

# The Developmental Systems Approach to Early Intervention (ISEI)

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As communities struggle to address today's challenges to early intervention — including limited resources, the need for professional development, and the changing role of families — they create programs that vary dramatically in quality, approach, and organization. A more consistent, coherent, and effective early intervention system is the goal of this enlightening book, which describes a state-of-the-art, research-based developmental systems model to guide programs for children from birth to 5 years of age. You'll examine

- Three core principles of the developmental systems model. You'll learn the importance of applying a developmental framework to early intervention, integrating the services of various agencies and personnel, and maximizing inclusion in home and community life for children with disabilities.
- Practices in the United States. Leading experts help guide decision-making
  with both broad suggestions and specific recommendations for improving
  practices in key areas (see sidebar) and across diverse communities.
- Practices in other countries. Experts from other countries including
   Austria, Australia, Great Britain, Greece, Israel, Italy, and Sweden share
   valuable insights and relate their early intervention approaches to the
   developmental systems model.

You'll receive expert guidance on improving

- screening and points of access
- interdisciplinary assessment
- assessment of family characteristics and needs
- preventive intervention for children at risk
- early intervention for children with disabilities
- evaluation of program effectiveness
- transitions for children with disabilities

Designed to help administrators, policymakers, and graduate-level students effect change for many years to come, this comprehensive guide will help you create early intervention programs that are based on research but still address the needs of individual children and families.

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#### **Editorial Review**

Review

"This book [gives] a better understanding of the possibilities and barriers to successful early intervention worldwide."

About the Author

Michael J. Guralnick, Ph.D., is Director of the Center on Human Development and Disability (CHDD) and Professor of Psychology and Pediatrics at the University of Washington, Seattle. Comprising both a University Affiliated Program and a Mental Retardation and Developmental Disabilities Research Center, the CHDD is one of the largest interdisciplinary research and training centers in the United States, addressing issues directly related to developmental disabilities. More than 600 faculty and staff members and doctoral and postdoctoral students operate within the four CHDD buildings on the campus of the University of Washington and in community sites to conduct basic and applied research, to provide clinical services to individuals and their families, to provide interdisciplinary clinical and research training, and to provide technical assistance and outreach training to practitioners and community agencies.

Dr. Guralnick has directed research and development projects in the fields of early childhood intervention, inclusion, peer relationships, and pediatric education. He has published more than 100 articles and book chapters and 7 edited volumes. Dr. Guralnick's publications have appeared in a diverse group of well-respected journals, including *Child Development*, *Pediatrics*, *American Journal on Mental Retardation*, *Journal of Early Intervention*, *Developmental Psychology*, *Journal of Developmental and Behavioral Pediatrics*, *Journal of Applied Developmental Psychology*, and *Development and Psychology*.

He currently directs a major research project supported by the National Institute of Child Health and Human Development designed to determine the effectiveness of a comprehensive early intervention program in promoting the peer-related social competence of young children with developmental delays.

Dr. Guralnick received the 1994 Research Award from the American Association on Mental Retardation and the 1997 Distinguished Research Award from The Arc of the United States. He is past President of both the American Association of University Affiliated Programs and the Council for Exceptional Children's Division for Early Childhood and is former Chair of the Mental Retardation and Developmental Disabilities Research Center Directors. He is currently Chair of the International Society on Early Intervention and is President-Elect of the Academy on Mental Retardation.

Dr. Gilliam is an Associate Professor of Child Psychiatry and Psychology at Yale University. He is also the Director of Yale's Edward Zigler Center in Child Development and Social Policy. His research involves policies regarding early childhood education and child care, ways to improve the quality of early childhood services, the impact of early childhood education programs on children's school readiness, and effective methods for reducing classroom behavior problems and the incidence of preschool expulsion.

Dr. McWilliam is the Siskin Endowed Chair of Research in Early Childhood Education, Development, and Intervention at Siskin Children's Institute. He is also a professor of education at the University of

Tennessee at Chattanooga and an adjoint professor of special education at Vanderbilt University. He has formerly been a professor of pediatrics at Vanderbilt University Medical Center, a senior scientist at the Frank Porter Graham Child Development Institute, and a professor of education at the University of North Carolina at Chapel Hill. Dr. McWilliam's research centers on infants, toddlers, and preschoolers with and without disabilities, with a specific focus on child engagement, service delivery models, and collaboration with families. He has provided consultation, training, and technical assistance across the United States and in some countries overseas on providing early intervention in natural environments and on the Engagement Classroom Model. His Routines-Based Interview (RBI) is a widely used method of assessing families' needs and developing individualized family service plan (IFSP) outcomes and individualized education program (IEP) goals.

Dr. Wolraich is Chief of the Section of Developmental and Behavioral Pediatrics at the University of Oklahoma Health Sciences Center. He received his M.D. from the State University of New York Upstate Medical Center in Syracuse. Dr. Wolraich completed a p ediatric residency between Upstate Medical Center and the University Oklahoma Health Sciences and completed a fellowship in developmental pediatrics at the University of Oregon Health Sciences Center. Dr. Wolraich has spent more than 30 years in research and clinical service related to attentiondeficit/ hyperactivity disorder (ADHD) and is a 2003 inductee in the Children and Adults with ADHD (CHADD) Hall of Fame. He has also been a major contributor to the development of guidelines for ADHD for primary care physicians by the American Academy of Pediatrics. Dr. Wolraich has been an author or coauthor on more than 150 journal articles and book chapters, including articles in the *New England Journal of Medicine, Pediatrics*, and the *Journal of the American Medical Association* and chapters in 20 books. His research is funded by the National Institutes of Health, National Institute of Mental Health, Maternal and Child Health Research Program; National Institute on Disabilities and Rehabilitation Research; the Centers for Disease Control and Prevention; and the Office of Special Education and Rehabilitation. Currently, he is investigating the prevalence and long-term outcomes of ADHD in five school districts.

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The recent history of early intervention services for children who are vulnerable and their families in the United States has certainly been one of progressive expansion and refinement. The model projects operating in select communities or university settings and the beginnings of more widespread programs in the 1960s and 1970s have been transformed into a vibrant and visible national program providing early intervention services and supports to which all eligible young children with established disabilities have access (see Guralnick, 2000a, in press-b). Preventive intervention programs for children at risk for developmental disabilities have exhibited considerable growth as well, although these programs lack the many legislative mandates and the coherence of programs for children with established disabilities.

Numerous factors working together created the conditions for these transformations as well as for the continuing support for further advances in contemporary systems of early intervention programs. Historical accounts of these factors, including philosophical shifts, knowledge gained from the developmental science of normative development and the developmental science of risk and disability, the results of intervention science, information derived from clinical practice, increased support for early childhood development programs for all children, and major legislative events can be found elsewhere (Gilliam & Zigler, 2001; Guralnick, 1997b; Meisels & Shonkoff, 2000; National Research Council and Institute of Medicine, 2000; Smith & McKenna, 1994). Taken together, what has emerged from all of these efforts is a strong commitment to make early intervention, in all of its forms, work.

Moreover, as programs in each state and local community have become more visible and prominent, the expectations for early intervention programs have increased considerably. Ensuring the availability of well-coordinated, highly effective early intervention programs in every community, each representing contemporary principles and practices, is held to be a reasonable goal by policy makers, parents, and professionals. It is further thought that the absence of uniformly high-quality early intervention programs can jeopardize the health and optimal development of our nation's vulnerable children and pose increasing challenges to the ability of families to function effectively. This systems-level thinking was central to the Education of the Handicapped Act Amendments of 1986 (PL 99-457) and related early intervention legislative changes articulating a national agenda. In particular, focusingon the birth-to-3 age group, the purpose of this legislation was "... to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families" (Individuals with Disabilities Education Act [IDEA] Amendments of 1997, PL 105-17, Section 631). States could also serve children at risk for developmental delays through this mechanism if they elected to do so.

The law identified a number of *structural components* required for such a statewide system including establishing criteria for eligibility for services, ensuring that timely and appropriate assessments occurred, developing a process so that a family's needs and priorities were identified systematically, creating a proactive early identification and referral mechanism, establishing a procedure for developing a specific plan for comprehensive intervention, and ensuring that transitions from one program to another were carried out effectively and seamlessly.

Three- to five-year-old children were served under different provisions of the law. Although differences between the systems serving infants and toddlers and those serving preschool children were often substantial (e.g., less of an emphasis on family involvement for preschoolers), the basic elements remained intact. Accordingly, these requirements were intended to ensure both the existence of a well-coordinated and integrated early intervention system in each state and to ensure the consistency of the systems' structural components across states and communities. Nevertheless, much was left to the discretion of states to interpret and implement the systems they developed. In this manner, states could build on existing relationships and structures, including financing mechanisms, to meet federal requirements.

Yet, despite considerable degrees of discretion accorded each state within the structure put forward, the reasonable expectation was that, over time, states would become more and more similar in their early intervention service and support systems. This would be brought about through national leadership and a common recognition by states and communities of the most effective approaches for each component of the system, gained through formal evaluations of the systems in effect and through informal communication channels. Of course, many differences would remain, but common fundamental components and corresponding practices would eventually come to characterize a national system. After all, the design of structural components of systems, such as those for effective screening and referral mechanisms or for multidisciplinary child assessments that could be conducted to obtain needed information, was based on

common sources of knowledge provided by researchers and clinicians in the field.

Similarly, it is reasonable to anticipate that neighboring states would soon see the value of establishing common eligibility criteria. Perhaps more difficult to achieve than the expected convergence with respect to structural components would be convergence with respect to various specific practices and service guidelines and even philosophical perspectives. But even here, it seemed reasonable that considerable agreement would evolve over time as approaches were clarified and evidence accumulated as to what were the most effective and efficient practices in meeting the needs of children who are vulnerable and their families.

Despite these expectations, analyses have revealed surprisingly large variations across states for many components of statewide early intervention systems. More specifically, substantial differences in practice have been found with respect to criteria for eligibility for services, ways in which families gain access to the system (points of access, transitions from program to program), and the comprehensiveness of the available services (Harbin, McWilliam, & Gallagher, 2000; Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000). Moreover, only limited state-level leadership has been apparent with respect to promoting systems-level issues. As the authors of a comprehensive study of infant and toddler early intervention systems, referred to as the National Early Intervention Longitudinal Study (NEILS), observed, "The early intervention professionals we interviewed in conducting the NEILS enrollment and those around the country with which we have discussed the NEILS have been surprised that there was so much variation in early intervention systems" (Spiker et al., 2000, p. 205). Of importance, considerable variation was found not only across states but also within states.

This general concern about early childhood intervention at the systems level was shared in a comprehensive report from the Committee on Integrating the Science of Early Childhood Development of the National Academy of Sciences. Their analysis indicated that Early childhood policies and practices are highly fragmented, with complex and confusing points of entry that are particularly problematic for underserved segments of the population and those with special needs. . . . The time is long overdue for state and local decision makers to take bold actions to design and implement coordinated, functionally effective infrastructures to reduce the long-standing fragmentation of early childhood policies and programs. (National Research Council and Institute of Medicine, 2000, pp. 309, 402)

#### PRINCIPLES OF EARLY INTERVENTION

As suggested, it was reasonable to anticipate not only that some common ground would emerge with respect to the various structural components of an early intervention system (e.g., points of access, eligibility, transition planning) but also that a set of common principles and corresponding practices governing systems design and implementation would emerge. That is, structural components and principles should jointly determine practices of the components and of the system as a whole. Indeed, certain principles were embedded in the legislation itself, which called for the early intervention system to center on families (maintain a strong developmental orientation), to maximize the participation of children and families in natural environments, to foster interactions with children without disabilities (inclusion), and to integrate and coordinate activities at all levels of the system. The press for child-find systems as a structural component reflected the principle of the importance of early identification. Moreover, the principle of individualization of intervention was found in many places in the legislation but especially in connection with the design of individualized family service plans (IFSPs) and individualized education programs (IEPs).

These and other principles that seem well accepted by the field are presented in Table 1.1. Nevertheless, as might be expected from the variability found in the implementation of the structural components, despite an apparent acceptance of these principles at a general level, considerable variability also exists with respect to the implementation of these principles in practice (Guralnick, in press-b; Harbin et al., 2000). Differences in

interpretations, access to information, and resource availability, or variations in commitment to certain principles and corresponding values, may account for much of this cross-community variability. As discussed next, variability is perhaps most apparent for what might best be referred to as core principles (i.e., developmental framework, inclusion, integration, and coordination). Although all of the principles listed in Table 1.1 could legitimately be considered "core," these four principles have been most prominent in the field, with important implications for concepts, values, and practices in early intervention systems.

#### IMPLEMENTATION OF PRINCIPLES

The most fundamental principle is that a developmental orientation should be represented in each structural component and corresponding practice of every early intervention system (Guralnick, 1998; National Research Council and Institute of Medicine, 2000; Sameroff & Fiese, 2000). The most critical feature of this developmental orientation principle is that interventions center on families. This principle includes concepts related to parent empowerment, the establishment of parent–professional partnerships, and recognition of the significance of family patterns of interaction to children's development and well-being. Yet, even when latitude is given with respect to interpretations of this principle and the diversity of practice settings, the general consensus is that the field of early intervention has not yet embraced a developmental framework as reflected in actual practice (see Bruder, 2000; Guralnick, in press-b; and Harbin et al., 2000, for details).

The same can be said for the principle of inclusion, although most subscribe to this principle at a conceptual level. Similar to the difficulties encountered for the principle of maintaining a developmental framework, universal access to inclusive programs is far from a reality, practices differ radically from community to community without any apparent rationale, and controversy is common across states with respect to how to interpret and apply the concept of natural environments (see Guralnick, 2001c, for a detailed review). In short, widely different practices exist with respect to maximizing the participation of children and their families in typical community settings and activities. Of note, the extraordinary compatibility of the core principles of inclusion and developmental framework is only now being recognized fully, given that integrating early interventions within family routines (Bernheimer & Keogh, 1995) and community learning activities (Bruder, 2001; Dunst, 2001) also support inclusive practices. Evidence also indicates that the core principle of integration and coordination has yet to be effectively applied to many components of the early intervention system. For example, at the systems level, interagency coordination approaches take many forms in different states, and these variations are associated with differing levels of comprehensiveness of services and set limits on the types of integration that can occur (Harbin et al., 2000; Spiker et al., 2000). Leadership through decision making and training mechanisms to establish policies to improve integration and coordination are similarly lacking across states (Spiker et al., 2000). It comes as little surprise that families frequently identify service coordination as a major concern (Harbin et al., 2000). Moreover, available evidence suggests that interdisciplinary teams designed to provide comprehensive assessments, as well as to deliver services, often lack the degree of integration and coordination needed to take full advantage of the benefits of interdisciplinary activities (Bruder, 1996; see Guralnick, 2000c).

The importance of cross-discipline collaboration poses additional challenges as collaborative consultation models are emerging as best practices in the field (McWilliam, 1996). This approach has the potential to integrate many disparate discipline-specific services into a coherent package of interventions that have considerable functional value for children and families (Dunst, Trivette, Humphries, Raab, & Roper, 2001; Hanft & Pilkington, 2000). As a consequence, when fully implemented, the collaborative consultation approach is consistent not only with the principle of integration and coordination but also with the other two core principles of developmental framework and inclusion.

The other principles listed in Table 1.1 that guide systems of early intervention, however, have not been fully realized in practice. Exemplary models that represent some of the principles do indeed exist, but they

constitute only isolated examples in a context of enormous variability in comprehensiveness and effectiveness. For example, few communities have comprehensive systems to identify children at risk as early as possible. In particular, it is difficult to coordinate approaches designed to identify children at substantial risk for developmental delays. Professional organizations continue to develop guidelines for early identification (e.g., American Academy of Pediatrics, 2001), but numerous barriers remain in the design of comprehensive systems, including costs (Dobrez et al., 2001) and general problems associated with interagency coordination. Moreover, sophisticated procedures for early identification of children with specific disorders such as autism are now emerging, posing additional challenges to effectively implementing the principle of early identification (Filipek et al., 2000).

Similarly, communication and professional training mechanisms are not importance of this principle of evidence-based practices has certainly been recognized, and progress continues to be made to develop appropriate practice guidelines (New York State Department of Health, 1999; Sandall, McLean, & Smith, 2000). Yet, the research-to-practice gap remains a major concern, (e.g., Bruder, 2000; Rule, Losardo, Dinnebeil, Kaiser, & Rowland, 1998). Indeed, considering possible future difficulties in narrowing the research-to-practice gap, the Committee on Integrating the Science of Early Childhood Development reached the following conclusion: "As the rapidly evolving science of early childhood development continues to grow, its complexity will increase and the distance between the working knowledge of service providers and the cutting edge of science will be staggering" (National Research Council and Institute of Medicine, 2000, p. 402). Clearly, much needs to be done to implement the principle regarding evidence-based practices in early intervention.

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