

R.A. McWILLIAM

# Routines-Based Early Intervention

Supporting Young Children  
and Their Families



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# Routines-Based Early Intervention Supporting Young Children and Their Families

by

**R.A. McWilliam, Ph.D.**  
Siskin Children's Institute  
Chattanooga, Tennessee

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# Contents

About the Author .....	ix
Prologue .....	xi
Acknowledgments .....	xvii
<b>Section I Introduction.....</b>	<b>1</b>
Chapter 1 Advances in Early Intervention.....	3
Concepts of Family Centeredness	
Natural Environments	
Inclusion and Embeddedness	
The Need for This Model	
Chapter 2 How to Use This Book .....	9
Model Fidelity	
Implementation Across Types of Programs	
Relevant Research Embedded	
Cast of Characters	
Items from the FINESSE	
Conclusion	
<b>Section II Understanding the Family Ecology.....</b>	<b>15</b>
Chapter 3 Intake .....	17
First Encounters	
Written Materials	
Initial Referral Call	
Intake Steps	
Telling the Child’s Story	
Items from the FINESSE	
Appendix 3.1 Intake Checklist	
Chapter 4 Constructing Ecomaps .....	31
How Do You Complete an Ecomap?	
Use and Interpretation	
Strengths and Concerns	
Review	
Treatment Fidelity Issues	
Examples	
Summary	
Test on Intake	
Appendix 4.1 Ecomap Checklist	
<b>Section III Needs Assessment and Intervention Planning.....</b>	<b>53</b>
Chapter 5 Assessment.....	55
Assessment Questions	
Assessment Postulates	

---

	Evaluation and Assessment in Part C	
	Assessment on the IFSP	
	Current Levels of Functioning	
	Service Coordinator Roles	
	Items from the FINESSE	
	Test on Assessment	
	Appendix 5.1 Infant/Toddler Assessment Checklist	
Chapter 6	The Routines-Based Interview .....	67
	Confluence of Two Models	
	Research on the RBI	
	What Are Routines?	
	Routines-Based Interview	
	Outcome Writing	
	Strategies and Review	
	The Most Common Concern Among Professionals	
	Sample Outcome Lists	
	Implementation	
	Items from the FINESSE	
	Test on the RBI	
	Appendix 6.1 Family Preparation Form	
	Appendix 6.2 RBI Implementation Checklist	
Chapter 7	Writing Functional IFSPs and IEPs .....	93
	Functional Outcomes/Goals	
	Eight Steps to Writing Participation-Based Outcomes	
	Other Criterion Types	
	FAQs	
	Writing Family-Level Outcomes	
	Hiding Family Outcomes in Other Places on the IFSP	
	Items from the FINESSE	
	Goal Functionality Scale III	
	Section Summary	
	Test on Needs Assessment and Intervention Planning	
<b>Section IV</b>	<b>Model of Service Delivery .....</b>	<b>107</b>
Chapter 8	Deciding on Services .....	109
	The Key Question	
	Items from the FINESSE	
	Sample Outcome List	
	Test on Service Decision Making	
	Appendix 8.1 Service Decision Checklist	
Chapter 9	Organizing Transdisciplinary Services .....	119
	Principles	
	Organizing the Program	
	Special Considerations for Consultation to Child Care	
	Working with Communities	
	Forming Teams	
	Making the PSP Model Work: Choosing a PSP	



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	The Joint Home Visit	
	Addressing Fears of Change	
	Services on the IFSP	
	Benefits of the PSP Model	
	Is Autism a Special Situation?	
	The Economics of the PSP Model	
	Items from the FINESSE	
	Checklists	
	Examples	
	Section Summary	
	Test on Organizing Service Delivery	
	Appendix 9.1 Transdisciplinary Service Delivery Checklist	
	Appendix 9.2 Primary Service Provider Checklist	
	Appendix 9.3 Consulting Team Member Checklist	
<b>Section V</b>	<b>Natural Environment Locations</b> .....	145
Chapter 10	Support-Based Home Visits.....	147
	How Children Learn and How Services Work	
	The Need for Support-Based Home Visits	
	Vanderbilt Home Visit Script	
	Items from the FINESSE	
	Support-Based Early Intervention	
	Summary	
	Test on Home Visits	
	Appendix 10.1 Vanderbilt Home Visit Script (VHVS)	
	Appendix 10.2 Support-Based Home Visiting Checklist	
Chapter 11	Collaborative Consultation to Child Care.....	171
	Settings	
	Consultation	
	Integrated Therapy and Special Education	
	Research Findings	
	“Direct” versus “Consultative”	
	Challenges	
	Items from the FINESSE	
	Test on Collaborative Consultation	
	Appendix 11.1 Consultation Checklist	
<b>Section VI</b>	<b>Effecting Change</b> .....	187
Chapter 12	Implementing the Model: Systems, Service Coordination, Personnel Preparation, and Evaluation.....	189
	Programs	
	Communities	
	States	
	Professional Associations	
	Service Coordination	
	Personnel Preparation	
	Evaluation	
	Conclusion	

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References .....	201
Glossary .....	209
Appendix Blank Forms .....	211
Families In Natural Environments Scale of Service Evaluation (FINESSE)	
Goal Functionality Scale III	
Examination of the Implementation of Embedded Intervention, through Observation (EIEIO)	
Vanderbilt Ecological Congruence of Teaching Opportunities in Routines (VECTOR), Classroom Version	
Practices for Instruction, Play, and Engagement Rating Scale (PIPERS)	
Scale for Teachers' Assessment of Routines Engagement (STARE)	
Therapy Goals Information Form (TGIF)	
Satisfaction with Home Routines Evaluation (SHoRE)	
Family Quality of Life–Autism Spectrum Disorder (FaQoL-ASD)	
Index .....	261

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# Prologue

This book is not intended as a survey of all the ways early intervention can be provided. It is not a balanced look at different models, strategies, and practices. Rather, it describes a framework for a coordinated, philosophically and empirically based approach to early intervention. It is a personal view of how services should be provided. This view has been shaped by my experiences providing services, supervising others who provide services, and consulting with hundreds of service providers, scores of programs, and over a dozen states. I do believe in organizing methods so people can keep the general principles in mind as they explore the complexities within those principles. From a policy development, management, and training perspective, this focus on a model prevents mushy thinking, being overwhelmed by the details, and philosophical drift. It will soon become obvious, however, that the details of each practice are clearly articulated; I have used checklists to do this.

These checklists describe steps to practices that are likely to be successful when carried out with a high level of fidelity. The practices fit within my philosophy of family centeredness and a focus on functionality. Others who share this philosophy and my interpretation of those broad constructs will find much with which they agree. They also, though, might have other ideas about how to provide services. The experts on providing support in natural environments are in general agreement about how to provide services (Workgroup on Principles and Practices in Natural Environments, 2007), even though they might use different terms, have a different model, and use different tools. Because of the similarity in our approaches, it is hard to be proprietary about the ideas or practices. I suppose how we package them in our frameworks, our terms, and our instruments is what makes us claim practices. For example, in March 2004, I sought the advice of Gerry Mahoney about a good term for what I have been calling, for years, “incidental teaching.” I suggested that “responsive teaching” might be a better, less confusing term. He said, “Stay away from responsive teaching, Robin. I’ve co-opted that term.” His tongue was in his cheek to some extent, but he also made a fair point.

As for ideas, it is hard for any of us to be too possessive. We have learned from each other and have moved with the times—often at the forefront, but nevertheless in more concert than disagreement. So the ideas presented here are not individually unique. What do set a person’s work aside are the model (i.e., the combination of practices or the conceptual framework), the terms, and the tools. This book is my opportunity to put my framework, labels, and instruments in one place.

## Evolution of the Model

The model described in this book comes from four principal confluences of my experience with evidence-based practices or with theory.

## Family-Centered Practice

From its inception, early intervention has been interested in helping *families*, but it was only in the 1980s that serious research and theory began to attend to what this meant. One leader in this movement was Carl Dunst, who was among the first to document the importance of social support on families of young children with disabilities (Dunst, Boyd, Trivette, & Hamby, 2002; Dunst, Trivette, Boyd, & Brookfield, 1994; Dunst, Trivette, & Deal, 1994; Dunst, Trivette, & Hamby, 1996) and then what professional practices could foster families’ well-

being (Dunst et al., 2002; Trivette, Dunst, Boyd, & Hamby, 1996; Trivette, Dunst, Hamby, & LaPointe, 1996). I was lucky enough to work with Carl from 1983 to 1988.

My role at the Family, Infant and Preschool Program was to coordinate Project SUNRISE and eventually other classroom programs. From 1983 to 1985, Project SUNRISE was funded to operate parent-run co-ops twice a week, with children attending on both days, and parents attending on one of the days—with the other day as time without their children. Typically developing siblings also attended, making these co-ops inclusive and family like. We used this project as an opportunity to learn about families' capabilities; the value of families' having time together, particularly when there was a task for them to do; and how best to operate group settings to promote engagement. These lessons were then translated into the development of Family Place, the full-time, classroom program staffed by professionals and paraprofessionals. The impact of all these experiences can be seen in the current model.

One of the practices our team developed was a method for working with families to develop the intervention plan. This was before the passage of Education of the Handicapped Act Amendments of 1986 (PL 99-457), the law establishing federal funding for services to infants and toddlers with disabilities and their families, so there was no "individualized family service plan (IFSP)." Dunst called such a plan the Family and Child Intervention Plan (FACIP). The method we used in the classroom programs at the Family, Infant and Preschool Program was to ask the family about home routines, to talk to them about classroom routines, and to use this conversation for families to select their "goals" for the child and other family members. We developed it primarily as a tool for working collaboratively with families we only had the chance to see at arrival and departure (McWilliam, 1992). The current version of the Routines-Based Interview (RBI) is merely an elaboration of that simple but effective method.

Another luminary in the field's understanding of families has been Don Bailey, who became my next mentor. Don was involved with one of the largest studies of families (Bailey, 1987) and developed numerous measures that have advanced both research and practice (Bailey, Simeonsson, Buysse, & Smith, 1993; Bailey, et al., 2006; Bailey et al., 1998). His work has included research on personnel preparation in early intervention, on grouping (same age versus mixed age) in classroom settings, on fragile X syndrome, on longitudinal effects of early intervention, and on outcomes in early intervention. Throughout his career, he has applied his interest in families.

I worked with Don from 1988 to 2002, as a research project coordinator and eventually a senior investigator. It was while working at the Frank Porter Graham Child Development Institute at the University of North Carolina that I had the opportunity to study family issues in a serious way. Gloria Harbin invited me to work with her on evaluating North Carolina's early intervention services, where I looked at family-centered services (McWilliam, Tocci, & Harbin, 1998) while she looked at interagency collaboration. In this project, we looked at the quality of IFSPs (McWilliam, Ferguson, et al., 1998), among other things (McWilliam, Snyder, Harbin, Porter, & Munn, 2000). This was instrumental in my understanding the great need for a process to develop functional, family-centered plans. She then included me on the Early Childhood Research Institute on Service Utilization, where I conducted a case study with 72 families (McWilliam, Tocci, & Harbin, 1998). This experience was informative in honing my interview skills and led to the inclusion of some key questions in the RBI. It also helped us adopt the RBI with families served through home-based, not classroom-based, services.

## Family Systems and Ecological Theories

A second influence was coming to an understanding of family systems and ecological theories. Family system theory has been described in various graphic ways. One way is to think of the family as a mobile, where movement in one part affects all the other parts. Another way is to think of the family in terms of concentric circles, with the child in the middle, those who live with the child in the next circle, people who have fairly frequent and

close contact with the family in the next circle, people who have less frequent and close contact with family in the next, and distant people with whom the family has fairly circumscribed interactions in the outermost circle.

This systemic way of thinking about families matches concepts of person-centered planning and the use of the ecomap, which is described later in the book. Person-centered planning has revolutionized services for people with intellectual or developmental disabilities and is characterized by such ideas as forming a “circle of friends,” planning with the person about the person’s long- and short-term goals, and assessing the person’s resources (Holburn, 2001; O’Brien, 2004; Orentlicher, 2008). The ecomap is a specific tool that shows people who are resources, stresses, or both in a person’s life. Both person-centered planning and the ecomap involve determining the ecological factors in a person’s life, including family members.

In our own family, we did not use these tools specifically, but the resources available and unavailable unquestionably shaped how we managed our family life. At times, we had friends and family to count on, but there were times and circumstances when we did not have them. We also learned that having resources available is one thing; being comfortable using them is quite another. Some people we know are not at all shy about asking favors from others. We admire these people in their audacity.

## Transdisciplinary Service Delivery

Early in my career, Dunst introduced me to the concept of transdisciplinary service delivery. When I went to meetings representing Project SUNRISE, I came across Geneva Woodruff (Woodruff & Shelton, 2006) and other pioneers who articulated this approach. I realized that, before I knew the term for it, I had used transdisciplinary practices in my first home-based early intervention job. In our small team of three people working in rural Piedmont North Carolina, we had enough money only for quarterly consultation from an occupational therapist, a physical therapist, and a speech-language pathologist. That meant we had to absorb as much information as we could as we whizzed around the county with the consultant on board, going from house to house. We had to support the family in carrying out the therapists’ programs. It was a marvelous way to learn about many different dimensions to early intervention.

In the co-ops, we spent so much time on functional, fun, developmentally appropriate activities that “therapy” became an afterthought. Eventually, we had therapists come into the rooms perhaps quarterly. They and we understood that their purposes were to see if the program needed to be changed (assessment) and to demonstrate interventions. They did not see the need for more frequent interventions, because they understood that the families were carrying out the interventions at home and the co-op staff were supporting the families to carry them out during co-op.

Our policy that therapists had to come into the classroom and work with us was different enough from common practice in the 1980s that I understood research was needed. Why were more people not providing integrated services? Therefore, Don Bailey and I wrote and were awarded a field-initiated grant. Our first problem on this grant was that our team of experts could not agree on the extent of pull-out services: How big an issue was this? We conducted a national survey that showed it was indeed a big problem. Incidentally, I used these data for my dissertation. Our next problem was that we discovered that it was not a simple question of in versus out of class, so we had to determine the various methods of providing services in both locations. Our third problem was that therapists would not agree to a study that involved random assignment of children to different types of therapy and they would collude with parents to refuse to participate. Our solution was to find sites and therapists who used different methods and to monitor the effects of naturally occurring therapy. These studies led to the publication of the edited book *Rethinking Pull-Out Services*

in *Early Intervention: A Professional Resource* (McWilliam, 1996), which featured chapters by experts in six disciplines.

The integrated-services work not only taught us about classroom-based services but also taught us about how to be consultants when infants and toddlers were in child care. Early interventionists are the specialists when they visit child care centers, and we now have evidence about how to consult collaboratively.

## Complexity of Home Visits

Home-based early intervention is a finely detailed masterpiece masquerading as finger painting. I know. In my early career, I was finger painting. Over time, however, I have come to understand the things we did in the early days that were indeed masterful and the things best forgotten. One study that helped me understand what worked and what did not was the large case study mentioned earlier that Gloria Harbin, Lynn Tocci, and I undertook as a part of the Early Childhood Research Institute on Service Utilization (McWilliam, Tocci, & Harbin, 1998). The case study consisted of 72 families and their 46 service providers. The families lived in nine communities—three in North Carolina, three in Pennsylvania, and three in Colorado. We interviewed the families live twice, we interviewed the service providers at least once, and we visited most settings if children were served outside the home (e.g., child care, specialized program, Head Start). The interviews in the homes and, in the case of the service providers, over the telephone gave us rich and thick descriptions of home visits. Analyzing these narratives gave us insights that advanced our thinking considerably.

As the model proposed in this book is described, its roots in family-centered practice, family systems, transdisciplinary service delivery, and home visiting will be obvious. The introduction to the model continues with a discussion of advances in early intervention that illustrate why a model was needed.

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SECTION I

# Introduction

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**T**his book describes a particular approach to early intervention—one focused on the family, on functioning in everyday routines, and on a team approach to intervention. To place the approach in context, the development of early intervention is reviewed.



## CHAPTER 1

# Advances in Early Intervention

The term *early intervention* is used to describe **interventions** for both at-risk children and children with developmental disabilities, and no doubt there is some overlap. But there are also fundamental differences in philosophy, approaches, and conclusions. Beginning with the possibility of overlap, however, Forrest Curt Bennett (2004), a developmental pediatrician at the University of Washington, provided an interesting overview of the evolution of early intervention. He pointed out that research in the field began by asking whether early intervention “worked”—the answer to which depended on what was meant by this term. For example, can early intervention cure potential developmental disabilities? No. Can it permanently raise IQ scores? No. Can it improve school functioning? Yes, because now the field is thinking about *function*. Can it improve adaptive behavior? Yes. It has been shown to have social and vocational benefits. Can it enhance daily care? Yes. It has been shown to enhance feeding, interacting, and behavior management. Can it help family functioning? Yes. It has been shown to improve the way families adapt to the child and pursue their interests.

According to Bennett (2004), in the medical field, there are three accepted types of early intervention:

1. Newborn screening for metabolic disorders (because there is evidence-based information)
2. Education for children with major sensory impairments (e.g., because of the success of early intervention for deaf and blind children, newborn hearing screening was developed)
3. Physical therapy for children with cerebral palsy (even though Palmer et al., 1988, showed that the commonly accepted physical therapy treatment was actually no more effective than a general early childhood education curriculum)

If these are the limits of accepted types of early intervention, Bennett leveled, questions remain about treatment for children at environmental risk for developmental disabilities

(e.g., children from low-income families). In fact, Bennett said we need to look at early intervention by group (e.g., income level), biological risk (e.g., low birth weight), and established developmental disabilities, not by putting them all together. Results of the Abecedarian Project, which was the nation's first investigation of the efficacy of child care to improve the cognitive skills of children in poverty, demonstrated a 15-point IQ difference between children who received an enhanced child care intervention and the control group (Ramey & Campbell, 1984), but these differences disappeared after the end of intervention. Later, however, " sleeper " effects such as academic achievement, grade placement, and graduation emerged (Campbell, Ramey, Pungello, Sparling, & Miller-Johnson, 2002). Notably, these findings were for children from low-income families, not children with disabilities.

Similarly, the Infant Health and Development Project was most effective for children from families of low socioeconomic status, regardless of weight or health (Liaw & Brooks-Gunn, 1993). By 5 years of age (2 years after the end of intervention involving child education and family support), differences had disappeared between the intervention and follow-up groups.

For children with low birth weights, Bennett (2004) mentioned that we have moved from an infant stimulation approach to a parent-focused, infant protection approach. So now, we have individualized nursing care plans, such as " environmental neonatology " and " developmental care. " Attention is being paid to brain care rather than just lung care.

Bennett said, " The most successful programs combine multiple interventions and deliver them repeatedly over time. " Although important differences between early intervention for children at risk for developmental delays and early intervention for children with disabilities exist, 1) disability can be considered to exist along a continuum and 2) the system of services for children with disabilities should exist within the system of services for typically developing children.

## Concepts of Family Centeredness

Since the beginning of early intervention, changes have occurred in the concept of family centeredness. In the 1970s, attention was paid to parent training and involvement (Field, Widmayer, Stringer, & Ignatoff, 1980; Forgatch & Toobert, 1979). Researchers discovered that parents could be taught to implement interventions with their children (Tudor, 1977). Later, this approach was perceived as paternalistic, especially when professionals decided what parents should be trained to do, and simplistic, when training was the extent of the involvement with the family (McWilliam, McMillen, Sloper, & McMillen, 1997). This takes us to the apparently unshakeable issue of parent involvement. Historically, professionals wanted families to become highly involved in the early intervention enterprise. The underinvolved family was blamed for underinvolvement, with scant attention paid to what the professionals had done to set the stage for family underinvolvement. In this book, I will argue that, when home visitors get it right, family involvement is a nonissue in the same way that people are " involved " when their neighbors come over. Lack of attention by a neighborhood host is a nonissue. Of course families are involved when the adults are visited. The problem is that too often the child is being visited, so the parents think their participation is optional or tangential.

Currently, we are in an era of *empowerment*—a term Carl Dunst applied to early intervention in his seminal book, *Enabling and Empowering Families* (Dunst, Trivette, & Deal, 1994). The current concept of early intervention places a high value on the family's

decision-making authority; this authority is built into legislation (the Individuals with Disabilities Education Improvement Act of 2004, PL 108-446) and definitions of recommended practice (Smith et al., 2002). Perhaps owing to the tie-in with legislation, professionals can give families choices during the planning process (for which the legislation is fairly prescriptive), yet ignore concepts broader than decision making in **service** delivery (for which legislation is less prescriptive). The zeitgeist is that all professionals know that family centeredness is socially appropriate and everyone claims to use family-centered practice.

Another current principle of early intervention is one of partnership. In fact, Dunst combined (1985) the two ideas in his proactive model of empowerment through partnerships. The concept of families and professionals working as partners is an elaboration of empowerment, particularly as it is related to families having decision-making authority. It is therefore an imperfect model, because families have ultimate authority, yet professionals have more knowledge about intervention. But then, perhaps all partnerships are imbalanced in different domains.

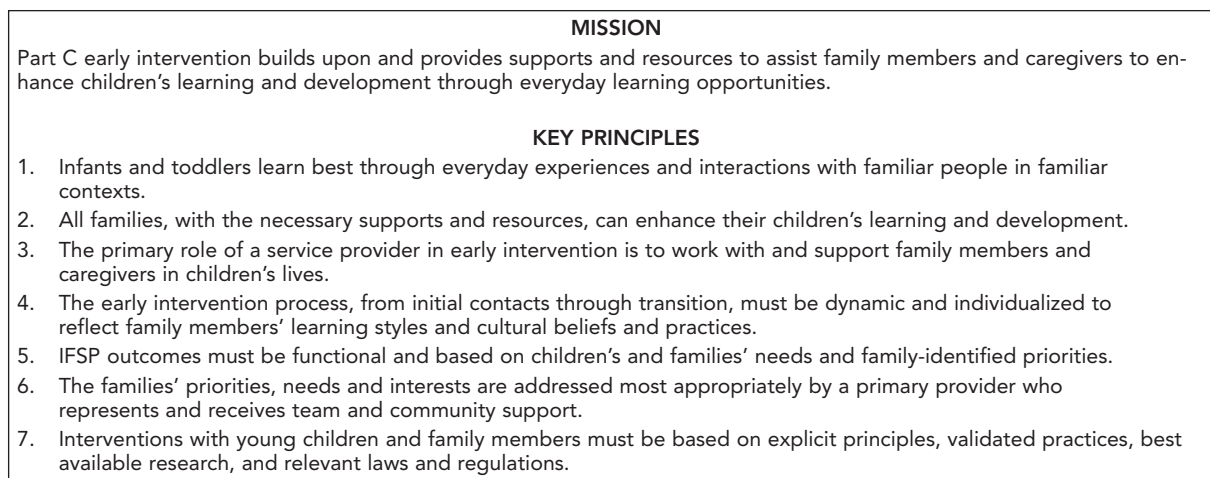
The future of the concept might well be family quality of life, which is ironic because this was important to many of today's experts in family centeredness right from the beginning. Nevertheless, I believe that when practitioners, family advocates, administrators, and researchers consolidate the research findings and make sense of the disparate movements in the field, they will see that the concept of enhancing family quality of life will be a unifying force. Measurement systems to track this construct have been developed (Hornstein & McWilliam, 2007; Turnbull, Poston, Minnes, & Summers, 2007). One critical dimension of family quality of life is satisfaction with **routines**, which is especially salient in the context of early intervention designed to take place in **natural environments**. Put another way, routines-based early intervention will directly address families' satisfaction with their routines.

From parent training and involvement, the field of early intervention made important steps forward in conceptualizing family centeredness when empowerment and partnerships were embraced. Refinement of the concept might well come with an acceptance of the goal of improving family quality of life.

## Natural Environments

The idea of providing early intervention in natural environments has probably been the hottest issue in the field since the mid-1990s. Curiously, some states and programs began the early intervention enterprise with an understanding that interventions (or at least learning opportunities) occurred throughout the child's day in places and at times that were part of the fabric of the child's and family's life. Other states and programs, however, developed their early intervention systems to be located primarily in specialized classrooms or clinics. For some people, therefore, early intervention in natural environments (EINE) is normal—familiar. For others, it is a change and a challenge.

This book is largely about EINE, so not much detail will be addressed here. But experts in this area have agreed upon the mission and principles shown in Figure 1.1. It is possible to meet the letter of the law regarding early intervention and still use a multidisciplinary model, still use a clinic-based approach on home visits, and still pull children out for treatment when they are seen in their community child care centers. This book makes the case that true EINE, however, includes transdisciplinary service delivery, support-based home visits, and integrated services in child care.



**Figure 1.1.** Mission and key principles of early intervention. (From Workgroup on Principles and Practices in Natural Environments. [2007]. *Agreed-upon practices for providing early intervention services in natural environments*. Retrieved July 6, 2008, from [http://www.nectac.org/~pdfs/topics/families/AgreedUponPractices\\_FinalDraft2\\_01\\_08.pdf](http://www.nectac.org/~pdfs/topics/families/AgreedUponPractices_FinalDraft2_01_08.pdf); reprinted by permission.) (Key: IFSP, individualized family service plan.)

## Inclusion and Embeddedness

When families want their children in group care, they mostly use inclusive, community settings such as regular child care. This is a result of EINE legislation, research findings (Odom et al., 2004), and values (Bailey, McWilliam, Buysse, & Wesley, 1998). It might be argued that we have been quite successful in increasing the extent to which inclusive placement is used, but not as successful in ensuring the quality of intervention that children receive. In addition to the general quality of the settings, we still need to pay attention to the extent to which inclusion is individualized (Purcell & Rosemary, 2008; Wolery, 1997). When it is individualized, assessment will include ecological congruence between the child's behavior and the demands of classroom routines, therapy, and early childhood special education that is integrated into classroom routines, and interventions that are embedded into regular classroom routines. Clearly, then, individualizing inclusion is consistent with EINE.

## The Need for This Model

Despite these advances, a need still exists for a model that students can learn, administrators can organize, practitioners can implement, and families can advocate. First, problems still exist with early intervention as it has evolved. These problems will be elaborated upon in the following chapters, but the most common ones are a pernicious slide toward overspecialization, an absence of functional-needs assessment in the evaluation assessment process (and, therefore, nonfunctional goals), a clinic-based model applied to home visits, and pull-out services in child care.

Second, it will be useful to have an integrated system from referral through transition. Experts have developed useful practices in assessment and intervention, but have generally not provided an approach that can be used from intake through transition out of the program.

Third, there is a way to evaluate the extent to which programs are consistent with the concept of EINE and use recommended practices. A tool that allows respondents to

identify their practices in various areas from not-recommended practices to highly recommended practices is useful. The Families In Natural Environments Scale of Service Evaluation (FINESSE), shown in the appendix at the end of the book and discussed further in Chapter 12, is such a measure (McWilliam, 2000a).

Fourth, despite the advances in early intervention, vast numbers of programs still are operated in an atheoretical manner with little regard to how early intervention really works. Children learn primarily through repeated interactions with the environment, with those interactions dispersed over time. They do not learn in lessons or sessions in which the “trials” are massed or the practice is concentrated, with little or no carryover to other situations. Therefore, the premise under which the common model of therapy or instruction is carried out, in which professionals work directly with children once a week or so, is questionable.

Children are better influenced by the caregivers who spend hour after hour with them during the week than they are by visitors. On the other hand, adults, because they can generalize and learn in sessions, can benefit from weekly visits from professionals. Therefore, professionals should work with adult family members, who can influence child development and skill acquisition as previously discussed. Intervention for the child therefore occurs between visits. This is when caregivers have multiple opportunities to provide learning contexts for children. In this way, early intervention really works as a process of various kinds of supports (including “training”) to the caregivers who are with the child for many hours throughout the week.

Although these dimensions of early intervention have been articulated in the literature (Dunst, Bruder, Trivette, Raab, & McLean, 2001; Dunst, Herter, & Shields, 2000; Pretti-Frontczak & Bricker, 2004; Widerstrom, 2005), until now they have not been organized into a model that states, administrators, or practitioners could grasp.