

CHAPTER 1

AN OVERVIEW OF THE DEVELOPMENTAL SYSTEMS MODEL FOR EARLY INTERVENTION

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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, 1997h; 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, focusing on 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

Table 1.1. Principles of early intervention relevant to the Developmental Systems Model

<p><i>A developmental framework</i> informs all components of the early intervention system and <i>centers on families</i>.</p> <p><i>Integration and coordination</i> at all levels is apparent. This includes interdisciplinary assessments, assessments for program planning, developing and implementing comprehensive intervention plans, and systems level integration.</p> <p>The <i>inclusion</i> and participation of children and families in typical community programs and activities are maximized.</p> <p><i>Early detection and identification</i> procedures are in place.</p> <p><i>Surveillance and monitoring</i> are an integral part of the system.</p> <p><i>All parts of the system are individualized</i>.</p> <p>A strong <i>evaluation and feedback</i> process is evident.</p> <p>It is recognized that true <i>partnerships with families</i> cannot occur without <i>sensitivity to cultural differences</i> and an <i>understanding of their developmental implications</i>.</p> <p>There is a belief that recommendations to families and practices must be <i>evidence-based</i>.</p> <p>A <i>systems perspective</i> is maintained, recognizing interrelationships among all components.</p>

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; Santeroff & 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 (Braden, 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 yet available to ensure that practices are fully evidence based. The 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.

PROSPECTS FOR SYSTEMS CHANGE

These many systems issues constitute legitimate concerns, and their impact on the effectiveness of early intervention programs should not be underestimated. At the same time, it is important to recognize the sources of this variability and to avoid the tendency to simply criticize the system and identify its inadequacies. After all, this variability may well be an intrinsic part of the evolution of the system of early intervention as it passes through various stages of development and refinement (see Guralnick, 2000a). The fact is, there has been a considerable increase in the number of children and families entering the early intervention system over the years. Services are provided annually to more than 800,000 children from birth to 5 years under IDEA '97 (U.S. Department of Education, 2001). The array of services provided is complex and diverse (Guralnick, in press-b; U.S. Department of Education, 2001), and families seem generally satisfied with those services. Nevertheless, increasing complexity poses a formidable challenge to any system, as does the rapid pace of knowledge and demands of professional training. Moreover, some of the variability can be traced to the fact that new systems should experiment with different models and try to work out the best approaches. Given the history of different working relationships and financing patterns, it is not surprising that communities would start at different points with different approaches.

Consequently, these differences found in states and communities with respect to both systems structure and adherence to generally accepted early intervention principles are understandable, at least to a certain degree. Yet, there do not appear to be any systematic efforts under way to examine these differences to determine the most effective strategies or to address the many problems that have been identified. Admittedly, the complexity of the task can easily overwhelm even the most dedicated of professionals. It is not that these problems are unrecognized but that there appears to be no framework to provide guidance for improving the system. To improve the system, the components of an "ideal" system need to be identified or clarified. Consideration must be given as to how the principles of early intervention can be applied to relevant structural components, and processes and protocols to guide specific practices consistent with systems components and principles must be available. Should this occur, and communities move to adopt such a system, consistency of early intervention programs across communities should increase substantially, and early intervention systems will be better able to effectively meet the needs of children and families.

It is important to point out at the outset that uniformity of early intervention systems across states and communities is not and should not be expected. Legitimate differences of opinion on

early intervention approaches do exist and will continue to exist. In fact, the absence of definitive information with respect to many practice aspects of early intervention will ensure that differences across communities and communities' interpretations of existing knowledge and principles will remain. As noted previously, however, professionals' knowledge has advanced so that systems components, principles, and practices can now be identified in sufficient detail to generate a rational framework for the design of a comprehensive early intervention system. One such approach, the Developmental Systems Model (Guralnick, 2001b), is discussed next and is the basis for the conceptual and organizational framework for this volume.

DEVELOPMENTAL SYSTEMS MODEL

The remainder of this chapter outlines the overarching framework for the Developmental Systems Model. This framework provides a rationale for many structural components and principles, with a strong developmental orientation. Next, each structural component of the model is discussed and its relationship to core and related principles as well as to the overarching framework is highlighted. This is followed by a discussion of steps and the type of leadership that will be required for this system to be developed and established. The final section discusses international perspectives for early intervention systems and the insights that such perspectives can provide with respect to the Developmental Systems Model or to other frameworks that may be put forward.

Overarching Framework

When considering the major experientially based influences on child development, the developmental science of normative development has identified that three types of family patterns of interaction are critical: 1) the quality of parent-child transactions, 2) family-orchestrated child experiences, and 3) health and safety- provided by the family (Guralnick, 1998, see Figure 1.1). Constructs associated with parent-child transactions have been extensively investigated, with demonstrated links either singly or in concert with child developmental outcomes. Most well established are the relationship constructs of reciprocating, being sensitive, providing effectively warm social exchanges, having- discourse-based interactions, and avoiding intrusiveness (e.g., Guralnick, in press-a; Landry, Smith, Swank, Assel, & Vellet, 2001; Landry, Smith, Swank, & Miller-Loncar, 2000; National Research Council and Institute of Medicine, 2000). Constructs in which families orchestrate specific experiences for their children also have been identified and have been consistently associated with child developmental outcomes. Providing developmentally appropriate materials, organizing activities compatible with the child's special interests or special needs, choosing quality child care, incorporating the child into family routines, and organizing social activities especially in connection with peers are examples of this family pattern of interaction (Bernheimer & Keogh, 1995; Bradley, Corwyn, Burchinal, McAdoo, & Coll, 2001; Ladd, Profilet, & Hart, 1992; NICHD Early Child Care Research Network, 2001).

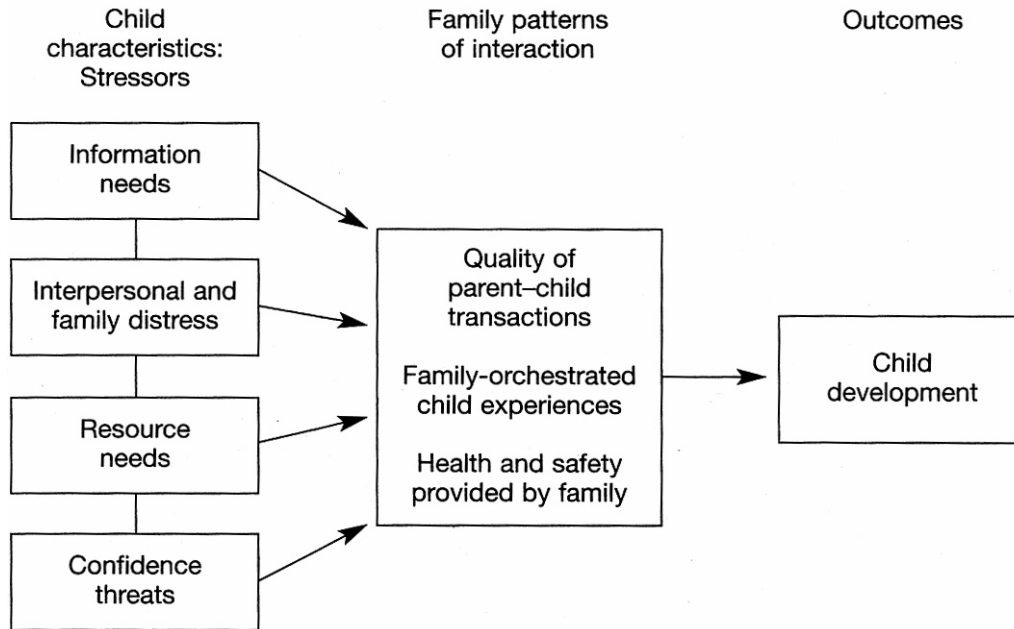


Figure 1.1. The relationships among potential stressors on families due to child characteristics, family patterns of interaction, and child developmental outcomes for children with a biological risk or those with established disabilities. (From Guralnick, M.J. [2000a]. *Early childhood intervention: Evolution of a system*. In M. Wehmeyer & J.R. Patton [Eds.]. *Mental retardation in the 21st century* [p. 40]. Austin, TX: PRO-ED; adapted by permission.)

The third family pattern of interaction addresses the health and safety needs of children. Parents are responsible for ensuring their children's well-being, the absence of which also poses significant challenges to other family patterns of interaction. Obtaining immunizations, providing adequate nutrition, and ensuring protection from harm are vital parental roles that have a potentially major impact on child developmental outcomes (Cicchetti & Lynch, 1995; Osofsky, 1995; Taylor, Zuckerman, Harik, & Groves, 1994).

Variations in family patterns of interaction can be considerable, and many reasonable pathways offer optimal developmental outcomes (Guralnick, in press-a; National Research Council and Institute of Medicine, 2000). Nevertheless, these relationships between family patterns of interaction and child developmental outcomes provide important details to guide the core principle of maintaining a developmental orientation in the Developmental Systems Model. More specifically, this orientation suggests that the central goal of early intervention for children who are at risk is to optimize these three family patterns of interaction. Child-focused therapeutic activities may be needed but are best considered among the experiences orchestrated by families. Relatedly, this overarching developmental framework for the Developmental Systems Model clearly indicates that it centers on families and that any interventions must similarly place families at the center.

Stressors to Family Interaction Patterns

When a child is born with a biological risk, such as being born prematurely with low birth weight, or when a child with an established disability enters a family, the developmental science

of risk and disability indicates that stress is placed on most if not all aspects of these three family patterns of interaction. As illustrated in Figure 1.1, the child-generated stressors that can perturb family patterns of interaction can take many forms. Information needs about a child's diagnosis and likely developmental patterns are of paramount concern to families early in the process. Accurate information and proper resolution of these issues are essential to ensure the quality of parent—child transactions as well as to maintain other aspects of family patterns of interaction (e.g., Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Pianta, Marvin, Brinier, & Borowitz, 1996). Later in the process, parents must make numerous decisions regarding intervention programs and activities and identify specialists sensitive to their needs (e.g., establish a medical home for their child). Evaluating these intervention options in the context of family life and routines is an important role for families, which can substantially affect family patterns of interaction (Bernheimer & Keogh, 1995). Similarly, interpersonal and family distress in the form of social isolation of the family, shared stigma, or negative emotional effects on families due to their child's developmental and behavioral problems can adversely affect numerous aspects of family patterns of interaction (Goffman, 1963; Krauss, 1993; Roach, Orsmond, & Barratt, 1999). More-over, a child with a biological risk or one with an established disability can require substantially increased resources. Financial stability can be affected, even with the availability of government-sponsored programs. Furthermore, families may confront considerable challenges with respect to caregiving and established family routines (Dyson, 1993; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). Clearly, this category of child-generated stressors, referred to as resource needs, can adversely affect family patterns of interaction. Finally, the cumulative impact of these child-related stressors can undermine the confidence of families in their ability to competently address the many child-specific and larger family issues that exist now or will arise in the future. Should such an attitude take hold in the family, it could have a pervasive and highly damaging influence on family patterns of interaction.

These are only a few examples of the challenges that families may contend with as a consequence of a child with a biological risk or one with an established developmental disability. Information needs, interpersonal and family distress, resource needs, and confidence threats can independently or jointly be of sufficient magnitude to stress one or more family patterns of interaction. When this occurs, optimal child developmental outcomes, above and beyond other factors influencing development, are compromised (see Guralnick, 1998, in press-a).

The operation of these processes is especially apparent for children with an established disability such as Down syndrome. The development of these children will clearly be adversely affected under any circumstances, but, as indicated, nonoptimal family patterns of interaction (i.e., due to stressors associated with child characteristics) can further contribute to children's developmental problems. Consequently, within this framework, the task of the early intervention system is to minimize or prevent these stressors from creating nonoptimal family patterns of interaction, thereby maintaining a family's strengths. This can be accomplished by first assessing stressors and then, where appropriate, working together with families to develop and implement an array of resource supports, social supports, and information and services. If carried out properly, then families will be strengthened in a manner that permits them to maintain as optimal a level of family patterns of interaction as possible (see Guralnick, 2004). When this occurs, evidence from intervention science suggests that child developmental

outcomes improve substantially (see Guralnick, 1997a, 1998).

The Developmental Systems Model attempts to be consistent with this framework. The assessment of stressors is a major component of the model, as is the provision of resource supports, social supports, and information and services linked to those assessments. The comprehensiveness of the early intervention program is especially critical, as the success of intervention will depend on the ability of the system to address the numerous issues that can stress family patterns of interaction. It is the cumulative impact that matters (see Guralnick, 2001a).

Environmental Risk

To this point, an assumption has been made that families possess the ability to generate optimal family patterns of interaction in the absence of stressors due to child characteristics. But, of course, many families are not so fortunate. Indeed, many family characteristics themselves can function to stress all aspects of family interaction patterns. Figure 1.2

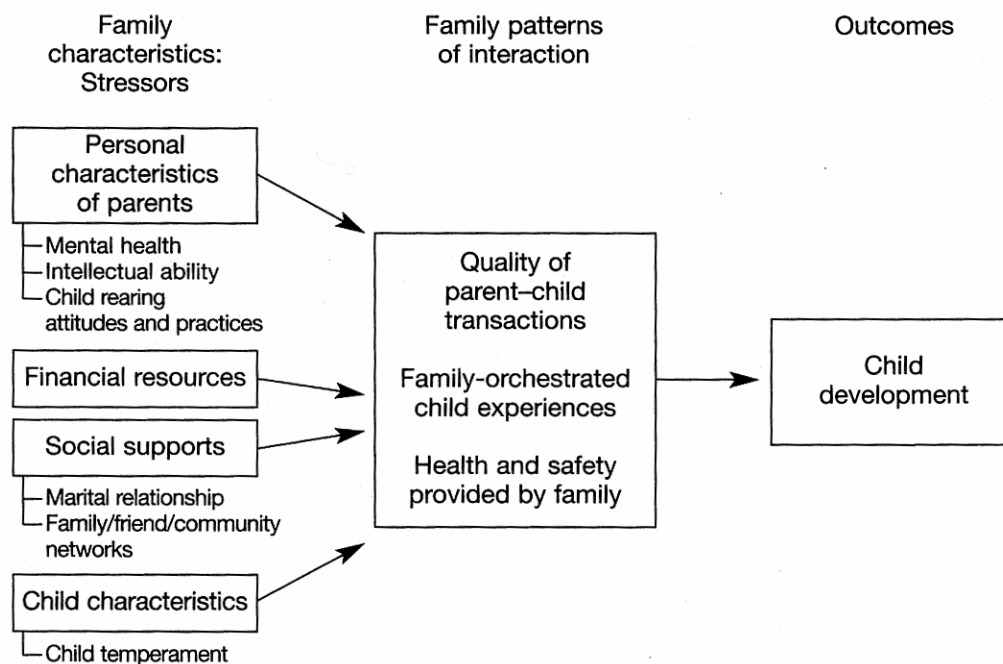


Figure 1.2. The relationship among potential stressors due to family characteristics, family patterns of interaction, and child developmental outcomes for children at environmental risk. (From Guralnick, M.J. [2001b]. A developmental systems model for early intervention. *Infants and Young Children*, 14[2], 3. Copyright © 2001 by Lippincott, Williams & Wilkins; reprinted by permission.)

illustrates this point. As indicated, personal characteristics of the family can be of considerable significance. More specifically, if a parent's mental health is compromised, especially if the

mother is depressed; if a parent's intellectual abilities are diminished; or if nonoptimal, usually intergenerationally transmitted, child-rearing practices are evident, then family patterns of interaction will clearly be perturbed (e.g., Feldman, 1997). Poverty, the absence of social supports, and even difficult child characteristics unrelated to the child's risk status or disability could create similar adverse effects (Crnic & Stormshak, 1997; Linver, Brooks-Gunn, & Kohen, 2002).

These family characteristics that can affect the three family patterns of interaction are often referred to as "risk factors" (Burchinal, Roberts, Hooper, & Zeisel, 2000; Sameroff, Seifer, Barocas, Zax, & Greenspan, 1987), suggesting that preventive intervention programs might be capable of at least minimizing adverse child developmental outcomes. The Developmental Systems Model includes a preventive intervention component. It also includes an assessment of stressors in connection with these family characteristics. Of importance, a comprehensive intervention program related to family characteristics has the same components as that for child characteristics that function as stressors to family interaction patterns (i.e., the provision of resource supports, social supports, and information and services). However, because of the unusual difficulties associated with adverse family characteristics, particularly difficulties in addressing serious parental mental health problems or issues related to chronic poverty, it is clear that interventions under these circumstances may well take substantially different forms. Primary among these approaches is intervention-oriented child care (Guralnick, 2000b). Nevertheless, the goal of strengthening families to maximize family patterns of interaction remains unchanged. Given the increasing association between adverse family characteristics, such as poverty and childhood disability (Bowe, 1995; Park, Turnbull, & Turnbull, 2002; Hanson & Carta, 1995), a comprehensive assessment of stressors stemming from both child and family characteristics will be needed in any early intervention system and will require a correspondingly comprehensive intervention program.

In summary, this section has attempted to integrate the developmental science of normative development and the developmental science of risk and disability into a coherent overarching developmental framework that has served as the foundation for the Developmental Systems Model. Experientially based mediators of child developmental outcomes (i.e., family patterns of interaction) have been identified and provide direction for early intervention systems design when those patterns are stressed either by child or family characteristics. The intent of the Developmental Systems Model (see the following summary of components) is to generate an approach consistent with the overarching developmental framework just described as well as with the core and related principles discussed previously in this chapter.

COMPONENTS OF THE DEVELOPMENTAL SYSTEMS MODEL

The key structural components and relationships among the components of the Developmental Systems Model are presented in Figure 1.3. Diamonds represent decision points, and rectangles represent activities. Each of the major components constitutes its own microsystem involving relationships with other components, a process to follow in order to establish and carry out goals and activities, and protocols and related tools to gather information and to guide decision making. As noted, each structural component is intended to be compatible with and to some degree represent the overarching developmental framework as well as the core and related

principles. This section briefly considers each component (see Guralnick, 2001b, for additional details) from an organizational perspective. Of note, the term community is used here in its most general sense and can be applied to an entire state, a single county, a designated service area, or any entity capable of incorporating all systems components. The central point here is that the Developmental Systems Model is intended to provide an overall framework for communities, including an organizational structure and corresponding principles, capable of guiding actual practices. There are issues and concerns associated with each component that must be addressed to properly implement the Developmental Systems Model from a practice perspective, and those are discussed next. For this model or any other approach to become a reality, however, the detailed functions of each component must be established and achieve some reasonable level of consensus. Accordingly, a major purpose of this volume is to begin that process with respect to the Developmental Systems Model.

Screening Program and Referral

The Screening Program and Referral component of the model is quite complex and is intended to be consistent with the principle regarding the importance of early detection and identification. For a variety of reasons, including the difficult task of integrating health, educational, and social services agencies in the process of screening and referral; concerns about the psychometric properties and cultural relevance of many screening tools; and the absence of a coherent cross-discipline approach to screening, community-based programs are highly variable (see Belcher, 1996). Important tools relying on parent reports are available (Bricker & Squires,

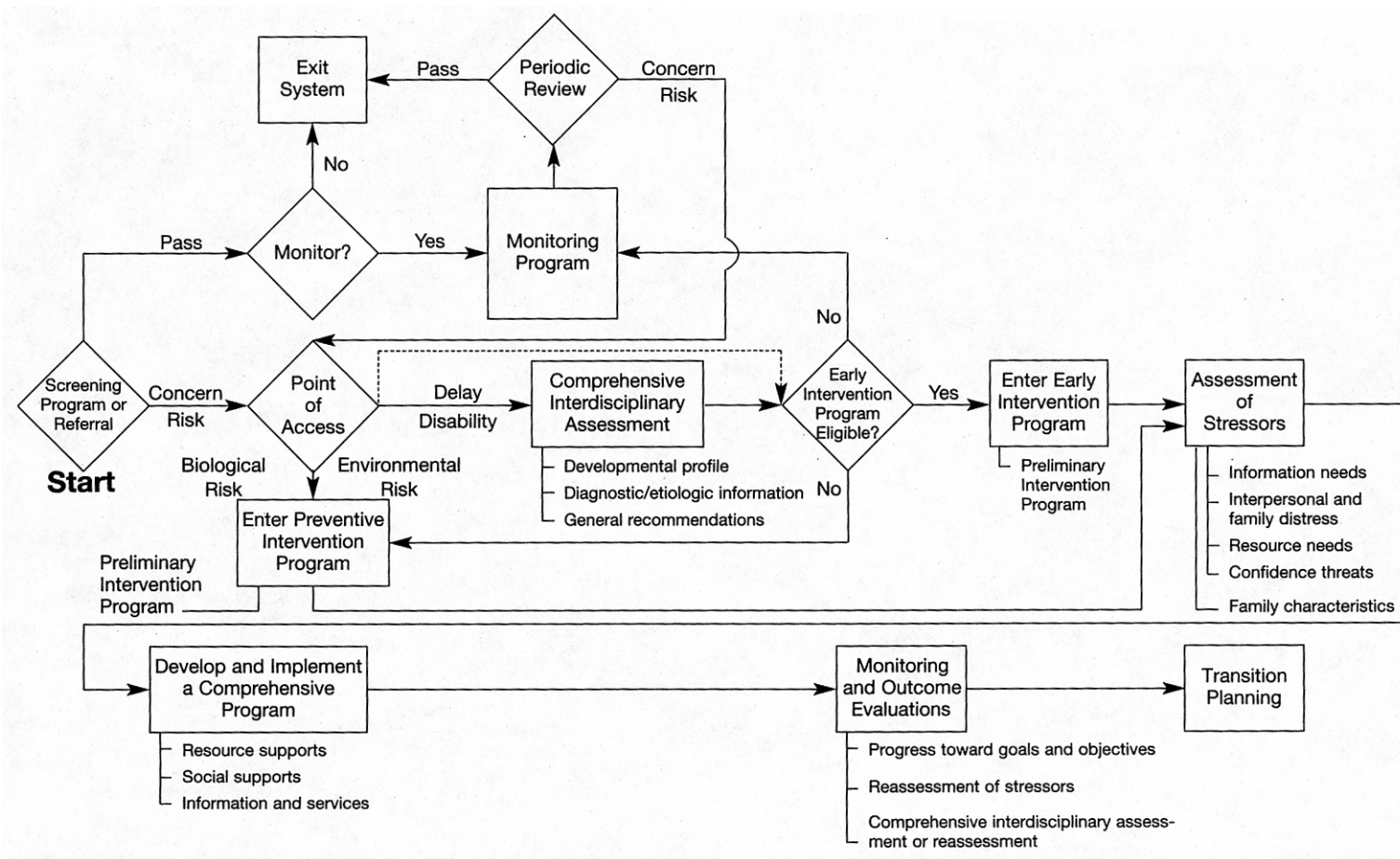


Figure 1.3. A developmental systems model for early intervention for vulnerable children and their families. (From Guralnick, M.J. [2001b]. A developmental systems model for early intervention. *Infants and Young Children*, 14[2], 4. Copyright © 2001 by Lippincott, Williams, & Wilkins; reprinted by permission.)

1999; Glascoe, 1998) as are well-developed protocols focusing on specific disabilities such as autism spectrum disorders (Filipek et al., 2000). Risk indices also are useful and available for the screening and referral process, despite considerable statistical uncertainty (Burchinal et al., 2000). Nevertheless, evidence-based practices certainly can be developed to guide the design of this microsystem for individual communities.

The creation of an effective and efficient community-based Screening Program and Referral component will require an extraordinary level of cooperation among relevant parties to reach decisions and implement practices regarding even fundamental issues such as whether to emphasize targeted or universal screening. How to best involve primary care health providers, what algorithms should be established to guide decisions for referral, and which instruments and related protocols should be selected to direct the entire activity remain key issues requiring resolution by communities.

Monitoring and Surveillance

A similar set of issues is relevant to the Monitoring and Surveillance component of the Developmental Systems Model. For children screened who do not meet referral criteria or who maintain some risk status, a decision must be made as to the degree of Monitoring (i.e., frequency, form, cost) and Surveillance required. Given the variability and ongoing vulnerabilities in children's development, decisions must be made on an individualized basis in accordance with well—thought-through protocols. Such comprehensive protocols remain to be developed.

Point of Access

When a concern about development reaches some criterion (including parental concerns resulting in self-referral) or risks to development are deemed high enough, entry to the next component in the model occurs in the form of a Point of Access to the early intervention system. At some location, the process of gathering, integrating, and coordinating information occurs, and families are introduced to the possible services and supports the system can provide. In addition, the way the Developmental Systems Model is currently constructed, a distinction is made at this point between children at biological and environmental risk for developmental problems and those already exhibiting developmental delays or disabilities. This distinction reflects current practice as systems for preventive interventions for risk conditions largely are functionally separate from systems focusing on children with documented delays or disabilities. This is not necessarily an ideal structure, and efforts are under way to address this issue at many levels. This distinction further suggests usually different Points of Access for these two groups of children and perhaps for other subgroups as well, even within local communities. Indeed, determining how many Points of Access should be available is an important community decision as Points of Access will vary with respect to size, complexity, comprehensiveness, family friendliness, and the like. Available evidence suggests that very few comprehensive community programs exist, including the component related to Points of Access, that thoroughly integrate child and family services for all children at this early stage in the process (Harbin et al., 2000). This includes both preventive and early intervention activities. Of note, the

way communities address Points of Access serves as an index of the overall level of integration and coordination of the service system in general—a core principle.

Comprehensive Interdisciplinary Assessment

For children with possible delays or disabilities, whatever the Point of Access, an important responsibility is to organize a Comprehensive Inter-disciplinary Assessment to obtain a general developmental profile for children, to evaluate aspects of family functioning, to gather information for diagnostic/etiologic purposes, and to make general recommendations (Guralnick, 2000c). This extremely valuable and complex assessment is often temporarily bypassed due to the need to move forward quickly or the limited availability of such comprehensive assessment teams in communities. In this case, a more streamlined assessment occurs with focused teams, often at the Point of Access. More formal interdisciplinary or single discipline assessments will follow as the need arises.

In view of the demands on the system for Comprehensive Interdisciplinary Assessments, communities must find ways to increase availability and increase the efficiency of teams. Moreover, the development of specialty teams for autism (Filipek et al., 2000) or metabolic disorders such as phenylketonuria (Trahms, Leavitt, Heffernan, & Garretson, 2000) must be included to optimize the effectiveness of this microsystem.

Eligibility

Whatever path is taken (see Figure 1.3), Eligibility decisions are made based on community-determined criteria, the next component of the model. This is the case for children entering the early intervention program (children with delays or disabilities) or those entering the preventive intervention program (based on biological and environmental risk factors). Two issues are important here. The first concerns the need for communities to ensure that those children not meeting Eligibility criteria remain in the system through the Monitoring and Surveillance component noted previously. Second, strong consideration should be given toward establishing consistent Eligibility criteria across states and certainly within states. To be sure, this decision will carry important financial implications, but having common Eligibility criteria is compatible with the spirit of IDEA '97 and addresses important issues of equity.

Assessment of Stressors

Once families enter the Intervention component (either preventive or early intervention), they will usually begin to receive services and supports immediately based on available information in what is generally referred to as a preliminary intervention program. This program, however, is modified and refined as the Assessment of Stressors component is implemented. In many respects, this component is at the heart of the Developmental Systems Model and embraces many of its principles. It most clearly reflects the overarching developmental framework, especially the focus on families; it sets the stage for the highly individualized nature of the Comprehensive Intervention Program to come; and it tests our ability in a very direct way to be

sensitive to cultural differences in the formation of parent—professional partnerships. For this component to be effective, processes and protocols must be available to guide professionals in their interactions with families. Determining families' information needs, possible interpersonal and family distress, resource needs, or threats to their confidence to parent appropriately, as well as obtaining information about relevant family characteristics, is a complex and challenging task. If not carried out well, however, then the entire early intervention enterprise is jeopardized because the Assessment of Stressors is the key to ultimately supporting families to enable them to create optimal family patterns of interaction.

Develop and Implement a Comprehensive Program

Discussions between families and professionals about service options during the Assessment of Stressors component (information needs) certainly require knowledge of evidence-based practices. But this principle is most critical when families and professionals become involved in the component of the model referred to as Develop and Implement a Comprehensive Program. Together, a plan specifying resource supports, social supports, and information and services thoughtfully tailored to the stressors identified earlier must be developed in an effort to minimize the stress on family patterns of interaction. If carried out properly, then the plan will fit well within family routines and maximize active family participation where appropriate. Professionals must be particularly thoughtful here in applying the core principles of developmental framework, inclusion, and integration and coordination for this component to be effective. Much can be lost in the implementation phase. The availability of decision-rules for individualizing would be helpful as well, but substantial deviations from this principle are not likely by this point in the process.

Monitoring and Outcome Evaluations

Ensuring the effectiveness of any early intervention system requires an array of well-designed monitoring and evaluation approaches. As the principle requiring a strong evaluation and feedback process indicates, evaluation must occur at many levels, including evaluating progress toward goals and objectives, determining when it is necessary to reassess stressors, and deciding when comprehensive interdisciplinary assessments or reassessments are needed. Structurally, this constitutes the Monitoring and Outcome Evaluations component of the Developmental Systems Model.

Evaluation at the systems level is also important as effectiveness depends on the ability of the components of the system to link together. It is also critical to validate whether the core and related principles are being realized for each of the systems components. Parent reports, self-evaluation protocols for administrators and early intervention professionals, or external evaluations are relevant strategies for this important component of the Developmental Systems Model. Much needs to be developed for this component of the model.

Transition Planning

The final component of the model is Transition Planning. Such plans are essential because the developmental and behavioral patterns of children who are vulnerable are highly fragile and easily disrupted. Ensuring continuity and creating as seamless a transition as possible are vital. Transition can take many forms, including the shift from infant—toddler to preschool programs, when children move to an inclusive child care program, or when the transition is made from preschool to kindergarten. Numerous strategies are now available to maximize the effectiveness of this component (Pianta & Cox, 1999; Sainato & Morrison, 2001) but need to be developed further to enable communities to adopt and adapt these strategies to meet their needs.

PURPOSE OF THIS BOOK

Prior publications presented the conceptual foundations (Guralnick, 1998) and the organizational structure and supporting principles (Guralnick, 2001b) for the Developmental Systems Model. This volume enables communities to begin to apply the model in practice to their system of early intervention. The conceptual framework, organizational structure, and guiding principles provide an invaluable context for practical application, but of course, the translation process remains a highly complex undertaking. Numerous reasonable practice alternatives exist for each decision point (diamond) and activity (rectangle) in the model (see Figure 1.3), and clinical experience must always be factored into all decisions. However, because early intervention practices in far too many communities do not appear to have evolved into coherent systems, the availability of a specific approach such as the Developmental Systems Model may at least serve as a catalyst for communities to examine carefully their own approaches and practices. Considerations by communities, clusters of communities, state-level agencies, and even national organizations of strategies to improve the system of early intervention services and supports will certainly be to the advantage of children who are vulnerable and their families.

Accordingly, the purpose of this volume is to provide the next level of specificity for the Developmental Systems Model for early intervention. In Section I, Principles, the core principles of the Developmental Systems Model are discussed, including the overarching developmental framework, coordination and integration (see Chapter 2), and inclusion (see Chapter 3). In Section II, Practices: National Perspectives, each of the key components of the Developmental Systems Model is discussed to provide more specific guidance for communities in the United States wishing to further develop a particular component or to examine their current practices. In some instances, broad guidance is provided; in others, specific protocols and instruments are suggested. Efforts to build on and integrate knowledge, along with specific recommendations for communities, can be found for each structural component.

The component now referred to as Screening and Surveillance in early intervention systems (a combination of the screening and monitoring components illustrated in Figure 1.3) is addressed in the first chapter in Section II (see Chapter 4). This is followed by discussions of Points of Access (see Chapter 5) and Comprehensive Interdisciplinary Assessments (see Chapter 6). Given the central role of assessing stressors that may perturb family patterns of

interaction in the Developmental Systems Model, four separate chapters focus on different stressors. This includes the child-related stressors of Information Needs of Families (see Chapter 7), Interpersonal and Family Distress as well as Threats to Confident Parenting (see Chapter 8), and the Resource Needs of Families (see Chapter 9). The Assessment of Family Characteristics that can serve as stressors completes this group of chapters (see Chapter 10). The final four chapters (Chapters 11—14) are concerned with the actual intervention features of the early intervention system. Chapters include Developing and Implementing Preventive Intervention Programs for Children at Risk, Developing and Implementing Early Intervention Programs for Children with Established Disabilities, Monitoring and Evaluation in Early Intervention Programs, and Ensuring Effective Transitions in Early Intervention.

It is important to emphasize that the information contained in this volume is merely designed to provide additional guidance for communities and will require considerable decision making and further development by individual communities for proper translations to practice to occur. For those communities interested in pursuing this model at the detailed implementation level, a process should be initiated among all relevant constituencies to examine their own practices using the Developmental Systems Model as a framework. If leadership were provided at the state level, then existing State Interagency Coordinating Councils would be most appropriate. If not, then local communities or clusters of communities around which early intervention services are organized could provide the leadership. It is hoped that when these planning groups complete their work, they will have selected specific protocols, instruments, and processes for each of the system components and ensured that the early intervention principles are thoroughly integrated within each component. It also is hoped that many of the suggestions made by experts in the various chapters of this volume will be of value and translate well to this next implementation level. But even if specific recommendations are not selected, communities in their deliberations certainly should consider the rationale for these suggestions.

Clearly, such a process will not result in a uniform set of services and supports across all communities. As noted previously, that is not the goal of the Developmental Systems Model, nor is it desirable. Yet, explicit or implicit adherence to specific conceptual approaches, organizational structures, and principles matters, as together these approaches, structures, and principles constitute a system of early intervention that influences the developmental course of young children who are vulnerable. Consequently, thoughtful development of a system of early intervention should be a high priority for every community.

Section III of this volume, Practices: International Perspectives, provides a discussion of various aspects of the Developmental Systems Model from international viewpoints. Leaders in early intervention in their respective countries have agreed to describe critical components of their early intervention systems and to relate them, wherever possible, to the conceptual framework, organizational structure, and principles of the Developmental Systems Model. Differences in history and culture make this country-by-country analysis especially interesting and instructive. Experts from Australia (Chapter 15), Austria (Chapter 16), Canada (Chapter 17), the United Kingdom (Chapter 18), Greece (Chapter 19), Israel (Chapter 20), Italy (Chapter 21), Spain (Chapter 22), Sweden (Chapter 23), and developing countries (Chapter 24) provide unique insights into the design of early intervention systems. Nowhere is the need for flexibility in systems more apparent than in these chapters.

Despite vast differences in early intervention systems across countries, efforts are under

way to bring professionals around the world together to share ideas and debate the issues. Perhaps the major forum for this is the International Society on Early Intervention (ISEI; <http://depts.washington.edu/isei/>), now representing professionals from 75 countries. Because many of the chapter authors in this section are active in ISEI, further discussions of global approaches to early intervention are assured, as this will continue to remain a topic of considerable importance as part of ISEI's Internet communications network, its formal publications (of which this volume is a part), and its conferences that bring people together for more intensive discussions. This exchange of ideas will certainly inform the Developmental Systems Model or other systems approaches to early intervention.

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