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ABSTRACT

The field of early childhood intervention, which strives to meet the needs of infants and toddlers with disabilities, has come of age, but interagency collaboration to provide family-focused multidisciplinary services remains more a goal than a reality. Issues in the development of multidisciplinary services include fragmentation of services, initiatives for coordination, public and private sector involvement, partnerships for collaboration and coordination, and use of a vertical or horizontal structure. Activities of the Select Panel on the Promotion of Child Health in advocating development of community-based services are described, followed by a discussion of the origins of the Federal Interagency Coordinating Council of the U.S. Department of Health and Human Services. The paper then reports on a number of leadership initiatives to improve the coordination of services through the promotion of public/private partnerships. The legislative impetus for change in service delivery is examined, and policy recommendations are offered. (Contains 25 references.) (JDD)

FEDERAL POLICY FOR EARLY CHILDHOOD: EVALUATION OF SERVICES FOR CHILDREN WITH DISABILITIES

Vince L. Hutchins, M.D., M.P.H.

Executive Director. National Ready to Learn Council

Carnegie Foundation for the Advancement of Teaching

The recognition of the needs of infants, toddlers with disabilities and their families (the Part H population) in the 1990s and beyond is the result of an historical evolution over the last several decades. This evolution—or perhaps more properly revolution—occurred due to the interplay of biomedical, political, social, and economic forces that molded current policy and programs. Edward F. Zigler, Sterling Professor of Psychology at Yale, has recently noted that, as a result, the field of early childhood intervention has come of age (Zigler, 1990).

Many Components But No System

Families who have infants and toddlers with developmental delay, or are at risk of delay, usually require the services of a variety of disciplines and agencies. The disciplines and agencies involved are located in a number of domains–health, education, mental health, social services, and financing. Since a disproportionate number of these families are disadvantaged by poverty and/or social disorganization, other related domains–housing, transportation, welfare, jobs, and food programs–may be involved in the array of services needed.

Fragmentation of Services. No single discipline or agency can serve every child's needs. Despite the recognized need by parents and professionals for an interdisciplinary, interagency approach to the provision of service, it has been difficult to coordinate services within domains and certainly across them. Professionals working in this field from a host of disciplines must become adept at two hallmarks of early intervention–an interdisciplinary approach and a family focus. In order to meet the needs of the times, professionals in the disciplines caring for this population have the responsibility to learn and expand their interdisciplinary skills and to learn how to reach out and develop partnerships with other disciplines, agencies, and families.

A decade and a half ago, Brewer and Kakalik (1979) documented the disorganization, complexity, and fragmentation of the existing service delivery system with their cross-agency evaluation of collaboration within federal and state programs for handicapped children. The study explicitly identified five major problems: (a) inequity (i.e., unevenness in accessibility of services); (b) gaps in service (found to occur by state, age, type of handicap, and geographic areas with a state); (c) insufficient information (i.e., lack of reliable data for planning); (d) inadequate control (referring to the lack of a national policy resulting in a varied, uncoordinated, fragmented, and unresponsive service system); and (e) insufficient resources (i.e., the need for dollars, personnel, and facilities, as well as improved and coordinated services and changes in the organizational structure of the service delivery system). Brewer and Kakalik's critique pertains today.

Initiative for coordination. To address the fragmentation and disorganization, and to encourage interagency service coordination, federal agencies have developed a variety of initiatives. Harbin and McNulty (1990) discussed these initiatives and grouped them according to the following four types: (a) development of federal Interagency Agreements and Memoranda of Understanding among agencies; (b) provision of incentives through the funding of a variety of local demonstration projects; (c) technical assistance through funded programs; and (d) federal regulations. The development and dissemination of guidance material to the field augment initiatives (c) and (d). Usually this guidance is developed by a single agency, sometimes with review and comment by another agency or agencies, and occasionally it is developed jointly with another agency or agencies. Although the family of a young child with disabilities is more likely to find multidisciplinary services today than previously, interagency collaboration to provide family-focused, multidisciplinary services remain more a goal than a reality (Hebbeler, Smith, & Black, 1991).

Public and private sector involvement. "Helping professionals" come to the aid of these Part H children and their families from both the public and private sectors. The building of partnerships of coordination and collaboration is made more complex by this public/private sponsorship of services. The proportion of public/private involvement varies according to the domain of human service. For example, the line between the public and private sectors in the provision of health services is often blurred. The vast majority of children receive medical service in the private sector, but many of these private services to children are funded by tax dollars (Title XIX/Medicaid).

Very different structures are at the heart of educational services than those underlying health services. While educational services are based upon the precept that every child has a right to be educated (and, therefore, the field of education is accepted as a traditional responsibility of government), federal, state, and local health services are provided by a complex amalgamation of public and private resources and service arrangements. Without the benefit of "a right to health," these arrangements have evolved in the unsupervised and largely unplanned fashion that reflects our present health service system—one typified by pluralism, local initiative, a high degree of specialization, a complicated mix of public and private services, and an unconscionable number of children and families who are uninsured or underinsured.

Partnership for collaboration and coordination. In order for agencies and helping professionals to collaborate in coordinating services, there has been in recent years an increased emphasis in forming partnerships. Many of them are partnerships between and among public agencies. Increasingly, partnerships are forming and being strengthened between public agencies and the private sector. Noteworthy among the private sector entities involved are professional organizations whose mission is the care of children. In addition, both human and material resources are available to families through a diverse group of voluntary organizations (e.g., Easter Seals, March of Dimes/Birth Defects Foundation, Cystic Fibrosis Foundation) and self-help groups which provide both services and advocacy. Professional organizations (e.g., Council for Exceptional Children, American Academy of Pediatrics, National Association of Social Workers) play a subtle but powerful role in shaping services for these children and their families. Philanthropic foundations (e.g., Grant, Pew, Robert Wood Johnson, Carnegie) and certain corporations provide or support leadership and innovation in the field. Raff and Hutchins (1990) noted two years ago: "The public-private partnership between the March of Dimes and Maternal and Child Health (MCH), in collaboration with our friends, over the past decade has been an important force in the development of genetic services in the nation." The purpose of these partnerships is to develop a system of services where no system presently exists and to decrease some of the problems in existing systems, such as those identified by Brewer and Kakalik (1979).

Structure. The partnerships that have developed can be described as either vertical or horizontal. The vertical partnerships are between levels of government or service: federal/state, state/regional, and state/local. Over time, these vertical relationships have evolved and changed. Certainly, the block grant philosophy changed, and in many ways strengthened, federal/state Maternal and Child Health (MCH) partnerships. For example, much of the authority and decision making devolved to the states, making the partners more equal. In the mid-60s, federal/community partnerships like the Office of Economic Opportunity programs were introduced, with little or no involvement of official agencies at the state or local level. The survivors of many of these programs have moved to closer interaction with official agencies.

The vertical partnerships tend to be categorically narrow, as determined by legislation and appropriations. Columns of funds and services form between the levels. The easy flow is up and down the columns, and horizontal flow is inhibited. These categorical columns encourage professionals and administrators to look inward, and thus make the development of horizontal relationships among and between agencies and providers at each level more difficult. The rules that accompany the funds down the categorical columns (e.g., eligibility, what can be paid for) do not enhance coordination at any of the levels, especially at the community level. Yet someone in the community at the level of families must put it all together--with some from this column, some from that column.

Horizontal partnerships at each level, of course, exist and function: public health with other public programs (e.g., Medicaid, education, protective services, mental health, WIC); public health with the private health sector, where most children and families are cared for (e.g., American College of Obstetrics and Gynecology, American Academy of Pediatrics, American Academy of Family Practice, American College of Nurse Midwives, National Association of Children's Hospitals and Related Institutions, Inc.); public and private health with private industry, with voluntary organizations, with Foundations, and with parent groups. These horizontal partnerships have traditionally been formed at national and state levels and, to a lesser extent, at the community level.

Community-Based Services

Select Panel, Movement Toward Decentralization – 1978-1990s

The Select Panel on the Promotion of Child Health (1978) told us over a decade ago:

> Routine care for all [children with special needs] should be in the home or as near to a normal setting as possible, with emphasis upon restoring the functioning effectiveness of families as well as enabling the young person to respond to the normal sources of support, affection, instruction and discipline.

The Select Panel also said:

> We believe that only at the levels of government closest to children and families–the Nation's towns, cities, and counties–can health care needs be assessed in detail, and services organized to meet these needs. . . Community participation in the design of local service structures also leads to grass-roots support of health services.

In recent years, community-based services have become a major focus of child advocates as the trend toward decentralized care continues (Hutchins & McPherson, 1991). For this movement to succeed, the community must provide parents and children with certain supports, training, and information to help them cope successfully with their roles in the family. The majority of children receive their medical and health care from the private sector, which sometimes is augmented by selected services from the public sector and with specialty health services from a variety of programs, hospitals, and voluntary agencies. Yet, necessary resources that include social services, in addition to health and mental health care, are not readily available at the community level (Hutchins, 1991). The Carolina Policy Studies Program, in a recent study of focus group discussions with health professionals in five states, confirmed this when it reported that more time was devoted by the participants to the descriptions of difficulties with availability and accessibility of resources than to any other topic (Fullagar, Crotser, Gallagher, Loda, & Shieh, 1991).

Origins of the Federal Interagency Coordinating Council

In 1978, when there was a threatened change to the core focus of child development in the Head Start program, Pam Coughlin, from the Office of Human Development Services in the Department of Health, Education, and Welfare, called together a group of colleagues from a number of the federal agencies for a strategy session. The threat to Head Start passed, but the group continued to meet on a regular basis to discuss common program interests concerning the preschool population. The American Association of University Affiliated Programs, under the leadership of Phyllis Magrab, Director of the Georgetown University Child Development Center, provided support and consultation to this ad hoc group. The group, eventually composed of representatives from six agencies (Administration on Developmental Disabilities, Office of Human Development Services, Health Care Financing Administration, National Institute of Mental Health, and the antecedents of the Maternal and Child Health Bureau [MCHB] and the Office of Special Education and Rehabilitative Services [OSERS]), appointed themselves the HEW Interagency Task Force.

Information exchange, strategy development, and collaboration planning were among the functions of the Task Force. Preparing the resource, "Community Workbook for Collaborative Services to Preschool Handicapped Children," which focused on community needs assessment, was an early group effort. Recognizing the need to involve the private sector, the HEW Interagency Task Force sent the draft of the workbook to the American Academy of

Pediatrics' Committee on Children with Handicaps for its review and comment. Subsequently, copies of the revised, completed publication were made available for dissemination. A second workbook, "Developing a Community Team," was written to facilitate the development of community-based systems of collaboration between service agencies and providers. These publications became the first of a series of "How-to" guides published over the ensuing years to assist workers in carrying out community-wide efforts to improve services to children and their families. The topics of these workbooks range from family empowerment to program evaluation.

When Public Law 99-457 of 1986 established State Interagency Coordinating Councils (SICC), there was no provision in the legislation for a Federal Interagency Coordinating Council (FICC). However, Madeleine Will, Assistant Secretary for OSERS, was convinced that the HEW Interagency Task Force, which had continued to meet on a regular basis, could function as an informal FICC. Eventually, the FICC was formalized through a signed interagency agreement. While the previous functions of the group continued, additional functions and tasks were also undertaken: review of developing regulations for Part H; responsibility for writing the required combined Department (Education and Health and Human Services) Report to Congress; joint budget and policy reviews; joint guidance development; joint project development and support; joint technical assistance; and joint planning and support for the Partnerships in Progress national meeting. One of the activities under the aegis of the FICC was an MCH-sponsored conference on Family Support in the Home held in Honolulu in February 1988. The conference brought together a diverse group of people to discuss the role of home visiting. The ensuing report (Roberts, 1988) explored the issues involved in implementing family support groups in the home as part of Public Law 99-457 and built on the concepts of family-centered care shared by individual agencies represented on the Council.

Considerable discussion occurred in the early years about expansion of the membership of the FICC. There was a modest increase in the inclusion of other public agencies, including the Indian Health Service and the National Institute of Child Health and Human Development. Despite informal requests from some elements of the private sector, the FICC decided not to extend membership to them. Some agency staff were concerned that private entities' attendance at FICC meetings might compromise the confidentiality of federal budget and policy development. After many months of discussion, three parent representatives–one component of the private sector–were invited to serve two-year terms. The parent members were elected from the parents organized for the Partnerships in Progress meeting.

The most recent amendments to the legislation finally codified the FICC with a specified and expanded membership. A voluntary partnership of concerned individuals who had been working effectively for this population under the insightful leadership of three women (Coughlin, Magrab, and Will) had filled a void in the initial legislation and provided a firm base for this legislative amendment.

Progress Toward Partnerships

A number of activities directly and indirectly related to the Part H population have provided both experience and direction in developing partnerships over the past few years. Four groups of events will be discussed here. The proportion of time expended by the private sector and the intensity of the private sector's involvement varies depending on the basic purpose of each group of events. These collaborative efforts toward partnership have some overlaps and their boundaries are not always clearly evident:

1. In 1977, following the enactment of Public Law 94-142 in 1975, the Division of Maternal and Child Health and the Bureau of Education for the Handicapped (the ancestors of MCHB and OSERS, respectively) developed a six-state collaborative project to demonstrate that health and education professionals could work together to provide needed services to disabled children (Nelkin, 1983). It is significant and not surprising that the recommendation for this endeavor came from a joint meeting in Chicago between the leadership of the State MCH (Title V) Directors and the State Directors of Special Education. The recommendation was: "Don't just develop an interagency agreement between the Feds; give us some money to see what we can accomplish in the community." The projects served both preschool and school-age populations with the funds spent chiefly at the community level. Although the focus of these projects was on agency collaboration, the projects found it vital to involve private, non-profit agencies and private physicians in providing services, on project and community boards, and in in-service training.

2. With the passage of Public Law 99-457 in 1986, child health physicians became concerned about being excluded from Part H. Public health nurses in MCH were also concerned. Early identification, diagnosis, and ongoing health care for disabled infants and toddlers had been historically under the purview of medical and related health professionals. Was this responsibility being legislated away? Would special educators be running rampant in newborn intensive care nurseries?

Recognizing these concerns, Madeleine Will invited representatives of the medical and health professions to a consultation meeting before writing the Part H regulations. Key OSERS staff were in attendance to listen. This openness on the part of OSERS did a good deal to alleviate the anxiety of the medical and health community and to begin to build the trust that was necessary to develop positive relationships between education and health professionals.

3. With his career-long interest in children with disabilities, former Surgeon General C. Everett Koop has been a major force in the promotion of public/private partnerships in the service of these families. Although his population focus was considerably broader than birth to 3 years, Dr. Koop has paid close attention to infants and toddlers. One of his early acts as Surgeon General was to call a Workshop on Children with Handicaps and Their Families in Philadelphia in December 1982. The Workshop was held in part to address the revolutionary transformations in medical technology that had occurred in the previous four decades. Addressing the participants, Dr. Koop noted that these

children "and their families frequently require long-term medical, social, educational, vocational, habilitative, and community service assistance . . . essential to the provision of comprehensive services" (1983). He encouraged the attending physicians, hospital staff, and agency personnel to assume these broad responsibilities to children and their families. The report of this Workshop was followed by a progress report (U.S. Dept. of Health and Human Services, 1984) a year and a half later.

In 1986, Dr. Koop requested MCH and the American Academy of Pediatrics (AAP), representing the public and private sectors respectively, to jointly sponsor a Surgeon General's Conference in June of 1987. At this conference in Houston, he released the Surgeon General's Report on Children with Special Health Care Needs (U.S. Department of Health and Human Services, 1987). The Report was a call to action and outlined seven steps in a national agenda to promote family-centered, community-based, coordinated care. Examples of collaboration among the public sector, the private sector, and parents were given under each of the seven steps.

The following year a second Surgeon General's Conference, under the same sponsorship, was convened in Washington (Gittler, 1988). More than 70 professional and voluntary organizations accepted invitations to cosponsor this conference that featured community-based service systems. In just over seven years, the "bully pulpit" of the Surgeon General's office, in concert with concerned individuals in public and private agencies, successfully promoted public/private partnerships at the community level as a national goal.

4. There is a long history of the MCH program (Title V of the Social Security Act) and the American Academy of Pediatrics (AAP) working together to assist children and their families (Ad Hoc committee for MCH Project, 1977; Committee on community Health Services, 1987). The relationship has been strengthened in recent years as a result of the increased number of studies reporting that the well-being of many of the nation's children is in jeopardy, the enactment of recent legislative amendments, and the rediscovery of the critical role of parents as full partners in the health care of their children.

After cosponsoring the Surgeon General's 1987 national conference and having participated in the OSERS consultation regarding Public Law 99-457, the MCH-AAP leadership decided that the next step was to hold a working conference for state leaders. A conference, "The Practicing Pediatrician and Family-Centered, Community-Based Health Care for Children with Chronic Illness and Disabling Conditions," was organized by Cal Sia, a pediatrician in private practice widely recognized for his advocacy of community organization. The conference was held in Hawaii in December 1987. The purpose of the conference was to explore the complementary responsibilities of caring for these children shared by pediatricians in practice, parents, and staff of official agencies. As a prerequisite to a state's participation in this conference, the State Chapter Chairman of the AAP and the State Program Director for Children with Special Health Care Needs had to submit a working proposal of issues and activities to be addressed jointly over the next year. Representatives from 29 states responded and attended. States used the consultation provided and the state caucus time during the conference to refine their plans. A report was subsequently published (Magrab, 1988).

In 1988, as Public Law 99-457 was being implemented, lead agencies were being established, and SICCs were organizing, it was apparent that many pediatricians in private practice still did not know about Part H and that others needed updating on the progress of its implementation. AAP and MCH convened the "National Conference on Public Law 99-457" in Washington that summer. The goal of this conference was to develop a series of strategies to be used at the federal, state, and local levels to ensure participation of primary care physicians in the implementation of this new legislation. Conference participants included representatives from each AAP chapter, as well as nationally recognized health policy experts affiliated with the AAP and MCH.

In February of 1989, AAP and MCH cosponsored a conference in Long Boat Key, Florida, hosted by the Georgetown University Child Development Center. This conference, "The Practicing Pediatrician and Family-Centered, Community-Based Health Care for Children with Chronic Illnesses and Disabling Conditions, Part II," repeated the format of the 1987 Hawaii conference, as well as its pattern of state representation. An increased number of states participated. The participants endorsed the movement toward decentralized care and advocated working toward developing a continuum of care that would include a strong medical home within the total system of care. Participants emphasized that the medical home must be appropriate and sensitive to the individual needs of different families and that advocates must be aggressive in assuring basic health care for all young children. As a result of the 1988 and 1989 conferences, an issue paper was prepared and widely disseminated (Bureau of Maternal and Child Health and Resource Development and the American Academy of Pediatrics, 1989).

The Communities Can Campaign is a collaborative effort between MCH and AAP to recognize communities that have made substantial progress toward the goal of family-centered, community-based, coordinated care for children with special health care needs. Selected communities must demonstrate successful function in five areas:

(1) identifying all children with special health care needs in the community,

(2) establishing a medical home for these children,

(3) implementing coordination of care,

(4) building parent-to-parent networks, and

(5) finding appropriate financing of care.

The first twelve communities selected participated in a working conference at Stowe, Vermont, in June 1990, with the AAP Chapter Presidents and the State Directors for Children with Special Health Care Needs–who had jointly nominated the communities. Coordination for the Communities Can

Campaign is provided by the National Center for Community-Based Services at the Georgetown University Child Development Center.

In order to alert pediatricians to recent changes in Title V programs and to support a national effort to enhance the development of coordinated systems of health and medical care, the AAP and MCH convened a conference in Philadelphia in August 1991. At this "National Conference on Supporting Children and Families Through Integrated Services" (American Academy of Pediatrics, 1991) a "team" from each state was invited. Teams, consisting of the AAP Chapter President or designee, the State Title V Director, and a parent representative, attended from nearly every state. Workshops highlighted the details of exemplary public/private partnerships that were working in several states. Each participant received a copy of the CME training program, "The Pediatrician and the New Morbidity," developed and field-tested through the MCH-funded Physician Involvement Project by Cal Sia and the Hawaii Medical Association. The CME training program goal is to provide primary care physicians with insights, skills, and strategies to deal effectively with the "new morbidity."[1] Each state team attending the conference was encouraged to return home with the knowledge and experience gained and begin to replicate models or elements of models that would work in their states and communities. The CME modules are designed to be planned and presented by a team consisting of a pediatrician and a parent. A follow-up survey conducted six months later revealed that many state teams had implemented new initiatives or were expanding existing ones.

These jointly sponsored events over the past five years have informed both the public and private sectors and have worked through state leadership to promote community partnerships. Underlying this collaboration is the axiom recently enunciated by Robert Haggerty, President of the Grant Foundation: "We do have a role in pushing the boundaries of health beyond traditional medical care" (Haggerty, 1992). Significantly, these events sponsored by MCH and AAP have increasingly included parents, so that by the time of the Philadelphia conference in 1991 parents were indeed equal partners as conference planners, presenters, and participants. This involvement of parents reflects the growth and recognition of the family movement in the last decade. Active recognition of the family movement by the medical and health sector is critical to developing the family-centered component of the service system (Shelton, Jeppson, & Johnson, 1987).

Legislation, Policy, Implementation

Not all of the legislative impetus for change in the field comes from the Education for All Handicapped Children Act and its amendments. The Omnibus Budget Reconciliation Act of 1989 (Public Law 101-239) contains extensive amendments to Title V (Maternal and Child Health Services Block Grant) of the Social Security Act. It requires each state: (a) to provide and to promote family-centered, community-based, coordinated care (including care coordination

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[1] With newer vaccines and antibiotics available, infectious diseases are declining. From this old morbidity, practitioners are now faced with the "new morbidity": intentional and unintentional injuries; chronic diseases; and developmental, behavioral, social, and educational disorders.

services) for children with special health care needs; and, (b) to facilitate the development of community-based systems of services for such children and their families. While this Omnibus changed the explicit philosophy of the implementation of Title V, it was in keeping with the national goal established by the Surgeon General two years earlier at the Houston conference.

The Department of Health and Human Services' national health promotion and disease prevention objectives for the year 2000 also speak to coordinating health systems. Objective 17.20 in Healthy People 2000 and Healthy Children 2000 (U.S. Department of Health and Human Services, Maternal and Child Health Bureau, 1991) reads: "Increase to 50 the number of states that have service systems for children with, or who are at risk for developing, chronic and disabling conditions, as required by Public Law 101-239."

By 1991, the concept of family-centered, community-based, coordinated care in a system of services was established as a national goal, enacted into legislation, and included in a system of measurable objectives. The focus on families, community services, and partnerships, including public/private, was explicit. The terms "culturally competent" and "comprehensive" were not included in either Public Law 101-239 or the national objectives publications, but are accepted because of their common use in technical assistance and guidance materials developed and disseminated by the MCH program in recent years.

These MCH/AAP collaborative efforts have focused on improving medical/public health partnerships with an increasing emphasis on including parents as equal partners. The discussion here, however, has been broader. Experience has taught us about the critical need for having partners from other disciplines to fully implement the concept of family-centered, community-based, coordinated care that is comprehensive and culturally competent. This concept has broader applicability than just to infants and toddlers. All children and adolescents–as well as post-adolescents through the transition years–benefit from this approach. The broader age focus occurred in some of the activities discussed above. Infants and toddlers become preschoolers, school-age children, adolescents, and youth. We need to have the physicians and practitioners of other disciplines trained in this concept and committed to helping young children (birth through age 3) eligible under Part H, but also helping children after the third birthday festivities are over, as well.

Recommendations

Policy recommendations promoting private/public partnerships that flow from this historical presentation are limited. In the past, legislative requirements for coordination have resulted in few successes and have been more likely to result in passive resistance. As has been shown in this paper, coordination, collaboration, and effective partnerships arise out of good leadership. Such leadership might be encouraged by legislative amendments that require agencies to prepare Congressional reports. These reports might organize activities and initiatives under the categories described by Harbin and McNulty (1990).

A more fruitful approach may be through the appropriation process. Selected agencies might have funds set-aside or earmarked for discretionary early intervention projects. Accompanying appropriation language could encourage use of these discretionary funds in collaborative and coordinated endeavors. Another advantage of this method is that priorities can more readily be altered or refocused than through the legislative process. The critical policy impetus for services and programs for this population is to keep families in the center of discussions and influence.

Summary

Services related to the health of developmentally delayed infants and toddlers, and those at risk, are central to the intervention. Elsewhere in this publication, Jack Shonkoff states that the crucial task is to explore how appropriate early intervention services for young children with special needs can be incorporated into a universal system of comprehensive care for all children (Shonkoff, 1992). If such a system of care is to evolve in this country, pediatricians in private practice must become involved with their colleagues in medical education and public administration in planning and implementing the system.

Leaders in the private and public sectors will need to provide direction and guidance to promote, create, and sustain the environment for effective collaboration at national, state, and community levels. This paper has reported on a number of leadership initiatives to improve the coordination of services through the promotion of public/private partnerships. These initiatives include: interagency agreements; consultation and technical assistance (especially through workshops, conferences, and proceedings, and through other written materials); and legislation and regulations.

The partnerships must increasingly focus on the community. Federal/state and private/public sector initiatives directed at the reorganization and restructuring of services for children and families are now seen in many domains, including health, education, and social services. This restructuring through the development of service delivery systems at the community level is a manifestation of the emerging paradigm of delivery of services to children and families. Since citizens in the community are most knowledgeable about the service needs and resources of their community, this new paradigm emphasizes the development of systems of services that are driven by community efforts and energies. Federal and state agencies, then, are to act as supporters and facilitators of these community efforts.

As we move through the 1990s toward the 21st century, we must acknowledge the pivotal role families play in the lives of children with special health care needs, the importance of having a reasonable level of services available and accessible at the family and community level, and the need for coordination of an increasingly complex array of services from public, private, and voluntary resources. If we accomplish this as a family of child advocates rather than as multiple dispensers of separate disciplines, we will provide a better world for the children of the 21st century (Haggerty, 1992; McPherson, 1992).

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