

CHAPTER 3

INCLUSION AS A CORE PRINCIPLE IN THE EARLY INTERVENTION SYSTEM

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In the context of the Developmental Systems Model of early intervention, the principle of inclusion represents all efforts to maximize the participation of children and families in typical home and community activities (Guralnick, 2001a). Although inclusion is often thought of in the context of encouraging interactions between children with and without disabilities, it is conceptualized in the broadest possible manner as a core principle in the Developmental Systems Model. The ideological and philosophical rationales for a principle that encourages full participation of all children in community life are important in their own right, but failure to translate this principle into practice within the early intervention system will likely have numerous adverse consequences on children's development, including limiting the full range of stimulation that children can experience, restricting social and educational learning opportunities, and perhaps creating low expectations for achievement (Guralnick, 2001b).

More specifically, inclusion emphasizes full involvement of the child in family routines and in social activities with relatives and friends, as well as taking advantage of the entire array of educational and recreational opportunities that communities have to offer (see Bruder, 2001; Dunst, 2001). Of importance, this principle has legal status with respect to the delivery of early intervention services. The Education for All Handicapped Children Act of 1975 (PL 99-142; now known as the Individuals with Disabilities Education Act [IDEA]), along with subsequent amendments, reauthorizations, and related legislation (PL 101-476, PL 102-119, and PL 105-17), sought to ensure that children with disabilities remained in as normal settings as possible while services and supports were being provided. For infants and toddlers, participation in natural environments was mandated (i.e., interventions should occur in places where one would usually find typically developing children; Walsh, Rous, & Lutzer, 2000).

For preschool-age children, the law required that every effort be made to ensure that children with developmental delays fully participate with their typically developing peers in early childhood programs. But again, inclusion as a core principle in a developmental systems framework has broader implications (see Guralnick, 2001a).

Unfortunately, powerful forces continue to exert pressure toward isolation and separation when a child has a disability. Despite considerable progress over the years, negative attitudes at

all levels of the community still surround children with disabilities (Stoneman, 2001), and state-administered early intervention programs have failed to meet most reasonable contemporary goals for inclusion (Guralnick, 2001b). But, it is also the case that family patterns of interaction involving a child with a disability can increase the risk of isolation from peers and from community activities and limit a child's participation in the life of his or her own family. For example, families of children with disabilities (see Chapter 1; Guralnick, 1998) often need information with respect to reading their child's cues or adjusting to their child's limited expressive language to achieve the proper development-enhancing balance in their relationship. In the absence of that information, the quality of parent—child transactions can be compromised, affecting the quality of the relationship between a child and other family members during daily family routines (Fiese, 2002; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). As a consequence, children's participation in those routines may become less productive from a developmental perspective, even distressing to those involved, and will ultimately occur less frequently. Similarly, parents' confidence in their ability to manage their child's behavior or perhaps interpersonal or family distress family or community activities stemming from their child's "disability status" can further limit children's experiences that would normally be initiated and organized by family members. These circumstances may even lead families to select unnecessarily restrictive early intervention alternatives such as a segregated preschool educational program.

Accordingly, as these examples illustrate, stressors created by a child's characteristics can affect family patterns of interaction (e.g., parent—child transactions, community experiences organized by parents) that influence a child's inclusion in home and community life and may adversely influence a child's development as well. A similar process operates for stressors on family patterns of interaction whose origins are linked to the characteristics of the families themselves. For example, families experiencing mental health problems or who have limited financial resources or social supports are far more likely to lack the ability to negotiate community life in a manner that orchestrates appropriately stimulating experiences for their child or the ability to engage in parent—child transactions during family routines that are enjoyable and developmentally enhancing (see Burchinal, Roberts, Hooper, & Zeisel, 2000; Sameroff, Seifer, Barocas, Zax, & Greenspan, 1987).

Clearly, then, for children with established disabilities or those at risk for developmental problems, these and related threats to inclusion must be addressed when families and children are involved in the early intervention system. Indeed, virtually every component of the early intervention system is relevant to inclusive practices. Accordingly, the purpose of this chapter is to suggest strategies designed to maximize inclusion in home and community life for children and families encountering the early intervention system as presented in the Developmental Systems Model. This discussion will be organized in accordance with the separate structural components of the model: screening program or referral, surveillance, point of access, comprehensive interdisciplinary assessment, entry into a preventive intervention program, entry into an early intervention program, assessment of stressors, developing and implementing a comprehensive program, monitoring and outcome evaluations, and transition planning. See Chapter 1 or Guralnick (2001a) for more detailed descriptions of each component.

SCREENING PROGRAM OR REFERRAL

People seeking services who encounter any service system, including one focusing on early intervention, risk being stigmatized. Stigmatization can, of course, occur in any component of the system, but initial contacts with a system can create long-lasting effects. As such, special care must be taken to thoughtfully discuss the meaning and implications of any screening results or reasons for referral (i.e., risk factors). Families are likely to have numerous questions about the implications of routine screening for their child's short- and long-term development. Therefore, a frank, professional discussion about the results, as well as recognizing the limitations of the screening process and the inherent variability in developmental rates, is in order. Similarly, expressing as much optimism as is reasonable and appropriate and ensuring that discussions remain firmly within a developmental framework should be essential features of these initial encounters with children and families.

SURVEILLANCE

If screening fails to result in a referral but concerns remain, then the surveillance or monitoring programs that are arranged should follow a similar approach outlined previously for screening. Questions by parents are likely to arise at each monitoring point but especially if concerns or risks are sufficient to result in a referral. Continuing to emphasize the value of full participation for children and families in home and community activities should be an integral part of the monitoring phase.

POINT OF ACCESS

Identified concerns or clear risks to a child's development that result in a referral (self or otherwise) generally initiate contact with what is best referred to as a point of access in the early intervention system. Inclusion would certainly be maximized if the point of access were part of a broader system of community-based child development supports and services to which all children had access. There are many advantages for such a comprehensive point of access beyond communicating that all children, irrespective of risk or disability, are part of the same community (see Harbin, McWilliam, & Gallagher, 2000). Nevertheless, most points of access are organized in accordance with risk and disability conditions and are quite diverse from community to community and state to state (Harbin et al., 2000; Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000). Given this situation, it is vital that special efforts be taken to avoid stigmatizing families as they make contact with what is usually a formal system and that information is gathered for future use for program planning and administrative purposes.

Minimizing the use of labels, stressing how this particular point of contact operates in the context of the larger community, providing a warm and inviting setting for families, and ensuring the confidentiality of information all can help in this regard. These strategies are especially important if points of contact are large agencies serving a fairly substantial community (usually established for reasons of efficiency) or if the agency is one that is highly specialized or disorder-focused (e.g., clinics specializing in metabolic disorders or autism spectrum disorders).

COMPREHENSIVE INTERDISCIPLINARY ASSESSMENT

Based on information collected and organized at the point of access, many children for whom there are concerns about their development in the form of a delay or disability participate with their families in a comprehensive interdisciplinary assessment (Farrell & Pimentel, 1995; Guralnick, 2000b; Thyer & Kropf, 1995). As a result of this process, a child's developmental profile is generated, information with respect to diagnostic/etiologic decisions is gathered, and general recommendations about next steps (e.g., referrals to early intervention programs or other specialists) are provided (Guralnick, 2000c). This encounter with an interdisciplinary team of specialists can be very intimidating to families and frequently occurs in highly specialized medical or evaluation centers.

Once again, the way in which complex information is communicated to families can substantially influence their orientation in terms of inclusion. First, diagnostic information must be presented in a way that helps families work through and resolve any issues surrounding acceptance and understanding of the diagnosis. Failure to do so increases the likelihood that families will have difficulty forming attachments with their child and adversely affect parent-child transactions (Pinta, Marvin, Britner, & Borowitz, 1996). As a consequence, full involvement of the child in family activities may be compromised. Second, maintaining a developmental perspective is critical in conveying information to families regarding their child's developmental profile. Variations and even atypical forms of behavior and development can and should be presented as part of a larger developmental framework pointing not only to similarities in their child's developmental trajectory and to the organization of their child's development common to all children but also to the important influences on development shared by all. Finally, even general recommendations for supports and services should focus on as many inclusive options as possible. Families should be encouraged to seek out services in their local communities and, to the extent possible, participate with their child's peer group of children without disabilities. Providing lists of local community agencies, such as child care programs, that can effectively accommodate children with disabilities is an example of a strategy that communicates an inclusive philosophy to families.

PREVENTIVE INTERVENTION PROGRAM

Those children who do not have an identified delay or disability but who are judged to be at sufficient risk for developmental problems are referred to a preventive intervention program. The reason for referral could be related to child characteristics (i.e., premature birth, low birth weight), but many children entering preventive intervention programs exhibit family characteristics (e.g., maternal mental health problems, limited financial resources, absence of social supports) that can stress family patterns of interaction, leading to social isolation and a general lack of involvement for families and their child in numerous activities. For families entering this component of the system, professional staff should give special attention toward establishing positive personal relationships and building trust and confidence (Berlin, O'Neal, & Brooks-Gunn, 1998). This relationship is an essential bridge to community involvement of the child and family and, if properly established, will likely yield a more valuable assessment of stressors that will form the basis for preventive intervention approaches.

EARLY INTERVENTION PROGRAM

Children for whom a delay or disability is highly likely or has been firmly established will now begin an ongoing relationship with a range of providers of early intervention services and supports. Establishing a positive relationship between parents and professionals is critical for families, even in the absence of family characteristics that would create additional risk factors. The way in which a preliminary intervention program is carried out when families enter the early intervention program, and the extent to which conscious decisions are made to promote community participation while developing a partnership with families, can clearly have a major effect both now and in the future on all aspects of inclusion.

Establishing that services and supports, even in the context of a preliminary intervention program, will be coordinated effectively constitutes another important potential influence on inclusion for families. Highly coordinated and integrated services and supports reduce parental anxiety and allow parents more time to pursue community activities with their child and foster their child's involvement in family routines. Additional child care demands alone can drain the energy of many families—further responsibilities for coordinating often disparate services can dramatically restrict a child's full participation in home and community life. Also, good parent–professional relationships and efficient service coordination can facilitate the ongoing assessment of stressors needed to develop and implement well-designed and effective comprehensive intervention programs, including components relevant to inclusion.

ASSESSMENT OF STRESSORS

For children with disabilities, information needs, interpersonal and family distress, resource needs, and confidence threats to parenting frequently arise as a consequence of a child's characteristics. This can lead to stress on family interaction patterns, which can adversely affect the child's development (Guralnick, 1998). Similarly, as noted previously, certain family characteristics or environmental risk factors can stress family patterns of interaction in a number of ways and contribute to a child's developmental delays. Assessing these potential child- and family-generated influences is one of the most critical components of the Developmental Systems Model (Guralnick, 2001a), and much of the information gathered in the course of this assessment is relevant to inclusion. Perhaps of most importance, the assessment should include considerable information about family routines and community activity patterns that families find important and satisfying. The ultimate goal is to work with families to try to maintain those patterns and include children with disabilities or those who are at risk. Increased attention has been given to strategies for gathering information on family routines and community activities and for determining family needs in connection with sustaining and enhancing these routines and activities in the context of early intervention (Bernheimer & Keogh, 1995; Bruder, 2001; Dunst, 2001; Dunst, Hamby, Trivette, Raab, & Bruder, 2000). In addition, a discussion with respect to a child's involvement with his or her peers should be initiated as this frequently is an area of concern for young children with disabilities (Guralnick, 1997). Parents' roles in organizing playgroups or arranging playdates should be part of the assessment. In this way, parental needs designed to help support a child's involvement with peers at home and in the community can be identified. Finally, families are unlikely to have sufficient information about the formal service system principles and options with respect to natural environments or

inclusive educational programs under IDEA. Introducing that topic and probing the family's level of understanding of the issues will allow more thoughtful decisions to be made during the development and implementation of a comprehensive program phase of the early intervention system.

DEVELOPING AND IMPLEMENTING A COMPREHENSIVE PROGRAM

The provision of resource supports, social supports, and information and services to families (i.e., early intervention services and supports) in order to support full participation of a child with a disability or a child at risk in home and community activities occurs in this component of the model. It is hopeful that families' contacts with the early intervention system all along have emphasized a community orientation and a developmental framework, and that assessments have focused on topics related to family routines and community activities. Having reached this point in the early intervention system, the decisions that families and professionals make about specific intervention programs should reflect that inclusive orientation. Indeed, the development of intervention plans should reference maximum participation as a goal. Specific family routines and community contexts should be considered to be central as well, with intervention plans embedded within those contexts (see Dunst, Trivette, Humphries, Raab, & Roper, 2001). Without question, services chosen by families of children

with disabilities should be considered in the framework of natural environments or inclusive early childhood programs. For families who are participating in preventive intervention programs, especially for those children at high environmental risk, the design and implementation of a comprehensive program should reflect similar efforts to support family routines and enhance developmental opportunities as part of community involvement. If intervention-oriented child care is part of the preventive intervention plan, then every effort should be made for inclusion (Guralnick, 2000a).

Access to various forms of inclusive programs is, unfortunately, not universally available. Similarly, there is a concern about the quality of many of these programs because they have difficulty appropriately accommodating to and meeting the individualized needs of all children in the setting (see Guralnick, 2001b). Yet, in well-designed inclusive programs, children do at least as well developmentally and socially in comparison with their participation in noninclusive programs (see Guralnick, 2001b). Consequently, for the development and implementation component of the early intervention system, those involved may be required to become advocates for more available and higher quality inclusive programs in order to maximize inclusion. Accordingly, discussions during the individualized planning processes that normally take place should focus on both of these issues. Admittedly, these are frequently difficult discussions, often pitting prospects to meet child and family needs against prospects for real change in the quality of programs.

MONITORING AND OUTCOME EVALUATIONS

To ensure that the core principle of inclusion is embedded in all components of the early intervention system, specific qualitative and quantitative assessments should be developed to evaluate both the extent to which that has occurred and how effectively efforts to support

inclusion have been implemented. Straightforward self-report checklists for professionals involved in various components of the early intervention system asking about activities that occur in support of inclusion serve not only an evaluative function but also as a reminder about strategies that may be useful. Periodic interviews with families focusing on how their experiences with various components of the system influenced their decisions about inclusive services and supports or helped guide their goals for their child provide a complementary perspective (see Bailey et al., 1998).

TRANSITION PLANNING

As children make transitions to other programs in the early intervention system, inclusive options should be a strong consideration. This is especially critical when children make the shift from the infant-toddler program to preschool educational programs. During the planning process, visits to the range of inclusive programs available should be encouraged along with frank discussions of the advantages and disadvantages of each option.

For transitions to appropriate inclusive settings to occur, the system needs to have a well-developed coordinating capacity among the various agencies involved and parents must, of course, be well informed about all options. Continuing efforts to prepare professionals properly to support children in inclusive settings and to prepare children to master the techniques to maximize their effective participation in inclusive environments must occur (see Sainato & Morrison, 2001).

CONCLUSION

In this chapter, strategies designed to maximize the inclusion of children and families in home and community activities are discussed in the context of the Developmental Systems Model for early intervention. Strategies are described for each of the model's major components which, taken together, provide a clear message for families (i.e., that full participation of the child and family in home and community life is possible despite circumstances of child risk and disability). The justification for this approach is based on philosophical, legal, developmental, and empirical grounds (see Guralnick, 2001b) and is clearly consistent with research and conceptualizations on the value of working within family routines to sustain interventions (Gallimore, Keogh, & Bernheimer, 1999) and findings indicating that families prefer interventions embedded in activities within community settings (Bruder, 2001; Dunst, 2001). A sensitive application of the strategies discussed in this chapter, as well as others to be developed, are critical for the success of the Developmental Systems Model for early intervention to incorporate in both letter and spirit the core principle of inclusion.

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