Young Children with Developmental Disabilities and Their Families: Needs, Policies, and Services

During the past two decades we have witnessed an increase in the proportion of young children who are identified as having developmental disabilities and related special needs. Current figures indicate that approximately 13% of all children, and 5% of preschool-aged children, receive special education services (U.S. Department of Education, 1990; 2001). The largest increase in service provision over the past decade has occurred in the birth-to-kindergarten population (National Center for Education Statistics, 2001). The increase is attributable to several factors. First, although more children with very low birth weight are surviving due to medical technological advances, they often experience a range of complications, including hypoxic (inadequate oxygen) ischemic encephalopathy (inadequate blood supply) (Shonkoff & Marshall, 2000). Such deprivation can result in neuropathology and eventual developmental delays or disabilities (Hack, Wright, Shankaran, & Tyson, 1995). Stanton-Chapman, Chapman, and Scott (2001), for example, reported that the rate of learning problems among boys born with very low birth weight is 2.4 times greater than that among boys born full term.

Second, children are being identified with potential disabilities, such as learning disabilities, at increasingly younger ages (Lyon, 1996). This may be a result of early screening programs at or before school entry (e.g., Child Find), which have led to identifying children at a young age with suspected developmental problems (Meisels, 1991). Further, our understanding of early indicators of developmental difficulties has grown, and children with certain disorders, such as autism, are now diagnosed at younger ages (e.g., Baron-Cohen et al., 1996; Frith, 2003). Finally, the growth of early intervention programs, as a result of federal legislation (Part C of the Individuals with Disabilities Education Act) (IDEA), has made such services more visible and accessible (Kochanek & Buka, 1998). With increasing evidence of the value of early assistance (Guralnick, 1997; Shonkoff & Hauser-Cram, 1987), pediatricians and other health care providers are replacing former practices that involved seeing if children "grow out of" their delayed or unusual development with new practices that incorporate referrals to early intervention services.

Health care providers serve a central role in identifying children who have a developmental
disability or delay. In the National Institute of Child Health and Development (NICHD) Study of Early Child Care, La Paro, Olsen, and Pianta (2002) found that the majority of very young children with special needs were identified by a medical professional. Increasingly, physicians and other health care professionals have become involved in the screening and referral processes for early intervention services (Soloman, 1995), yet many health care providers report they have a lack of familiarity with federal laws and the early intervention system (Soloman, Clougherty, Shaffer, Hofkosh, & Edwards, 1994). The purpose of this chapter is to provide an overview of policies related to young children with developmental disabilities and a review of research on the needs of their families and the effectiveness of early intervention services.

Federal Policy About Young Children with Special Needs

Enormous policy changes related to services for young children with disabilities and their families have occurred over the past few decades in the United States. Indeed, as a nation we have moved from an implicit policy of institutionalizing children with special needs, especially children with Down syndrome and other forms of intellectual disabilities, to an explicit one of supporting families as they raise children at home (Meisels & Shonkoff, 2000). Legislation developed over the past three decades has required publicly supported services be provided to younger and younger children.

Legislation

In the 1970s Congress passed landmark legislation for children with disabilities, Public Law 94-142 (the Education for All Handicapped Children Act of 1975), which established the right to a free and appropriate public education for school-aged children with disabilities. Although the law did not require states to provide services for children under school age, it did endorse the importance of such services. Over 10 years later, in 1986, Congress enacted Public Law 99-457, which encouraged (but did not mandate) states to provide services for infants and toddlers with disabilities and also strengthened incentives for states to provide services for preschoolers with disabilities.

This was soon followed by legislation in 1988 (P.L. 102-119, the Individuals with Disabilities Education Act) (IDEA), which required states to both 1) develop a system of early intervention services for children from 0 to 3 years old (referred to as Part C) and 2) provide free and appropriate public education and related services to children with disabilities beginning at age 3 (referred to as Part B). Although the public schools were to be responsible for services for children of preschool age, each state had discretion as to the state agency responsible for administering and implementing the system of early intervention (EI) services. Therefore, the lead agency for EI varies by state. About one-third of the states initially selected education as the lead agency, whereas slightly fewer chose public health, and fewer still selected mental health or human services (Garwood, Fewell, & Neisworth, 1988). Current trends indicate that more departments of health and fewer departments of education are taking the lead (Meisels & Shonkoff, 2000). The legislation requires that regardless of lead agency selected, the EI system should emerge from the coordination of health and education agencies at the state and local level. Such collaboration between the medical and educational communities is a unique feature of the early intervention system.

Eligibility

One critical issue in providing EI services is in determining who is eligible to receive them. The law states that such services should be provided to children who are experiencing developmental delays and to those who have a diagnosed condition
that results in a high probability of subsequent delays. States have the option of also providing services to children who are "at risk of having substantial delays if early intervention services are not provided" (20 U.S.C. # 1432). States have difficulty determining which children are "at risk" and vary substantially in the extent to which services are provided to these children (Hebbeler et al., 2001). A recent survey indicates that 58% of children enter EI due to developmental delay, 29% because of a diagnosed condition (e.g., Down’s syndrome), and 13% because they are "at risk" for developing delays (Hebbeler et al., 2001). The most common reasons for receipt of EI services are listed in Table 14.1, and, as indicated in that table, most children who exhibit developmental delays do so because of speech or communication problems.

An important requirement of IDEA is the development of an individualized education plan (IEP) for children aged 3 or older and of an individualized family service plan (IFSP) for children in early intervention. Like the IEP, the IFSP delineates the needs and goals for the child, but unlike the IEP, the IFSP also specifies family strengths and needs. The importance of the family as the primary niche in which young children are nurtured and learn is clearly recognized in the legislative requirements relating to the IFSP. Although some concern has been expressed about the construction of the IFSP as a potential intrusion into family life (Krauss, 1990), the family focus inherent in the legislation reflects contemporary perspectives about the importance of the family in enhancing the optimal development of young children with disabilities.

### The Needs of Parents of Young Children with Developmental Disabilities

All families need to adjust to the birth of a child, but adjustments can be more pronounced when the infant experiences health or developmental problems. Much has been written about the grief and "chronic sorrow" that parents experience in learning that their infant has a developmental disability (e.g., Solnit & Stark, 1961). It is now widely recognized, however, that individuals vary considerably in their responses to this event, and that expectations that all parents experience "chronic sorrow" may be misguided. Some variation in parental responses relates to parents’

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech/communication impairment or delay</td>
<td>41</td>
</tr>
<tr>
<td>Prenatal/perinatal abnormalities (e.g., low birth weight)</td>
<td>19</td>
</tr>
<tr>
<td>Motor impairment or delay</td>
<td>17</td>
</tr>
<tr>
<td>Delayed development (global)</td>
<td>12</td>
</tr>
<tr>
<td>Cognitive disorders (e.g., Down syndrome)</td>
<td>9</td>
</tr>
<tr>
<td>Intellectual/cognitive impairment or delay</td>
<td>7</td>
</tr>
<tr>
<td>Central nervous system disorders (e.g., cerebral palsy)</td>
<td>7</td>
</tr>
<tr>
<td>Social environment risk factors</td>
<td>4</td>
</tr>
<tr>
<td>Social/behavioral impairment or delay</td>
<td>4</td>
</tr>
<tr>
<td>Sensory impairment (e.g., vision, hearing impairment)</td>
<td>3</td>
</tr>
</tbody>
</table>


*Percentages sum to more than 100 because children may have more than one reason for receipt of services.
sociocultural beliefs about the etiology of the disability (e.g., the child is a gift to parents who can master the challenge, or the child's disability is a punishment for parents' past behaviors) (Garcia Coll & Magnuson, 2000). For most parents, the knowledge that their infant may exhibit unusual or delayed development requires an adjustment, but the assumption that all parents will endure "chronic sorrow" lacks empirical evidence.

In the 1960s and 1970s, a stage theory was proposed to health professionals as a way to predict parents' reactions to the birth or diagnosis of a child with disabilities (Blacher, 1984). The three proposed stages followed those reported for individuals coping with the illness or death of a close family member (Kubler-Ross, 1997). In the first stage, parents experience disbelief and "shop" for physicians and treatments. The second stage is characterized by guilt, anger, and disappointment. The third stage occurs when parents reorient themselves toward adjustment and acceptance of their child and take on an advocacy role. Although this stage theory may be appealing, the empirical evidence for these stages has been found to be weak (Blacher, 1984). Therefore, research has turned away from delineating stages toward understanding parents' adaptive functioning.

**Studies of Maternal Behavior**

Much research has been conducted on caregivers, especially mothers, of young children with disabilities. Many studies on the mother–child dyad have been guided by the transactional model (Sameroff & Chandler, 1975), which emphasizes the bi-directional interactions between a mother and a child. This theoretical model does not assume that influences occur only from mother to child but instead focuses on the responses that each has to the other in complex changing patterns. Barnard and colleagues (1989) refer to these interactive patterns as a "mutually adaptive dance." Investigations of the mother–child dyad of typically developing children indicate that responsive reactions by mothers that are contingent on children's behaviors promote positive cognitive and social-emotional development in children (Osofsky & Thompson, 2000). In contrast, mothers who repeatedly ignore children's responses or are highly controlling and intrusive into children's activities reduce children's opportunities for self-efficacy (Heckhausen, 1993).

Research on the mother–child dyad when the child has a developmental disability demonstrates that maternal contingent responsiveness during children's early years is an important predictor of development of positive cognitive and communication skills over time (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). Such productive mother–child interaction appears to be more challenging in dyads where the child has a disability than in other dyads, however. Children with certain disabilities, such as those with Down's syndrome, may provide fewer, more delayed, or less appropriate signals to parents during interactions (e.g., Beeghly, Perry, & Cicchetti, 1989; Landry & Chapieski, 1990). Children with autism and related disabilities may rarely make eye contact with the mother or caregiver (Hoppes & Harris, 1990), which results in reduced opportunities for mutually responsive interaction and joint attention. Thus, the child with a developmental disability may display fewer or unusual cues, making it difficult for a caregiver to respond contingent to the child's actions.

Possibly as a result of children's unusual or unexpected cues, mothers of children with disabilities, in comparison to other mothers, appear to be more directive to children with disabilities (Marfo, 1990). For example, Mahoney, Fors, and Wood (1990) found that during free play activities, mothers of children with Down syndrome, unlike mothers of typically developing children, directed their child's attention away from the objects the child was using and toward more challenging tasks. Crawley and Spiker (1983) found that parents were more directive of children with Down syndrome who showed less interest in play and initiated fewer interactions with objects.
Such directiveness could result in either promotive or deleterious outcomes for children. Directiveness could diminish children's attempts at self-initiation as has been found in research on dyads where the child is developing typically (Lepper, 1981). Alternatively, directiveness could assist children in their interactions by providing necessary scaffolding (i.e., incremental support and guidance as the child works on a task), for example, by making materials easier for the child to reach or asking questions that will aid in problem solution. Tannock (1988) found that maternal directives assisted children with Down syndrome in more fully participating in the interaction. Roach, Barratt, Miller, and Leavitt (1998) reported that mothers of children with Down syndrome were both more directive and more supportive than were other mothers of both mental-age-matched and chronological-age-matched typically developing children. They found that the combination of maternal directiveness and support elicited more object play and vocalizations by the children with disabilities. Thus, it appears that although mothers tend to interact using a more directive style with young children with disabilities, benefits accrue to those children when that style is complemented by maternal support of children's actions.

**Parenting Stress**

Maternal-child interaction occurs within a family system that may be functioning well or poorly (Minuchin, 1988). If individuals experience high levels of stress, their parental functioning is diminished. According to researchers who focus on the family system (McCubbin & Patterson, 1983), the adaptation of the family to the birth or diagnosis of a child with disabilities can be explained by several factors, including the meaning ascribed to the disability, and the internal and external resources of the family.

Of the many factors that comprise parental well-being, parenting stress appears to be the one most frequently studied in relation to parenting a child with a disability. Although many have claimed that parents of infants with disabilities have exceedingly high levels of stress, empirical work indicates otherwise. Studies indicate that, on average, parents report normative stress during their child's infant and toddler years (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). Increasing stress levels occur during early childhood (Innocenti, Huh, & Boyce, 1992), with high stress levels during the middle childhood years (Hauser-Cram et al., 2001; Orr, Cameron, Dobson, & Day, 1993).

These findings are based on families who have received early intervention services, however. It is possible that such services provide sufficient support to parents to temper the levels of stress parents feel during the infant and toddler years. When the family support services of EI are withdrawn and children make the transition from EI to preschool and school services, parental stress levels increase. The child-focused services of the school years may offer some families respite from intense involvement in services and the concomitant demands made by such involvement but may also lack the means for providing support for the family system as a whole.

Mothers and fathers evince different patterns of parenting stress. Although mothers, in comparison to fathers, often provide more caregiving functions for children during the infant and toddler years, fathers in general report more stress at that time (Hauser-Cram et al., 2001). Fathers' increasing levels of stress appear to be moderated by problem-focused coping skills. Fathers who approach their stressful problems by selecting problem-solving strategies report less stress over time than fathers who lack such strategies. The stress levels of mothers, on the other hand, are moderated by the construction of satisfying social support networks (Hauser-Cram et al., 2001). Mothers who find their support networks, whatever the size, to be helpful show less increase in stress. These different patterns of stress and its
moderators for mothers and fathers suggest that different types of assistance would be valuable to different family members.

The Role of Fathers

We have little information about the service needs of fathers, however, because fathers have been relatively neglected in studies of children with disabilities (Lamb & Billings, 1997). Indeed, many studies have used the mother as a spokesperson for the family or viewed fathers only as adjuncts to mothers. In summarizing studies on fathers of children with disabilities, Hornby (1995) concludes that they paint "a negative picture" (p. 105). For example, Wikler, Wasow, and Hatfield (1981) suggest that fathers are more affected (than mothers) by the physical aspects of a child's disability. Schillinge, Schinke, and Kirkham (1985) contend that fathers have more difficulty accepting their sons with disabilities than accepting their daughters.

Many of the prior studies, however, are based on autobiographical accounts and clinical impressions, and most are dated in terms of contemporary family arrangements and roles. Because many mothers of young children with disabilities are now in the workforce (Landis, 1992), the roles of fathers in families have changed. Therefore, we need carefully constructed research on fathers' perspectives in today's family.

A few investigations have focused on the positive changes that have occurred in individuals' lives as a result of parenting a child with a disability. Abbot and Meredith (1986) interviewed parents of children with mental retardation and found that 88% reported positive outcomes, such as having greater compassion and developing stronger families. Based on survey research, Scorgie and Sobsey (2000) found that parents of children with disabilities reported personal growth, improved relations with others, and changes in their philosophical or spiritual values as a result of their parenting experiences. Such studies indicate the complex emotions associated with parenting a child with a disability, which have yet to be fully investigated.

As the core of the family system, parents set the emotional tone for the family and determine the opportunities available to children. Most families are composed of other members as well, and research attention is increasingly focused on the enduring importance of sibling relationships.

siblings share a powerful and complex emotional bond that is often the most abiding of familial relationships (Seligman, 1999). Early interactions between siblings provide a context for the development of social competencies and a significant influence on emotional, behavioral, and cognitive development (Dunn, 1999). When one sibling has a disability, the relationship may take on additional complexity. For the child with a disability, who may experience limited peer interaction and few friendships (Gresham & MacMillan, 1997), the sibling relationship may provide the primary context for positive socialization experiences with peers. Furthermore, the nondisabled sibling may assume the role of caretaker and companion in adulthood (Seltzer, Greenberg, Krauss, & Gordon, 1997; Seltzer & Krauss, 2001). Clearly, a child's disability has an impact on all members of the family, including siblings.

Just as early studies of parents of children with disabilities focused on negative outcomes, early investigations of siblings also assumed maladjustment. Traditionally, investigators hypothesized that the presence of a child with a disability is a source of developmental risk for other children in the family (e.g., Farber, 1959). Much early work indicated that sisters of children with developmental disabilities often assumed much greater caregiving and household responsibility than their peers. This disproportionate responsibility
was considered to be related to increased levels of depression and anger (Farber, 1959), a higher incidence of antisocial behavior (Gath, 1973), and decreased coping effectiveness (Grossman, 1972). Researchers now suggest that these early studies may not reveal an accurate picture.

For example, these studies were conducted before the passing of IDEA, when few, if any, special services or supports were available to families of young children with disabilities. The presence of a child with a disability may well have been a source of stress for the entire family, which had to face the challenges of raising the child with little or no support from the community. Thus, these early studies may reflect an anachronistic understanding of the meaning of disability (Lamorey, 1999).

Furthermore, several methodological criticisms of this work exist. First, studies were largely retrospective reports based on patients referred for clinical assistance (Cuskelly, 1999). Thus, they failed to recognize the many siblings who did not suffer from psychological adjustment problems. Second, these reports were based largely on anecdotal evidence and self-report. They did not empirically investigate actual differences in responsibility between siblings of children with disabilities and siblings of typically developing children, nor did they demonstrate any correlation between responsibility and poor psychological outcomes through systematic measurement (Damiani, 1999).

The Role of Siblings

More recent work has also focused on the roles that siblings of children with disabilities may play within the family. Research largely supports earlier findings that siblings, particularly sisters, of children with disabilities spend more time involved in caregiving activities, such as babysitting or helping with feeding, dressing, or bathing (McHale & Gamble, 1989), even when the typically developing sibling is younger (Stoneman, Brody, Davis, Crapps, & Malone, 1991). However, generally speaking, female children appear to shoulder greater responsibility in the home, regardless of the presence of a sibling with a disability (McHale & Gamble, 1989; Stoneman, Brody, Davis, & Crapps, 1987). Gender aside, when other home responsibilities, such as household chores and self-care activities were considered, Cuskelly and Gunn (1993) found no difference in levels of responsibility between siblings of children with disabilities and those of nondisabled children. It appears that, regardless of gender, siblings of children with disabilities do assume more childcare responsibility in the family, but they are not expected to simultaneously take on more household chores or self-care responsibilities.

Although it is largely accepted that when there is a child with a disability in the family, siblings bear greater childcare responsibility in the home, it is not clear that this heightened responsibility leads to global adjustment problems. Although McHale and Gamble (1989) found a positive relation between amount of time spent in childcare activities and anxiety, they also reported that depression, self-esteem, and conduct problems were not related to home responsibilities. Others report a positive relation between responsibility and socioemotional functioning of siblings. For example, Cuskelly and Gunn (1993) found that sisters of children with disabilities exhibited fewer conduct problems when they had more responsibilities in the home. Finally, there is some indication that when typically developing siblings of children with disabilities have greater caregiving responsibility, these sibling relationships are characterized by low levels of conflict (Stoneman et al., 1991).

There is a belief that siblings of children with disabilities may be at increased risk for adjustment problems because they receive less attention from parents than their brothers and sisters (Stoneman, 2001). This is supported by the literature on typically developing siblings in which differential parental attention is often associated
with deleterious sibling outcomes (Brody, Stoneman, & Burke, 1987). Nonetheless, evidence is mixed about whether siblings of children with disabilities actually receive less attention (Kaminsky & Dewey, 2001; McHale & Gamble, 1989; Stoneman et al., 1987). Furthermore, studies on siblings of children with disabilities do not clearly indicate that the effects of differential attention are detrimental. Corter and colleagues (Corter, Pepler, Stanhope, & Abromovitch, 1992) found no relation between maternal partiality and sibling interactions. Pit-ten Care and Loots (2000) reported that although siblings perceived a difference in parental attention, they were accepting of it and largely recognized and appreciated their parents' attempts at justness.

### Sibling Interactions

Interactions between siblings when one has a developmental disability may differ appreciably from those in which both siblings are typically developing. Although McHale and Gamble (1989) found no difference in the amount of time sibling pairs spent in interaction with each other, the nature of the interactions and the type of activities were very different when one sibling had a disability. In addition to more caregiving, siblings of children with disabilities often display more managerial behavior and engage in less cooperative interaction with their brothers and sisters when compared to siblings of typically developing children (Dallas, Stevenson, & McGurk, 1993; Stoneman et al., 1987). Additionally, when compared to siblings of typically developing children, siblings of children with Down syndrome have been observed to be more nurturing towards their brothers or sisters, regardless of birth order (Abromovitch, Stanhope, Pepler, & Corter, 1987).

There is substantial evidence that the sibling relationship develops differently when one member has a disability. In dyads in which the typically developing sibling is older, there is a high degree of role asymmetry in the relationship as the older sibling assumes a position of dominance (Abromovitch et al., 1987; Dallas et al., 1993; Stoneman et al., 1987). Although this is typical of any sibling relationship, when one sibling has a disability, the imbalance of power is not minimized over time but rather may become more pronounced (Stoneman, 2001).

When the child with a disability is the older sibling, the development of the sibling relationship may be even more atypical. Over time, the pair may experience a reversal of roles as the younger sibling catches up to, and bypasses, the older sibling in terms of cognitive ability and/or functional skills, eventually assuming the dominant role (Abromovitch et al., 1987; Brody, Stoneman, Davis, & Crapps, 1991; Dallas et al., 1993; Stoneman et al., 1991). Although the development of the relationship between children with disabilities and their siblings may not be normative, there is no evidence that this asymmetry is in any way detrimental to the development of the individuals or the relationship. Stoneman (2001) emphasizes that relationships that are atypical may be considered adaptive, rather than necessarily pathological or problematic.

Many current investigations regarding the siblings of children with disabilities consider the complexity of both the sibling relationship and the family context and recognize a range of possible psychological outcomes. It is important to understand the different processes and mechanisms by which these potential outcomes occur (McHale & Gamble, 1989). For example, Dyson (1989) compared older siblings of children with disabilities to older siblings of typically developing children and found no significant differences between the two groups on measures of self-concept, social competence, and behavior problems. She reported, however, significant within-group variation related to both child and family characteristics. In other words, Dyson found that for both groups, those with and without siblings with disabilities,
there was great variability in adjustment and behavior. For all siblings, some demonstrated high levels of self-concept and social competence with few behavior problems, whereas some exhibited the opposite. This suggests that such distinctions have more to do with individual differences and differences in family functioning than with whether or not a child with a disability is present in the home. In a follow-up study, Dyson, Edgar, and Crtic (1989) indicated that family context variables, such as parental stress, family relationship, social support, and the family’s emphasis on personal growth, were significant predictors of self-concept, social competence, and behavior problems in siblings of children with a variety of disabilities.

**Sibling Adjustment**

Sibling adjustment is related to many factors, including the type and severity of the sibling’s disability and the temperament of both siblings; however, evidence increasingly points to the importance of the family context. Parents’ psychological well-being, interactions, and responses to stress affect the well-being of the individual children within the family. In a 3-year longitudinal study, siblings of children with pervasive developmental delay (PDD) exhibited more behavior problems than either the siblings of children with Down syndrome or those of typically developing children (Fisman, Wolf, Ellison, & Freeman, 2000). Sibling behavior problems in all groups, however, were related to parental stress, and parents of children with PDD were found to maintain the highest stress levels over time. McHale and Gamble (1989) found no direct connections between the characteristics of children with disabilities and the well-being of their older brothers and sisters, but they did find that siblings who experienced more negative interactions with their mothers exhibited more depression, anxiety, and low self-esteem. Thus, family environment is a critical factor in understanding sibling adjustment to childhood disability.

Some recent studies have found that the presence of a child with a disability has a positive impact on family climate and sibling adjustment. In one study, siblings of children with Down syndrome were collectively found to have above average scores on a measure of self-concept (Van Riper, 2000). Then again, higher self-concept scores were related to greater family resources and fewer stressful events experienced by the family. These family characteristics, as well as coping strategies and effective problem-solving communication techniques, also predicted the sibling’s social competence.

Although family context is important in understanding the relationships that exist between siblings when one has a disability, focus on this topic is just emerging in the research literature (Stoneman, 2001). There is evidence that children regard their siblings with an intellectual disability more positively when they perceive their families as communicative and emotionally responsive (Weinger, 1999). This indicates that in families in which members are safely able to express a range of feelings, children express a greater acceptance of their siblings with disabilities. More investigation is needed, however, to determine the process by which the family climate influences the relationship between siblings when one has a disability.

In general, many children reflect positively on the experience of having a sibling with a disability (Eisenberg, Baker, & Blacher, 1998; Grossman, 1972; Kaminsky & Dewey, 2001; Pitenen Cate & Loots, 2000; Roeyers & Mycke, 1995; Van Riper, 2000). These children tend to rate their sibling relationships more positively than do comparison children (Roeyers & Mycke, 1995), report fewer conflicts, and express greater admiration for their siblings (Kaminsky & Dewey, 2001). Many children acknowledge that they have benefited from having a sibling with a disability.
They credit their siblings with helping them gain virtues such as patience, tolerance, benevolence, and appreciation of health and family (Eisenberg et al., 1998; Van Riper, 2000).

The Role of Support Groups

When children talk about the negative aspects of having a sibling with a disability, they often cite worry about health concerns and the future (Eisenberg et al., 1998). In one study, 75% of siblings reported that they sometimes worried about their sibling's health, or future, or both (Pit-ten Cate & Loots, 2000). Damiani (1999) suggests that worry is quite prevalent among the siblings of children with disability and that this might present one of the greatest risk factors for these children.

Given the worries of these siblings, such children may benefit from support groups that address the concerns and uncertainty that they feel about the future lives of their brothers and sisters and their place in it. Research also indicates that siblings have a need for information. Roeyers and Mycke (1995) found that brothers and sisters of children with autism rated their sibling relationships more positively when they had more knowledge about the nature of autism. In a sample of Dutch children, aged 10 to 19 years, with siblings with physical disabilities, many of the participants were unable to provide details regarding their siblings' disabilities, but when given the opportunity asked many questions about medical matters (Pit-ten Cate & Loots, 2000). This is a further indication that siblings may need a reliable and accessible source of information about disabilities outside of the family, health care professionals could be a source of such information.

Siblings may also benefit from services targeted at supporting their psychological well-being, particularly in the presence of multiple risk factors. A group of low-income children, all having a sibling with a developmental disability, demonstrated decreased levels of anxiety, depression, and stress, and improved self-esteem after participating in a 15-week after-school program (Phillips, 1999). The program consisted of recreational activities, assistance with homework, and discussion groups focused on issues of developmental disabilities. A comparison group of children, who received no intervention, showed no similar gains over the same time period.

Clearly, siblings of children with disabilities have much to gain from interventions focused on their unique needs. The importance of the family context, however, carries additional implications for intervention. Given the existing empirical evidence, interventions focused on reducing parental stress, anxiety, and depression and increasing family communication and coping strategies may provide benefits for all members of the family. Many EI programs aim to support families as they raise children with disabilities and, as discussed in the next section, do so by providing a range of highly individualized services.

Early Intervention Services

Early intervention services are multidisciplinary services provided to children with developmental disabilities, delays, or risks during the first few years of life. The goal of these programs is to promote the health and optimal development of the children as well as to support adaptive parenting and positive functioning of their families (Shonkoff & Meisels, 2000). A wide range of disciplines are involved in providing such services, including public health, medicine, education, psychology, social work, child care, speech and language services, and occupational and physical therapy, and, therefore, a broad range of services are provided (Table 14.2). The specific services are usually highly individualized based on child and family needs and strengths.

Early intervention programs are serving almost 60% more children and families now than they were a decade ago when states were first mandated to provide such services (U.S. Department of Education, 2001). In addition to improved early
diagnostic methods, the increased demand for services seems to be driven by a strong advocacy movement for and by individuals with disabilities and a heightened public awareness of the importance of the first 3 years of life in shaping developmental outcomes (Guralnick, 1998).

Notwithstanding the growing emphasis on, and awareness of, EI as an important factor in promoting optimal development for young children with disabilities, several challenges to research on the EI system persist. First, researchers disagree about how to determine the effectiveness of EI. Debates exist about which child outcomes deserve to be studied; whether family outcomes also should be evaluated; how to measure and reliably record the types, intensity, and individualized nature of services themselves; and the extent to which both quantitative and qualitative approaches are needed to understand family processes (Hauser-Cram, Warfield, Upshur, & Weisner, 2000). Historically, evaluation research on EI focused almost exclusively on cognitive outcomes with a neglect of socioemotional functioning of children and families (Shonkoff & Hauser-Cram, 1987). There appears to be considerable agreement that children with established disabilities who receive EI demonstrate less deterioration in their scores on standardized tests of intellectual ability than their peers who do not receive comprehensive services (Guralnick, 1998; Guralnick & Bricker, 1987; Hines & Bennett, 1996; Spiker & Hopmann, 1997). These advantageous effects, however, have generally been found only during the first 5 years of life; long-term gains remain to be examined (Guralnick, 1998).

Despite the focus of EI services on family strengths and needs as well as on the individual child, few evaluation studies have considered parental benefits of participation in EI. Examining parental benefits of EI services is important in its own right because positive adjustment to parenting a child with a disability has potential advantages for all family members. Furthermore, because the family context is central to the optimal development of children, including children with disabilities (Hauser-Cram et al., 2001), assisting families with maintaining a supportive context for parenting is an aim of most EI

---

**Table 14.2** Types of Early Intervention Services Commonly Provided to Children and Families\(^a,b\)

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage(^c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service coordination</td>
<td>80</td>
</tr>
<tr>
<td>Speech/language therapy</td>
<td>53</td>
</tr>
<tr>
<td>Special instruction</td>
<td>44</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>39</td>
</tr>
<tr>
<td>Physical therapy</td>
<td>38</td>
</tr>
<tr>
<td>Developmental monitoring</td>
<td>38</td>
</tr>
<tr>
<td>Health-related services</td>
<td>25</td>
</tr>
<tr>
<td>Family training</td>
<td>20</td>
</tr>
<tr>
<td>Other family support (e.g., counseling)</td>
<td>14</td>
</tr>
<tr>
<td>Audiology</td>
<td>14</td>
</tr>
<tr>
<td>Social work services</td>
<td>12</td>
</tr>
</tbody>
</table>

\(^a\)Services most commonly provided within the first 6 months of enrollment.

\(^b\)Source: National Early Intervention Longitudinal Study (U.S. Department of Education, 2000).

\(^c\)Percentages sum to more than 100 because children and families often receive multiple services.
programs. In one of the few studies on parental outcomes associated with EI participation, Warfield and colleagues (Warfield, Hauser-Cram, Krauss, Shonkoff, & Upshur, 2000) found that at the end of the EI experience, mothers who had received more hours of EI services reported improved family cohesion and more helpful social support networks in comparison to other mothers in EI.

**Evaluating Early Intervention Programs**

Most studies of EI effectiveness have focused on the program as a whole. In an attempt to determine which features of EI programs were most effective, researchers at the Early Intervention Research Institute conducted a series of longitudinal studies employing randomized experimental designs. These studies yielded little information about the relative effectiveness of various program components, however. For example, White et al. (1994) reported no outcome differences for children who received intensive, family-centered intervention services in comparison to those who received center-based services once per week. One reason why so few program variation effects were found may be that not all children and families benefit equally from equal amounts of intervention (Dunst & Trivette, 1997). Indeed, given the diversity of children enrolled in the system and the wide range of services provided, it is difficult, and perhaps not even particularly meaningful, to consider the effectiveness of EI at a macro level (McCollum, 2002).

Additionally, Marfo and colleagues (1992) found that factors such as a child's developmental competency at entry into EI and the home environment were stronger predictors of developmental outcomes than were specific program variables. In other words, children who entered EI with the greatest delays tended to show the least improvement in developmental scores, but the quality of the home environment and parental expectations also contributed significantly to post-intervention developmental status. These are important findings for several reasons. First, that entry-level child characteristics were the most influential predictor of developmental outcomes highlights the need for parents and professionals to be realistic in their expectations of what EI can accomplish for young children with significant deficits. Second, the importance of family ecology in determining developmental outcomes underscores the necessity for EI services to focus not only on the child, but also on the family as a whole.

Guralnick (1997) makes a useful distinction between first-generation and second-generation research in EI. First-generation research focuses on investigating the general effectiveness of comprehensive EI programs. In contrast, second-generation research addresses more specific issues that are aimed at optimizing individual outcomes, informing program design, and increasing our understanding of the influence of individual child and family characteristics on intervention efficacy. Some researchers maintain that global efficacy of EI has been established by first-generation research, and second-generation studies are now needed to inform the development of services that are responsive to individual needs and will evoke the most advantageous outcomes (Guralnick, 1997; McCollum, 2002). Such studies are difficult to conduct, however, given the individualized nature of EI and the heterogeneous population of children and families served.

**Challenge of Inconsistency and Fragmentation**

A related challenge to the evaluation of EI services is due to the inconsistency and fragmentation within the EI system. For example, EI programs vary widely from state to state. Not only does federal legislation allow the states latitude in choosing a lead agency, it also gives them considerable discretion in the determination of who is eligible for services. Although all states must serve chil-
Early Intervention Services

Children with established disabilities and developmental delays, these criteria are not clearly defined by the federal government for children under 3 years of age, and states are allowed to establish their own criteria. State definitions of "developmental delay" vary widely (Hebbeler et al., 1999).

For example, Massachusetts has specific guidelines about the minimal extent of delay required for a child to be eligible for EI based on the child's age (e.g., 1.5 months delay for children aged 6 months or less, 6 months delay for children aged 19-36 months) (Massachusetts Department of Public Health, 1998). In Utah, a significant delay is defined as 1.5 standard deviations at or below the mean or below the 7th percentile in one or more areas of development based on a standard assessment (Utah Department of Health, 1999). In Alabama, infants or toddlers must be delayed by at least 25% in their cognitive, communicative, social, emotional, or adaptive development to be eligible for EI services (Alabama Department of Rehabilitation Services, 2003). Additionally, states may also decide whether or not to provide services to children "at risk" for exhibiting delays. This has resulted in great inconsistency; many children who are eligible for services in one state are not in another. Hence, although there exists a federal mandate to serve infants and toddlers with disabilities, there is little equity with regard to who may participate in EI programs (Bailey, 2000).

Additionally, there is considerable variability among states along several other dimensions. Specifically, states differ with regard to the number and type of agencies that are involved in the provision of services and in the ways that services are coordinated among agencies. There is even significant disparity in the degree to which states manifest within-state differences in local systems (Hebbeler et al., 1999).

For example, in Illinois each local area has an entity called "Child and Family Connections" under contract from the state lead agency, which is responsible for intake and for connecting families with the local service provider. This system provides some uniformity across the state in terms of intake, referral, and services. In contrast, in Ohio each county has a collaborative group that is responsible for establishing an EI system. That system varies widely from county to county; one county may have a single entry point to EI services, and the adjacent county may offer several points of entry.

Any general discussion of EI and its effectiveness is made more difficult by the heterogeneous nature of the children and families who participate in EI services. State differences aside, children may be eligible for EI services for a variety of reasons. The heterogeneity of children entering EI is illustrated by early reports from the National Early Intervention Longitudinal Study (NEILS). Commissioned by the Office of Special Education Programs, NEILS involves a nationally representative sample of more than 5,000 children and their families (Hebbeler et al., 2001; U.S. Department of Education, 2000). Preliminary data include a total of 305 specific descriptors of reasons for participants' initial eligibility for EI services, such as visual impairment, Down syndrome, spina bifida, or homelessness, to name but four. These descriptors can be classified into diverse categories, such as sensory impairments, congenital disorders, central nervous system disorders, and social environment risk factors (Hebbeler et al., 2001; U.S. Department of Education, 2000).

Because EI serves children with a broad range of abilities and needs, systems nationwide offer a wide array of services to both children and their families. These services are provided by many different types of practitioners and professionals, frequently through multiple agencies. Services may be child focused, such as occupational therapy, physical therapy, or speech and language services; medical care or special education services may also be included. Parents may receive mental health counseling, social services, or attend parenting classes, information sessions, or support groups. EI services may also be provided in a range of
environments, from the home, to community settings such as childcare centers, to segregated, self-contained programs. Goals may focus on improving cognitive outcomes, communication skills, physical functioning, or social and emotional competencies. A systemwide objective of EI is that children and their families receive a package of services that is individualized to meet their needs.

**Developmental Systems Model**

Given the diversity of the participants, the range of goals, and the breadth of services provided, combined with the inconsistencies and fragmentation that characterize the system at the state and national levels, it is small wonder that questions about effectiveness have been difficult to address with scientific rigor, and a coherent framework in which to view and discuss the EI system has been elusive. However, despite this diversity, there are some unifying themes that emerge when EI is considered overall. Although service delivery models may differ from state to state, the federal legislation (Part C of IDEA) requires an interdisciplinary collaborative system of services and agencies that serve children and families with a wide range of abilities and needs.

When we look at the various models of EI that currently proliferate, two overarching principles emerge (McCollum, 2002). First, EI practices are guided by an ecological perspective of human development that recognizes that the child develops within multiple intersecting environments (Bronfenbrenner, 1979). Second, service delivery models adopt a "systems of service" framework that stresses coordination and collaboration among various agencies and professionals. Taken together, these guiding themes underlie the developmental systems model of EI (Guralnick, 2001).

**FAMILY**

The developmental systems model recognizes that the family is the primary context of development for the young child (Bronfenbrenner, 1986). Guralnick (1997) notes that within this context, families influence child development in three ways: through the quality of parent-child interactions, through the types of experiences that are made available to the child, and by ensuring the child's health and safety. These three patterns are largely determined by both personal characteristics of the family, such as psychological well-being and intellectual ability, as well as environmental characteristics, such as the availability of social support and the family's financial resources. Furthermore, this model adopts a transactional perspective (Sameroff & Fiese, 2000) by recognizing that these factors interact with child characteristics, such as the nature and severity of a child's disability and the child's individual temperament, to shape the family ecology and create a unique developmental context for every family.

Current configurations of EI emphasize family by providing a system of services aimed at supporting a family ecology that optimizes child development. EI programs routinely include services focused on providing support and information to family members, including mental health services, counseling, and educational programs focused on parenting a child with a disability. Furthermore, many child-focused therapeutic services take place in the home environment and/or involve family members actively.

**SCHOOL AND COMMUNITY**

Present EI practices also recognize the importance of other, more distal, contexts of development beyond the family, most specifically, school and community. There is considerable emphasis in both EI theory and practice on encouraging participants in EI programs to engage in inclusive community settings and activities. Such practices promote peer relationships and enhanced social competence (Guralnick, 2000). It is understood that one role of EI is to enable young children with disabilities to participate in the same developmental contexts as their typically developing peers.
• peers (McCollum, 2002), including daycare and preschool settings. Toward this end, practitioners make every attempt to provide EI services in inclusive natural environments (Walsh, Rollins, & Lutzer, 2000). Thus, to the maximum extent possible, all services and therapies are provided in home, school, or community settings, as opposed to segregated settings. Indeed, Guralnick (2001) considers community inclusion to be one of the three core principles of a developmental systems model, along with a focus on families and integration at the systems level.

EI's focus on family and community contexts draws heavily on current theories of human development, recognizing that the factors that influence optimal development for children with and without disabilities are many and diverse, and often interact in complex ways. Clearly, no single provider or agency can address all of these factors in the wide array of developmental needs that may be presented by the heterogeneous community of children and families who participate in EI programs. To provide the comprehensive, individualized package of services that has become the hallmark of the EI system, an integrated, multidisciplinary system of services consisting of multiple practitioners and agencies is essential.

For such a system to operate smoothly, a high level of collaboration and cooperation among the various components is warranted. Additionally, a service coordinator is an important component to help successfully navigate the complexities of the system and smooth transitions for families. Family members also may be viewed as integral components of the system of service. The formation of parent–professional partnerships that recognize parents as cocooordinators and co-providers of services for their children is key to the success of EI services (Turnbull, Turbiville, & Turnbull, 2000).

The formation of such partnerships, however, requires EI service providers to be knowledgeable of and sensitive to the various ethno-theories that parents hold about intervention practices and about the nature of developmental disabilities. Parents' belief systems, and the cultural contexts in which such beliefs develop, are an often overlooked but important part of the provision of services (Garcia Coll & Magnuson, 2000; Super & Harkness, 1997). The future of the EI system will depend on its ability to attend to the development of cultural competence of service providers (Hanson, 1998).

**Conclusion**

In conclusion, research on the effectiveness of EI faces many challenges. Nevertheless, this system of services has much to offer young children with disabilities and their families. It is an evolving system that requires responsiveness to a heterogeneous range of children and families. Health care providers are important sources of information about such services, and they will serve families well by becoming knowledgeable not only about the particular needs of children with disabilities and their families but also about the various EI services provided in their local communities.

**References**


References


References


Handbook of Human Development for Health Care Professionals

Kathleen Thies, PhD, RN  
Associate Professor, Graduate School of Nursing  
University of Massachusetts Medical School  
Worcester, MA  

John Travers, EdD  
Professor, Lynch School of Education  
Boston College  
Chestnut Hill, MA  

2006