# Early Intervention of Developmental Disabilities

A report of the Conference on Early Intervention of Developmental Disabilities

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### **Preface**

About the Early Childhood Unit . . .

The Early Childhood Unit of the Indiana University Developmental Training Center serves as a catalyst for the provision of comprehensive services to young handicapped children and their families from birth to five years of age.

The Unit considers itself a model for demonstrating the delivery of comprehensive and interdisciplinary services, and a training site for pre-service and in-service professionals, paraprofessionals, and parents. Research and inquiry related to parent-child interactions, instructional strategies, and other topics are seen as key activities in the Unit. It is committed to maintaining the service functions already in operation through demonstration, training, and research, while building upon this base to extend and expand its field-based consultative effort.

The Early Childhood Unit currently consists of two model demonstration programs and a curriculum development project. Program PREPARE, formerly a federally-funded model demonstration program for handicapped infants and toddlers and their families, is now state-supported and provides services to families of young handicapped children as well as technical assistance to service providers within Indiana.

The Monroe County Multi-Categorical Model Preschool Program is a federally-supported model demonstration program for handicapped preschool children ages 3-5. A joint effort with the Monroe County Community School Corporation and the Indiana Department of Public Instruction, the preschool has as its goal the successful integration of handicapped preschoolers into the public school.

The Indiana Home Teaching System, formerly funded by the Indiana Department of Mental Health and now funded by Region V HEW Developmental Disabilities Office, is designed to provide a comprehensive, coordinated, cost-effective system for young handicapped children and their parents living in rural areas. Currently being field tested in the six states of Region V, it is designed for agency and/or home utilization.

The Early Childhood Unit personnel also work closely with the Preschool Consultant of the Division of Special Education in the Department of Public Instruction for purposes of training, dissemination, and technical assistance.

### **Introduction and Conference Overview**

Introduction: In January, 1979, the Early Childhood Unit of the Indiana University Developmental Training Center was awarded a contract by the Ohio State University Research Foundation in conjunction with the Region V UAF Consortium Project. The purpose of the contract was to plan, develop, and conduct a State of the Arts Conference dealing with early intervention of developmental disabilities which would provide imput to a regional futuristic conference on developmental disabilities.

The purposes of the conference, as defined by the Early Childhood Unit, were as follows:

- 1. To enhance knowledge about early intervention strategies and their effectiveness;
- 2. To facilitate the identification and coordination of various state and federal programs;
- 3. To utilize current knowledge of programs and practices in the planning for the future;
- 4. To produce futuristic guidelines that reflect the content of the conference and can be utilized for future planning.

Organization of the Conference: The conference was held on May 18 and 19, 1979, in Nashville, Indiana. It included the presentation of three papers, followed by discussion among participants and small task force discussions on four predetermined topics.

The first paper, Social, Psychological, and Ethical Foundations for Early Intervention for the Developmentally Disabled, was delivered by John Gliedman, Ph.D. and addresses the application of a minority group model to the educational problems of handicapped children.

The second, Current Status in Research Relating to Model Development and Early Intervention for Young Handicapped Children, was delivered by Nicholas J. Anastasiow, Ph.D. It presents an overview of the model early intervention programs, and deals with research findings and program effectiveness.

The third paper. Current Status of Personnel Training for Early Intervention Programs, was delivered by Elouise Jackson, Ph.D. This paper describes the training efforts of four major systems involved with providing services to handicapped children: the National Diffusion Network, the Bureau of Education for the Handicapped, Project Head Start, and Parent-Child Development Centers.

Initial discussions addressed a definitional problem, the need to identify the nature of the population for whom early intervention was being recommended. The participants agreed that the focus of the discussion/conference was the child, chronologically 0-8 years, who is impaired in that there exists some kind of interference in the child's ability to use his brain, nervous system, and/or his visual, tactual, and auditory modes in mastering his/her environment. The term *developmental facilitation* was selected by the participants to express the main topic of the conference, because it avoids the negative connotations of the more familiar term *intervention*, which, it was felt, accentuated problems associated with the social pathology model that has so long characterized the field.

With agreement as to the population to be served and the kind of service desired, task forces were then formed to prepare futuristic guidelines for the following areas: Community Mobilization, chaired by Myrtle Scott, Ph.D.; Program Implementation, chaired by Howard Spicker, Ph.D.; Personnel Preparation, chaired by Susan Shuster, Ph.D.; and Evaluation and Dissemination, chaired by Egon Guba, Ph.D.

The three papers and the four task force reports are included in this document.

Conference Participants: The conference participants were representatives from departments of public instruction, departments of mental health, federal and state model programs, University Affiliated Facilities, as well as instructors from institutions of higher education, parents, and graduate students.

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# Special Education and Minority Education: The Path Not Yet Taken—

Social, Psychological, and Ethical Foundations for Early Intervention for the Developmentally Disabled

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In a famous lecture of twenty years ago Sir Charles Snow spoke of the problem of the "two cultures"—of a gap between how the world is viewed by those trained in the humanities and by natural scientists. Increasingly, Snow claimed, humanists and scientists talk past each other. Each has valuable insights, yet lacking a common language, each has great difficulty communicating these insights to the other. My theme is about another kind of cultural divide—that of the different way experts view the educational problems of handicapped children and of able-bodied minority group children. Here too there is a basic difference in intellectual frameworks. But something more than a bridge between these two paradigms is needed. If special education is to flourish, and if early intervention programs are to progress, a new intellectual integration will be required. In the pages that follow I shall suggest why this integration is so important, why it has been so long in coming, and the main directions that it is likely to take.

### The Social Pathology Model in the Past

A generation ago there was no two cultures gap in education. A single model informed the way that educators perceived, studied, and attacked the school problems of minority group children and handicapped children. Following a number of recent critics—as well as traditional practice—I shall refer to this paradigm as the social pathology model. 1 As its name suggests, this model was patterned after the physician's approach in intervention in acute illness. The child's problems were defined as deviations from the universal norms of childhood, much as the doctor defines disease as a deviation from the norm of physical health. Then—and the analogy to medicine is exact—the educator devised special programs to help the child compensate for his educational deficiency. This focus on compensation encouraged the educator to interpret the developmental significance of the child's behavior with little or no reference to its meaning in the context of the social environment, for by definition a deviation from a universal has an absolute character. Just as measles is the same disease regardless of the race, sex, or social class of its victim, so too, an educational deficiency has the same meaning regardless of the child's cultural milieu. Of equal importance, the social pathology paradigm encouraged the educator to define individualized instruction in a manner resembling the way the doctor treats an acute disease. By "individualized" it meant: compile a comprehensive catalogue of the child's deviations from the norms of his age group. No child is exactly the same, but it was assumed that a sufficiently refined diagnosis of his deficiencies would serve to distinguish him from other children with school problems.

During the 1960's special education remained true to the medical model, but those who worked with minority group children slowly began to adopt a different approach. By the end of the decade, a new perspective on minority education had taken shape. Increasingly, those who worked with minority group children argued that the field's traditional reliance on compensatory strategies was wrong.<sup>2</sup> Far from helping the child better cope with the demands of the classroom, the emphasis on compensation diverted the teacher's attention from the many strengths displayed by inner-city children, conveyed the sociological message that the school considered them to be inferior, and confused culturally-determined differences in normal behavior and cognitive style with pathological deviations from the norms of child development. In place of the traditional approach, educators like Mario Fantini and Gerald Weinstein proposed "contact strategies," attempts to help the child apply the learning styles fostered by his social and cultural experience to the tasks of the classroom.<sup>3</sup> As Frank Riessman has noted, these approaches are far more successful than the compensatory methods inspired by the social pathology model.<sup>4</sup>

A start was also made towards understanding how the child's perceptions of race stereotypes, prejudice, and discrimination affect his development. Building on the earlier work of the Clarks, many studies found that by age three black children have started to internalize society's stereotypes about race. This result further undermined the social pathologist's claim that the minority child's school and pre-school behavior can be safely assessed by the same criteria customarily employed with white middle class children, because at an early age the child already sees himself as different. Recent work by

John Ogbu has gone still further. Ogbu's research suggests a direct connection between the black child's generally poorer academic achievement and his perceptions of the second class social status of black adults. Ogbu found that black children often take school and school-related activities less seriously than white children because they are aware that the ultimate social benefits of school achievement are much smaller for black people than for whites. These findings have not yet been generalized to pre-schoolers, but they raise important questions about the ways that apparently pathological cognitive and social behaviors in very young minority children may represent developmentally appropriate responses to what they see in the world around them.

The educator's growing dissatisfaction with the traditional premises of minority education has also led to a reappraisal of the role played by the social pathology model in parent education programs. For decades the concensus view was that lower-class parenting styles were more or less pathological deviations from the middle-class ideal. If these deviations could be corrected by parent education, the disadvantaged child could bring to the classroom a set of behavior and cognitive skills more conducive to subsequent academic achievement than those he would otherwise acquire. Especially in the past few years critics have pointed to many crucial flaws in this analysis. Perhaps the most important of these criticisms is that middle-class parenting strategies that correlate with good school performance simply may not be appropriate for helping the member of a politically and socially oppressed minority succeed in school, let alone cope with the daily strains of poverty and discrimination. Indeed, far from helping the child, the professional's didactic efforts actually may be harmful—by suggesting that experts believe the parents belong to an inferior social group, by conflicting with values (such as the importance of discipline and order) that may be highly prized in the parents' subculture, and by otherwise undermining the parents' sense that they are competent care-givers.

Finally, policy-oriented research has led to a new understanding of the role that education can play as an agent of major social change. Guided by the social pathology model, generations of reformers pinned their hopes on the schools. They reasoned that if the minority group child could be cured of his educational pathologies, he would do as well in school as the average American child, and that if he met the educational standards of the mainstream, his chances of escaping from poverty would be greatly enhanced. The research of Christopher Jencks and his associates suggests a different conclusion: even after the leveling of all educational differences between the races, substantial racial differences in income, wealth, and occupational distribution would remain. Education alone, argues Jencks, is a weak tool for economic change, and only massive social and political reforms can eliminate the unfair economic advantages that the white majority currently enjoys.

However, other research does suggest that education is a very good social insurance policy. For example, during a period of massive structural reforms in society, improved schooling can help a minority group take full advantage of its new social options. Moreover, there is ample evidence that minority groups must constantly upgrade their educational credentials simply to retain their traditional share of jobs and income during periods, such as our own, when educational requirements for most kinds of work are continually rising.<sup>10</sup>

### Special Education and the Social Pathology Model

Experienced workers in special education agree that prejudice and discrimination are important factors in the lives of many handicapped children. In the absence of social reforms, experts agree that economic and social discrimination will fetter many handicapped children when they become adults a decade or two hence—even if these children receive first-rate educational services while they are growing up.

Professionals are acutely aware of the shortcomings of society's general view of the nature of disability. They agree that what the man in the street understands about the handicapped child's innate abilities is frequently a social invention, a product of stereotypes and prejudices about the nature of

disability no different in kind from the racist's belief that blacks are innately inferior to whites.

Why, then, given this broad concensus about the importance of social context, does special education continue to ignore (or insufficiently emphasize) the ways that stigma and discrimination may shape the handicapped child's mental and social development? Why isn't special education full of attempts to do justice to *both* the social pathology model and the minority group model? Why not strike a balance between focusing on the often overwhelming biological limitations, and on those aspects of a child's problems best approached using the insights of minority group analysis? Why is there a two cultures problem in education, a sharp divergence between the way that the educator approaches the minority group child, and the way that he approaches the handicapped child? Perhaps most puzzling of all, why is there so little awareness among professionals that there is a two cultures problem?

The special characteristics of the handicapped child's minority-group status certainly contribute to this highly unsatisfactory stage of affairs. Black and hispanic children have black and hispanic parents, and both blacks and hispanics form distinct (if highly diverse) cultural communities. In contrast, most handicapped children have able-bodied parents and siblings, and disabled people do not form anything like a distinct cultural community. This lack of an obvious minority-group identity means that the disabled face some of the same problems of group visibility as women, gay people, and the elderly, all of whom have achieved general standing as disadvantaged or oppressed social groups only as the result of vigorous efforts to claim their legitimate civil rights. Because the disability civil rights movement is new, disabled people have had less time than most other disadvantaged segments of the population to argue the case for a minority-group analysis with professionals and with the public at large.

But there is, I believe, a more fundamental reason why the recent changes in minority education have not had a significant impact on special education. Many years ago the social psychologist Kurt Lewin discussed the role that society plays in defining a collection of individuals as a distinct social group. 12 Speaking of the situation of European Jews in the 1920's and 1930's, Lewin noted that the members of an oppressed minority often have little more in common than the fact that society singles them out for systematic discrimination. He called the defining characteristic group an "interdependence of fate," and argued that the social expectation was that the lives of those in the group would follow a similar pattern. Lewin's use of the word "fate" points to what is perhaps the most important reason for the two cultures problem in education. Oppressed groups, such as those described by Lewin, are given social reality by the fact that their members are seen to share a common sociological or political destiny. American society has traditionally acknowledged that disabled people share an interdependence of fate, but it has blamed their problems only on a biologically determined fate, and not on a destiny that is in part socially produced. As the dictionary definitions of "disability" and "handicapped" suggest, disabled people are defined as those individuals whose biological limitations exclude them from normal pursuits or seriously imperil their ability to lead a normal life. But society's emphasis on the biological nature of disability has constantly impeded the efforts of the disabled to secure their most elementary civil rights. (The opinion recently handed down by the Supreme Court in the Davis case eloquently testifies to the scope of this problem.<sup>13</sup>) In special education too the prevailing interpretation of disability as biological has played a harmful role, for it has ranged our commonsense intuitions about the nature of disability on the side of the social pathology model.

I know no better way to suggest how much the social pathology model owes its continued dominance in special education to the cultural meaning of disability than by briefly examining a few of the "deep structure" rules that govern able-bodied society's phenomenological definitions of disability. These definitions seem to be part of everyone's cultural baggage, layman and professional, handicapped and able-bodied. Subtle and all-pervasive, they contribute to a Zeitgeist that makes it hard to perceive the existence of a two cultures problem in education, a cultural background that obscures many of the most important similarities between special education and minority education. Perhaps most important, these concepts create mental sets that prevent the educator from integrating his (often

extensive) first-hand experience of the social dimension of disability with the actual strategies of research and intervention that he pursues in his work.

### Handicap as a Social Construction'

Conjure up in your mind a military man with an eye-patch. Is there not something romantic and heroic about the injury? Doesn't it suggest a dark and complex past, a will of uncommon strength, perhaps a capability for just enough brutality to add an agreeable trace of sinister and virile unpredictability to the man? Depending on one's politics, it can suggest a resourceful ally or a dangerous enemy. Mustn't a man be tough and competent to escape so lightly from what must have been a brush with death? No doubt these reactions explain why Madison Avenue once used a disability to enhance the glamour (and salability) of a commodity, in the Hathaway Shirt ads of the 1960s.

Now replace the image of the Hathaway Man wearing an eye-patch with the image of a seven-year-old girl who wears one. For most people, something happens. The romance and mystery disappear. What we see is a handicapped child. There is something sad and even pitiful about her; we fear for her future and worry about her present. We think: this poor kid is going to have a hard time growing up and making it in this world. Where the presence of an eye-patch made an Israeli leader seem even more of a general (an adult role), the presence of an eye-patch on a child is a sign of damage, a cause for pity, an indication that this is a child whose ability to fit into some adult role in the future is in jeopardy.

Similar shifts in valence occur with numerous minor disfigurements or cosmetic blemishes, as an acquaintance of mine learned to his astonishment when, after a hiking accident that left him hobbling about for several weeks, he was told by a number of friends that he looked so distinguished using a cane that he should consider always using one. Needless to say, this is not something that one says to a young child similarly disabled.

Many striking illustrations of the impact of social function on the perception of a handicap are found in films. For example, in Jean Renoir's *Grand Illusion*, Erich von Stroheim plays the part of a German commandant with a brace under his chin, a lame leg, a body scarred by burns, and a back injury which requires that he wear a steel corset. While this enumeration suggests a severely disabled man, we do not perceive the commandant as handicapped, because our tacit social grammar responds to his character, his job, and the period during which the film is set so as to make his disabilities recede into the background.

To begin with, the movie is set during wartime, and during war our tacit definitions of disability are relaxed. We adopt a saner approach. What counts is not so much how a man looks (within limits) but whether he can still function. This German officer is perfectly capable of discharging the duties of his assignment behind the lines.

In addition, the social identity of the character von Stroheim plays helps to block our tendency to see him as handicapped. An old Prussian aristocrat with a spartan sense of morality and honor, his fidelity to the symbols of his social position—fastidious appearance, perfect manners, a deliberate cultivation of an aesthetic sense—makes it impossible for us not to regard the man as a social adult. Finally—and perhaps most important—his military duties as commandant of a prisoner-of-war directly conflict with the attribution of social powerlessness which stands at the core of able-bodied society's definition of handicap. This technically disabled officer controls the lives of hundreds of able-bodied prisoners.

Similar transformations in our conventional perceptions of particular disabilities occur when the bearer is a movie villain: one of those real-world deviants who are granted a conditional legitimacy in our fantasies, provided, of course, they are defeated in the end. Here too even severely incapacitating handicaps can signal that, far from being a pitiful social incompetent, the villain is usually resourceful and cunning. Hence the false arm of Dr. No in Ian Fleming's James Bond thriller, *Dr. No* or the Smersh factorum in Fleming's *From Russia With Love*, a thug with a hook on his arm which can cut through metal and glass. Neither do the cluster of disabilities that afflict Dr. Strangelove in Stanley Kubrick's film of that

name—an arm not fully under his control, and partial paralysis which results in his being pushed about in a wheelchair and wearing braces on his legs—cause us to view this president's advisor as handicapped, for all of these villains are highly effective within their special roles.

Each of these examples of "positive" handicaps represents a kind of gift of social convention, a physical trait which, in certain settings and for certain social roles, enhances, or at least does not actively undermine, the individual's claim to be taken seriously as a social being. It is the magnitude of this gift that commands our attention. In contrast, the racist's perception of a black individual as a member of the "Negro race" remains unchanged regardless of whether the black is perceived as a deviant (e.g., a Nat Turner) or as a loyal and capable house servant. However, there is no such thing as a "good" handicap. In those rare instances in which the able-bodied world's social grammar decrees that, for a certain role in a certain setting, a disability is not socially incapacitating, the person is simply perceived as not suffering from a condition: he is permitted to pass over into the world of social normals.

For most handicapped individuals, the rules of the able-bodied world's tacit social grammar work against them. In nearly all cases, the cripple, the blind man, even the adult who admits to a reading disability must overcome the world's working hypothesis that, until proven otherwise, the handicap renders the individual incapable of fulfilling the social roles expected of able-bodied individuals of similar age, sex, and social background. Overcoming this presumption of inferiority requires a sociological tour de force. Because the attributes "successful" (excelling in one's social role) and "handicapped" are mutually incompatible, the able-bodied world finds it almost impossible to perceive of a successful individual as also handicapped. But for the person with a handicap this contradiction also provides a social loophole which, in rare circumstances, he can exploit. Defined by society as a conspicuous failure, the disabled person can prove that he is the exception to the rule if he can achieve a conspicuous success in some area of life.

How this success affects the way disabled persons are remembered demonstrates dramatically the arbitrary way in which the able-bodied world perceives of handicaps as biological conditions. We do not think of Franklin D. Roosevelt as a great crippled president; we think of him as a great president who, among many other things, happened to be crippled. Nor do we customarily think of John F. Kennedy as a handicapped president cut down before he could fulfill his promise. Yet he suffered from Addison's disease, a chronic illness that qualifies its bearer to carry the handicapped label. And while both Alexander the Great and Julius Ceasar were epileptics, it takes Jose Luis Borges (himself blind but not considered handicapped) to remind us that in Caesar's case, his handicap changed the course of history.\*

Nor do we remember above all that Byron had a club foot and Pope curvature of the spine. Elizabeth Barrett Browning was a paraplegic. Milton was blind when he wrote *Paradise Lost*, Beethoven deaf when he wrote the Ninth Symphony; Nietzche was a syphilitic, Doestoevsky an epileptic. Numerous poets from Keats on have been tubercular. Edison was deaf, and Freud spent the last sixteen years of his life wearing a prosthesis on his jaw. To speak of these men and women as handicapped seems a contradiction in terms. It seems so, we believe, because success means that a chronologically adult individual can carry out certain adult functions so well that his inability to perform other adult functions is judged irrelevant.

Again, note the contrast with society's traditional racist perceptions. Merely to mention such individuals as Paul Robeson, Jackie Robinson, and James Baldwin is to signal the difference between being perceived as the member of a social group, however stigmatized the group may be, and being perceived as the victim of a condition that defines one as incapable—until proven otherwise—of fulfilling any positive role in normal society. Because Paul Robeson or James Baldwin cannot escape their racial

<sup>\*</sup> While swimming in the Rhine, Caesar had a seizure and nearly drowned. Only rescue by a soldier from shore saved his life, and as a result of the incident, Caesar decided not to mount a major invasion of what is now Germany.

identification, their conspicuous success works to discredit traditionally demeaning stereotypes about blacks. But in the past at least, the example of the successful disabled person has not similarly conflicted with beliefs about the abilities of handicapped people in general. Instead, the successful person has been perceived as in effect escaping from his condiction. He has not challenged our belief that handicapped people are socially incompetent as a rule. Rather he has persuaded us that he is an exception to that rule, the one man in a thousand who has overcome the incredible odds of his liability and has achieved a positive social identity.

If a similar state of affairs prevailed in race relations, every black would "escape" the category of black the moment he achieved conspicuous success. The class of black individuals would, by definition, always consist of individuals who were social failures or only capable of the modest social roles traditionally accorded blacks in American society.\* While this analogy may seem extreme, it not only captures the logic of lay society's traditional idea of disability, but also represents the operational definition of disability that has been employed in nearly all government surveys of the general demographic characteristics of disabled adults. Virtually all surveys of the employment of disabled adults have traditionally excluded from their count any blind man, cripple, or other handicapped person who does not describe himself as economically disabled by his handicap—that is any disabled person whose success has allowed him to escape even official recognition of his condition.

All of these examples illustrate how our apparently objective perception of handicaps as socially incapacitating biological conditions are the products of a prior—and unconscious—social construction. Only when our tacit social grammar decrees that the disability is a stigma of deviance do we see a handicapping condition. But the moment that grammar decrees otherwise, either because of conspicuous success or because of some combination of social role and setting, we cease to perceive a handicapping condition. Thus, it is not the biological characteristics of the disability *per se* that determine our perception of it, for this can be overcome, as we have seen. Far from being a response to an unalterable biological fact, our perception of a handicap nearly always reflects the way our social grammar treats normal social function and the possession of a handicap as mutually exclusive attributes. No wonder, then, that we find it so natural to continue to apply the social pathology model to the handicapped child. That paradigm confirms our culture's perception of disabilities as socially incapacitating kinds of deviance, and logically suggests a strategy for dealing with this kind of deviance in the most humane and moral fashion possible.

### Consequences for Special Education

Even today, during a period of unprecedented advance, special education pays a heavy price for its exclusive reliance on the social pathologist's analysis of the handicapped child's needs. We deplore the stigma and discrimination that the handicapped person faces in childhood and adulthood, yet we do not explore the adjustments these special socialization experiences require in the design of early intervention strategies, of strategies for older children, and in the advice we provide the handicapped child's parents. No other child in America can experience such extreme social contrasts in a single day, let alone over the course of a childhood: love, understanding, and stimulation at home, intense stigma in the classroom, and, from all too many adults, the tacit message that society's concept of disability is indeed correct, that the child is nothing more than his condition. No other group of disadvantaged children contains so many children who are physically different from their parents and sociologically different as well. Nor does any other group of children contain so many individuals who, because of the physical

<sup>\*</sup> Something like this may be the case in Brazil where social status appears to significantly alter perceptions of race membership and where, as the Brazilian saying goes, "money whitens."

limitations and social stigma they face, have such powerful incentives for channeling their best mental and emotional energies into learning to manipulate the rules of social interaction to their own advantage. These sociological facts cry out for integration into a broadly based educational strategy for the handicapped child and his parents.

Let me emphasize that I am calling for an integration that would join the best elements of the traditional paradigm with those insights into the role of social context that have been gained by workers in the field of minority education. For while concerning minority education, the perspectives of the social pathologist and the civil rights advocate are often opposed, they nicely complement each other when applied to the far more complex family ofeducational problems posed by disability. The social pathology model plays a valuable role in special education whenever consideration of the medical aspects of the child's disability is appropriate. It is also useful as a quide to some of the most immediate obstacles to the severely handicapped child's intellectual and social growth—the barriers to information gathering, data interpretation, social communication, and self expression that stem from biological limitations. The model encourages us to do everything possible, for example, to help the blind child compensate for his lack of visual inputs, perhaps by providing him with compensatory auditory and tactile stimulation. It urges us to compensate as much as possible for the retarded child's slower mental development, possibly by exposing him to an array of enrichment experiences or by giving him intensive training in discrete skills. Similarly, the model directs our attention to finding ways to compensate for the cerebral palsied infant's poor motor coordination—to do whatever we can to meet his developmental need for interaction with the environment, in the face of a diminished ability to actively manipulate and explore the physical and social world.

However, when it comes to suggesting specific strategies for aiding the handicapped child's development, the social pathology model is highly unsatisfactory, and it must be supplemented by a perspective like that useful in understanding minority group problems. The basic difficulty is that existing theories of infant and child development uncritically assume that all children, regardless of temperament, cultural background, or social experience, pass through essentially the same stages of development. However, no theory—not even Piagetian cognitive theory—can provide convincing support for this claim. Still less has any developmental approach seriously confronted the special theoretical challenges posed by the handicapped child, whose pathways of optimal development may differ from able-bodied norms because of his physical or mental differences, his often extraordinarily complex socialization experiences, or some combination of these factors. Because it rigidly imitates medical modes of explanation, the social pathology model rules out in advance any consideration of these issues. Indeed, so powerful is the paradigm's influence, it prevents most educators from even perceiving that these problems pose legitimate questions for research, let alone that they are of the highest practical importance.

Up to now, even the boldest innovators in special education have taken for granted the existence of universal norms of child development, norms that hold for handicapped children as well as for the able bodied. They have ignored the possibility that some handicapped children may develop according to a healthy logic of their own. Yet given our present understanding of child development, this hypothesis must be treated as seriously as the conventional notion that all children move through the same developmental stages, pass through these stages in the same invariable sequence, and that all major deviations from age specific developmental norms represent pathological aberrations requiring compensatory intervention.

The widespread acceptance of able-bodied norms for child development casts a long shadow over the many reforms now underway in the education of handicapped children, and it is likely that present day developmental criteria discriminate against children with handicaps. Forestalling this possibility requires more than general exhortations about the importance of adopting a developmental perspective suited to special education, although such efforts are important in a field that traditionally has treated

many handicapped children as small patients rather than growing children. Painstaking basic research is required, research that tests the applicability to handicapped children of virtually every developmental theory, from Piagetian cognitive theory to Kohlbergian moral theory to the major theories of personality development. This research will be costly and time consuming. It will have to be carried out for each major disability group, and it will have to take into account a host of complex social variables, not the least of which are ethnic group, social class, age, and gender. Yet unless this research is conducted, we shall be basing our intervention strategies on mere supposition rather than on the firm result of empirical investigation, and the issue is far too important to be decided by fiat.

The social pathology model is equally unsatisfactory as a tool for constructing the psychometric and clinical tests that we need to assess the handicapped child's development. Whether the test is one of intellectual aptitude or social maturity, our present diagnostic armamentorium either imposes ablebodied norms on the handicapped child or, as in the case of intelligence tests for the blind and deaf, applies to a disabled population testing methodologies of dubious value for even able-bodied children, let alone children with handicaps. Lacking valid ways to assess the handicapped child's growth, it is hardly surprising that it is difficult to demonstrate any consistent long term benefits from early intervention programs in the child's academic performance or general development. Because of their reliance on norms for the able bodied, conventional assessment procedures may look at the wrong aspects of the child's behavior, and they may misinterpret the significance of the behavior that they do examine. Here too, the social pathologist's assumption that able-bodied norms do not discriminate against handicapped children must be subjected to careful experimental scrutiny.

Many of the most important advantages in using the minority group model involve the handicapped child's parents. They need an overview of the relative importance of biological and social factors which limit their child as part of a complete diagnosis of the effects of his handicap. Yet relatively few parents are likely to obtain this information from physicians, who, perhaps understandably, tend to emphasize the biological dimension of disability. And most parents are just coming to terms with discovering their child's handicap when they first meet with professionals to plan a special education program. For many of these parents, a minority group analysis can be far more than just another kind of information received from experts. It can help them come to terms with their child and with themselves. It can provide perspective on their guilt and anxiety, and it can suggest appropriate ways of redirecting their anger towards a society whose architecture, transportation systems, hiring practices, and prejudice often pose far greater barriers to their child's development and social independence than the physical or mental limitations connected with his disability.

A social analysis is especially important becuase most parents with handicapped children are themselves able-bodied. As a result they lack the first-hand experience of the discrimination and prejudice that will confront their child and that minority group parents automatically possess. Lacking a shared sociological destiny with the child, some parents have difficulty recognizing the many specifically social and political hazards that await the child during childhood and adulthood, and they may underestimate their child's immense stake in the success of the disability civil rights movement.

Psychologists generally agree that mother-child interactions play a crucial role in fostering the child's development in every area of life. Indeed, some of the most effective early-intervention programs—such as the one carried out by Phyllis Levenstein and her associates at the Verbal Interaction Project in Freeport, Long Island—have concentrated upon suggesting new ways for the mother to interact with her young child. That disability frequently impedes the normal flow of mother-child interaction is a common clinical observation. But how can one remove some of the barriers that can come between the mother and her handicapped child? Possibly a greater emphasis upon the social aspects of disability also may help to clarify these difficult questions. This is suggested by the findings of Therese Gouin-Decarie and Monique O'Neil concerning Canadian children born deformed because their mothers had taken the drug thalidomide:

... This problem is not primarily a medical problem. It is first and foremost, a social problem. Let us but mention a single indication of this fact. The initial reactions of mothers of Thalidomide children, their perception of their child's handicap (which, moreover, continued to evolve over time) and their emotional relationship with their child was always a function of the social norms of the surrounding social milieu. In every case the seriousness of the malformation only played a secondary role. <sup>16</sup>

But the minority group model is not only best suited to exploring this possibility in a systematic fashion. It also reminds the educator that the parent is an adult whose decisions concerning the child must outweigh the professional's preferences in all but the most extreme instances of parental misconduct. As a consequence, it can serve as a useful corrective to the tendency of school personnel and other professionals to explain away the parent's attempts to have the last word about the child as symptoms of psychopathology. Again, an observation of Gouin-Decarie and O'Neil is apposite:

Finally let us note in conclusion that the categories so often used in the work dealing with handicapped children (acceptance, rejection, over-protection, guilt feelings, etc.) appear to us to be neither adequate nor functional. The phenomena in question are so tightly intertwined with the sociological context that the methods of analysis of social psychology (especially those used to treat the problems of minorities) appear to be far better able to do justice to the reality [of the child's handicap] than the methods of analysis of clinical psychology . .. <sup>17</sup>

#### Towards Reunion in Education

If we are to resolve the two cultures problem in education, special education must profit from the experience of minority education. Something of the old culture—the field's traditional reliance on the social pathology model-will have to be retained, because only a medical model can do justice to the complex biological dimensions of disability. But a new awareness of the minority group characteristics of the handicapped is also required. The professional needs to draw on this awareness every time he explores with the parents the significance of their child's handicap in his education, for in a society that treats disabled children and adults as second class citizens, prejudice and discrimination have powerful effects during development. The minority group paradigm, in many other ways, can play a crucial role in improving the quality of special educational services provided to handicapped children and their parents. It can ensure that the educator devotes as much effort to understanding the sociological situation behind the child's behavior as he does to helping the child compensate for the physical limitations of his disability. It can alert the inexperienced teacher to the ease with which culturally conditioned beliefs about the nature of disability can be confused with true limitations of body and mind. It can stimulate better research into the developmental psychology of handicapped children, and it can help to foster the kind of applied research required to improve our ability to assess the child's developmental needs, to chart his progress, and to tailor individualized instructional programs to his specific strengths and weaknesses. Not least, the perspective afforded by minority education calls attention to what will probably be the central theoretical issue in special education for many years to come: the possibility that some handicapped children develop according to a healthy logic of their own.

### **Reference Notes**

- <sup>1</sup> For useful overviews, see C. Wright Mills, "The Professional Ideology of the Social Pathologists", in Irving Louis Horowitz, ed. *Power, Politics, and People: The Collected Essays of C. Wright Mills* (New York: Ballantine Books, 1963); Christopher Lasch, *Haven in a Heartless World: The Family Beseiged* (New York: Basic Books, 1977); and John Gliedman and William Roth, *The Unexpected Minority: Handicapped Children in America* (New York: Harcourt Brace Jovanovich, 1980).
  - <sup>2</sup> For a lengthy critique of compensatory strategies see Gliedman and Roth, *The Unexpected Minority*.
- <sup>3</sup> Mario Fantini and Gerald Weinstein, *The Disadvantaged Child: Challenges to Education* (New York: Harper and Row, 1970).
  - Frank Riessman, The Inner-City Child (New York: Harper and Row, 1976).
  - <sup>5</sup> For a research review, see Gliedman and Roth, The Unexpected Minority.
- <sup>6</sup> John U. Ogbu, *Minority Education and Caste: The American System in Cross-Cultural Perspective* (New York: Academic Press, 1978).
- <sup>7</sup> See Lasch, *Haven in a Heartless World.* See also Alison Clarke-Stewart, *Child Care in the Family: A Review of Research and Some Propositions for Policy* (New York: Academic Press, 1977).
- <sup>8</sup> For good overviews, see Kenneth Keniston and the Carnegie Council on Children, *All Our Children: The American Family Under Pressure* (New York: Harcourt Brace Jovanovich, 1977), and Richard H. de Lone, *Small Futures: Inequality, Children, and the Limits of Liberal Social Reform* (New York: Harcourt Brace Jovanovich, 1979).
- <sup>9</sup> Christopher Jencksef al.. Inequality: A Reassessment of the Effect of Family and Schooling in America (New York: Basic Books, 1972), and Christopher Jencks et. al., Who Gets Ahead: The Economic Determinants of Success in America (New York: Basic Books, 1979).
  - <sup>10</sup> This research is reviewed in Gliedman and Roth, *The Unexpected Minority*.
- <sup>11</sup> For more extensive discussions of this point see Gliedman and Roth, *The Unexpected Minority*, and John Gliedman, "The Wheelchair Revolution," *Psychology Today*, 13, August 1979.
  - <sup>12</sup> Kurt Lewin, Resolving Social Conflicts (New York: Harper and Brothers, 1948).
- <sup>13</sup> Southeastern Community College v. Davis, No. 78-711 (U.S. Supreme Court, June 11, 1979). The Supreme Court found no violation of Section 504 of the Rehabilitation Act of 1973 in the college's refusal to admit Francis B. Davis, who had a serious hearing impairment, to its registered nursing program.
  - <sup>14</sup> For a more extensive discussion, see Gliedman and Roth, *The Unexpected Minority*.
- <sup>15</sup> See Gliedman and Roth, *The Unexpected Minority,* for an extensive discussion and full documentation of the points made in this section.
- <sup>16</sup> Therese Gouin-Decarie and Monica O'Neil, "Quelques aspects du developpement cognitif d'enfants souffrant de malformations dues a la thalidomide," *Bulletin de Psychologies*, No. 310, 5-9,1973-1974, pp. 286-303 (author's translation).
  - <sup>17</sup> Gouin-Decarie and O'Neil, pp. 286-303.