

An Agenda for Change in Early Childhood Inclusion

Early childhood inclusion represents a concept and practice with the potential to alter radically the way society perceives individuals with disabilities and their families and the way individuals with disabilities and their families perceive themselves. For these families, the level of involvement in all aspects of the larger community has special meaning in the early years, as these initial experiences establish a pattern and set of expectations with respect to community participation. As noted in the chapters in this book, since the mid-1970s, there have been remarkable advances with respect to early childhood inclusion. Yet, as also revealed in this book, despite our best efforts to address factors that influence the goals of inclusion, much remains to be accomplished. In particular, significant concerns are apparent with regard to the four central goals of early childhood inclusion: 1) achieving universal access to inclusive programs, 2) agreeing on and establishing feasible programs, 3) having confidence that children's developmental and social outcomes are not compromised by participating in inclusive programs, and 4) socially integrating children with one another in meaningful

ways. Moreover, the field has yet to resolve many long-standing issues stemming from differences in values, philosophies, and practices. The figure in Chapter 1 of this volume depicting the key factors that influence the four inclusion goals is reproduced here (see Figure 23.1). The reader should consult Chapter 1 for additional details.

Perhaps of greatest concern is the absence of a national-in-scope agenda designed to address the four inclusion goals, to resolve critical issues, and to achieve an agreed-on set of principles and practices governing early childhood inclusion. Despite isolated and often impressive statewide or local community efforts, the absence of direction and leadership in this field is most obvious and may be contributing to the slow pace and the fragmented process of change that characterize the field of early childhood inclusion. What has failed to emerge are systematic goals, plans, monitoring systems, or a forum to articulate issues and to at least attempt to achieve a consensus. Similarly, there is no corresponding systematic research agenda or any movement to consider early childhood inclusion in relation to the larger community.

The purpose of this chapter is to present an outline of such a national-in-scope agenda for change in the field of early childhood inclusion and to propose a mechanism for national leadership. To do so, I have drawn extensively on the opinions and advice of the expert contributors as presented in the preceding chapters and also relied on in-depth discussions of the issues with numerous colleagues throughout the years. Nevertheless, the proposed agenda remains my responsibility, and any flaws should be attributed to me alone.

Of course, meaningful change can only occur at the state and local levels. Consequently, even with a national agenda and national leadership, extensive involvement and communication with state and local groups is essential to develop and carry out any agenda for change. A thoughtful national agenda for change and its corresponding mechanisms for change must address overarching issues, but they must be directly relevant to every state and local community. Moreover, any national-in-scope agenda must not only recognize the important

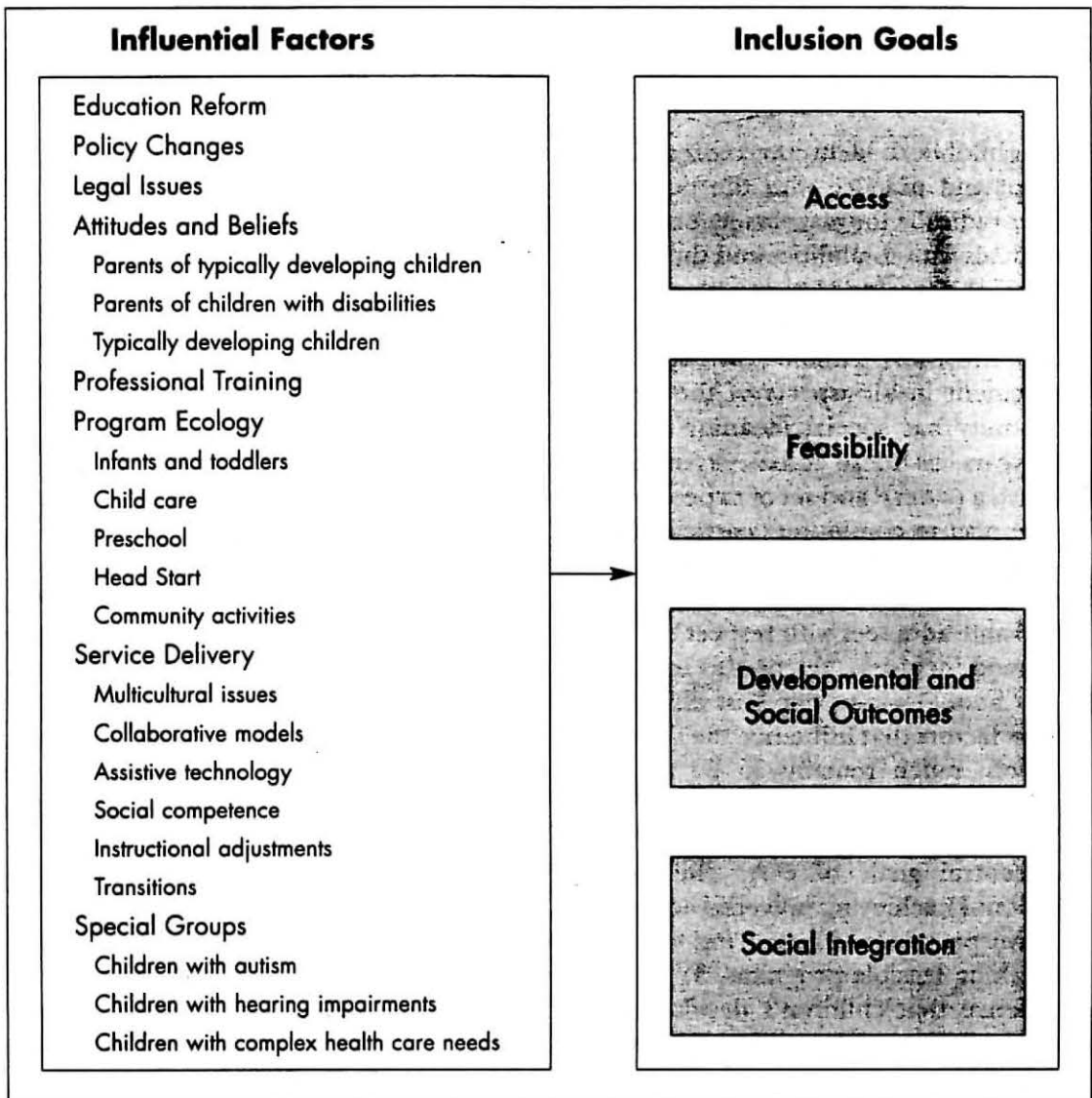


Figure 23.1. The relationship between influential factors and the goals of inclusion.

challenge to develop solutions to promote change that have predictable and common elements across communities but must also allow reasonable flexibility for local implementation.

A NATIONAL LEADERSHIP FORUM ON EARLY CHILDHOOD INCLUSION

To provide the necessary national leadership, I propose that the U.S. Department of Education establish a national panel called the National Leadership Forum on Early Childhood Inclusion (NLF-ECI) charged with the responsibility of both developing and implementing a national agenda for change in early childhood inclusion. The four inclusion goals noted previously and elaborated on in Chapter 1 can serve as an initial framework for this group, but other goals may emerge over time. This panel should be established for a minimum period of 10 years and consist of national experts in early childhood inclusion, state and local leaders (representing Parts B and C of the Individuals with Disabilities Education Act [IDEA]), representatives of key parent groups, members of both the early childhood and early intervention communities, government officials from other federal agencies related to health and to family and child services (e.g., Head Start, child care), and representatives of professional organizations who provide related services. Sufficient resources should be made available by the Department of Education to hold forums to address specific agenda items, to develop position papers, to establish relevant databases, and to produce and distribute informational documents. The Department of Education and related agencies should also commit resources to solicit grant proposals to address high priority areas in early childhood inclusion as identified by the NLF-ECI.

In the following sections of this chapter, I suggest possible national-in-

scope agenda items that are designed to provide an initial framework for the NLF-ECI. These agenda items have been organized in the areas of systems change, program development, and research. Only a brief justification for each specific item is described, as the many chapters in this volume provide the necessary background information. Where appropriate, implementation strategies are recommended, such as establishing statewide task forces or a central dissemination resource. It should be noted that no attempt has been made to be exhaustive but rather to identify possible directions that will ultimately enhance our ability to achieve the four key goals of early childhood inclusion discussed previously.

Systems Change

The nature and interrelationships among the factors influencing inclusion goals will require an agenda that addresses many systems change issues. The major influential factors that have been discussed throughout this volume (see Figure 23.1)—education reform, policy changes, legal issues, attitudes and beliefs, professional training, program ecology, service delivery approaches, and adjustments for special groups of children—all reflect the long-standing and complex forces that must somehow be considered from a comprehensive systems perspective. As such, systems change mechanisms must be in place at all levels (national, state, and local) for this to occur. Ten agenda items are identified in this section on systems change representing both mechanisms and specific goals. Emphasis is placed on state and local involvement, information gathering, and developing and disseminating information and strategies with the potential for general use.

Agenda item #1: *Establish a task force on early childhood inclusion in each state.*

Rationale: A successful national effort will require state and local support and involvement. Chairs of each state task force should be in close contact with the NLF-ECI, and the task force's goals and composition should be similar to that of the NLF-ECI. Each task force would provide input to the NLF-ECI and be the focal point for NLF-ECI developed guidelines, position papers, research summaries relevant to state and local issues, recommendations for legislation or regulations, and related issues. Each task force would be responsible for adapting, communicating, and utilizing that information at state and local levels.

Agenda item #2: *Create a national reporting system on inclusive practices at the early childhood level.*

Rationale: The absence of reliable information with respect to having access to inclusive programs is a clear impediment to change. State task forces should take responsibility for gathering relevant data, including the type of placements (especially various forms of inclusion) as well as child and family characteristics, and report annually to the NLF-ECI. The NLF-ECI should develop a streamlined reporting system with appropriate definitions to permit valid cross-state analyses.

Agenda item #3: *Establish a national dissemination unit that regularly summarizes current knowledge and practice relevant to early childhood inclusion.*

Rationale: Extensive research has been conducted with respect to feasibility, developmental and social outcomes, and social integration that should be summarized in a concise manner. Summaries of administrative or court decisions that are relevant should be included as well. Both parents and professionals should find this information valuable in making placement and program decisions. The national dissemination unit, responsible

to the NLF-ECI, would also be charged with providing state task forces with updates on new findings, reports of solutions to policy and practice problems from various sources, and any other relevant information. This unit should function as a resource to both the NLF-ECI and state task forces.

Agenda item #4: *Develop recommendations and guidelines for determining circumstances in which it is most appropriate for children to be placed in various types of inclusive placements as well as specialized placements.*

Rationale: Despite the presumption that children with disabilities should be full participants in programs for typically developing children, children with seemingly similar characteristics and needs are placed in a diverse array of programs ranging from specialized to fully inclusive, with no obvious rationale for those placements. Some universal framework needs to be established by the NLF-ECI to help guide decisions that are consistent from community to community and state to state. Guidelines can be developed that retain the integrity of the principle of individualization. Part of the framework would include not only the relationship between placement types and child characteristics and needs but also early childhood program conditions (i.e., feasibility; see the "Program Development" section) that must exist to ensure the appropriateness and effectiveness of that placement. In addition, by establishing these conditions a priori, any discrepancies or inadequacies could serve as catalysts for change.

Agenda item #5: *Develop policy guidelines on the meaning and application of natural environments for infants and toddlers with disabilities.*

Rationale: Identifying natural environments for infants and toddlers has become a divisive issue and is indeed a

challenging problem. Focusing on natural environments for the family emphasizes typical family routines in which services can be integrated but threatens long-standing models of specialized, child-oriented service centers. Defining what constitutes a natural environment, determining how services and supports can be integrated effectively into a family's normal activities in the community, giving due consideration to parent preferences, and figuring out how to utilize existing professional expertise even in specialized contexts will require the NLF-ECI to develop policy guidelines that consider all of these issues. Of importance, these policy guidelines for natural environments create a rare opportunity to promote community acceptance of infants and toddlers with disabilities.

Agenda item #6: *Develop a set of strategies to help resolve potential parent-professional disagreements with respect to placement decisions.*

Rationale: Even with a more extensive knowledge base, recommendations and guidelines that may emerge from agenda item #4 will nevertheless be subject to differing interpretations. These interpretations are influenced by numerous factors, but one's individual values, preferences, and priorities are certainly among the key factors. In many instances, parents and professionals may well have widely differing values and priorities that must be articulated for a reasonable resolution to occur. Differing perceptions of the quality of programs, the adequacy of specialized and related services, or concerns about social isolation and peer rejection are likely to arise. By identifying these issues and developing strategies to consider alternatives with all relevant information available, decisions based on false and sometimes unreasonable expectations can be minimized. Moreover, these strategies would provide a context for

information exchange and, I hope, minimize administrative hearings or legal actions.

Agenda item #7: *Contribute to efforts to expand the number and improve the quality of early child care and early childhood education programs with special reference to children with disabilities.*

Rationale: The NLF-ECI can add its name and expertise to the continuing battle to improve early child care quality in the United States and to increase the availability of early childhood programs. By supporting those larger efforts, particularly by enhancing state-sponsored early childhood education and improving standards for child care, and providing information with respect to how to include children with disabilities, the quality of child care can be improved for all children.

Agenda item #8: *Explore new approaches for professional training to support inclusive practices.*

Rationale: The NLF-ECI must address a number of interrelated professional training concerns. First, strategies must be developed to improve the knowledge and skills of general early childhood educators and child care staff with respect to children with disabilities. Close collaborations with accrediting agencies and professional associations, such as the National Association for the Education of Young Children, are essential. Second, strategies at state levels must be developed to increase the availability of well-trained early childhood special educators who can assume various roles, particularly as consultants in inclusive environments. Consideration should be given to developing new professional training approaches that include a consultant specialist who would serve as the key resource for disability issues in local programs. Third, specialists from different

disciplines will need more professional training coursework and practicum experiences devoted to consultant and collaborative models, as these approaches are more compatible with inclusive practices.

Agenda item #9: *Develop a set of recommended policies and procedures for consideration by states that address administrative barriers to inclusive services.*

Rationale: In view of the diverse array of public and private early childhood programs available for typically developing children in local communities, equally diverse approaches are needed to include children with disabilities. The federal and state requirements designed to ensure appropriate services for children with disabilities, however, are often not compatible with programs for typically developing children (e.g., issues of staff certification, program standards, evaluation requirements, transportation issues, restrictions placed on funding options). As most of these problems are common across states, the NLF-ECI, with state task force input, should develop a set of explicit policies and procedures to address these issues.

Agenda item #10: *Promote national efforts for education reform to further integrate the general and special education domains.*

Rationale: The historical separation between general and special education at all levels has emphasized differences in approaches to child development and educational practice rather than commonalities and minimized creative efforts to expand curricula and programs to accommodate children with diverse skills and abilities. This systems issue is critical, as it constitutes the infrastructure that generates attitudes and beliefs about the value of inclusion and the importance of developing inclusive practices. The NLF-ECI must join with higher education and state education groups to promote a reform agenda at all levels that meaning-

fully integrates the domains of special and general education.

Program Development

In addition to the extensive and complex agenda for systems change, there exist a number of agenda items that support these efforts but fall primarily in the domain of program development. As is seen next, many of the agenda items for program development have systems implications but are perhaps best considered as potential resources for systemwide applications. For the most part, these program development agenda items constitute model building or efforts to clarify or define issues that can serve to limit inclusive practices. The NLF-ECI can serve as the catalyst to address the following program development agenda items by promoting these topics as worthy of federal or state support and by gathering and disseminating relevant information for state task forces.

Agenda item #11: *Develop community-based child care models using the cluster concept that can appropriately and effectively support infants and toddlers with disabilities.*

Rationale: Quality child care remains a major problem in the United States, and no short-term solutions are apparent. Ideally, virtually all child care should eventually be able to accommodate children with disabilities, but this is highly unrealistic at the beginning of the 21st century. Alternatively, community models should be developed that would be designed as child care programs most appropriate for children with disabilities. These inclusive child care programs would have appropriate staff and resources adequate for all children participating. The procedures required to establish these models and to conduct a process evaluation together constitute an important agenda item.

A variety of inclusive models creating a mix of child care, family supports, and specialized services for children with disabilities could be developed. A community could then decide how many programs are needed for each geographic area. In part, this would depend on the size of the child care program and the number of children with disabilities in the community. Care must be taken to ensure that clusters of children with disabilities remain small. Moreover, work to enhance the quality of other child care programs in the community should continue.

Agenda item #12: *Develop models and guidelines for placement of children with disabilities in dual programs designed to accomplish different goals.*

Rationale: Because of parental choice and the unique needs of children, some form of dual placements may be required to provide inclusive opportunities. That is, children may participate in half-day specialized programs (or even a reverse inclusion model) and then shift to some form of a more inclusive program (usually a child care center) for the remainder of the day. For the inclusive program to be effective, coordination must occur with the more specialized program and strategies designed to ensure positive experiences for the child. Peer relationships are especially vulnerable for children with disabilities, and a well-coordinated plan is critical. The development of models for dual programs and the creation of guidelines to maximize coordination and the advantages of both programs are needed. Similarly, carefully thought-out guidelines addressing when this dual model is appropriate should be developed, as it can produce many complications for children and families.

Agenda item #13: *Develop models and guidelines for placement of preschool-age children in public and private programs.*

Rationale: The limited number of preschool programs for typically developing children operated by local education agencies restricts access, as parents often choose to place their child in available specialized programs. Local education agencies with state support must regularly pursue creative options to ensure that everyone has access to inclusive programs. Child care models outlined in agenda item #11 could be expanded for preschool-age children, cluster models could be further developed, and more extensive contractual relationships could be established with private nursery or preschool programs. Guidelines are needed to ensure placement in a quality program with resources sufficient to meet the individualized needs of children with disabilities (see agenda item #14).

Agenda item #14: *General agreement must be established with respect to the feasibility of inclusive programs.*

Rationale: The feasibility construct represents issues related to the ability of an inclusive program to maintain its integrity and to accommodate and meet children's individualized needs. At minimum, feasibility provides an index of the quality of the program from the perspective of children with disabilities. What are needed are relatively straightforward checklists (process measures) to ensure that this inclusive placement is indeed capable of effectively meeting the needs of all children in the program. From a more general perspective, domains on such checklists would likely include assessments by staff and others that their program is functioning in a manner anticipated, that all children are engaged in the curriculum as expected, and that the program's educational philosophy has not been altered to any significant degree. From the perspective of children with disabilities, these checklists would address progress toward individualized

family service plan (IFSP) or individualized education program (IEP) goals, the availability of specialized services, and the extent to which stigmatization is minimized (see Chapter 1). Broader issues of overall program quality remain, but feasibility at least is intended to ensure that a program's integrity is maintained when children with disabilities are included, yet the program is able to serve as an appropriate and effective environment for these children. If inclusive programs are not feasible, the information gathered through this process could serve as a tool to encourage program modifications. In turn, this may enhance the overall quality of the program. The NLF-ECI can be helpful in coordinating the design of such checklists.

Agenda item #15: *Priority must be given at an individual program level for specialists in the disability field to engage in a dialogue with staff in the general early childhood community.*

Rationale: Discussion and debate primarily at the academic level have produced a rapprochement in many areas between the disability and general early childhood communities, yet at the day-to-day level, time constraints have not allowed a systematic dialogue to develop on a child-by-child basis to address issues of concern. Differing perspectives and assumptions about development and learning are likely to emerge at the more concrete level. Similar types of issues exist for members of various disciplines attempting to adapt service delivery models to inclusive programs. Without this dialogue, many solvable problems are not articulated and constitute a threat to feasibility and harmony. The challenge at the program development level is to ensure that this is a priority and that adequate time is available for this dialogue to occur.

Research

The agenda items in this section address problems that can benefit from the direct

and systematic efforts of researchers in the field. The number of research questions that can be legitimately asked is quite extensive, and no attempt in this section has been made to be exhaustive. Rather, the agenda items represent research relevant to program development and to systems change agenda items. Of note, the following research agenda items reflect an awareness of the practical limitations of conducting research in inclusive programs, particularly the ability of researchers to control important variables. Nevertheless, large-scale evaluation research in conjunction with smaller-scale focused studies can be carried out in a manner that does not compromise the quality of the science. Different questions will suggest correspondingly different research strategies varying from single-subject studies, the use of playgroup methodologies, small-scale randomized prospective controlled designs, and numerous others. It will be the cumulative impact and convergence of data from these various sources that will contribute to the degree of confidence in the findings and their value to the systems change and program development agendas.

Agenda item #16: *Establish a national evaluation network under the auspices of the NLF-ECI to gather developmental and social outcome data.*

Rationale: Sufficient evidence is available to suggest that inclusive programs produce at least similar developmental and social outcomes for children with disabilities in comparison with children enrolled in specialized programs and that there are no adverse effects for any group of children. Additional research employing randomized prospective controlled designs is not practical on a general basis for a variety of reasons. Nevertheless, gathering outcome data from programs differing in feasibility, related ecological

characteristics, and other dimensions—and reporting that information to a national clearinghouse—would permit researchers to address important questions. Evaluation could address a wide range of programmatic or ecological factors (e.g., child characteristics, program type, educational or instructional model) that could influence outcomes. Aspects of feasibility could also be evaluated with respect to both child and family outcomes. The NLF-ECI should establish a set of common outcome measures, develop protocols to gather information on programmatic and ecological features, evaluate a program's documentation of feasibility, and provide technical assistance (e.g., on-line reporting, training in outcome measures if needed, spot-check reliability). With researchers aggregating data on a large national sample of children with and without disabilities, important information can be obtained that can also be of considerable value to program development and to systems change agenda items.

Agenda item #17: *Examine the issue of children with disabilities being stigmatized through participation in inclusive programs.*

Rationale: Participation in programs with children who have widely diverse skills and abilities invites social comparisons among children and sets the occasion for the formation of subgroups based in part on children's developmental characteristics. Outright rejection by peers is not a frequent occurrence, but exclusion of children with disabilities by typically developing children is far more common, especially during unstructured activities, and can continue to occur despite the best efforts to minimize these patterns. In addition, teachers can contribute to children's feelings of being different through their own ways of relating, instructing, and organizing their programs. Researchers have only limited

understanding of the possible stigmatizing effects of social interaction and instructional experiences, particularly their impact on the self-perceptions of children with disabilities. Accordingly, researchers should be encouraged to develop creative ways to evaluate possible stigma and to develop techniques to understand the factors that contribute to stigma should it exist. Once this has been accomplished, a more systematic program of research can be put into place to develop strategies to minimize these difficulties and provide guidelines that can be used by individual inclusive programs.

Agenda item #18: *Intensify research efforts to develop strategies that promote the peer-related social competence of children with disabilities.*

Rationale: Exclusion of children with disabilities from the social activities of typically developing children remains a common occurrence in inclusive programs despite extensive efforts. Friendships seem to be particularly affected. One major contributing factor is unusual peer competence problems characteristic of children with disabilities. Research should be encouraged to develop new means of enhancing the peer competence of children with disabilities with special emphasis on unstructured situations in which exclusion occurs most frequently.

Agenda item #19: *Develop reasonable expectations for and new approaches to maximize social integration in inclusive programs.*

Rationale: As indicated previously, social separation between children with and without disabilities is a common occurrence in inclusive programs. Researchers—working closely with parents, teachers, and others—should develop a framework to establish appropriate expectations for social integration, a framework that should be strongly influenced by developmental considerations. Among the issues to be addressed are the types of

relationships that can be reasonably expected between children with and without disabilities and how the relationships are affected by the type and severity of children's disabilities. Paralleling this effort, new approaches need to be developed and systematically evaluated that are designed to maximize social integration, including friendship development within the framework of a child's current level of peer-related social competence.

Agenda item #20: *Evaluate and enhance the relationship between inclusion in early childhood programs and inclusion in community and neighborhood activities.*

Rationale: The social dynamics created by participation in inclusive programs may carry over to participation, or at least efforts to participate, in inclusive activities in one's community or neighborhood. In particular, relationships formed in inclusive programs may extend beyond the early childhood program, and parents may develop increased confidence in encouraging their child to be active in typical community activities. Researchers should attempt to evaluate this potentially important indirect result of inclusive programs and understand the mechanisms (e.g., parent activity) through which this may occur. Similarly, researchers should be encouraged to develop and evaluate explicit strategies and supports that community programs can use to encourage the participation of young children with disabilities in community activities.

Agenda item #21: *Conduct research with respect to the feasibility and effectiveness of different models of delivery of specialized services in inclusive programs.*

Rationale: There exists a range of service delivery models that can be implemented in inclusive programs. Models that attempt to integrate specialized services into routine activities seem to be particularly compatible with inclusive programs

conceptually, but only a few comparative studies of different approaches have been carried out. Researchers should be encouraged to evaluate the feasibility of various models (e.g., influence on program integrity) as well as carefully evaluate the impact of those services for specific child outcomes (effectiveness).

Agenda item #22: *Conduct research to determine the feasibility and outcomes of providing highly intensive or unique services to children with disabilities in inclusive programs.*

Rationale: One of the most difficult problems facing inclusive programs is their ability to effectively accommodate children with especially challenging behaviors or developmental characteristics (e.g., children with autism, sensory impairments, or complex health care needs). Often, services need to be provided with considerable intensity or uniqueness, increasing the risk of stigma, exacerbating social separation, and threatening the integrity of an inclusive program's model. These problems still remain despite extremely creative efforts to address these issues. Consequently, researchers should be encouraged to evaluate different existing models (e.g., cluster) when highly intensive or unique services are needed to ensure feasibility and maximize social and developmental outcomes. The role of dual models also should be given special consideration in this context. Alternative models, their timing, and their relationship to the child's larger early intervention program should also be explored.

CONCLUSION

In this chapter, I have attempted to outline major agenda items for future work on early childhood inclusion in the areas of systems change, program development, and research. Many of these agenda items are not new, but activities in the domain of early childhood inclusion

since the mid-1970s have allowed a more thoughtful organization and refinement of the issues and directed questions quite specifically to the goals of inclusion that have been identified. Fortunately, the numerous fine suggestions presented in this volume by the many contributors offer an excellent beginning for a national effort focused on change. In addition, the general framework presented here highlights the interrelationships that exist among the areas of systems change, program development, and research and will, I hope, encourage even further collaborations among policy makers, parents, early childhood staff, providers of specialized services, researchers, and others who care about inclusive practices.

To pursue an agenda for change, I have proposed the establishment of a national-in-scope program coordinated by the NLF-ECI. Without vigorous and

persistent leadership, the fragmented efforts that exist at the beginning of the 21st century will remain, and there will be no press for systematic change. This state of affairs is simply not acceptable in view of the far-reaching implications of inclusion in the lives of children and their families.

Finally, it is important to note that many vital yet overarching issues that can substantially affect inclusion have not been included in the agenda items. Issues related to enhancing respect for diversity in general, for example, are a matter of concern that should and, I hope, do extend well beyond more parochial interests in inclusion. It may well be that the agenda for change in the field of early childhood inclusion will serve as a catalyst for change for this and more general issues affecting young children and their families.