or being a marked person has tenaciously attached itself to individuals with disability and

continues to affect our thinking today. No one can research the roots of medicine and morality without finding them inextricably intertwined. Ancient moral writings link physical perfection with moral superiority and physical “blemish” with inner or spiritual deficit. Until well into this century, the United States census actually counted handicapped people and willful criminals as one class. Our prevailing philosophy is tinged with sin in self as being the root of all social strife. The Darlings want us to understand that “sin” does not begin and end with the self. This is a work that may encourage us to know ourselves *and each other*, to forgive ourselves *and each other*, and to look beyond our uniqueness and interactions, even to our customs and social institutions, and ask how they are affecting us and whether the effect is good.

And so I dare to think that this book will challenge us to think about values—values that not only affect our social institutions, attitudes, and laws, but also our most intimate, everyday lives. These values have, in the past, promoted a type of medicine that featured analyzing and changing the individual alone. Parents of children with disabilities need more than just to talk about their feelings; they need solid information on which to base decision making, and they need hard service, such as hands-on help with child care, to survive as a unit and even to enjoy their lives.

It is ridiculous to memorize in school lists of imports and exports of countries whose borders change regularly and whose products are made obsolete with the changes in times and technology while learning nothing that would prepare one for the birth of a child with spina bifida or the stroke that renders a beloved grandparent unable to walk or talk. And yet, where is the political action that would replace nonsense with meaning in our schools or that would replace the obsession with cure (or alternately neglect) in medical settings with some manner of sustained care and concern? Where is the advocacy that protests a double standard that allows for the prescription of penicillin over the phone for a valued citizen and the withholding of the same in a child with a defect whose infection would easily respond to such therapy but who is instead to be “allowed to die”? Where is the public protest of heavy doses of barbiturates, which ensure a “low calorie” diet and lead to eventual starvation of many infants with defects? Where is the redress to the child and family for the child who lives on with new defects and substantial pain because he did not succumb to this “passive euthanasia” as hoped? Where is the redress for the child who exists in an institution because of a physician’s recommendation? Or, more to the point, *what* is adequate redress for people who are crippled or retarded needlessly or who grow up without family, friends, or a real home? A book that addresses the professional’s responsibility for up-to-date information and advocacy is long overdue for as I sit at this manuscript, lives are being wasted, sometimes irretrievably.

A few of us out here have been trying to promote advocacy through understanding. We give lectures to students, show slides, take family albums into schools, and conduct handicap awareness days when typical children have an opportunity to use crutches, wheelchairs, blindfolds and canes, and language boards. We do “in-service training” for teachers, nurses, and physicians, but there is no systematized program of education or insight using parents and people with disabilities as paid professionals and true colleagues.

And surely we do not think that all of the public education, sensitivity training, or social acceptance in the world can eliminate all of the loneliness, grief, and pain. Many of us would not if we could, perhaps, for we have come to believe that difficulties can strengthen us. We realize that if spina bifida or Down's syndrome were researched out of existence, accidents would cause conditions that paralyze and retard. We understand that what cannot be helped can be painful, but it is the *needless* and sometimes heartless pain and struggle we protest. We do, as the Darlings say, want the truth although we may ask easy forgiveness for wishing the truth were different. And we want the truth with human concern and an awareness that we are common in our vulnerability and that only a small percent of what is important is inherent in any body, disease, or condition. Most of the reality of disability lies in societal *response* to special need. That larger part of the truth is ours for the making. Not ours as parents alone, certainly not ours as "patients," "victims," "sufferers," or "the afflicted," as those who apparently believe in an active agent of vengeance persist in calling us. It is we as citizens who will forge new values, underwrite increased social supports, and create a new society built on the age-old principle of working together to do good for each other. The time is right, and the book the Darlings give us is an important milestone.

Betty Pieper, 1981

Betty Pieper is the parent of a 20-year-old son with spina bifida. She is a member of the board of the Spina Bifida Association of America and has published numerous books and pamphlets on parenting a handicapped child. She has been widely recognized for her work on behalf of individuals with spina bifida and has recently received the "distinguished parent award" from TASH, The Association for the Severely Handicapped of Seattle, Washington.

PREFACE

It is appropriate that this book was begun in the International Year of the Child and completed in the International Year of Disabled Persons. These designations mark a growing public awareness of what parents and professionals have known for a long time: disabled children have needs and rights that have been neglected by a society that has devoted its resources to the “normal” majority. Many disadvantaged groups have become more vocal in recent years. In most cases, however, disabled children cannot speak for themselves. As a result their parents have been their advocates. As representatives of the “system,” professionals—physicians, nurses, educators, psychologists, social workers, and others—have often been their adversaries. The time has come when these professionals can no longer be negative or neutral; they must join with parents as co-workers in bringing about needed social change so that *all* children may enjoy a life of dignity, hope, and self-fulfillment.

This book is written primarily for professionals and students who work with or who are planning to work with families of congenitally handicapped children. Our experience has shown that most of the literature currently available in professional education has been written by professionals who have employed a “clinical” perspective. These writings have, in other words, been based on various theories of human behavior rather than on the direct, personal experiences of families with disabled children. A considerable amount of literature from the family’s perspective *does* exist; however, these books and articles—written mostly by parents—are directed primarily to a lay audience. As a result professionals read materials written by professionals, and parents read materials written by parents. In this book we hope to provide a synthesis. Although we are professionals, we will be trying to provide a guide for professionals that is based largely on the experiences of families.

We are both sociologists and, consequently, have been trained to take the points of view of all participants in an interaction situation into account. We are also symbolic interactionists, that is, we identify with a perspective within sociology that suggests that social situations are not fixed entities but rather dynamic processes based on the continual renegotiation of roles and definitions by the actors involved. Thus we believe in change. Parents and professionals have sometimes had an antagonistic relationship in the past because each learned to define their situations of mutual interaction differently and as a result played roles that produced conflict. Both parents and professionals can learn to define situations in ways that take each other’s perspectives into account. We hope that

this book will contribute toward broadening the professional's point of view and, consequently, facilitating interaction with clients. The helping process will then be made more effective.

Although we are both sociologists, we each bring our own background to this book. One of us (R.B.D) is a medical sociologist, and the other (J.D.) is a sociologist specializing in marriage and the family. In addition, we both have had clinical, research, and teaching experience with mentally retarded and physically handicapped children and adults and their parents and with the professionals and paraprofessionals who work with them. The senior author coordinates a home-based infant stimulation program for handicapped preschool children in a county in western Pennsylvania.

The many parent quotes and descriptions of family experiences included in the book are derived from interviews with parents and other family members. As indicated in the text, a large amount of material is based on a study of the mothers and fathers of 25 congenitally handicapped children conducted by the senior author in a metropolitan area in new England in 1976 and 1977. (Further information about this study can be found in: Darling, R.B. *Families against society*. Beverly Hills: Sage Publications, Inc., 1979.) In addition, 10 families in western Pennsylvania were interviewed in depth in 1980 and 1981 to provide further information and an informal indication of the generalizability of the New England findings. These 10 families were involved in various parent groups or had children involved in preschool education programs. Many other parents have also been interviewed informally by the senior author. Although no attempt was made to obtain a truly random statistical sample for these latter interviews, the experiences related by these parents were remarkably consistent with those of the New England parents, as well as with those related in almost every published parental account we have read.

This book could not have been written without the help of many people. Primarily, we wish to thank all the parents who so graciously and generously shared their time, experiences, and feelings with us. Virtually no one refused to be interviewed. Although, in the interest of anonymity, they cannot be thanked by name, we want these parents to know that this book would not have been possible without their help and cooperation. In addition, we want to thank the staff at the Laurel Highlands Health Sciences Library Consortium and Fred Wilson at the Conemaugh Valley Memorial Hospital Library in Johnstown, Pennsylvania for their assistance. We would also like to thank our editors at The C.V. Mosby Company, Diane Bowen and Mary Dolan, and their staffs who have been most patient with our many delays and postponements and have been very supportive of our efforts. Finally, we want to thank our children, Eric and Seth, who have endured 2 long years of "Not now, I'm busy writing." We hope that they will understand and forgive us.

**Rosalyn Benjamin Darling
Jon Darling**

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PART ONE

WHO ARE THE VICTIMS?

No one is immune to birth defects, yet not everyone is equally susceptible. Specific defects occur in varying proportions in different national, racial, religious, and socioeconomic groups. Even the same defect, however, may affect different social groups in widely divergent ways. Each group has a unique set of values, meanings, and life-styles that constitutes its *culture* and is learned by individual members of the group from the time they are very young. Values toward disability are learned in the same way as other parts of a culture. An understanding of the meanings and values attached to birth defects in any given group, then, becomes important in understanding the effects of a birth defect on the individual.

Cultural meanings have three levels of effect: the society as a whole, the family, and the individual. On the broadest, society-wide level are the popular beliefs, attitudes, stereotypes, and myths that are generally accepted in a group. Within the larger society, too, are various subcultural groups, whose ideas and views may differ from those of the majority. The majority group arbitrarily decides who is "normal" and who is "deviant." In American society perfect physical and mental health are the norm, and those with permanent disabilities are regarded as deviant. As a result the society is structured to meet the needs of normals, and those with various mental and physical handicaps must contend with architectural and social barriers and obstacles. Subcultural groups representing the minority continually challenge the existing meanings, values, and structure, however, in an attempt to bring about change.

Within the larger social structure, families with congenitally handicapped children are affected both by the larger cultural norms and by their experience within the family group. Family members are, thus, affected from without by their interactions with friends, neighbors, relatives, and various other lay and professional persons and from within by their interactions with the handicapped child and with each other. The meanings that emerge from intrafamily interaction may contradict those of the larger society, and what is seen as deviant by the majority may come to be viewed as normal by the family group.

Finally, the meanings and values of the society filter down to the individual, through the intermediation of the family. As a result individuals learn the views of the majority culture, but they also learn to judge those views in terms provided by the family. Congenitally handicapped children, then, learn to define themselves and their situation in ways suggested by their parents and others with whom they have close contact. Consequently, they do not necessarily see themselves as deviant.

The chapters in Part One will consider the three levels of effect of congenital handicaps. Chapter 1 will consider the societal effect from an epidemiological viewpoint; the nature and prevalence of various birth defects in American society will be discussed in descriptive, demographic terms to indicate the extent of effect on the population in general.* All remaining chapters will focus especially on birth defects that are permanently disabling. Chapter 2 will be concerned with the societal effect in terms of the meanings and values generally attached to birth defects in American society. Chapter 3 will look at the effect of the congenitally handicapped child on the family, and Chapter 4 will consider the effect on congenitally handicapped children themselves. Part One, in its entirety, will provide the background for a closer look at family coping processes and an exploration of the provision of services for families presented in detail later in the book. The chapters in Part One, then, will define for the professional the general social parameters of the birth defects situation.

*Available rates for each birth defect vary widely. As Christianson et al. report, such variation is the result of different definitions of defects that investigators use in the studies, the methods of detection used, the time period over which a group is studied, and cultural characteristics of the group studied, such as ethnicity and socioeconomic status. Studies following children's development over long time periods, for example, are more likely to report higher incidence rates for the same defect than those based only on information known at birth. The incidence rates cited throughout Chapter 1 are, therefore, only estimates and should not be viewed as definitive. (Christianson, R.E., van den Berg, B.J., Milkovich, L., and Oechsli, F.W.: Incidence of congenital anomalies among white and black live births with long-term follow-up, *American Journal of Public Health* 71:1333-1341, 1982.)

CHAPTER 1

THE NATURE AND PREVALENCE OF BIRTH DEFECTS

Data from many countries and regions verify that at least one tenth of all children are born with, or acquire, impairments—physical, mental or sensory—that will interfere with their capacities for normal development. . . . This is a minimum estimate. The numbers can be much greater, ranging up to 15 or 20 per cent of all children, depending on the conditions included, the definitions of disability being used, the age of the child population studied, and other factors.

UNICEF, 1980

In the United States some 8 million of the nation's children have such impairments (United States Bureau of the Census, 1978:363). Some 15 million Americans alive today have congenital impairments, that is, defects that are present prior to, during, or shortly after birth. Some 250,000 infants are born with such defects each year in the United States (March of Dimes Foundation, 1981).

A great many congenital defects affect human populations. For example, one widely used work on the subject, *The March of Dimes Birth Defect Compendium* (Bergsma, 1979), lists 1,005 different birth defects. Although birth defects are generally rare, some defects are more likely to occur than others, some are more likely to occur in selected social groups, some become apparent early in life whereas others appear later, some are obvious whereas others are invisible, and some are correctable through medical or surgical intervention whereas others are permanently disabling or even life-threatening.

Birth defects can result from a wide range of causes. Sometimes the defect results from genetic deficiencies or incompatibilities in either or both parents' genetic material or from a genetic accident; sometimes the defect is inherited from previous generations; sometimes the defect results from an interaction between genetic material and the environment (as in the case of the interaction between genes and viruses, drugs, radiation, or industrial pollutants); and sometimes the defect is entirely environmentally caused (as in the case of a newborn's receiving insufficient oxygen at birth). Regardless of cause, the result is a structural or chemical abnormality in the child.

Not all birth defects will interfere with normal function. Some minor structural defects, such as a missing or misshapen finger or toe will be relatively mild in impact. Other more serious defects may be totally correctable, as in the case of an imperforate anus or intestinal blockage that is surgically opened. Still other defects will have cosmetic but



Ron Stewart

Fig. 1 Photograph by Ron Stewart. From Gearheart, B.R.: Special education for the '80s, St. Louis, 1980, The C.V. Mosby Co.

not functional impact, as in the case of an oddly shaped head or an undescended testicle. Although such defects may have psychological effects on parents and their children, their *social* meaning will be different from that associated with defects that involve functional impairment. Defects that seriously interfere with the normal performance of social roles will be the subject of this book.

Throughout the text, the terms *handicapped*, *disabled*, and *defective* will be used interchangeably to refer to individuals with physical or mental impairments that interfere with the performance of life functions. For many these terms have value-laden connotations that suggest an acceptance of society's labeling of the "normal" and the "deviant." No such connotations are intended in this text. We have chosen to avoid the use of euphemisms such as "special needs children" because these children are in fact handicapped. In our view, however, their handicaps are as much caused by the inconveniences imposed by society as by their physiological limitations. Similarly, our use of the term *normal* to connote those who are not handicapped does not imply acceptance of societal distinctions between normal and deviant. By *normal* we mean *typical*. We use the term *normal* because we want to emphasize the societal label as the major determinant of life chances for the disabled.

This chapter will provide a brief description of the more commonly occurring and more serious birth defects. In addition to descriptive summaries of the defects, information will be provided concerning rates of incidence and prevalence, causes, treatments, prognoses, and possible preventions. This information will provide a background for later chapters, which will focus on the effects of these defects on the families of their victims and suggest appropriate strategies for professional intervention.

More common birth defects apparent at birth or in infancy

Defects that are apparent at birth or during infancy will constitute the main subject matter of this chapter. Some birth defects (Huntington's chorea, for example) do not become apparent until later in life. Although these later appearing defects certainly have a social impact on their victims, that impact is different from the effect on parents of having a baby that is "different." Because this book is intended for pediatric practitioners and other professionals who work with families of young children, only those defects that become apparent very early in life will be included. Some of the more common defects will be discussed in depth, and some others will be mentioned briefly.

Neural tube defects

Several defects related to the development of the spinal column (neural tube) are recognized as serious birth defects. One such defect is *anencephaly*, a defect in which the fetus is born without a complete brain. This condition is incompatible with life, and such infants do not survive. Two other major varieties of neural tube defects, *spina bifida occulta* and *spina bifida cystica*, occur somewhat more commonly and are associated with greater survival potential. The difference between the two types of spina bifida is one of