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Family Investments in Response to the Developmental Challenges of Young Children with Disabilities

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Virtually all parents have concerns about their child's development at some point. Major developmental milestones are keenly anticipated, and parents are acutely sensitive to the reports by friends and relatives of the course of development of other children. Indeed, parents often compare their own child to those reports, to observations of their child's peers, and to memories or records of their child's siblings' growth and development. Moreover, their child's adjustments or reactions to novel or challenging circumstances are often scrutinized for signs of precocity, as a window to help them understand emerging personality, or as a signal that not all may be well.

For the most part, any developmental concerns that arise constitute only minor tensions compared with the sheer pleasure of the parent-child bond and parents' appreciation of their child's emerging capabilities. However, sometimes concerns warrant professional consultation, a process that can forever alter the life course of all family members.

This process generally begins with professional assessment and diagnosis, with evaluations focusing on the various domains of a child's health and development. To varying degrees, children's cognitive, language, socioemotional, motor, and sensory development are examined. If developmental problems are detected

during early childhood in one or more domains, categorical labels may be applied, such as cerebral palsy, developmental (cognitive) delay, specific language impairment, autism disorder, or deafness. Occasionally, etiologic information also is generated as genetic or infectious causes may be identified, but more often than not etiologic information is problematic and speculative. The assigned labels carry important information but, of course, fail to describe the complexity of the child's characteristics and how relationships and parenting tasks will be irrevocably altered.

For young children with an established developmental disability—that is, when the developmental problems identified are likely to be substantial and life-long—varying levels of services and supports over time, that generally involve professionals from multiple disciplines, will be required. The family must now adjust to a set of unexpected and uncertain issues that will affect all family members and virtually all aspects of home and community life.

This chapter offers a developmental framework to help understand the adjustments families must make to accommodate a young child with an established developmental disability. This discussion reveals the tasks and demands facing parents who are seeking to optimize their child's development. The extent of the adjustments parents must make to maximize their child's development is also discussed. The reallocation of time, energy, and resources to accommodate their child requires careful analysis within the broader family context. Finally, the willingness of parents to take advantage of early interventions is examined in conjunction with a commentary on how government-sponsored early interventions can be designed to support appropriate parental adjustments and thereby optimize children's development.

DEVELOPMENTAL FRAMEWORK AND PARENTING INVESTMENTS

Most parents display an intrinsic interest in and natural instinct for supporting and promoting their child's development. For optimal results, however, parents must invest considerable and sustained psychological and material resources (see Bornstein, 2003). Much is known about which resources are important and how to organize those resources to promote children's development (e.g., Belsky, 1984; Bronfenbrenner, 1979; Dunst, 1985; Sameroff, 1993). However this occurs, it is clear that investments must relate to specific family patterns of interaction. There are three categories of family interaction that can be applied generally to both typical development and conditions related to risk and disability: (a) the quality of parent-child transactions; (b) family-orchestrated child experiences; and (c) health and safety provided by the family (Guralnick, 1998; see Fig. 5.1).

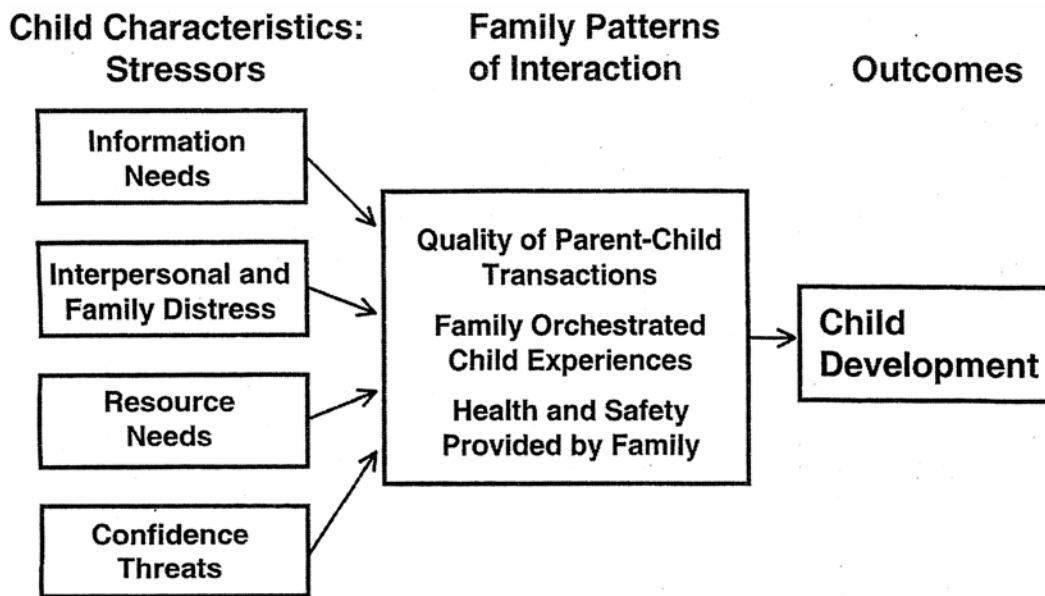


FIG. 5.1. Figure slightly modified from "Early Childhood Intervention: Evolution of a System" by M. J. Guralnick, 2000, in M. Wehmeyer and J. R. Patton (Eds.), *Mental retardation in the 21st century*. Copyright © 2000 by PRO-ED, Inc. Reprinted with permission.

The first category, parent—child transactions, consists of interactions that appear to govern critical aspects of children's cognitive and social competence (Bornstein & Tamis-Lemonda, 1989; Landry, Smith, Swank, Assel, & Vellet, 2001; Landry, Smith, Swank, & Miller-Loncar, 2000; National Research Council, 2000; Wachs, 1992). These interactions include the sensitivity and responsiveness of the parent, the ability to scaffold tasks in an affectively warm and nonintrusive manner, and the ability to engage in discourse-based interactions.

Recent research on responsive parenting provides insight into both the complexity of these interactions and the persistence and vigilance required of parents to maximize their child's development (e.g., Landry et al., 2001). Perhaps most important, these recent findings provide strong evidence that the work of supportive and responsive parenting must occur in many contexts as part of the various daily routines and be consistent over time. Given the demands of everyday contemporary life, this can be quite a challenge.

The second family pattern of interaction that directly influences child development is family-orchestrated child experiences. These include providing developmentally appropriate toys and materials and organizing social experiences that are stimulating and that extend the advantageous parent—child transactions previously noted. Introducing the child to the parents' social network is an example. It may also mean selecting an appropriate childcare environment if both parents are working. Appropriate childcare is an important decision, given that the

quality of caregiver–child transactions affects children's cognitive and social competencies in ways similar to that of parent–child transactions (NICHD, 2001).

Many parents also promote their child's social development by encouraging relationships with peers. These investments often involve significant levels of supervision. The result, however, can be improved peer relationships for their child (Ladd, Profilet, & Hart, 1992). Optimal development also requires parents to invest considerable energy and time in finding experiences that match their child's special interests, talents, and needs. Beyond attentiveness to their child's emerging interests or sensitivity to often subtle developmental concerns, parents may require professional assistance and guidance. For children experiencing substantial developmental problems, investing in special programs may be critical for maintaining or perhaps restoring optimal family patterns of interaction. This is discussed later in this chapter.

The third family pattern of interaction affecting child development involves the ability of the family to ensure the health and safety of their child. For example, protecting their child from experiencing or even witnessing violence, although difficult to accomplish in many circumstances, constitutes a fundamental task with important developmental consequences (e.g., Osofsky, 1995). Other parent actions include obtaining proper immunizations, accessing health care as needed, and providing adequate nutrition. Although the mechanisms involved governing the relation between nutrition and child development are complex, failure to provide proper nutrition to young children is likely to result in less than optimal development (Georgieff & Rao, 1999; Gorman, 1995).

Taken together, these three family interaction patterns are viewed as essential to optimal social and cognitive competence of young children. The resultant social and cognitive competencies can then be employed in fostering children's individual and culturally relevant goals. It must be admitted, however, that a full understanding of how these family patterns of interaction exert their influence, including how they interact with one another and the number and extent of family activities and routines in which they must be implemented to achieve the anticipated developmental benefits, remains to be achieved. Similarly, there is a need to refine our measures of these constructs, particularly as development unfolds, and to determine whether other higher order dimensions may emerge as more valid constructs of these three family patterns of interaction. Nevertheless, the proximal patterns identified to date appear to matter. Evident as well is the fact that, despite parents' natural tendencies and inclinations to do so, gathering and deploying resources in connection with these family patterns of interaction is a complex and demanding task for all families.

PARENTAL CHALLENGES WHEN CHILDREN HAVE A DISABILITY

The developmental and behavioral patterns of children with disabilities create unusual and often perplexing difficulties for families at every level. Not only do typical and expected interaction patterns between parents and children often fail to be realized, but families also begin to consider the broader and longer term implications of having a family member with a developmental disability. It soon becomes apparent that they must consider special issues with respect to the nature of parent—child transactions, the types of family-orchestrated child experiences, and the health and safety concerns of their child with an established disability.

The developmental science of risk and disability has carefully documented these challenges to optimal family patterns of interaction (Guralnick, 1997; Shonkoff & Meisels, 2000). Viewed within the developmental framework outlined earlier, children with established disabilities have the potential to create a set of stressors that can perturb family patterns of interaction and further compromise child development. These potential stressors of family patterns of interaction generally take four forms (see Fig. 5.1).

First, parents require considerable information, the absence of which can easily adversely affect all three family patterns of interaction. Parents usually initially grapple with the diagnostic and assessment process, a complex sequence of events that can be frustrating and distressing (Carmichael, Pembry, Turner, & Barnicoat, 1999). Failure to adequately come to terms with a diagnosis can result in relationship difficulties with long-term negative implications for a child's development (Pianta, Marvin, Britner, & Borowitz, 1996).

On a day-to-day basis, the quality of parent—child transactions is stressed by numerous child characteristics. Discrepancies between children's receptive and expressive language, unusual affective patterns, or their child's under- or overactivity leave many parents wondering how best to promote their child's development. Children with established disabilities often have problems with emotional expressiveness, joint attention and social referencing skills, initiating social interactions, responsiveness to others, and they can exhibit unusual behavior problems (Spiker, Boyce, & Boyce, 2002). These patterns are complex and vary widely by individual, even among children with the same identified disability (Guralnick, 2002). Moreover, certain subgroups of children, such as those with autism, pose special relationship challenges, whereas those with sensory impairments require families to become knowledgeable about technical supports for their children. Certainly, not all of the developmental challenges to parental interaction are fully recognized by families, but parents are well aware that substantial information and corresponding adjustments are needed to optimize parent—child transactions.

Information needs can seem never-ending, extending well beyond day-to-day parent—child interactions. Perhaps most significant is the need to orchestrate an

array of coordinated supports and services that families now face. Seeking out the best professionals and programs, including daycare, is a task that can consume the considerable energies of most families. Information is also needed as families involve their child in their own social network. For example, the family must consider which details of their child's disability should be provided to friends and family members. Similarly, information is needed about the numerous health and safety issues that are certain to arise.

A second category of potential stressors is interpersonal and family distress. Family members, including siblings, soon realize that changes in family routines are necessary, and parents may not entirely agree on how to address fundamental issues that arise (e.g., whether to enroll their child in an inclusive or specialized early intervention program). Social isolation from friends and family can easily occur for many reasons, not the least of which is the family's feeling that somehow they share the stigma related to their child with a disability (Coffman, 1963).

Characteristics of children with disabilities are clearly associated with perceived parental stress (e.g., depression, role restriction, competence threats; Roach, Orsmond, & Barratt, 1999), with child behavior problems often being the most disruptive (Baker, Blacher, Crnic, & Edelbrock, 2002). Contemplating the long-term implications of the child's quality of life can be distressing as well. Taken together, increased interpersonal and family distress can be debilitating, distracting, and isolating, resulting in less than optimal family patterns of interaction.

Resources needs, the third category of potential stressors, emerge in many forms. Increased expenses for health care or certain types of professional services can rapidly become overwhelming even for families with reasonable financial resources. The disrupted daily routines and the additional time demands needed for therapeutic services also can become a constant source of problems for families. The search for respite care becomes a high priority.

Finally, all of these stressors can combine to threaten the confidence parents have in their ability to effectively parent. This shaken confidence (the fourth category of potential stressors) can undermine all aspects of family patterns of interaction, creating a sense of helplessness. A family's sense of mastery and control remains a critical element in the development of all children (Affleck & Tennen, 1993).

RESPONSES AND INVESTMENTS BY FAMILIES TO ADDRESS STRESSORS

The cumulative effect of these four types of stressors on children's development is to produce or contribute to a decline in cognitive and social competence during the first few years of life (Guralnick, 1998; Sameroff, Seder, Barocas, Zax, & Greenspan, 1987). That is, without addressing these stressors, one or more of the family patterns of interaction will be perturbed enough to alter the optimal course

of child development. Of course, children's developmental delays and disabilities have substantial effects on all aspects of competence, reflected in their lower developmental trajectories. Nevertheless, stressors affecting family patterns of interaction appear to contribute to additional developmental delays. Fortunately, most parents soon become aware of the potential impact of these stressors, and generally recognize the need to seek additional resources, to solidify or expand social supports for the family, and to obtain information and services about their child's unique developmental needs.

At the same time, however, parents must consider how these new activities related to their child's disability affect family life in general. Indeed, it has been argued that a major goal of families is to create or maintain "a sustainable and meaningful daily routine of family life" (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993, p. 186). Within this framework, it is these routines that create the context for family activities relevant to development and, more generally, for expressing family goals and values (Gallimore, Keogh, & Bernheimer, 1999). It is the types of new activities families choose to engage in (or accommodations they may or may not make) in connection with stressors that reflect these larger family goals and values; many of which may be competing with one another (Gallimore, Weisner, Kaufman, & Bernheimer, 1989).

Analyses of interview data with 102 families of young children with nonspecific developmental delays reveal the responses or accommodations families make. Based on previous work (Gallimore et al., 1989; Weisner, 1984), the following 10 domains of accommodation were identified: (a) family subsistence and financial base; (b) accessibility of health and educational services; (c) home and neighborhood safety and convenience; (d) domestic tasks and chore workload for the family; (e) childcare tasks; (f) child playgroups and peers; (g) marital role relationships; (h) social support; (i) father's role; and (j) sources of parental information and effort to obtain this information. The coding system required that accommodations be specifically linked to a response to their child with a disability. Examples of these accommodations are presented in Table 5.1.

TABLE 5.1
Domain Example

Family subsistence	Hours worked; flexibility of work schedule; adequacy of financial resources; amount of coverage provided by medical insurance
Services	Availability of services; eligibility for services; sources of transportation; amount of parent involvement required
Home/neighborhood safety and convenience	Safety and accessibility of play area; alterations in home (installation of locks, fences related to safety concerns); choice of particular neighborhood
Domestic workload	Amount of work that needs to be done; persons available to do it; amount of time spent by different family members
Childcare tasks	Complexity of childcare tasks; presence of extraordinary childcare demands (medical problems, behavior problems); number and availability of caregivers
Child peer group	Child's play groups (children with disabilities vs. typically developing children); amount of parent supervision needed; role of siblings as playmates
Marital roles	Amount of shared decision making regarding child with delays; degree to which childcare and household tasks are shared
Instrumental/emotional support	Availability and use of formal (church, parent groups) and informal (friends, relatives) sources of support; costs of using support
Father/spouse role	Amount of involvement with child with delays; amount of emotional support provided
Parent information	Reliance on professional versus nonprofessional sources of information; amount of time and effort spent accessing information

Note. From "Weaving Interventions Into the Fabric of Everyday Life: An Approach to Family Assessment" by L. P. Bernheimer and B. K. Keogh, 1995, *Topics in Early Childhood Special Education*, 15, 415-433. Copyright © 1995 by PRO-ED, Inc. Reprinted with permission.

Overall, the research identified an average of nearly seven accommodations per family (Gallimore et al., 1993). As might be expected, there was substantial variability in the accommodations, but all 10 domains were affected. Of considerable importance is that social support, childcare tasks, and sources of information were identified by approximately 75% of the families as producing either moderate or high levels of accommodation.

RESOURCE SUPPORTS, SOCIAL SUPPORTS, AND INFORMATION AND SERVICES

The three most common domains that emerged from the analysis of these families seem to confirm that families accord high priority to expanding or maintaining social supports, to obtaining resource supports, and to gathering information and obtaining services. The critical point is that all of these accommodations constitute investments that have at least the potential to reduce the stressors that can alter optimal family patterns of interaction (Guralnick, 1998).

More specifically, participation in parent-support groups for families of children with disabilities can be extremely valuable but is often time consuming and psychologically demanding (Krauss, Upshur, Shonkoff, & Hauser-Cram, 1993; Santelli, Turnbull, Sergeant, Lerner, (Sz. Marquis, 1996). This more formal form of social support complements the informal accommodations involving family members and friends to provide both instrumental and emotional forms of support (Crnic & Stormshak, 1997; Dunst, Trivette, & Jodry, 1997). Information regarding child-rearing advice can also be considered a form of social support. Indeed, many parent-to-parent groups are a source of highly technical information about disability issues.

Childcare tasks increase in complexity, generally requiring additional caregivers or caregiver time. Sometimes such help can be found within families (e.g., accommodations by siblings or grandparents, flextime at work), but more consistent and extensive caregiver assistance is needed when both parents are employed outside the home. Locating high-quality, affordable, and competent childcare is a major task for most parents given that it ultimately affects both the financial status and career plans of family members. But as Kelly and Booth (2002) pointed out:

Parents of children with disabilities face additional challenges of finding care that is accommodating to their child's special needs, overcoming barriers to inclusive practices in child care settings, finding trained care providers to care for their children, and coordinating other special services with their children's child care arrangements. (p. 71)

As might be expected, parents report substantial difficulties finding satisfactory childcare arrangements for young children with disabilities (Booth & Kelly, 1998). The commitment of time and energy to select an appropriate caregiver and coordinating special services is considerable. Many families make a different type of accommodation with respect to the domain of childcare as more mothers of infants with disabilities choose to postpone work or not return to school. This constitutes a clear investment toward the child with a disability and away from themselves and, indirectly, other family members (Booth & Kelly, 1998). During the child's first year of life, caregiving primarily occurs in the home by mothers, fathers, relatives, or nonrelatives. The quality of care is usually higher in these home settings than in childcare homes or childcare centers (Booth & Kelly, 1998; Kelly & Booth, 2002). Even as children with disabilities become older, in-home care provided by a relative or baby-sitter is preferred by parents (Warfield & Hauser-Cram, 1996). These arrangements are complex and shifting—balancing career goals, financial needs, and the responsibilities of family members, yet trying to ensure that the child with a disability receives proper care, developmental stimulation, and supports.

The third frequent accommodation by families—seeking information related to their child's disability—is an ongoing process. Gathering information to enable more optimal family patterns of interaction and help families explain the situation to others continues to be a high priority (Mahoney & Filer, 1996). Inevitably, the information leads families to seek out a range of services for their child.

INVESTMENTS IN EARLY INTERVENTION PROGRAMS

Some families make these accommodations independently, including service-related accommodations, recognizing needs, and then identifying service agencies, family members, friends, employers, or professionals to assist them. These families have the resources and problem-solving ability to do so, particularly when the accommodations required are relatively modest. Most families, however, take advantage of state-administered early intervention programs authorized as part of the federal Individuals with Disabilities Education Act (IDEA). Part C of that act provides families of eligible infants and toddlers with a comprehensive array of services and supports at no or modest cost, including assessments, information on developmentally oriented and disability topics, therapies, and related interventions. In many respects, these programs can point to beneficial accommodations that the family may not have considered, was not certain could be done, or felt were beyond their resources.

A number of important principles guide the design of these early intervention programs, including maximizing child and family participation in natural

environments or inclusive activities, and ensuring that intervention is family-centered such that partnerships with families are formed to strengthen a family's ability to provide a more optimal developmental environment for their child. That is, both family and child needs are considered in developing an intervention plan. In fact, the intent is consistent with providing families with an array of social supports, resource supports, and information and services. As such, the comprehensiveness of the services and supports and their coherent coordination is emphasized. Home and center-based programs are available, and many specialists can be involved.

The plan is realized through a jointly agreed on Individualized Family Service Plan (IFSP). Continued interventions are available when children reach preschool age, although the focus shifts primarily to child-oriented services through an Individualized Educational Program (IEP).

Particularly for the infant/toddler program of IDEA, family participation in early intervention is a major and sometimes extraordinary investment. Administrative, planning, and progress review meetings regarding IFSPs (or IEPs) can be time-consuming and demanding, but proper planning and monitoring are critical for their success (Shonkoff & Hauser-Cram, 1987). Being available for home visits, transporting their child to center-based activities, actively participating in therapeutic activities, involving themselves in parent groups, sifting through often contradictory information to select the most reasonable intervention program, and even advocating for more intensive or different services are common for parents participating in IDEA.

Taken together, families generally seek out resource supports, social supports, and information and services. Although their approaches may differ, families are usually responsive to stressors that can alter optimal family patterns of interaction, and are therefore working to prevent or minimize adverse effects on their child's development. To be sure, the interests of family members or broader family goals and values often compete with accommodations that would minimize stressors (Gallimore et al., 1989). Nevertheless, families are generally creative in making accommodations and organizing family routines in a manner that supports their child's development (Fiese, 2002; Gallimore et al., 1993; Kellegrew, 2000). Many families address these stressors entirely within the framework of IDEA. Even addressing sensitive and complex family issues of social isolation, depression, or marital discord are within the boundaries of IDEA, at least for infants and toddlers. Families also supplement services and supports within IDEA through other professional and personal relationships (Kochanek, McGinn, & Cummins, 1998; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). However this is accomplished, these family investments can substantially influence their child's development in a manner consistent with the developmental model that is the framework for this discussion. Of course, even with well-planned and comprehensive early intervention programs, effects range from minimal to dramatic depending on the type of child disability, intervention quality, and active

family participation (Guralnick, 1997). Nevertheless, effect sizes for well-designed programs average .50 to .75 SD, and are capable of minimizing or preventing entirely the decline in development that usually occurs in the absence of these interventions (Guralnick, 1998).

DETERMINANTS OF PARENTAL INVESTMENT

The range of parental investment in children with disabilities is extensive (see Shonkoff et al., 1992). Some families respond to a diagnosis of a disability by devoting all their time and energy to promoting their child's health and development. These parents seek out and absorb as much information as possible and involve their child in numerous medical and behavioral therapies, sometimes choosing therapeutic approaches that are highly questionable from a scientific perspective. Other parents, even those with considerable resources, take little initiative, seeking only limited information and enrolling their child in only the most basic of services.

Even beyond these extreme and unusual responses, many forces compete within the family accommodations and routines. In fact, career aspirations, financial exigencies, or concerns about devoting sufficient time and resources to other family members can lead to decisions that may not optimize family patterns of interaction.

We do know, however, that several family characteristics are associated with parent involvement in organized early intervention programs. As noted, full participation in these programs requires considerable investment in all its forms. Gavidia-Payne and Stoneman (1997) developed a structural equation model linking family education and income, social supports, stress (hassles and depression), coping (turning to religion, absence of denial, being problem focused), marital adjustment, and family functioning to parental involvement in early intervention programs. Parental involvement was indexed in a number of ways: (a) through parental attendance at IFSP or IEP meetings and attendance at workshops and related activities designed to help parents select appropriate services for their child; (b) through knowledge of their child's disability and laws governing services and supports; and (c) through parental cooperation in various projects, particularly in learning how to support their child's developmental goals in the home. Although models for mothers and fathers differed somewhat, parents with higher levels of education, more financial resources, lower stress levels, more active and diverse coping strategies, greater support from spouse, friends, and relatives, and stronger religious affiliations were more involved in early intervention programs for their children. Relations were complex but reflected important interactions among these family characteristics. For instance, family

demographics (family financial income and educational levels) contributed indirectly through better family functioning and reduced stress, but also constituted an important direct path to involvement in early intervention. Social supports appeared to play an especially important role in coping strategies. In fact, the various forms of cognitive coping were important mediators of parental involvement.

The exact interrelations among family characteristics and parental involvement in early intervention remain to be determined. Nevertheless, these patterns and related research suggest that families with fewer resources and more difficulties overall are simply less able to engage in a process that requires consistent and organized involvement. Although families with limited resources tend to enroll their children in early intervention programs (Hebbeler, Wagner, Spiker, Scarborough, Simeonsson, & Collier, 2001), program effects are likely to be limited, given that child-focused programs for infants and toddlers are usually of low intensity, averaging only a few hours per month (Shonkoff et al., 1992). More-over, the families themselves are unlikely to compensate for this lack of involvement.

As is well known, limited financial resources, low social support, marital stress, and limited education are among the family risk factors associated with adverse child developmental outcomes (Burchinal, Roberts, Hooper, & Zeisel, 2000; Sameroff et al., 1987). Of importance, these family risk factors adversely influence the same three family patterns of interaction that influence child development outcomes, thereby further increasing the vulnerability of children with established developmental disabilities (Guralnick, 1998). As a consequence, the lack of parent participation in early intervention is certain to substantially limit child developmental outcomes within the current approach to intervention services. Comprehensive services and supports and family involvement are critical elements in any successful intervention program.

Individual differences in parental investments may also reflect the extent to which both formal and informal early interventions are consistent with broad family goals, priorities, and routines (Bailey et al., 1998; Filer (St. Mahoney, 1996; Gallimore et al., 1993). This issue of consistency is likely to arise in many circumstances, including when families receive recommendations from an individual therapist or when participating in the IFSP or IEP early intervention program. As Bailey and colleagues (1998) pointed out, it would be especially helpful if family perceptions of the early intervention experience could be obtained with respect to their influence on both child development and well-being and family life. Without positive expectations or perceptions, the likelihood of incorporating therapeutic recommendations into family routines and taking advantage of child-focused services decreases considerably.

SUMMARY AND RECOMMENDATIONS

The challenges confronting families of young children with established developmental disabilities can be formidable. Seeking out and evaluating frequently complex and even inconsistent information, interpersonal and family distress, difficulty accessing resources, and doubting one's ability to confidently and competently parent a child with a disability are frequent problems. Unless these issues are addressed, family patterns of interaction become stressed to a point that the parents fail to support their child's optimal development. Nevertheless, parental investments in time, energy, and personal resources on their own initiative or as part of a formal early intervention system can successfully address these stressors and enhance their child's development.

Yet, the level of investment by families varies considerably. Some of this variation can be attributed to idiosyncratic responses by parents, often extreme in nature. Other sources of variation, however, appear to be linked to the way early intervention programs are organized and to certain family characteristics. In addition, many families fail to make the appropriate investments not because they lack motivation, but because early intervention recommendations are inconsistent with family goals, priorities, and daily routines.

Useful frameworks are now available or are emerging that can, if implemented properly, begin to address these issues. In particular, collaborative goal-setting strategies and techniques can be effective in identifying and resolving differences between parents and professionals in the design of early intervention programs (Bailey, 1987). Clearly, a process of negotiation must be present for a true partnership to exist. Similarly, a theoretical and practical structure is emerging in which an awareness and understanding of the accommodations that affect family routines are considered in the context of IFSP or IEP development (Bernheimer, Gallimore, & Weisner, 1990; Bernheimer & Keogh, 1995). In addition, as early intervention programs become more firmly developmental in their orientation (Guralnick, 2001; Harbin, McWilliam, & Gallagher, 2000; Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000), the relevance of assessing stressors as a means of helping strengthen family patterns of interaction will become more apparent.

Approaches to assessing child and family stressors that can facilitate this process are now being developed (Guralnick, in press). From an intervention perspective, the renewed legislative emphasis on providing supports and services in natural and inclusive environments and the availability of creative strategies for doing so (Dunst, 2001) are most compatible with family routines, thereby increasing the prospects of parental investments in their child's development.

During this negotiation process, professionals may well encounter family goals, values, and priorities that they consider not to be in the best interests of the child's development. Indeed, parental employment and daycare decisions, for example, may be designed to meet broader family needs, ones not entirely compatible with maximizing resource and social supports or information and services in relation to their child with a disability. Nevertheless, by recognizing these sometimes competing priorities, and especially by organizing early interventions to be responsive to these priorities, families are far more likely to make investments, to sustain the investments they do make, and to access programs needed to maximize their child's development.

The daycare dilemma for working parents provides a good example. As discussed earlier, a child's disability can limit families' options for quality childcare. For a variety of reasons, families prefer some form of in-home daycare, especially when children are infants. Training skilled providers and integrating services for the child continue to be a challenge, but they are essential for parents who, for financial or personal reasons, choose to work outside the home. Clearly, policies directed toward addressing this issue are vital. As a partial solution, quality childcare options in inclusive settings (which usually contain both early childhood educators and specialists in disability) are becoming available in which child-focused services and even parent support groups are integrated (O'Brien, 1997, 2001; Wesley, 1994).

However, if an inclusive childcare option is unavailable, parents must figure out how to use an early intervention program as a "home base" for resource and social supports as well as for information and services while meaningfully coordinating with the child's childcare environment (Guralnick, 2000).

From the broad family support perspective, unless early interventionists are able to adjust their time schedules to accommodate parents who are employed, few opportunities will exist for early intervention programs and services, such as parent training. Moreover, it has been extremely difficult for early intervention programs to influence family patterns of interaction, particularly parent—child transactions, in families with a child at high developmental risk owing to adverse family characteristics (Guralnick, 2000). Available evidence suggests, however, that intensive intervention-oriented daycare can prevent many developmental problems for children at risk owing to environmental factors (Burchinal, Campbell, Bryant, Wasik, & Ramey, 1997). For the increasing number of families that face high levels of stressors associated with family characteristics, ensuring the availability of and encouraging families to strongly consider this option may be in the best interests of all concerned. Although this assumption remains to be tested, the availability of intensive early intervention programs may enable parents to make a minimal investment of time, energy, and resources to achieve what may well be the best outcome for their child. Ideally, paralleling these child-oriented

programs would be efforts to address the complex array of stressors generated by family characteristics (e.g., poverty, mental health problems, lack of social support).

Finally, for families to invest in early intervention programs most effectively and efficiently, the programs must be visible, accessible, and well organized, emphasize inclusive options, be consistent with generally accepted best-practice approaches, and have a well-articulated developmental framework. Such a "developmental systems" framework is now available (Guralnick, 2001), and efforts are underway to provide a blue-print for communities to adopt these principles and practices (Guralnick, in press).

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