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Future Directions in Early Intervention for Children with Down's Syndrome

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10.1 Introduction

Early intervention remains one of the most visible and potentially important enterprises in the field of developmental disabilities today. Grounded in sound developmental theory and supported by an often compelling logic, early intervention programmes for children with a wide range of disabilities as well as those at-risk for developmental problems have now achieved a reasonable level of political and scientific acceptance worldwide (Guralnick, in press).

Yet it is only relatively recently that our field has achieved the level of understanding of child development and disability, and identified the mechanisms through which biological and environmental factors exert their influence, to appreciate both the value and limits of early intervention programmes. Of special significance is our emerging appreciation not only of the impact that can be achieved on intellectual development, the most frequent target of early intervention for children with Down's syndrome (DS) as well as others with general developmental delays, but of the potential for influencing other complex and integrative developmental domains such as social competence.

Accordingly, in this chapter, I will attempt to characterize the value and effectiveness of early intervention for children with DS within a contemporary developmental framework. In so doing, I will discuss not simply the traditional emphasis on children's intellectual development but also their social development, especially social competence with peers. It is anticipated that, by adopting a broader developmental framework, emerging knowledge of the influence of motivation, social-cognition and family processes, for example, on various aspects of the development of children with DS will advance our field. It is this interplay between developmental knowledge and early intervention programmes that provides an innovative, yet realistic framework to guide future directions for research and practice.

10.2 Effects on Intellectual Development

Assessments of the course of children's development in the absence of systematic early intervention programmes have provided an important perspective for researchers. Findings for children manifesting various risk factors and those with established disabilities have consistently revealed that without participation in early intervention programmes, measured intellectual development gradually declines over the first few years of life. The magnitude of this decline, assessed in terms of effect size, is approximately one-half to three-quarters of a standard deviation. This phenomenon has been observed repeatedly for children at biological risk primarily due to prematurity/low birthweight (Brooks-Gunn *et al.* 1993; Liaw and Brooks-Gunn 1993; Rauh *et al.* 1988), those raised in disadvantaged circumstances (Campbell and Ramey 1994), and those with broadly-based developmental delays (Dunst *et al.* 1986). Even the course of motor development for children with cerebral palsy follows a similar pattern in the absence of comprehensive early intervention (Palmer *et al.* 1988).

Of importance, research reported in the 1970s consistently revealed a similar pattern of decline in assessed intellectual development for children with DS not experiencing early intervention (Carr 1970; Connolly 1978; Melyn and White 1973; Morgan 1979). Even a recent report from South Africa, in which early intervention programmes were not yet available, yielded a similar outcome (Neser *et al.* 1989). It should be pointed out that in the case of assessed intellectual development, declines observed during the first few months of life, up to perhaps 18 months of age, are to be expected, due primarily to the dependence, early on, of tests of general intelligence on motor skills, and the strong biological constraints that operate for that domain (Bendersky and Lewis 1994; Shonkoff *et al.* 1992). Accordingly, the initial and most rapid decline that occurs during the first 18 months of life may well reflect the transition from motor to more cognitive and language-based test items. However, the continued decline may reflect, to some extent, non-optimal developmental environments – a circumstance that may be altered through early intervention programmes.

Consequently, a reasonable expectation regarding the benefits of intervention beginning as early as possible is to prevent or substantially minimize this continuing decline in intellectual development. Indeed, this is precisely what occurs. Evidence from longitudinal studies from Australia (Berry *et al.* 1984), Israel (Sharav and Shlomo 1986), the United States (Schnell 1984) and Wales (Woods *et al.* 1984) indicates that comprehensive early intervention programmes can substantially prevent this decline in intellectual development from occurring for children with DS. Despite sometimes extensive differences in programme content and related factors, and the existence of legitimate methodolog-

ical concerns (Gibson and Fields 1984; Guralnick and Bricker 1987), effect sizes of approximately one-half to three-quarters of a standard deviation are obtained in these studies of children with DS. Moreover, compatibility with findings from other risk and disability groups provides additional indirect support for the effectiveness of early intervention (Guralnick 1991).

10.3 Components of Early Intervention Programmes

The heterogeneity of intervention approaches and strategies found in programmes for children with DS, coupled with the fact that analyses of individual programme components were rarely conducted, did not permit an identification of those features of early intervention programmes that were responsible for the positive outcomes. Nevertheless, as these early intervention programmes evolved, a number of common features became established, thereby providing some insight into those components that, taken together, are likely to have promoted development. Specifically, systematic and usually highly structured and individualized programmes following curricula based on developmental milestones were common. Educational and developmental programmes were carried out at home and in specialized centres, and individual therapies were provided, especially physical therapy. Anticipatory guidance from professionals provided a wealth of information on education and health issues and strong parent-to-parent networks provided emotional, instrumental, and other forms of support (Guralnick and Bricker 1987). Information obtained from descriptive studies of the development of children with DS as well as research on parent-child interaction patterns appropriately formed the basis for specific intervention recommendations to foster more supportive, contingent, and sensitive transactions occurring between parents and children. Advice and strategies to help parents identify the often difficult-to-read cues of their child, to adapt to frequently hard-to-obtain eye contact, to adjust to episodes of vocal clashing during early parent-child 'conversational' interactions, to enhance environmental stimulation in an effort to almost drive development and encourage self-action, and to accommodate to the child's arousal and information-processing capacities constituted key elements of these programmes (Guralnick and Bricker 1987; Spiker 1990). As Spiker (1990) noted, much of the emphasis was on cognitive and language development, although other developmental areas have certainly been of interest. Moreover, parents were often enlisted as adjuncts in this intervention process, carrying out prescribed exercises and activities. Taken together, this array of components appeared capable of preventing continuing declines in overall development for

children with DS in comparison with circumstances in which virtually no coordinated services existed, support and information were minimal, and community expectations were typically low.

10.4 Future Directions

Having said this, the issue that immediately arises is whether this is all that we can accomplish. Is it, in fact, possible to enhance further the effectiveness of early intervention programmes for children and families? If so, what directions should be pursued, and do we have any basis for optimism?

Perhaps what is needed is not a change in the content or components of early intervention programmes, but rather simply an increase in the intensity of what currently exists. After all, the formal aspects of early intervention programmes for children with DS are not very demanding, even during the preschool years (Guralnick and Bricker 1987; Shonkoff et al. 1992). Moreover, programme intensity seems to be an important dimension for children with other disabilities. Young children with autism appear to be remarkably responsive to extraordinarily intensive interventions, producing gains that are sustained over substantial periods of time (Lovaas 1987; McEachin et al. 1993). A replication of this highly intensive early intervention programme is now in progress for children with mild to moderate developmental delays with positive, though preliminary, findings being reported (Smith and Lovaas 1993). Unfortunately, children with DS were excluded in this investigation. Similarly, intensity appears to be an important factor contributing to the effectiveness of preventive intervention programmes for children at-risk due to prematurity and low birthweight (Ramey et al. 1992). Interestingly, for disadvantaged children, intensity in the form of programmes of longer duration (i.e., extending beyond the preschool years) has produced positive effects on assessed intellectual development and academic achievement that remain even after the intervention has been discontinued (Campbell and Ramey 1994; Reynolds 1994). The durability of gains from early intervention has been a major concern for children with DS (Gibson and Harris 1988), thereby warranting consideration of more intensive and/or extended interventions.

Alternatively, it may be advisable to reorganize content areas and instructional strategies in light of recent developmental research. For example, a stronger emphasis on memory, consolidation of skills, or motivational aspects of children with DS are potentially important directions (Wishart 1993). Moreover, it may be especially constructive to refocus the content of early intervention programmes entirely and to give priority to areas of development other than cognition or language. As argued elsewhere (Guralnick 1990a), a focus on promoting children's social competence, especially competence with peers, may be of partic-

ular value. This long-neglected area may offer special promise for children with DS, and is discussed below.

10.5 Peer-Related Social Competence

Developing peer relations and establishing friendships is a critical developmental task that is a challenge to all young children at some level during the preschool years. Parents of children with and without disabilities highly value and are concerned about this aspect of their child's development (Guralnick *et al.* 1995; Quirk *et al.* 1984). Successfully developing relationships with peers and establishing friendships has important developmental implications as well, with benefits associated with cognitive, communicative, and general prosocial development, as well as an emerging sense of self (Bates 1975; Garvey 1986; Hartup 1983; Howes 1988; Rubin and Lollis 1988). The importance of peer-related social competence as a determinant of social integration and social acceptance in classroom and community settings, as well as its importance to later life adjustment, has also been well established (Guralnick 1992).

In view of the developmental significance of peer-related social competence, it is discouraging to note the unusual difficulties experienced by young children with developmental disabilities in this domain. The limited social contacts and friendships reported for children with DS (Sloper *et al.* 1990) parallel reports for diverse groups of children with disabilities (Lewis *et al.* 1988). Moreover, a substantial body of research confirms that these difficulties are likely to be a consequence of problems associated with an unusual pattern of social interaction deficits. Indeed, particularly for children with general (cognitive) delays, including those with DS, problems in peer-related social competence extend well beyond those which would be expected based simply on a child's developmental level (Guralnick and Groom 1985, 1987, 1988).

10.6 Family Processes

Given the developmental significance and magnitude of the problem, can early intervention programmes foster the peer-related social competence of young children with DS? What information is available that might suggest particular directions? One highly active contemporary area of research focuses on the linkage between caregiver–child relationships and children's subsequent social competence, particularly peer-related social competence. This linkage between family processes and social competence has been well established (Guralnick and Neville, in press, for a review), with patterns holding for early caregiver-child relationships, typically evaluated in terms of the security of attachment relationships, as well as for subsequent interactions that emerge during

the late toddler and preschool years. Indeed, recent research related to both attachment and later parent-child interactions for children with DS and their families suggests intervention directions that may well benefit children's peer-related social competence.

10.6.1 Attachment relationships

The quality of attachment formed between children and parents has yielded consistent associations with children's peer-related social competence in general (Cohn 1990; La Freniere and Sroufe 1985; Pastor 1981), as well as friendships (Elicker *et al.* 1992; Grossman and Grossman 1991). Moreover, a number of explanations for the effects of the secure attachment–social competence association have been put forward, including generalization of an 'internal working model' to other relationships, formation of a generalized positive social orientation, and availability of a secure base from which children can confidently explore both the physical and social world. The development of reciprocity patterns and enhancement of self-efficacy have also been implicated (see detailed discussion in Guralnick and Neville, in press).

Early research by Cicchetti and Serafica (1981) provided evidence that, in accordance with developmental levels, attachment relationships were organized in a similar manner for children with and without DS. Yet recent research has revealed that rather disturbing differences may well exist with regard to the attachment-related behaviour of children with DS (Vaughn *et al.* 1994). In particular, during the separation/reunion episodes that are central to the attachment assessment protocol, a disproportionate number of children with DS fail to show expected levels of distress and rarely seek contact or proximity with their mothers. Social cues that most typically-developing children exhibit to elicit parental behaviours of comforting are far less evident. These rather dramatic differences are likely due to many factors, including dampened arousal mechanisms (Emde *et al.* 1978). It appears that, although the meaning of attachment and its measurement are problematic for children with DS, the patterns observed by Vaughn *et al.* (1994) nevertheless remain a challenge to the emergence of harmonious and synchronous early parent-child relationships.

In view of associations between the early caregiver-child interactions and later social competence, a more focused and substantial effort by early interventionists to foster early caregiver-child relationships may prove to be a fruitful direction for the future. Some promising approaches for high-risk populations are available (Lieberman *et al.* 1991; van den Boom 1994), but the problems unique to children with DS, particularly emotional expressiveness and readability, will require highly imaginative early intervention strategies.

10.6.2 Parent-child interactions

The quality of parent-child interactions occurring during the late toddler and preschool period is also predictive of the quality of children's peer-related social competence (Guralnick 1986; Guralnick and Neville, in press). The parent-child dyad provides the context for learning and practising interpersonal skills that are relevant to the peer context (Martinez 1987). In fact, children are more likely to influence successfully the behaviour of their mothers in comparison to the behaviour of peers (Kochanska 1992), thereby having an opportunity to develop important social skills in the parent context related to social tasks such as conflict resolution or maintaining social exchanges. The parents' role in eliciting affective responses from their child during parent–child play has also been associated with children's peer-related social competence (see Parke *et al.*, 1992). Apparently, regulating one's emotions in the context of social play, indicating an ability to encode and decode emotions, serves an important role in developing social competence. As might be expected, contrasting parental styles such as those dominated by controlling or intrusive relationships are associated with lower levels of peer-related social competence for their children (Putallaz 1987).

Accordingly, the frequently observed tendency of many parents of young children with disabilities, including parents of children with DS, to adopt more controlling and directive styles while interacting with their children poses a potential concern for children's peer-related social competence (Mahoney *et al.* 1990). Admittedly, the nature and implications of this directive pattern are controversial (Marfo 1990). For example, individual differences are extensive, directive patterns may actually reflect an appropriate adjustment to less interactive children in many instances, and directive patterns must be understood in a broader context of parent–child relationships that include dimensions of warmth, sensitivity, and responsivity (Berger 1990; Crawley and Spiker 1983; Landry *et al.* 1994). However this is resolved, there nevertheless appears to be a substantial subset of parents of children with DS who exhibit a performance-oriented pattern of parent–child interactions, frequently seeking to elicit from their child some behaviour at as high a level of competence as possible (Mahoney *et al.* 1992). The resulting directive and controlling relationship may well create a pattern in which reciprocity and playfulness are relegated to minor roles, and fail to permit a child to develop an interaction pattern based on his or her own interests. These circumstances are inconsistent with fostering a child's ability to relate with peers (see Guralnick and Neville, in press).

Once again, it is this type of information that provides direction for future intervention strategies for families of children with DS during the

early years. In this case, the challenge is first to develop tools sensitive enough to identify families exhibiting interaction patterns that may be counterproductive, and then to design appropriate interventions that do not themselves intrude or damage the core parent–child relationship. Interventions in this area will constitute a demanding test for the parent-professional partnership.

10.7 Improving Children's Peer-Related Social Competence: Child Focus

Successful interventions guided by recent developmental research to foster attachment and parent–child interactions may well prove beneficial for children's peer-related social competence, at least to some extent. Moreover, thoughtful efforts to expand the peer social network of a child with DS and interventions that support social exchanges with peers in high quality inclusive settings can also be of value (Buysse and Bailey 1993; Guralnick 1990b), as experience with peers is so critical for furthering the development of peer-related social competence. Yet, I would suggest that even if interventions based on family processes and the expansion of a child's social network are successful, substantial difficulties beyond those expected based on the child's developmental level (or language level) will remain. Recent advances in theory and research have led to a more in-depth understanding of cognitive and emotional regulation processes governing young children's peer-related social competence, and these are relevant to children with and without disabilities. Unfortunately, many of these underlying processes are likely to pose special difficulties for children with DS, suggesting that improvements in peer-related social competence will require highly sophisticated efforts that are child focused and consider these processes directly.

Figure 10.1 captures the key elements of a model I have developed over the last few years to guide the development of an assessment and intervention programme in the area of peer-related social competence (Guralnick 1992). Although it is beyond the scope of this chapter to provide an in-depth discussion, a consideration of its elements provides a sense for the issues involved (Dodge 1991; Dodge *et al.* 1986; Guralnick 1992, 1993, 1994).

First, as suggested by the bracketed area on the right of Figure 10.1, peer-related social competence is best thought of as being composed of a series of social tasks. In fact, three social tasks have been identified in the literature as being central to our understanding of peer-related social competence. These tasks are:

1. Gaining entry into a peer group;
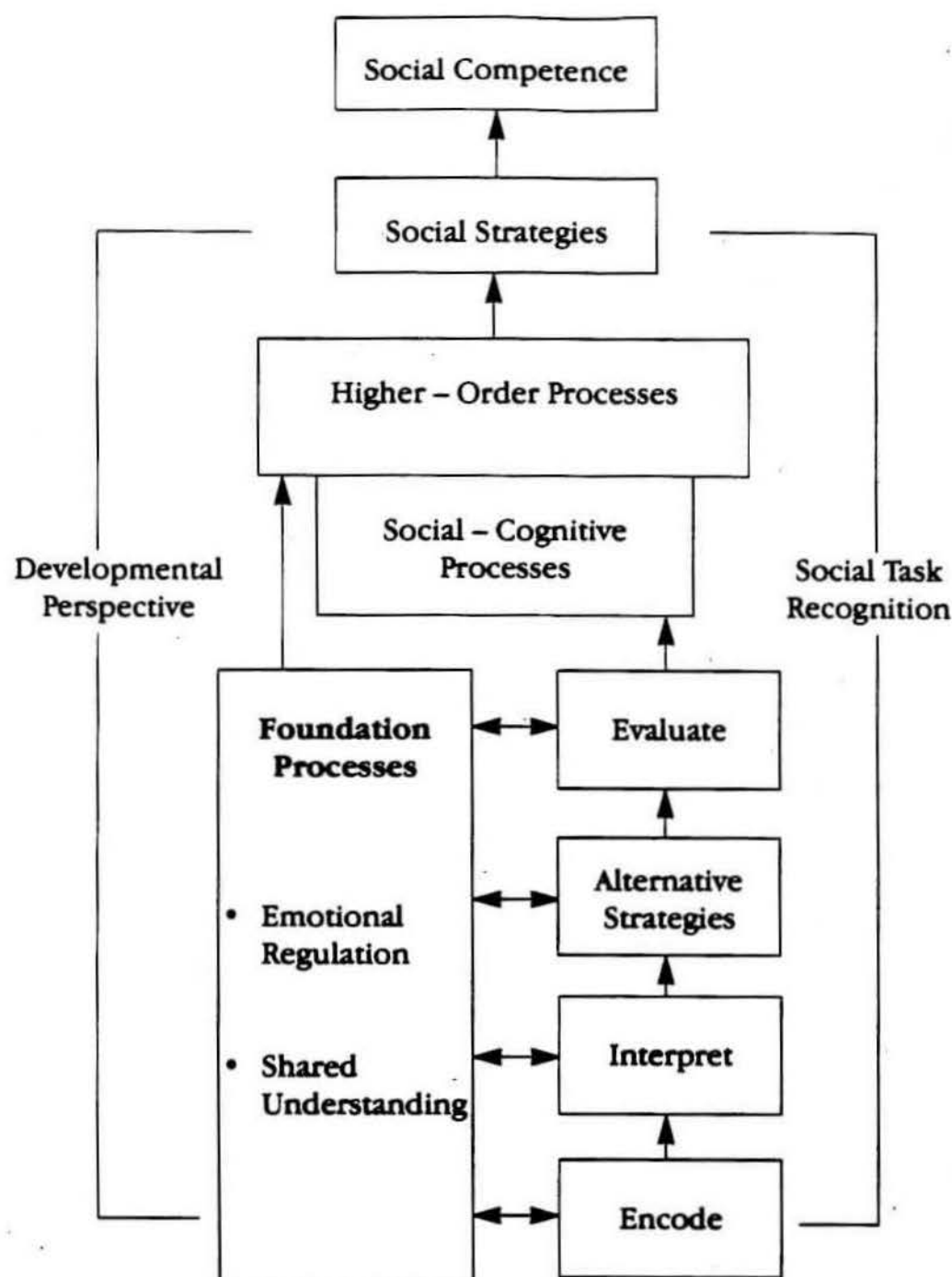2. Resolving conflicts;
3. Maintaining play with peers.

Figure 10.1 A process model of peer-related social competence. From: Assessment of Peer Relations, MJ Guralnick 1991, Seattle WA: University of Washington, Center on Human Development and Disability. Reprinted by permission.

Competence is typically evaluated in the context of one or more of these social tasks in terms of the effectiveness and appropriateness of the social strategies that are employed. These social strategies, in turn, depend upon the operation of four interrelated processes. The first two processes are referred to as foundation processes. One involves the pattern employed by a child to regulate his or her emotions during a

social task. The unusual problems experienced by children with DS, ranging from often reported lower arousal to difficulties settling once an emotional event is triggered (see Cicchetti, Ganiban *et al.* 1991), are likely to be of special concern.

The other foundation process is referred to as shared understanding. Knowledge of sequences of behaviours (i.e., scripts) associated with everyday events (e.g., cooking) form the substance of dramatic play sequences. Moreover, mutually agreed upon and understood social rules (e.g., turn-taking, possession) are relevant, and together constitute the basis for connectedness essential for socially competent interactions with peers (Nelson 1986). For children with DS, memory and self-organizing difficulties as well as problems integrating social and non-social activities required by scripts pose challenges to the development of a well-developed, shared understanding (Beeghly *et al.* 1989; Gibson 1992; Kopp 1990; Krakow and Kopp 1983; Mundy *et al.* 1988).

The last two processes (see Figure 10.1) emphasize the information-processing components of the model. Social-cognitive processes are composed of elements related to how children encode information, interpret it, produce alternative strategies, and evaluate those strategies in terms of the context. Similarly, a higher order process proposed as an integrator of this information requires that children recognize the social task they are engaged in, sustain attention, and monitor outcomes. Available neuropsychological models of social competence are consistent with this approach (Pennington and Welsh 1995).

It is precisely those deficits in information-processing (Lincoln *et al.* 1985), verbal coding and decoding (Gibson 1992), failures to produce alternative types of strategies in related tasks (Kopp *et al.* 1983), and to recognize emotional expressions (Knieps *et al.* 1994) that again create special problems for children with DS. Moreover, Wishart (1993) states: 'From a very early age, it would appear that the DS [Down's syndrome] children are avoiding opportunities for learning new skills, making poor use of skills that are acquired, and failing to consolidate skills into their repertoires' (p. 400). These new as well as longstanding motivational and learning style issues which Wishart has now put into perspective for children with DS are even apparent in early exploratory object play (Ruskin, *et al.* 1994a,b). Clearly, difficulties observed during cognitive tasks are likely to adversely influence social tasks that rely on social-cognitive processes.

Having now developed a better understanding of the processes likely to affect children's peer-related social competence, the critical question revolves around what approaches can be taken to intervene during the preschool years. At the present time, an intervention approach that focuses on techniques that adapt to problematic processes and provide structured experiences to enhance the peer-related social competence of young children with disabilities is being evaluated. Vignettes to foster

script development for dramatic or even physical play sequences as well as for social task recognition have been developed. For children with DS, techniques involving social imitation, providing predictable and often repetitive sequences with variations in context, and arranging involvement with peers in small group settings are only some of the strategies being employed.

10.8 Conclusions

Considerable progress has been achieved in the field of early intervention for children with DS, particularly in terms of reducing the continuing decline in intellectual development over the first few years of life. However, we are now at a critical point, seeking to determine what more can be accomplished. Intervention research with other disability or risk populations suggests the possibility that increasing the intensity of interventions can produce further benefits, particularly enhancing the durability of effects. It is uncertain as to whether that also will be the case for children with DS. Alternatively, an emphasis on promoting children's peer-related social competence, an area of special concern, through a combination of parent- and child-focused strategies may prove to be fruitful. Programmes developed in response to recent developmental information on parent–child relationships, children's learning styles, as well as cognitive and emotional processes associated with children with DS constitute important directions for early intervention research and practice.

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