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An interdisciplinary view of the special education child and his family is presented in this book. The text comprises a useful collection of articles that will be invaluable to the person seeking the latest, most innovative ideas in the field of developmental disabilities. A total picture of the special education scene is presented with something of interest to everyone; the professional will value the expertise of his colleagues while the parent will find vital information on relevant topics. This book is a unique and important contribution to the field of special education.

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DEVELOPMENTAL DISABILITIES OF EARLY CHILDHOOD

Edited by

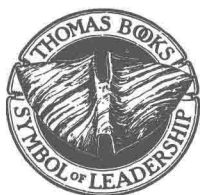
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PREFACE

IN APRIL, 1976, the Little Village School for Developmentally Disabled Children and Sagamore Children's Center cosponsored a professional conference, "Developmental Disabilities of Early Childhood." A unique blending of many disciplines was achieved. The papers published in this book are based on proceedings from this conference. The editors would like to take this opportunity to thank all the participating authors for their outstanding contributions.

It is hoped that the knowledge and research presented in this book will serve to further the needs of the developmentally disabled child and his family.

CARYL BANK
BARBARA FEINGOLD

INTRODUCTION

**EARLY INTERVENTION
IN DEVELOPMENTAL DISABILITIES:**

A Job For Everyone

MARY HAGAMEN, M.D.

It was six men of Indostan to learning much inclined

*Who went to see the elephant (although all of them
were blind)*

That each by observation might satisfy his mind.

JOHN GODFREY SAXE 1818-1887

THOUGH fifty years is scarcely an eyeblink in the recorded history of the world, during this time the medical community has gained a greater majority of the present knowledge of the pathology that affects man.

The field of medicine has moved from looking only at disease to looking at health and what measures are necessary for its preservation. Of necessity, this calls attention to groups of apparently normal people who, from their constitutional and social history, are about to develop a particular ailment. The medical field abounds with screening programs focused on persons who are *high risk*. Populations that are high risk for hypertension, diabetes, lung cancer, and coronary artery disease, etc. have been delineated. Such programs are aimed at finding an illness in its asymptomatic prodromal stages, so that intervention can begin before there is any debility. Another important function of screening programs is helping people understand the factors, components of their life-style and environment, that tend to exacer-

bate any heredity predisposition to a disease in themselves.

Today, educational programs help the layman realize the role of heredity and its interaction with environmental factors, such as diet, smoking, and drinking. These are bonafide components of public health programs.

Certainly, the seeds of the hereditary-environmental philosophy seem to fall on the most fertile of soils in the field of obstetrics and pediatrics, where, theoretically, there is the longest period of time with the most strategically placed fulcrum to utilize the energies of the medical profession in preventing disease and disabilities. Although dramatic battles have already been won on this frontier through our understanding and intervention in such conditions as Rh incompatibility and phenylketonuria, much pioneer work remains to be done. Perhaps the most enigmatic among the problems of children are those classified as *developmental disabilities*. These problems lie in the territory where professional responsibility overlaps with that of the disciplines such as education, law, social services, and the clergy. Very often preventive measures suggested through advances in medical technology are incompatible with social and religious values. Bioethics has become an important topic of discussion among all those interested in promoting the "good life" and the "pursuit of happiness."

Because of the overlapping of professional responsibility among the various disciplines that deal with children, there is an enormous potential for confusion that can be likened to the blind man who so diligently studied the elephant.

If we are to apply all that we know about the prevention of developmental disabilities, whether it is in the primary, secondary, or tertiary level of preventive care, it is necessary first to coordinate the knowledge and services of those specialists and subspecialists within the medical profession: general practitioners, geneticists, obstetricians, neonatologists, pediatricians, and child psychiatrists.

There is a need for interdisciplinary understanding within the limited fields of psychology and education. Interchanges must work between behavioralists and analysts. Teachers at a level of

kindergarten through college must understand both their own role in educating the average youngster and the variety and forms of special education.

Some of the fiercest prejudices exist at an interdisciplinary level in all fields. Psychology, education, and medicine each have denominations within their ranks. If we are to do well with the developmentally disabled, we must create programs of enlightenment geared to illuminating facts, not fads, as well as the opportunities for dialogues between all those interested. If this can be accomplished, many prejudices will be reduced, if not erased. Social services to children and families need to be free of the cumbersome bureaucratic entanglements that discourage many marginally needy people from the services for which they are eligible.

Perhaps most important, there needs to be a cross-fertilization between the traditional human services fields (health, education, and welfare) and the legal profession. No one disagrees that the rights of children in the United States are a basic heritage deserving of protection, but something has gone wrong when the rights of the child are pitted against the rights of the parents in litigation. Lawyers eager to defend a valid philosophy sometimes intensify the complex problems they have set out to ameliorate.

On the other hand, service-oriented professionals working with another set of facts are apt to develop a religiosity that rigidly resists compromise. Well-meaning parents can be caught in the middle with the poor understanding of their child, rights, and responsibilities.

If the battle against developmental disabilities is to progress, it will be necessary to overcome intra- and interdisciplinary differences in the creation of a master plan that provides for dialogue at every step of the way — a dialogue that diffuses information to such a degree that it, in essence, acts to remove the blindfolds on the wise men who are so carefully examining the elephant of developmental disabilities. For on this frontier, there is a job for everyone — doctor, lawyer, teacher, social worker, scientist, student, child-care worker, and, most of all, the informed consumer — the parent.

Human development, as defined by Meier,⁴ refers to “a change in a person’s function or capacity in any one or combination of four interacting domains; physical, emotional, social and intellectual.” Development is distinguished from growth. *Growth* relates primarily to change in size or quantity, whereas *development* relates more to change in function or quality.

The human baby is dependent upon a variety of factors to support optimum development. There must be:

1. A normal genetic endowment
2. An insult-free, ten-month intrauterine life
3. A nontraumatic birth
4. A consistent, loving, stimulating environment safe from infections and accidents

With these attributes, a child can usually be assured of life without a developmental disability.

However, despite the rapid increase in technology and man’s control of nature in the twentieth century, it is increasingly difficult to assure every baby born the attributes for normal development.

As a result of technology, the lives of more babies who have had insults to their nervous system, *in utero* or at birth, have been saved. However, children who in earlier times would have died in infancy because of anatomic or physiologic deficits are being given a good chance for a normal life expectancy through the advent of surgical and biochemical intervention. Yet, we are increasingly less able than preceding generations to assure babies of a living, stimulating, and safe environment maintained by an intact marriage and supported by an extended family. Thus, in the last quarter of the twentieth century, there seem to be increasing numbers of children with developmental disabilities of both a major and minor nature. The major disabilities are usually associated with moderate and severe mental retardation, while the minor disabilities affecting far greater numbers of children are reflected as mild retardation and learning disabilities.

Another way of looking at developmental disabilities is by analyzing their roots of origin; that is whether the handicap is

intraindividual, resulting from a constitutional deficit within the individual, or whether the handicap is the result of an *experiential* deficit having its origin in the environment.

Examples of intraindividual problems are demonstrated by children who —

1. Have a genetic deficit, i.e. Down's syndrome, PKU, etc.
2. Traumatic uterine sojourn, i.e. babies born to mothers who have had rubella in early pregnancy or
3. Have been premature, traumatized at birth, or suffered infections or accidents early in life

The developmental disabilities *individual* in origin, are those secondary to the experiences that the child had in the critical pre-school years. A multitude of investigators^{1,3,5} have shown that over two-thirds of "slow learners" and "school failures" are retarded on the basis of experiential deprivation frequently associated with the "culture of poverty." Although such children are physically intact, they have a developmental deficit that is as real and disabling a problem as any of the more grossly identified disabilities. Because of the much larger number of such individuals, their handicap has a more profound and devastating effect on our social system. Although the causes that are clearly intra- and extraindividual in their roots of origin can be isolated, what is happening in the individual child is more difficult to define. The past decades of observation have shown that the child reacts on his environment to a greater degree than formerly was believed possible. Under closer scrutiny, some conditions that were frequently blamed on parent behaviors have turned out to be only reactions to the primary problem in the child. The prime example of this finding is the condition known as *autism*. By the same token, some children who have been subject to severe deprivation of a devastating degree seem to have come through such experiences only to excell among their peers. Developmental disabilities in children represent a complex of actions and reactions both intra- and extraindividual in origin.

Today, it is only the more severe conditions related to cerebral palsy and retardation that are thought of under the designation

of developmental disabilities. However, as we begin to organize a system for identifying children who have mild to moderate disabilities of mixed intra- and extraindividual origin, the numbers of children eligible for developmental disability resources may increase up to tenfold and will present an interdisciplinary challenge.

Because of the massive social implications of increasing numbers of experientially handicapped individuals, President Lyndon B. Johnson's administration initiated Project Head Start as a major part of the war on poverty in the mid-1960s. This heroic nationwide effort to overcome the results of early cultural deprivation on educational development of children in the poverty cycle was too large and uneven in the quality of implementation to be properly evaluated. It was not as effective as many had hoped, but it was a critical milestone in calling the attention of all persons interested in children to the potential value of early childhood programs.

In the field of education, investigators had been looking long and hard at what determinants of development in a child's life could be manipulated to overcome the developmental disabilities that were extraindividual in origin.⁶

At the same time, leaders in the field of education for the handicapped had been working to discover how they could create an environment for the child with a handicap of intraindividual origin that would minimize his deficits.

One of the lessons evident from Project Head Start was the need for intervention to begin before the preschool period in order to be maximally effective. The United States government followed this lead with the initiation of the Parent and Child Development Centers, aimed at helping parents understand and participate in the enrichment program for their children. The vital role of parents was recognized initially through programs designed to provide early intervention for children disabled by extraindividual cause. However, application of the principle of parent involvement plays an even greater role in the lives of children who have a developmental disability of intraindividual origin.

Although the seed of the parent-professional partnership was born in the field of early childhood education, it was rapidly disseminated to those interested in education of the handicapped. For some readers, there may seem to be nothing new in this concept. For years, there has been a kind of parent-professional partnership between teachers and parents as evidenced by the Parent-Teacher Association (PTA) chartered more than half a century earlier. However, this began when the child was five or six years old and was often more a social liaison than a working relationship in which parents participated in teaching. In more recent years, parents have often been sharply discouraged from becoming involved in the teaching of reading and other educational skills to their offspring.

As results are compiled from programs in which the goal is to increasingly involve parents in verbal interaction with their children, it is becoming evident that early intervention in developmental disabilities of an extraindividual type can best be done in a home, with a mother who has a close relationship with some type of parent support center administered by professionals. In the same vein, investigators, such as Weikert Fraiberg have shown that to minimize the intraindividual developmental disability, it is necessary to provide a program in which the mother or another member of the child's family is taught to understand and participate in a home-based, infant-stimulation program.

Intervention involves developing a system that will provide the mother with emotional support, as well as guidance in how to play and talk with her baby. If a newborn baby is known to be in a high-risk category, or if there is a known birth defect, it is ideal to enroll the child and mother at once in an infant-intervention project. Although such programs are now few and far between, they are increasing in number across the country and within the next decade should be as available as were kindergartens thirty years ago. Because of the low incidence of birth defects, it will always be hard to provide direct service to parents of handicapped children in sparsely populated areas. However, the increasing electronic technology may help resolve some of the isolation of these families.

It has been shown that a system of services that can provide the mother and father with information and understanding of their child's condition, as well as emotional support necessary to help them work through the feelings about their child, is essential in early intervention. It is also important that the parent be trained by those experienced in the specific care of the infant with a developmental disability. In order to accomplish this training, physicians have turned to teachers and psychologists to forge the link necessary for early intervention and a parent-professional partnership. Effective programs usually encompass a psychologist, nurse, and teacher who work to educate, train, and support parents in providing the care and stimulation necessary in early intervention.

When intervention is done, it has been shown that the child with extraindividual handicaps develops in a way comparable to his middle-class peers, and furthermore, contrasts the gains made by Head Start children. These gains are retained when mothers are provided with understanding, attention, and support in a program that encompasses videophone and training by T.V. cassettes. This program enables parents to learn to enjoy and to interact with their babies. With children whose handicap is of intraindividual origin there are also gains, not the least of which is the satisfaction of the parents in knowing that they are participating and contributing useful information to their youngster's treatment plans. As often happens, programs that involve parents in the home are the most effective. From a monetary standpoint, they are the most efficient, having a cost effectiveness far superior to intervention programs that depend on bringing the child out of the home and into a child-care center.

Summary

Early intervention in developmental disabilities is dependent upon the origination of a master plan that provides for a coordinated effort by a wide variety of professionals, in combination with consumers, to work together to assure that every baby born has the opportunity to develop to the full level of his or her potential.

Cooperation at both intra- and interdisciplinary levels is essential if all the information presently available in early intervention programs is to be utilized.

No program can be successful without the involvement of the parent or those who are the child's primary caretaker(s). In contrast to earlier programs of parent involvement where parents were seen to be counseled, the new intervention programs seek to have the parents as active partners to the professional in implementing an organized plan that assures the optimum development of their child.

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