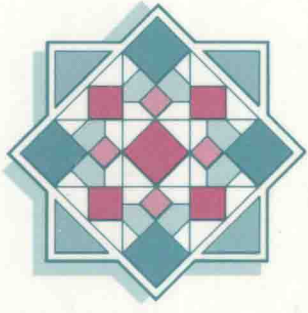
Educating Children with *Multiple Disabilities*

A Transdisciplinary Approach *Second Edition*



Fred P. Orelove
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Second Edition

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Preface

The first edition of this book, published in 1987, was based on the belief that a transdisciplinary model of service delivery has much to offer school-based teams that work with individuals with multiple disabilities. Since then this belief has been strengthened. Many school districts have caring and competent teachers, administrators, and related services staff. In many places, the concept of functional assessment and instruction has gained a solid footing. Moreover, there is increasing commitment to integrated education.

Despite advances in curriculum, instructional technology, and inclusive education, however, we have seen many instances in which professionals feel frustrated, not necessarily by their students, but by their own inability to work together harmoniously and efficiently to do what is best for their students. We do not suggest that the job is a simple one. Children with multiple disabilities present many challenges, and educators and related services personnel must be knowledgeable across many areas, in addition to being creative, dedicated, and tireless, among the many qualities found in any professional working in school programs. We do suggest, however, that the challenges presented by students with multiple disabilities demand that professionals employ a model of services that respects and takes advantage of their different fields of expertise.

Thus, the second edition continues to advocate for a transdisciplinary service delivery model, arguing that the increased presence of children with special health care needs makes this model even more valuable. Indeed, this edition has added two chapters (5 and 6) that examine issues concerning maintaining optimal health, in addition to prevention of and intervention for health care problems in children. Some topics, such as child abuse and HIV infection, are new in this edition. Others, such as seizures and medications, have been updated and revised.

This edition also continues to present a practical array of techniques useful in educating children with multiple disabilities. Therefore, some areas traditionally covered in textbooks for students with severe disabilities (e.g., assessment) are omitted here in favor of rather specialized topics (e.g., mealtime skills) treated in greater detail.

Educating Children with Multiple Disabilities continues to infuse a variety of values into the material in its 13 chapters. We have a strong commitment to family, children, and teamwork. This commitment translates into support for nonaversive medical or behavioral interventions and for integrated school programs. New material on these topics has been added to this edition. The final chapter, on trends and issues, also has been expanded to explore a greater range of current controversial topics.

Despite these additions and updates, this edition retains the basic format of the

original book. Chapter 1 examines teamwork models, specifically focusing on transdisciplinary teams. Chapters 2–6 present basic terminology; information on physical, medical, and sensory characteristics and development; and basic techniques for handling and positioning. Readers are advised to complete these chapters as a basis for appreciating the remainder of the book.

Chapters 7–11 discuss general principles in curriculum and instruction, as well as specific strategies for developing adaptations and for teaching communication, mealtime, and self-care skills. Suggestions are provided within each chapter for working within transdisciplinary teams.

The final two chapters are issue-oriented, rather than focusing on intervention. Chapter 12 deals with issues related to understanding and working with families. Chapter 13 discusses current issues, such as guidelines for treating newborns with disabilities and individuals in a persistent vegetative state, and presents a rationale and strategies for establishing integrated school programs.

This edition continues to avoid using jargon; where this was not possible or desirable, we have tried to define or describe terms within the text. We hope that this approach will appeal to a broad readership, spanning a wide variety of disciplines and laypeople.

The ultimate test for this book, of course, is whether it contributes to the information and skills of the reader and whether, in turn, this translates into improved education and services for children. We hope this book contributes to these outcomes at least in part, and we wish all readers the very best success in meeting their own needs and those of the children with whom they work and whom they love and care for.

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We also would like to thank the many students, professionals, and reviewers who responded to the first edition of this book. The reinforcement gave us the impetus to work on a second edition, and the critical feedback has, we believe, made for a better book.

A special "thank you" to Melissa Behm, Vice President, and Natalie Tyler, Production Editor, Paul H. Brookes Publishing Company, for their expertise and, especially, their unflagging support and understanding throughout the development and production of the book.

Finally, each of us owes a great debt to those families, students with disabilities, and team members who have provided knowledge, support, and training opportunities that were truly transdisciplinary and that have resulted in our personal and professional growth. We hope that this book reflects at least some of their inspiration and strength.

To our children
Emma and Samuel Orelove
and
Ananta, Constance, and David Sobsey,
with love.

Contents

Chapter 1

Designing Transdisciplinary Services

This chapter focuses on a system of providing services to individuals with multiple disabilities that has proved successful—the transdisciplinary model. Major features of the model are discussed, with particular emphasis given to team decision-making and implications for providing school-based services. Problems in implementing a transdisciplinary model are also presented. This chapter begins, however, by: 1) discussing the needs of students with multiple disabilities, 2) surveying professionals who work with the students, and 3) describing educational teaming approaches.

NEEDS OF CHILDREN WITH MULTIPLE DISABILITIES

As used throughout the book, the phrase "children with multiple disabilities" refers to individuals with: 1) severe to profound mental retardation, and 2) one or more significant motor or sensory impairments and/or special health care needs. These individuals are an important subgroup of students commonly referred to as "severely handicapped" by the federal government and in the professional special education literature. Because of their combinations of physical, medical, educational, and social/emotional needs, children with multiple disabilities present an immense challenge to professionals responsible for their education. The remainder of this section highlights the varied needs these children bring to the educational setting.

Physical and Medical Needs

The increased frequency of physical and medical problems in individuals with severe disabilities has been well documented (e.g., Mulligan-Ault, Guess,

Struth, & Thompson, 1988; Thompson & Guess, 1989). Within this larger group, the individual with multiple disabilities almost always presents two or more of the characteristics described below.

Restriction of Movement The single largest identifiable organic cause of multiple disabilities is cerebral palsy. The hallmark of cerebral palsy (see Chapter 2) is disordered movement and posture. Because of the damage to or improper development of the brain that causes cerebral palsy, the vast majority of children with multiple disabilities are unable to walk. Many of these children, in fact, have voluntary movement that is limited both quantitatively and qualitatively, making it difficult or impossible for them to move freely about their environment or to change their positions (Campbell, 1987). Proper positioning and handling (see Chapter 3) are vitally important in facilitating proper movement and posture and in preventing secondary deformities.

Skeletal Deformities Many children with multiple disabilities are born with or, more commonly, develop physical disabilities secondary to their primary disability as a result of brain damage (Campbell, 1989). Such problems typically include: 1) scoliosis (curvature of the spine) and other back and spinal disorders, 2) contractures (permanent shortening of muscles and tendons), 3) partial or total dislocation of the hips, and 4) disorders of the foot and ankle. These and other problems within the bones, joints and connecting muscles, tendons, and ligaments not only cause discomfort and interfere with movement, but actually can be life-threatening in severe cases.

Sensory Disorders In addition to experiencing difficulty in movement, students considered to have multiple disabilities are more likely than other persons with severe handicaps to have vision and hearing loss. While the number of children considered to be truly "deaf-blind" is relatively small (Fredericks & Baldwin, 1987), it is not uncommon to find children with one or more impaired sensory systems.

Seizure Disorders As is examined further in Chapter 6, almost one-third of individuals with severe disabilities experience seizures (Spooner & Dykes, 1982). Although seizures frequently are controlled with medication, many students with multiple disabilities present a challenge to the physician trying to regulate seizure activity. Moreover, the medication itself can result in adverse physiological and behavioral side effects.

Lung and Breathing Control Largely because of their muscle and skeletal disorders, children with multiple disabilities are at greater risk of incurring breathing and lung problems. Such problems often occur during mealtimes, when the student may have trouble handling food in the mouth and swallowing. Other children may accumulate excessive amounts of mucus or other secretions in the airway and lungs, obstructing normal breathing. Still others may have an underdeveloped respiratory system, requiring dependence on mechanical respirators.

Other Medical Problems In general, children with multiple disabilities

are less healthy than other children (Thompson & Guess, 1989). Their problems range from ear and bladder infections to skin ulcers and constipation. They are more likely to take a variety of medications, from antibiotics to anticonvulsants to stool softeners. Certainly, proper attention to such matters as physical activity, diet, positioning, and medical referrals can reduce students' discomfort, enhance their education, and improve the overall quality, if not length, of their lives. (Chapter 5 discusses health care issues in greater detail.)

Educational Needs

Many of the educational needs of students with multiple disabilities are similar to those of any individual with severe handicaps. The loss of or decrease in function within sensory or motor systems, however, makes more urgent the demand for organized, systematic instruction and management.

Appropriate Positioning and Handling It was suggested earlier that good positioning and handling of children with multiple disabilities could reduce their pain and prevent further complications of their structural impairments. Because of their possible lack of voluntary control and sensory impairments, it is equally important that these students be positioned to allow them to see, to hear, to reach, and to otherwise become engaged with individuals and materials. Appropriate positioning is essential for efficient movement in all activities.

Appropriate Methods of Communication Most children with multiple disabilities are unable to communicate through speech. Almost all, however, can express basic wants and needs if given appropriate training and if staff are attuned to students' individual behaviors and personalities. Communication is a basic need of any human being, and it certainly is critical for those individuals who are physically unable to retrieve or seek what they want, including food, drink, and the bathroom.

Means to Choose Because children with severe disabilities usually cannot say what they want or make the movements necessary to reach it, adults often choose for them. There has been an increasing emphasis on facilitating choice for all learners (Guess & Siegel-Causey, 1985) as an essential catalyst for reducing dependence and the sense of "learned helplessness" that can accrue from lack of control over the environment (Campbell, 1989).

Other Educational Needs Some of the medical and physical characteristics of children with severe disabilities described earlier impinge on their educational programs. Examples include: 1) the child with seizures who cannot go swimming, 2) the child on anticonvulsant medication who sleeps half the day, 3) the student whose lungs must be cleared of secretions before he or she eats lunch, and 4) the student in the body cast to correct scoliosis who needs community instruction. The challenge for the team is to determine how to work with and around the students' medical and physical needs to provide an appropriate education, rather than turning the school day into an extended therapy

session. Therapy and specialized health care procedures should *facilitate*, not replace, instruction.

Social/Emotional Needs

Children with multiple disabilities are more than conglomerations of educational and medical problems. They are, first of all, children; they are the sons and daughters of parents who care about their well-being. Like all other individuals, children with disabilities need affection and attention. They should never become mere passive recipients of services. If you can imagine what it would be like to be trapped physically by your own body and to be unable to tell anyone how you felt or what you wanted, then you can begin to understand how you might interpret and respond to a child's crying or "noncompliant" behavior.

Professionals, no matter how skillful or caring, are unable to provide all of the emotional support children need. Children with multiple disabilities need opportunities to interact with, and, especially, to develop friendships with other children (Forest & Lusthaus, 1989; Strully & Strully, 1989). Professionals can, and should, facilitate those opportunities, not as a "frill," but as an essential part of a student's educational and emotional life.

IMPORTANCE OF A VARIETY OF DISCIPLINES

It is probably evident from the preceding description of the needs of children with multiple disabilities that a range of expertise is necessary in educating these children. Skills are needed from fields as diverse as special education, nursing, social work, and physical therapy (and sometimes from fields less traditionally associated with education, such as rehabilitation engineering, dietetics, and respiratory therapy). It should be clear that no one or two individuals can possibly meet all the needs that these children have. Whitehouse recognized the need for interdependence among professionals as far back as 1951:

> We must understand that there are no discrete categories of scientific endeavors. Professions are only cross-sections of the over-all continuum of human thought. Fundamentally no treatment is medical, social, psychological, or vocational—all treatment is total. Yet members of each profession within the narrowness of their own training and experience will attempt to treat the whole person. Obviously, no one profession can do this adequately under present conditions. (p. 45)

Although Whitehouse was speaking of the rehabilitation field, his words are equally true today for educating students with multiple disabilities. The remainder of this section briefly explores the nature of the disciplines that work with these children.

This book emphasizes the importance for persons representing different disciplines to work together and to share some of their skills. It may seem odd, therefore, to parcel out descriptions of individual fields. Nevertheless, it is essential to recognize that different professions do have distinct training back-

grounds, philosophical and theoretical approaches, experiences, and specialized skills. Moreover, the success of an educational team depends in part on the competence of the individual team members and on a mutual understanding and respect for individuals' skills and knowledge.

The roles of those persons who are typically part of the school-based educational team are described first. The roles of other valuable professionals found less commonly within the school setting are then described.

Persons on Educational Teams

Special Educator Gaylord-Ross and Holvoet (1985) summarized five major roles of a teacher of students with severe handicaps: 1) educator of learners with severe handicaps, 2) liaison between the parents and school district, 3) supervisor and teacher of paraprofessionals, 4) member and coordinator of a team of professionals who will work with the students, and 5) advocate for the students. The specific skills required in each of those roles are too numerous to be described here. As the profession continues to define itself, and to reach a consensus on best practices, the teacher's role becomes more complex, encompassing a broad spectrum of concerns. More on the special educator's role, in terms of being part of the team, of particular interest here, appears in the "Transdisciplinary Model of Delivering Services" section of this chapter.

Associate Sometimes referred to as a teacher's aide or a paraprofessional, the associate in a classroom for students with multiple disabilities frequently plays a vital role in the daily functioning in the classroom. In addition to helping to conduct instructional activities, the associate often is heavily involved in handling and positioning students and in providing for their physical health and comfort.

Physical Therapist The physical therapist is trained to prescribe and supervise the following types of activities: gross motor activity and weight-bearing, positioning, range of motion, relaxation, stimulation, postural drainage, and other physical manipulation and exercise procedures (Fraser, Hensinger, & Phelps, 1987). An essential member of the team, the physical therapist often provides information and direct instruction to team members on appropriate positioning and handling and on the use and construction of adaptive equipment (Copeland & Kimmel, 1989).

Occupational Therapist Occupational therapy generally is oriented toward the development and maintenance of functions and skills necessary for daily living. Accordingly, occupational therapists in school programs attempt to prevent deterioration of those functions and help remediate deficits that impair performance (Lansing & Carlsen, 1977). These professionals often have special expertise in prescribing and constructing adaptive devices (especially for fine motor activities) and in conducting mealtime activities for individuals with physical involvement.

Communication Therapist Because a large percentage of students with

multiple disabilities not only are nonverbal, but also lack any systematic means of communicating, language or communication therapists play a specialized and important role. They are responsible for assessing and training students directly on methods of communicating, teaching other staff these methods, and monitoring students' communication progress (Stremel-Campbell, 1977). Communication therapists also may consult with audiologists when an individual experiences hearing loss. Finally, because of the anatomical and functional relationship between eating and speech, many therapists are trained in assessing and facilitating mealtime skills.

Family Member Although not typically present in the school on a regular basis, a parent or other family member should be recognized as a central part of an educational team. Apart from parents' rights to participate in assessment and planning, it simply makes good sense to invite their participation as individuals with the most knowledge of their child and the greatest stake in the child's future. The degree to which individual parents are able to or choose to participate will vary. (Chapter 12 examines this and other issues concerning families in greater detail.)

Professionals Who Serve Students with Multiple Disabilities Usually Outside of the School Setting

The daily contact that individuals described in this section have with children varies with the size and organization of the school division and the degree of specialization of the professions. In some cases, involvement of professionals (e.g., social worker, psychologist, nurse) may be extensive and ongoing. Other persons (e.g., audiologist, dietitian) may be consulted on an as-needed basis.

Psychologist The role most often associated with school psychologists is that of evaluator of a child's intellectual and adaptive abilities. The child with multiple disabilities, however, presents significant obstacles to traditional psychometric instruments and procedures. Thus, psychologists in some cases have taken increasingly more visible roles in designing strategies for reducing excess behaviors. They could be particularly instrumental in working with teaching staff to develop alternative, long-term adaptive behaviors in students who lack key social or self-regulatory skills (Meyer & Evans, 1989). Additionally, psychologists can be helpful in working with families (and professionals) in times of stress and grief, such as at the death of a child.

Social Worker School social workers serve as facilitators of access to services and advocates for the child and family (West, 1978). They are trained in communicating with and gaining access to community resources. Some programs employ individuals with specialized training to coordinate services between school and home and community.

Administrator Administrators include those persons responsible for policy, decision-making, and implementation in areas such as placement, tran-

sition, curriculum development, transportation, related services, equipment, and scheduling. The administrator is also responsible for ensuring compliance with local, state, and federal regulations. It is clear that the administrator (e.g., principal, program director, special education supervisor) is highly influential in the quality of students' educational programs.

Vision Specialist A large number of children with multiple disabilities experience loss in visual function; therefore, the vision specialist has come to play a more important role. These professionals are equipped to assess students' vision, and to adapt activities and materials to make full use of each child's residual vision. The orientation and mobility specialist is a professional with specialized training in vision in relation to mobility across environments. Along with the communication, occupational, and physical therapists, the vision specialist provides vital information related to alternative communication systems.

Audiologist The audiologist is trained to identify type and degree of hearing loss and to provide guidelines on equipment and procedures to help students compensate for their impairment (Gaylord-Ross & Holvoet, 1985). The audiologist who works with individuals who experience a combination of cognitive, physical, and sensory impairments must be knowledgeable about a variety of alternative, nontraditional assessment strategies.

Nurse The school nurse is often the best source of readily available information regarding the physical well-being of children with multiple disabilities. This information covers a range of needs from seizure control to medication to emergency first aid. Nurses also are invaluable for helping students (and teaching staff) who require specialized procedures such as catheterization, suctioning, and nasogastric tube feeding, as well as routine procedures, such as skin care and cast care (cf. Graff, Ault, Guess, Taylor, & Thompson, 1990 and Chapter 5 of this book).

Nutritionist/Dietitian Nutritionists and dietitians can help with increasing students' caloric intake, minimizing the side effects and maximizing the effectiveness of medications, and designing special diets for individuals with specific food allergies or health care needs (Crump, 1987; Worthington, Pipes, & Trahms, 1978). Unfortunately, nutritionists and dietitians are not included on most school teams, which is probably attributable to a general lack of information about their skills and about the relevance of diet and nutrition to the physical and instructional needs of students (McCamman & Rues, 1990).

Physician/Pediatrician The physician can help the school team by revising effects of medications and screening for and treating common medical problems. This professional is most effective when engaged in ongoing communication with school staff.

Other Medical Specialists School staff and parents are also likely to need the services of one or more of the following specialists: dentist (teeth),