

**INTERVENTION WITH INFANTS
AND TODDLERS**

INTERVENTION WITH INFANTS AND TODDLERS

The Law, the Participants, and the Process

By

JOYCE S. TAYLOR, PH.D.

*Professor Emerita
Southern Illinois University at Edwardsville*

With Contributions by

Lynn Taylor Clark, M.A.



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This manuscript is dedicated to the memory of my Golden Retriever Therapy Girl, "Katie", who was with me at the beginning but left to join my other four-footed friends in a place known to animal lovers as the Rainbow Bridge. She added so much to the happiness of so many and is missed by all whose lives she touched.

FOREWORD

As a parent of a child with a disability and an early intervention provider, I am honored that the author has asked me to write this for her book.

Early intervention for my daughter, Sarah, involved researching what was available and making phone calls to the *only two* early intervention (EI) programs that existed 15 years ago. Sarah received developmental therapy through the early intervention program which cost me nothing at that time. That is all they offered. Sarah's developmental therapist supplied me with developmentally appropriate activities to do with Sarah on a daily basis and she was there to support me emotionally.

I had Sarah evaluated for physical and occupational therapy later on and was told she did not need those services. If she had needed them, I would have had to go to the only pediatric therapy provider there was at the time, located in a hospital. When Sarah was 17 months of age, I inquired about speech therapy services. We received this service outside of the early intervention program. My husband and I had to pay out of pocket for speech therapy because our insurance did not cover it.

The early intervention system has evolved in the last 15 years. There is one phone number to call to make an early intervention referral and that number connects the parents to the point of entry for the services to begin. Each family is assigned a service coordinator who walks them through the process and assists the families in choosing appropriate therapists for their child. Therapies may include developmental, occupational, physical, counseling, nutrition, nursing, and speech. The possibility for multiple therapies has grown since my daughter participated in the program.

The point of entry, known as Child and Family Connections, was put into place to make this process easier for families and other persons who make referrals on behalf of families. Service coordinators assist with other community resource referrals that may be pertinent for families at any given time. The system today is monitored more effectively by the Child and Family Connections staff as well as by Department of Human Services

(DHS), who oversees the early intervention program. Families are required to pay a family fee and have insurance billed for certain therapies if they qualify. Even if this process had been in place 15 years ago, it would have been worth it to possibly get Sarah more therapy if she had needed it.

There are many more options available to families today, but we have a long way to go to make it a perfect world. Many people still do not know about early intervention or what it entails. Some physicians do not believe in early intervention; therefore, children who could benefit from the services are not referred and the parents are not informed.

I do not know what I would have done if Sarah had not had early intervention. I learned so much about development for her and how to assist her in achieving goals in her early years. I met families who had children with disabilities and gained knowledge and support through them. Sarah's developmental therapist was a great source of support and a wealth of information for me. Early intervention is available to provide infants and toddlers with developmental disabilities and delays and their families the assistance they need to reach developmental milestones that are necessary to take the next steps in life.

Lisa McGlothlin, Parent

PREFACE

My career as a speech-language pathologist (SLP) spanned three and one half decades and, by all rights, was over in 1996. Prior to that time, I had spent five years as a school-based SLP (we were called speech correctionists then), followed by another five years in “Ph.D. school,” and then 27 years as a university professor and administrator. When I retired, I was doing a little consulting but otherwise devoted myself to being a farm owner. Then, the State sent out a request for SLPs to participate in early intervention and I responded with the required materials. This was strange because I considered myself retired, and also since my areas of interest and so-called expertise did not include the birth-to-three population. At any rate, I became a private provider and learned how little I really knew about the laws governing early intervention, the contributions of my colleagues in related professions, and the nuances of service delivery. Having paid my dues, so to speak, I decided to share what I had learned with others who may be contemplating work with toddlers. The intent is to reach both students in training as well as persons like me whose professional experience did not include extensive intervention with these little ones. I hope that I have been successful in providing the necessary information.

Joyce S. Taylor

INTRODUCTION

Too often, it seems, articles are written, books are published, lectures are given, and issues are debated with each individual or group of individuals viewing the topic from a single perspective: their own. In fact, at the outset, the working title of this manuscript was *Early Intervention: The Perspectives of a Speech-Language Pathologist*. And then the irony struck me. I served as a member of a quality enhancement team involved in looking at the services provided to infants and toddlers in a state early intervention region; the chair of the team was a developmental pediatrician. As we discuss the various toddlers, their diagnoses, and the reports and recommendations of the therapists, she frequently comments that each service provider may be failing to see the “big picture.” As a speech-language pathologist, for example, I may recommend that a toddler with Down Syndrome is most in need of language intervention and request that he be seen once or twice weekly. On the other hand, the physical therapist may feel that the child’s lack of mobility is a priority, while the occupational therapist determines that the toddler’s disabilities are preventing him from functioning as a child; both of these professionals may recommend therapy on a weekly basis, as well. And then, the developmental therapist notes that the child’s parents seem confused in relating to their toddler with a disability and wishes to see the child and his family. (Pity the poor case manager whose responsibility it is to coordinate these services!) Is any one of these professionals wrong? Does the toddler require assistance from everyone? Most likely, they are not wrong and, yes, the child would benefit from their individual expertise. The problem may be, however, that each professional is viewing the child from his or her own perspective and missing the “big picture.” We must be able to respect the toddler’s right to have time to be just that: a toddler; we must also allow parents to parent. By understanding the goals and strategies of each professional we may be able to generate common goals for the toddler that complement each other while reducing the amount of time we impose upon the family.

How can we achieve this goal that some call “teaming?” Perhaps first, we must remember that we all have the same goal and we are all directed by the same guidelines. The goal is to assist the toddler in reaching his potential and

to support the family in caring for the child and promoting his development, and empowering them as advocates for their toddler. I think that all providers accept and understand the goals but sometimes the intent and means become fuzzy. For example, how does IDEA direct early intervention? We know how PL 94-142 came to be; how the people of the Pennsylvania Association for Retarded Children took the Commonwealth to court and were able to draw attention to the ways in which some children with disabilities had been excluded from public education. But, how about PL 99-457? What does Part C of IDEA tell states that they must do to comply? It may not be appealing to all professionals, but it is imperative to understand the law, its intent, and its implications. It is also important to be aware of the ways in which the law has been tested through litigation. These issues are covered first.

Next, legal compliance of several states is reviewed. It would be impractical and probably irrelevant to examine the compliance strategies of all states but the selected states (which will remain unnamed) are considered to be representative. Then, the professional participants in the process of early intervention, including their qualifications, responsibilities, and roles in the team effort, are explored.

Implicit and explicit in the birth-to-three intervention intent is that parents and professionals form partnerships. In order to accomplish this goal, providers need to understand and respect diversity of all types: family structure, family members, and family variations. An unfortunate issue with which interventionists may need to deal is that of child abuse and/or neglect; that topic is included, as well. Although the influences of cultural and socioeconomic influences are considered through this book, specific attention is afforded in Chapter IV. The process of intervention is the same for all providers and included are such responsibilities as the establishment of goals and objectives, reporting styles and requirements, and service delivery options. The complexity of billing receives some attention since those of us in the helping professions are not necessarily known for our facility with numbers.

No book of this sort would be complete without sampling the opinions of others about our ability to work together in the interest of our consumer. Unfortunately, our primary consumers respond best in the form of hugs and kisses (or bites and bruises); therefore, their caregivers' comments are includ-

Nota bene: Two pieces of literary housekeeping are necessary before proceeding. First, as indicated above, this is my third manuscript and some of the material included in the discussion of the law and qualities of the service provider appeared in my previous books. According to Keith R. St. Onge (in personal communication dated simply Flag Day, 2002), noted authority on plagiarism and author of the book, *The Melancholy Anatomy of Plagiarism* (University Press of America, 1988) and an essay entitled "Plagiarism: You Know It When You See It (Really?)" [03-18-02 Historians and History], a simple disclaimer such as this removes the need for self-attribution in this manuscript. I am proud to add that Dr. St. Onge is a former colleague and dear friend.

ed. In addition, there was a need to determine how professionals view each other as team members and anonymous comments are included. Finally, it would be difficult to write a book without including personal experiences if they serve to make a point or bring levity to sometimes grave situations. The experiences are not all mine and are altered enough to protect the innocent who are, of course, the infants, toddlers, and families whom we serve.

Also, in the interest of readability, references to hard copy materials are done in the traditional manner; however, web sites are indicated by topics in the text which correspond in the references at the end of each chapter.

ACKNOWLEDGMENTS

Perhaps the first thanks should go to the wonderful world of technology which allows one to access a wealth of information without the embarrassment of getting lost in the stacks. Pat Traylor of the Illinois Early Childhood Intervention Clearinghouse was the living equivalent of technology; she and her staff maintain current bibliographies of books, articles, and videotapes in all areas of early intervention. All that I had to do was review the bibliographies, fill out an order, and, within days, the friendly UPS person delivered the materials directly to my doorstep. That service was a godsend. My gratitude also to Lynn T. Clark who contributed to this manuscript (specifically Chapters III and IV) as she wrote about family, cultural, and socioeconomic issues from the perspective of a sociologist, to Judy Johnson who shared information on diversity, and Lisa McGlothlin who wrote the Foreword. Major kudos go to Sharon Schaefer who undertook the task of translating my drafts into a manuscript, suggesting clarifications, putting the references into an acceptable package, and getting the whole thing on a diskette. Finally, I am grateful to the caregivers, families, and toddlers who allowed me into their homes and lives, if only for a short period of time.

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INTERVENTION WITH INFANTS AND TODDLERS

Chapter I

FEDERAL LEGISLATION AND STATE COMPLIANCE

Dr. William H. C. Smith founded the Beverly Farm in 1897. Smith, his wife Ellen Blake, and their sons, Groves Blake and Theodore Hammond operated the Beverly Farm Home and School for Nervous and Backward Children. (Alton Board of Trade publication, 1912, as reproduced in the *Alton Telegraph*, November 16, 2002, p. 2) [We have come a long way, but miles remain.]

A. INTRODUCTION

Once upon a time, in a place called Topeka, Kansas, a little black girl named Linda walked one mile to attend an all black school. Her trip took her through a railroad switchyard. Meanwhile, seven blocks from her house, white children attended an all white elementary school. When Linda Brown's father attempted to enroll her in the school closer to her home, his request was denied. Mr. Brown enlisted the assistance of the local branch of the National Association for the Advancement of Colored People (NAACP) and the rest is history. Initially, the United States District Court held in favor of the Board of Education, stating that the schools were separate but equal. However, an eventual appeal and decision from the United States Supreme Court "ruled in favor of the plaintiffs and required the desegregation of schools across America." Specifically, the October, 1954 document ordered the District Court to all action that was necessary "to admit to public schools on a racially nondiscriminatory basis with all deliberate speed the parties to this case."

Fast forward to another place, this one called the Commonwealth of Pennsylvania. Here, thirteen "retarded" children and members of the Pennsylvania Association for Retarded and Handicapped Children (PARC) moved boldly, but probably with some fear and trepidation, to challenge the Commonwealth's treatment of what were then called "retarded" children

(Gilhool, 1973). They were inspired by Gunnar Dybbled who drew an analogy between the civil rights involved in the Brown case and the civil rights of children with disabilities. Although the state professed to meet the educational needs of all citizens, there was a flaw in its school code which exempted those children with IQ scores below 50 from public schools. This eliminated the group who could not meet that standard. The PARC group was seeking first to make public education accessible to all children regardless of their IQ scores. Their second objective was to ensure that this education be appropriate and that parents be involved in the placement of their child. The Commonwealth acknowledged these concerns and also recognized that they had no system in place to meet the needs of “challenged” children. In 1972, the final decree between PARC and the Commonwealth was signed; it guaranteed a free public education for all children, involvement of parents, and the initiation of the concept of least restrictive environment.

Were this a fairy tale, it would have ended with all children, not only in Kansas and Pennsylvania, but throughout the country, receiving the educational attention that they need and deserve. But this is not a fairy tale. As this chapter and the ones to follow demonstrate, progress has been made; however, much still needs to be done before children with disabilities have the opportunity to live happily ever after.

B. RELEVANT PUBLIC LAWS

Individuals with Disabilities Education Act, IDEA as it is known today, was the culmination of a series of public laws. And, the subject of this book—early intervention, was one of the last issues to be addressed. Since education is a right of individual states, federal laws can only provide incentives; participation cannot be mandated. Early targets of the public laws included the construction of research sites and the training of professionals to work with the “mentally retarded” (PL 88-164, 1963) and improvement of services to children of lower income families (PL 89-10, 1965), The Elementary and Secondary Education Act). The following year, PL 89-750 amended that act and defined the term “handicapped children”; preschool (three to five) “handicapped” children were included. In 1973, the Rehabilitation Act was intended to prevent discrimination against “handicapped individuals”. The well-known Section 504 of PL 93-112 stated that:

No otherwise qualified individual in the United States shall, solely by reason of his handicap, be excluded from participation in, or denied the benefits of or be subjected to discrimination under any program or activity receiving federal financial assistance.

A civil rights statute, Section 504 contained six parts. Subpart A was concerned with general provisions, B with employment practices, C with program accessibility, E with postsecondary education, F with health, welfare, and social services, and G with procedures. Subpart D considered the education of preschool and school-aged children and adolescents. The provisions of this act resembled PL 94-142 (1975).

They basically require that recipients operating public education programs provide a free appropriate education to each qualified handicapped child in the most normal setting appropriate. The regulation also sets forth evaluation requirements designed to ensure the proper classification and placement of handicapped children, and due process procedures for resolving disputes over placement of students. While the Department does not intend to review individual placements, it does intend to ensure that testing and evaluation procedures required by regulation are carried out, and that school systems provide an adequate opportunity for parents to challenge and seek review of these critical decisions.

In 1974, PL 93-380, Education Amendments of 1974, was enacted. Among the significant sections of the Act was Section 513, known popularly as the Buckley Amendment or the Family Educational Rights and Privacy Act of 1974. Part a, 1. dealt with the rights of parents “to inspect and review any and all official records, files, and data directly related to their children.” Further, Part a, 2. provided the opportunity for parents to request a hearing

to challenge the content of their child’s school records, and to ensure that the records are not inaccurate, misleading, or otherwise in violation of the privacy or other rights of students, and to provide an opportunity for the correction or deletion of any such inaccurate, misleading, or otherwise inappropriate data contained therein.

Section 438 also prohibited the release of confidential information without the written permission of the parents. Sections 611-621 specifically addressed the education of the “handicapped” and offered financial assistance to the states in developing complete educational programming at the preschool, elementary school, and secondary school levels; the appropriations were applicable to FY75. The rights of parents and children with regard to due process were emphasized in Section 612, as was the concept of the least restrictive environment. The law required the states to ensure that:

To the maximum extent appropriate, handicapped children including children in public or private institutions or other care facilities are educated with chil-

dren who are not handicapped, and that special classes, separate schooling, or other removal of handicapped children from the regular education environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Finally, the Act required that states formulate a plan for meeting the needs of all handicapped children and establish a time frame for implementing the plan.

1. PL 94-142

a. Purpose

In 1975, the codification of much of the previous legislation was seen in PL 94-142. Despite earlier incentives, it appeared that the majority of the eight million handicapped children living in the United States continued to have unmet educational needs. Additionally, one million children were excluded entirely from education with their peers. The document also stated that many children had unidentified handicaps and were forced to receive services from outside agencies because their needs could not be met in the public school setting. Assuming that, given appropriate financial assistance, local and state educational agencies could provide services to these children and that it was the responsibility of these agencies to provide such services, the federal government concluded that it was in the best interest of the nation to provide financial assistance to state and local educational agencies so that they could implement programs for the handicapped and assure such individuals equal protection under the law. The purpose, then of PL 94-142 was presented as follows:

It is the purpose of this Act to assure that all handicapped children have available to them. . .a free appropriate education which emphasizes special education and related services designed to meet their unique needs and to assure that the rights of handicapped children and their parents are protected, to assist states and localities to provide for the education of all handicapped children, and to assess and assure the effectiveness of efforts to educate handicapped children.

b. Individualized Education Program (IEP)

The law provided definitions of the “handicaps” covered, “special education services,” and the Individualized Education Program (IEP). With regard to the latter, PL 94-142 specified that: