

Chapter 5

Developmental and Systems Linkages in Early Intervention for Children with Down Syndrome

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The purpose of this chapter is to emphasize the correspondence between a general developmental approach to child development and the system of early intervention programmes for children with Down syndrome. Of course, the value of a developmental perspective in understanding children with Down syndrome has been thoughtfully articulated for many developmental domains and developmental contexts (see Cicchetti and Beeghly 1990). These analyses reveal that a general developmental framework can accommodate most empirical findings. However, there remain concerns that specific and to some extent unique developmental patterns exhibited by children with Down syndrome have not been adequately appreciated (Gibson 1991; Spiker and Hopmann 1997). These differences become highlighted in the context of early intervention programmes, as clinicians are often faced with the need to design practical strategies that do not, on the surface, seem compatible with a developmental framework.

To examine this issue I will first present a general developmental model and link it to well-established short-term early intervention benefits for children with Down syndrome. Central to the developmental model are the notions of proximal family patterns of interaction which mediate more distal family characteristics to influence child developmental outcomes. It is further suggested that these pathways of influence are applicable to all families, irrespective of the child's developmental status. Another pathway of this model consists of unique sets of 'stressors' created by a child's disability. It is the effect of these stressors and their interaction with other possible stressors associated with family characteristics that provide the basis for accommodating to the uniqueness of children with Down syndrome within a larger developmental framework. Addressing these stressors also provides the conceptual and practical linkage to the early intervention system. Considered in this chapter as well are ways in which this framework can

help promote longer-term effects of early intervention for children with Down syndrome, with an emphasis on incorporating new developmental findings into early intervention programmes.

Developmental Framework

Figure 5.1 illustrates the major components of the developmental model. The purpose here is to organize and account for the salient *experiential factors* governing child developmental outcomes. The model attempts to accommodate children with a wide range of risk and disability conditions (see Guralnick 1997b, 1998 for details), and has therefore relied upon diverse developmental approaches including Belsky's parenting model (Belsky 1984), Sameroff's transactional model (Sameroff 1993), Ramey's biosocial model (Ramey et al. 1992), Dunst's social support model (Dunst 1985), and Bronfenbrenner's (1979) ecological model.

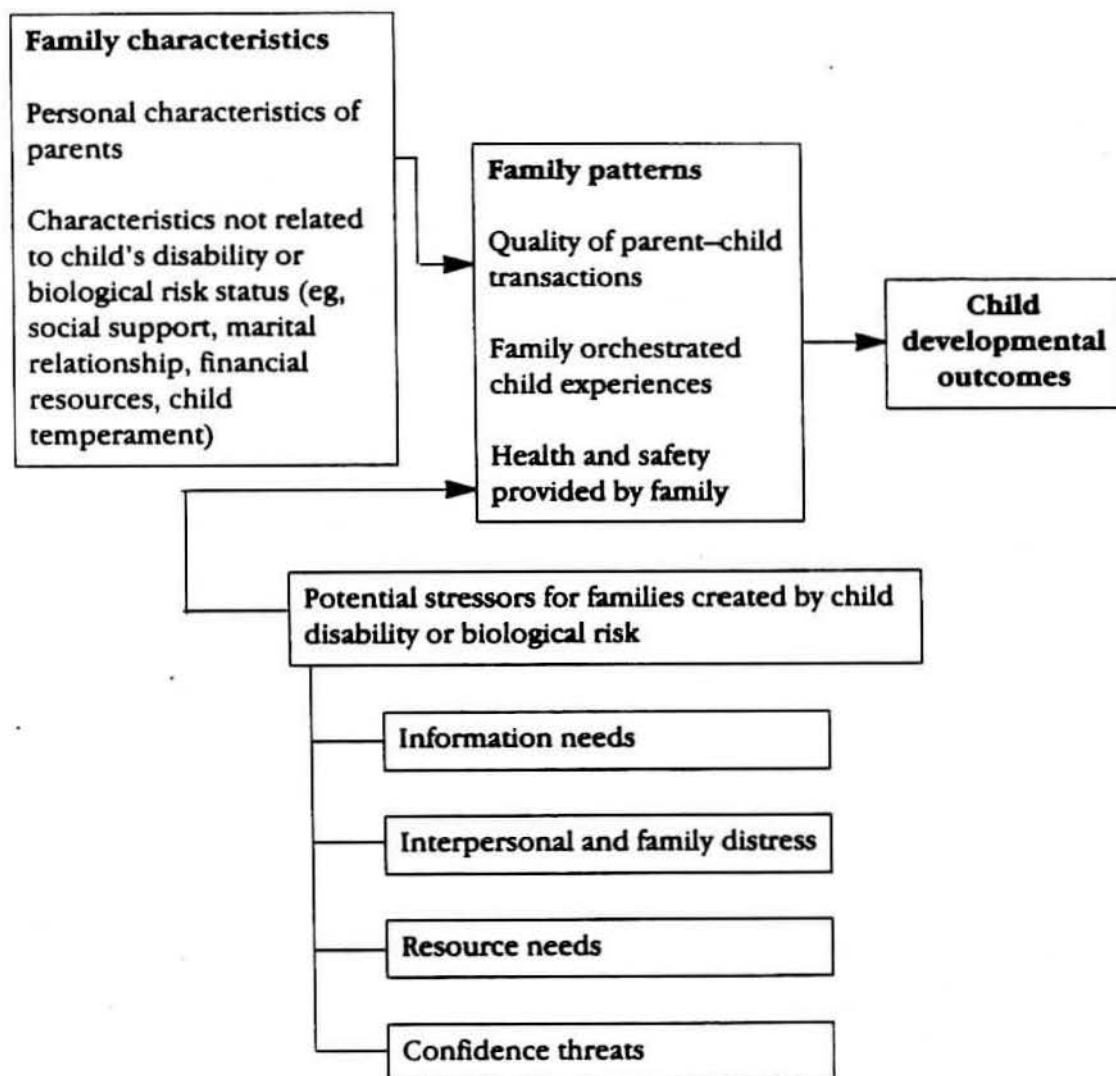


Figure 5.1 Factors influencing developmental outcomes for children. Source: Guralnick 1997b. Reprinted by permission.

Sufficient evidence is available to suggest that at least three primary and proximal patterns of *family interaction* substantially contribute to child developmental outcomes. First, the quality of parent-child transactions has been most frequently studied and directly linked to child outcomes through various parent-child transaction constructs such as responsiveness, sensitivity, scaffolding, and engaging in nonintrusive, affectively warm, and discourse-based exchanges. These well-defined constructs can be readily measured and have been linked to both general and specific forms of child outcome (eg, Baumrind 1993; Clarke-Stewart 1988; Landry et al. 1997; Wachs 1992). Second, experiences families provide and orchestrate for their children, such as the provision of developmentally appropriate and stimulating toys in the home, organizing social interactions with adults and children as part of the parents' social networks, or through the quality of alternative child care options selected, all constitute important experiences linked to child outcomes (eg, Wachs and Gruen 1982). General arrangements for educational, recreational, or special developmental experiences to take advantage of or accommodate their child's unique interests and needs also constitute important family-orchestrated child experiences that influence child developmental outcomes (eg, NICHD Study of Early Child Care 1997; Parke and Ladd 1992). Third, family patterns of interaction that regulate the health and safety of the child, such as nutrition (Gorman 1995), correspond closely to child outcomes.

In turn, the model indicates (see Figure 5.1) that these three proximal patterns of interaction are governed by a set of *family characteristics*. These include personal characteristics of the parents such as intergenerational and culturally transmitted attitudes and beliefs about child rearing, parental mental health, and parents' intellectual abilities. Of importance, should any of these family characteristics not be optimal, they can adversely affect child developmental outcomes (Cicchetti and Toth 1995; Crowell and Feldman 1988; Feldman 1997; Murphey 1992). Moreover, if these more distal, nonoptimal family characteristics are evident, it is suggested that the pathways of influence are mediated by the three family patterns of interaction. In essence, these family patterns are 'stressed' by adverse family characteristics in the sense that they create the basis for nonoptimal family interaction patterns. Risk factors is another term often applied to these stressors.

In many instances, these stressors are longstanding, such as those associated with personal characteristics of the parents. Other family characteristics that can influence family interaction patterns may vary more with external circumstances, and therefore be more amenable to change. In particular, these include failure to establish adequate social supports (Cochran and Brassard 1979; Melson et al. 1993), stressful marital relationships (Emery and Kitzmann 1995), and limited financial resources (Duncan et al. 1994; McLoyd 1990); all of which have been associated with nonoptimal child developmental outcomes. Moreover,

individual child characteristics (eg, temperament), unrelated to a child's risk or disability status, also can create stressful parent-child transactions (Lee and Bates 1985; Sameroff 1993).

Stressors Related to A Child's Disability

When a child is born with Down syndrome, a set of additional potential stressors capable of perturbing family patterns of interaction come into play. These stressors can be organized into four types (see Figure 5.1). First, stressors emerge in the form of information needs. Issues related to the health of their child (Cooley and Graham 1991; Hayes and Batshaw 1993), emerging discrepancies between receptive and expressive language (Fowler 1990; Rondal 1996), attentional difficulties (eg, Kasari et al. 1995), or lack of correspondence between child and parent affective expressions (Knieps et al. 1994), can all potentially adversely affect family patterns of interaction. Similarly, parents of children with Down syndrome may experience difficulties organizing playgroups with peers for their children (Guralnick 1997a; Stoneman 1993) and, like other families of children with disabilities, must continuously consider questions about the value of specific therapeutic services and how to gain access to the best professionals and programmes (see Sontag and Schacht 1994). Different issues, of course, emerge as development proceeds, but all have the potential to perturb optimal family interaction patterns.

Interpersonal and family distress, the second type of potential stressor, can also adversely influence family interaction patterns. The birth of a child with a disability results in an intensely emotional experience, often creating reassessments of expectations and goals within the family (eg, Hodapp et al. 1992) and adjustments in family roles and routines (Barnett and Boyce 1995). Many families of children with disabilities do indeed adapt extremely well (eg, Trute and Hauch 1988), and this is certainly true for families of children with Down syndrome. Nevertheless, the same forces that create distress for children with disabilities in general seem to operate for families of children with Down syndrome (Cahill and Glidden 1996). In fact, affective distress engendered by the parenting process itself has been well documented for families of children with Down syndrome (Atkinson et al. 1995), and distress to varying degrees is likely to recur as the child moves through different developmental stages and transition points (Wikler 1986). Finally, the risk of social isolation for families remains, as even contemporary Western societies have failed to discard the all-too-pervasive negative attitudes toward people with disabilities and their families (see Stoneman 1993).

The third type of potential stressor that can disrupt family interaction patterns concerns unusual resource needs that frequently arise as a consequence of having a child with Down syndrome. As noted, the usual routines of a family are often disrupted and can affect the quality of

caregiving (Beckman 1983; Dyson 1993). Locating and sometimes coordinating services is a responsibility often assumed by families, thereby creating additional demands on their time and resources (Rubin and Quinn-Curran 1985). Financial concerns may mount as well as a consequence of increased health care and related expenses. In fact, caregiving responsibilities may limit mothers' opportunities for out-of-home work and the income it generates (Barnett and Boyce 1995; Kelly and Booth 1997).

Finally, taken together, these three sources of stressors can ultimately undermine parental confidence in their ability to provide appropriate caregiving. This insidious process can have long-term negative consequences as families are certain to encounter challenge after challenge as their child develops (see Cooley 1994).

Impact of Stressors on Development

Should these four types of potential stressors actually have an effect, the model suggests that they do so by adversely influencing one or more of the three family interaction patterns. Available evidence indicates that in the absence of early intervention, these stressful influences do, in fact, manifest themselves for families of children with Down syndrome. In particular, a consistent finding is a general decline in intellectual development that occurs across the first five years of life (Carr 1970; Connolly 1978; Melyn and White 1973; Morgan 1979). The order of magnitude of this decline is approximately .50-.75 SD (8-12 IQ points) and does not appear to be related to a cohort effect, although the relatively steep decline across the first 18 months of life may well be due, in part, to an increasingly larger proportion of test items devoted to cognitive and language development (Guralnick and Bricker 1987; Nesor et al. 1989). However, the continuing decline may well be attributed to experiential factors; ie, to stressors linked to family interaction patterns.

It is important to note that considerable individual differences exist with regard to the extent to which stressors actually produce an adverse impact. The severity of the stressors themselves will certainly account for some of that variability. However, as Figure 5.1 indicates, family interaction patterns are a joint function of stressors due to a child's disability and family characteristics. As such, even significant child disability-related stressors may be able to be mitigated by family resources or related protective factors. The coping capacities of families should not be underemphasized. On the other hand, family characteristics can produce stressors of their own, interacting with stressors associated with a child's disability and risk status to create substantial perturbations in family interaction patterns. Of note, in the United States approximately one-third of families of children with disabilities live at or below generally accepted definitions for low income (Bowe 1995). This 'double vulnerability' can have very damaging effects on child development (see Bradley et al. 1994).

The Early Intervention System

If this developmental model is correct, then effective early intervention programmes should be organized to respond to these stressors. In fact, as suggested in Figure 5.2, analyses of existing components of early intervention programmes indicate that programmes do indeed appear to be structured in that manner. Three general components can be readily identified. First, resource supports are provided in the form of organizing and coordinating the many-faceted aspects of health, educational, and social services. Service coordination is always a challenge, yet a coherent, comprehensive set of services and supports is critical for successful early intervention (Guralnick, 1998). In addition, as noted earlier, many families require supplemental supports such as financial assistance and respite care.

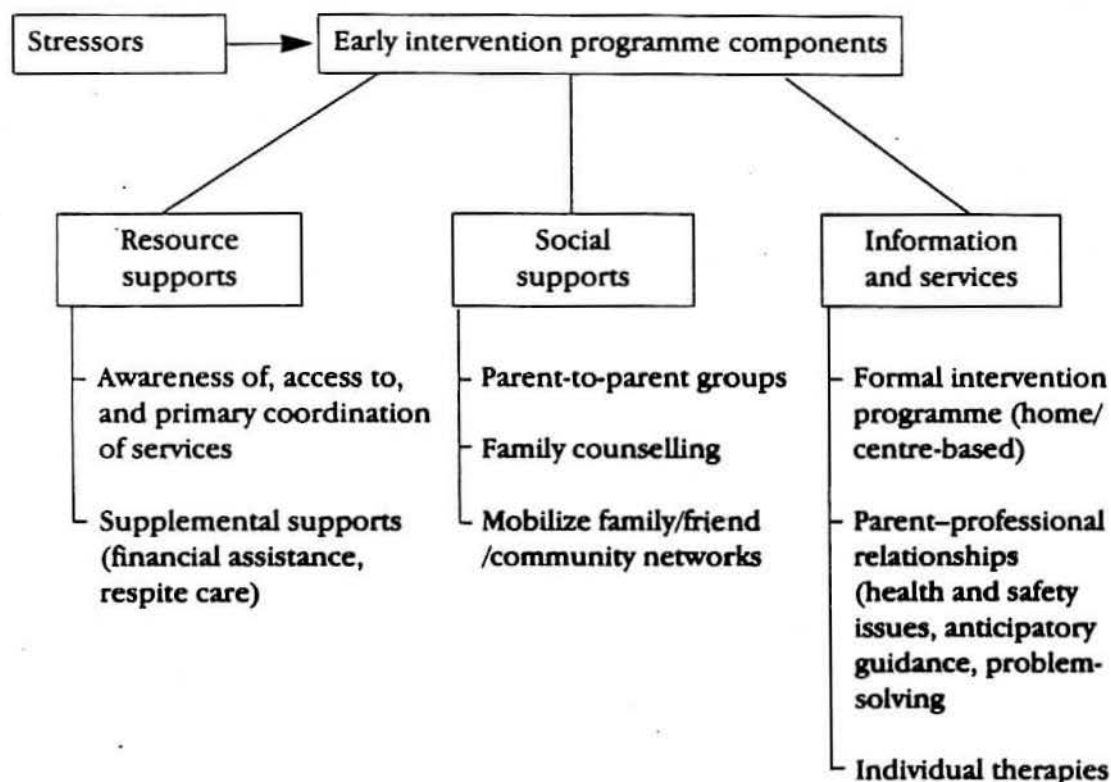


Figure 5.2 Components of early intervention programmes as a response to stressors. Source: Guralnick 1997b. Reprinted by permission.

Social supports provided by numerous and well-established parent organizations, in particular, have emerged as a vital component of the early intervention system (Santelli et al. 1995). These and more specific family counselling services can have a significant positive impact on interpersonal and family distress and provide families with important information in a timely and sensitive manner.

Perhaps the most visible component of the early intervention system is that concerning information and services. Children participate in some

combination of home- and/or centre-based programmes as part of the formal aspects of the early intervention system. In these programmes, children experience clinician-organized or -directed interventions, usually guided by specific curricula (Bailey 1997; Bruder 1997). The structure and direction provided by these diverse curricula appear to be essential for their effectiveness (Shonkoff and Hauser-Cram 1987). Special therapeutic services are usually provided in the context of these more formal programmes, although parents often build important relationships with professionals who provide therapeutic services outside of this context. These partnerships can form a vital professional support network that can help resolve many parental dilemmas and serve as resources for anticipatory guidance and general approaches to problem-solving. It is important to note that even with therapeutic services that are integrated in the formal intervention programmes, the total amount of such services tends to be small. For infants and toddlers with Down syndrome in the United States, the average amount of time spent in these formal intervention programmes is approximately seven hours per month. However, as reflected in Figure 5.2, it is the totality of the supports and services that must be considered in both the design and evaluation of early intervention programmes. Together, these three components can have the effect of increasing parental confidence and competence, characteristics so essential for effective outcomes (see Cooley 1994).

Short-term effectiveness

When comprehensive early intervention programmes are provided to children with Down syndrome and their families, a substantial positive effect is obtained. In fact, when children are enrolled during the first year of life, much of the decline in intellectual development described earlier that occurs in the absence of early intervention can be minimized substantially or eliminated entirely while children are enrolled in programmes (Berry et al. 1984; Schnell 1984; Sharav and Shlomo 1986; Woods et al. 1984). Of course, significant delays are still present, but the reductions in decline constitute an important accomplishment. Presumably, resource supports, social supports, and information and services are appropriately matched to individual child and family needs in well-designed early intervention programmes so that potential stressors influencing family interaction patterns are minimized.

Long-term effectiveness

Despite consistent evidence supporting the immediate and short-term effectiveness of early intervention for children with Down syndrome, concerns exist with regard to the impact of these programmes on children's long-term development. After all, the expectation that long-term effects will result and the corresponding justification for a substan-

tial investment in the early years have a firm basis in developmental psychology and developmental neurobiology (Anastasiow 1990; Guralnick and Bennett 1987; Rutter 1980). Yet, as Gibson and Harris (1988) point out, the fact is that virtually no evidence is available to indicate that children with Down syndrome do better in the long-term as a consequence of participation in early intervention programmes. Certainly the quality of the post-early intervention environment is critical, and has yet to be taken fully into account. For the most part, however, adequate studies have simply not been carried out to evaluate this issue.

Despite this state-of-affairs, except in countries with poorly developed early intervention systems, it is unlikely for practical reasons that well-designed clinical trials of the long-term effectiveness of early intervention for children with Down syndrome will be possible. This is certainly true for straightforward comparisons of children receiving or not receiving early intervention services.

Nevertheless, the question of long-term effectiveness has been addressed for related populations of children with disabilities and those at risk for developmental delays, and can provide useful information for programmes for children with Down syndrome. A recent analysis conducted by Guralnick (1998) has revealed that sustained long-term effects can be reliably obtained if early intervention programmes are comprehensive, time intensive, or of extended duration (eg, extend throughout the child's first five years of life), and are available to help families through important transition points. It is likely that most, if not all, of these same features are relevant to the early intervention system serving children with Down syndrome. Of importance, a number of hypotheses about long-term effectiveness can be generated and tested to determine the extent to which these and other factors can influence long-term effectiveness of early intervention. Clinical trials comparing different intensities of intervention, for example, can materially contribute to evaluating long-term effectiveness yet continue to provide needed services to children and families.

Programme improvements

Ongoing developmental research further suggests that existing early intervention programmes can become even more effective by considering recent findings. In essence, research is now focusing on the identification of subgroups of families whose family interaction patterns do not appear to be optimal in specific ways. If properly identified, special targeted interventions could be provided and the variability in early intervention outcomes further reduced. This process of refinement of the early intervention system may have implications for both short- and long-term effectiveness.

For example, recent evidence suggests that the ability of parents of children with Down syndrome to sustain their attention to child-selected toys is related to more advanced child receptive language (Harris et al. 1996). Presumably, this increased level of joint attention to an object of the child's interest allows the child to allocate adequate cognitive resources to the receptive language features of the context. Again, this interaction pattern is apparent only for some parents of children with Down syndrome. Similarly, research continues to suggest that there exists a small subgroup of parents of children with Down syndrome who tend to adopt a more 'performance-oriented' approach when interacting with their child (see Mahoney and Powell 1988; Mahoney et al. 1992; Spiker and Hopmann 1997). This highly directive pattern is not consistent with optimally promoting children's cognitive development, as it limits opportunities for more discourse-based, child-initiated, and challenging exchanges.

Other aspects of the relationship between parents and their children with Down syndrome can be affected as well, with potentially widespread developmental implications. In particular, recent findings suggest that an avoidance coping style adopted by some parents of children with Down syndrome can reduce sensitivity to their child's cues (Atkinson et al. 1995). Other work has demonstrated that some parents of children with Down syndrome direct fewer internal state words related to both emotion and cognition to their children than do parents of typically developing children (Tingley et al. 1994). These differences in parents' lexicon may have long-term consequences for children's self-regulation of affective and cognitive abilities. Taken together, through continuing research and programmatic efforts to fine-tune early intervention programmes by considering these issues based on emerging developmental research for specific subgroups of families and determining the configuration of programme elements that maximize long-term outcomes, even greater short- and long-term benefits of early intervention for children with Down syndrome are likely to be realized in the future.

Conclusions

The positive short-term effects of early intervention, particularly on the cognitive development of children with Down syndrome, can be well understood within a developmental framework. The concept of stressors that can adversely affect family interaction patterns can be linked to the design of responsive early intervention systems. However, additional research is needed to evaluate the long-term effectiveness and the factors influencing these outcomes. Finally, fine tuning of early intervention programmes to unique parent-child patterns of subgroups of families of children with Down syndrome may be especially beneficial.

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