Family-Centered, Community-Based, Coordinated Care for Children With Special Health Care Needs

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In June 1987, at a conference sponsored by the American Academy of Pediatrics (AAP) and the Bureau of Maternal and Child Health and Resources Development, Department of Health and Human Services, the Surgeon General of the US Public Health Service, C. Everett Koop, MD, ScD, issued a report concerning children with special health care needs. In the report, Dr Koop identified the following seven steps to improve access to care and quality of life for these children: (1) A pledge of a national commitment to all children with special health care needs and their families, (2) encouragement of localities in the building of community-based service systems, (3) assistance in ensuring adequate preparation of providers of care, (4) development of coalitions to improve the delivery of services, (5) establishment of guidelines to control costs of services, (6) encouragement and support of the development of adequate health care financing, and (7) continuation of research and dissemination of information.

Dr Koop also called for the establishment of a national agenda for families and professionals involved in the care of children with special health care needs to work together to improve the lives of these children and their families through a system of family-centered, community-based, coordinated care. In this paper, we will define what is needed to carry out this agenda, discuss some associated problems and solutions, and suggest the role that pediatricians can play.

DEFINITION OF THE NEED

Family-Centered Care

Family-centered care is the focus of philosophy of care in which the pivotal role of the family is recognized and respected in the lives of children with special health needs. Within this philosophy is the idea that families should be supported in their natural care-giving and decision-making roles by building on their unique strengths as people and families. In this philosophy, patterns of living at home and in the community are promoted; parents and professionals are seen as equals in a partnership committed to the development of optimal quality in the delivery of all levels of health care. To achieve this, elements of family-centered care and community-based care must be carefully interwoven into a full and effective coordination of the care of all children with special health needs.

To accomplish the centralization of care within the family, pediatricians, other health professionals, and families must work together to achieve better understanding by parents and siblings of the illnesses concerned, to cope with the illnesses and their physical, psychologic, and social effects on the affected children and families, to operate as partners in the identification, delivery of, and receipt of appropriate services at the appropriate time, and to improve access to community services. All children could benefit from a family-centered approach to their health care, but it is especially beneficial to the 10% to 15% of children who have some form of ongoing health problem, whether major or minor, short term or chronic. Included are the approximately 5% of children with conditions that can cause a marked degree of functional impairment, such as spina bifida, rheumatic diseases, ma-
lignancies, and hemophilia; the 6% identified by the schools as having impairments such as mental retardation, sensory disabilities, and speech problems; and the 3.7% who are limited in the amount or kind of usual activities of children their age in which they can participate. The first step in the process of providing the services these children need is the development of family-centered health services.

Community-Based Care

Children with special health care needs should have the opportunity to live at home and to share in the everyday family and community experiences that those without such needs take for granted. The challenge is to provide accessibility to the kinds of care that will make this possible. Such varied resources as special education, nutrition, vocational rehabilitation, financing, recreation, transportation, housing, and therapeutic services should not only be available but, as nearly as possible, based in the child's home community.

Special school services are among the most important community-based services. They provide alternatives to classroom teaching such as instruction for the home-bound and combined part-time classroom and home-bound instruction. Optimally, they also provide physical adaptations such as elevators, classes on the same floor, duplicate sets of books at school and at home, and additional time for changing classes. Additionally, special school services should provide adaptive physical education, individual educational plans, therapy in the school setting, transportation, school counseling, nutrition, and education of school personnel who deal with children with special needs.

Family to family networking as a community service to provide psychosocial support and information is a great, largely unmet, need for families of children with special health care needs. Although there are many parent groups focused toward the needs of specific diseases, provision of better local systems is needed. Some tasks involved in providing such systems in which pediatricians and family practitioners might logically become involved include identifying and screening parents to act as resource "parent pals," training parent pals in communication, acting with sensitivity, and other related issues, development of a resource directory for services and parent groups, and increasing professional and community awareness of family needs.

Another needed community-based service is an available team of health professionals organized to train families, school personnel, or others to use medical devices or equipment such as mechanical ventilators or catheters. Such teams should not only provide the necessary expertise, but they should also help classroom teachers and fellow students to be at ease with and accept the child being helped.

Coordinated Care

Implicit in the concept of coordinated care is the recognition that medicine currently has a complex array of people and services available for children with special health care needs. Appropriate, flexible, and reasonable ways must be found to link them together to provide maximum benefit to these children and their families.

In communities distant from tertiary centers, emphasis on local care by teams of health professionals supervised by a general pediatrician is a timely idea. According to MacQueen, there are three groups of children who can be cared for as well, or better, in a community center or a level II facility as they can in a tertiary center: (1) the many children whose disorders are diagnosed and who are started on a regimen of therapy in a tertiary center but who can be observed by a cooperating and coordinated community service system; (2) those children whose disorders can be diagnosed and who are managed at a community-based center without ever visiting a tertiary center; (3) children who have survived their original problems who have new problems as a result of new diagnostic and therapeutic technologies.

EFFECTING A SOLUTION

Case Managers (Care Coordinators) and Community Health Teams

Services for children with special health care needs and their families remain fragmented and poorly coordinated. Inadequate communication among professionals, lack of an organized service system, lack of coordinating services, varying eligibility requirements for services and for financial aid, and insufficient or inappropriate fiscal resources all contribute to this problem. Research points to a need for more effective involvement of primary health care professionals in providing care and for improved linkages between primary and tertiary care services (D. K. Walker, S. L. Gortmaker, and M. Weitzman, unpublished manuscript, 1981). Frequently, children with special health care needs are served only in tertiary settings that are basically inappropriate for achievement of a coherent approach to the health care of these children.

There is a pressing need for local case managers oriented toward focusing energies of not only the child's car promoting con communiti originate f i cies, vary and should composed profession relation to also with served. Th health tea rather than illy's pediet mananager or ical manag of commun working, etc the provi child and fa role in one or coordin use of heal children to ceive appro These servi difficulty b to cover th family's if in the government urged to in for the serv Major is develop ing appropr appropr viing comm the services transition o to adult car ent to pare was of wo patients. A family's pri of the team is essential

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child's care but also of family decision making, thus promoting a sense of family rather than professional control. The case manager should be in the community and readily accessible. He or she can originate from a multitude of professions or agencies, varying with the resources of the community, and should be part of a community health team composed of appropriate, locally available health professionals. Its composition may vary not only in relation to the professionals available locally, but also with the needs of the individual child being served. The case manager and the community health team should work with and complement rather than supplant the care provided by the family's pediatrician or family practitioner. The case manager or coordinator's role is to help with medical management plans, access to and coordination of community-based services, family to family networking, educational aid, financial planning, and the provision of counseling and advocacy for the child and family. Concentration of the coordinating role in one member of the team, the case manager or coordinator, provides more efficient and effective use of health care resources and assists families and children to understand better, cope better, and receive appropriate services at the appropriate time. These services are not generally available now, one difficulty being the failure of insurance companies to cover them. Given the time and compensation, the family's pediatrician or family practitioner might in many cases be the best care manager. Both governmental and private insurance plans must be urged to insure and to provide adequate payment for the service of "case management."

Major issues that must be addressed by each developing community health team include providing appropriate services at the appropriate time by appropriate professional members of the team, providing compensation for the time of the team and the services of each of its members, facilitating the transition of older teenage and young adult patients to adult care settings, developing appropriate parent to parent networks, and developing effective ways of working with noncompliant families and patients. A close working relationship with the family's primary physician, preferably as a member of the team, and with appropriate tertiary centers is essential to success.

Tertiary Medical Centers

Community-based care must be linked to specialty care. It is not necessary, or possible, to have each component of specialty care and high technology available in every community in this country; it is necessary to find new ways to link families in communities to all of these services. Ways of forming new, more effective relationships between community teams and those providing highly specialized care in children's hospitals and university departments of pediatrics must be sought and developed, perhaps as consultative partnerships.

Coordination at and Between Various Levels of Care

Both horizontal and vertical coordination of care is essential to achieve the goal of family-centered, community-based, coordinated care of children with special needs. Horizontal coordination involves chiefly communication and coordination among the members of the community health team and between the members and other local resources such as schools, girl or boy scouts, little leagues, community swimming facilities, foster grandparents, and other organizations or individuals who might be of help to the child with special needs and his or her family. Vertical coordination involves communication and coordination among parents, the community health team, and secondary and tertiary medical facilities and resources. The case manager or care coordinator is an indispensable facilitator in this network. Parents may serve in this capacity if able and so inclined; they should always be involved in the initiation and finalization of any plan for their child.

Financing Coordinated Care

Few insurance carriers will pay for the services of a case manager or for time spent in planning conferences by health professionals, including physicians. The only health services that most carriers, including governmental agencies, will reimburse are those delivered directly to patients by physicians and occasionally by others, usually with the supervision or orders of physicians. Many children and families are either underinsured or uninsured, even for such services. Imaginative methods, backed by insurance and governmental funding, must be developed and used to improve financing for these children. Strategies such as insurance benefit packages to support ambulatory community-based services, more realistic Medicaid and Medicare insurance coverages, and high-risk pools or catastrophic coverages for "high-cost" children must be evaluated. Prospective payment plans to develop a comprehensive service package for children with special health care needs and their families should also be developed.

ROLE OF THE PEDIATRICIAN

The pediatrician's office should be the medical home for the child with special needs in his or her

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practice, because he or she is the logical initiator of virtually all medical services. For similar reasons, the child's pediatrician optimally should serve on that child's community health team. In a survey of a general pediatrician's practice, it was shown that 13% of patient visits involved children with long-term illnesses or conditions. This indicates that a significant segment of pediatric practice is now devoted to such children and that pediatricians should adjust their own education and practices to provide optimal service to these children and their parents.

The role of the primary pediatrician in relation to children who have special health care needs and their families goes beyond that of providing primary care, yet it differs from the role of the subspecialist in a tertiary center. The challenge is to provide a true medical home for all such children in their communities to supply an ongoing source for continuous, comprehensive, coordinated health care. The community pediatrician, in establishing a medical home for children with special health care needs, will provide the following: medical management of the basic medical condition, as well as of recurrent illnesses, usual and special preventive health services; knowledge of and attention to problems peculiar to the child's handicap or disease; family/parent counseling; consultation with the public (or private) educational system; and communication and coordination with other professionals and agencies also serving the child and the family.

The last three provisions (counseling, school consultation, and agency communication and coordination) will be helped greatly by care coordinators and/or community health teams.

Pediatricians interested in providing family-oriented, community-based, coordinated care to children with special needs should equip themselves with the knowledge, skills, and resources necessary to establish a true medical home for these patients and their families. In Hawaii, Mitsunaga observed that currently the pediatrician is expected to be more than an ordinary-illness doctor. Garrell believes that participation in long-term care coordination must be a personal decision by each practitioner. He has prepared a self-assessment questionnaire to help the practitioner make this decision. A few pediatricians are limiting their practices to children and families with chronic illnesses and disabling conditions.

**ISSUES OF CONCERN TO PEDIATRICIANS**

**Barriers to Overcome**

Apparent barriers to participation in the care of children with special needs that must be overcome are as follows: inadequacy of fees that can be charged and collected to compensate for the time necessary to do the job; inertia in changing habits of practice; inadequacy of training in the long-term care of children with special health care needs; bewildering fragmentation of care of children with special needs among the many community services available; lack of knowledge of service resources available; lack of knowledge about comprehensive care of children with long-term conditions; lack of available resources to help coordinated care; and discouraging problems of territorial sovereignty, both within and outside of the medical care system.

**Should All Pediatricians Participate in Coordinated Care?**

The usual practice of primary pediatricians is concerned primarily with basic preventive measures and care of acute illness. Many pediatricians, therefore, have an acute care focus, are most comfortable with care of conditions in which a rapid response to therapeutic measures is shown, and become uncomfortable, impatient, or both with care that is time consuming and lacking in promptly visible results. Thus, to maintain the pediatrician's personal satisfaction and the satisfaction of those receiving the care, participation in the time-consuming process and slow progress of patients who need long-term coordinated care must be a personal decision by each practitioner.

**Lack of Reimbursement for Extraordinary Time for Care**

Children with special health care needs often require two or three times the amount of time per visit compared with the amount of time needed to care for children with the usual self-limited illnesses. Current reimbursement policies of both private and public sources of health care financing provide inadequate compensation to make full participation in the care of children with special health care needs economically viable for most practicing primary care physicians.

**Relationship to Tertiary Centers**

Many pediatricians feel excluded from the care of patients whom they have referred for tertiary care. Communication is poor, and a partnership does not exist. Pediatricians who practice significant distances from the tertiary center often are left "out in the cold" to coordinate services and provide care in between visits to the tertiary center, without the communication necessary to coordinate community-based services and to provide care that is appropriate.
Relationship of Pediatricians to Educators

A perceived intrusion of the public school system into traditional medical areas by schools addressing the needs of children with minor handicaps within the mandate of Public Law 94-142 has strained relations between educators and pediatricians, with pediatricians annoyed about apparent takeover by school systems of the care of medical problems that have traditionally been within the province of the pediatrician. Pediatricians also worry justifiably about the quality, coverage, and built-in fragmentation of such care. Educators, on the other hand, express concern that pediatricians do not seem to understand what information is needed by them in reports and referrals, and that pediatricians do not communicate adequately with them to ensure that children are handled appropriately in school healthwise.

Loss of Income to Providers of Coordinated Care

Most of the many facets of family-centered, coordinated care are currently provided inadequately, if at all, in most pediatric offices. Therefore, these providers are not vying with pediatricians for the care they provide, but, rather, enhance the care provided in the usual pediatric office.

Loss of the Physician’s Image of Omnipotence

Two opposing philosophic views are held by practicing pediatricians. At one end of the scale is the traditional view that the physician directs the lives of parents and children medically. The extreme opposing view is that the physician’s role is to explain the facts and options and then to help parents carry through on the decisions made by them. A more moderate and more workable position, and one that provides the best medical care for children with special health care needs, is one in which the physician works together with parents to reach an informed decision and arrive at a mutually conceived and jointly implemented plan of management that is practical for all parties. The pediatrician must realize that the day when a single health professional could function alone as an omniscient counselor and omnipotent effector of all things medical and medically related has disappeared, and that there is little reason to feel threatened by the efforts of parents, fellow professionals, and community teams exerted in the best interest of the subject of coordinated care.

Parents Educating Parents and Others

A number of physicians are concerned about the possible spread of misinformation through parent networking in an effort to help families of children with special health care needs and of parents whose children have been a long time to develop the skills in coping. Some pediatricians fear resultant harm to the child and his or her management. However, the benefits that have come from these efforts by parents exceed this legitimate concern of the primary pediatrician.

POSSIBLE STRATEGIES FOR PEDIATRICIANS CONSIDERING PARTICIPATION IN COORDINATED CARE

Examine your practice interests and attitudes to see where you can and whether you wish to participate. Examine your professional skills and decide which of them need to be strengthened and which others need to be acquired. Participate in attempts to persuade the Residency Review Committee for Pediatrics to require more adequate and appropriate training in the care of chronically ill and/or handicapped children, to include the development of a greater appreciation of family-centered, community-based, coordinated care for children with special health care needs. Encourage the AAP to help define the role of the pediatrician in family-centered, community-based, coordinated care of children with special health care needs. Encourage the AAP to address the barriers to better care for families and children with special health care needs. Attempt to influence your medical school to include more training of its medical students and residents in family-centered, community-based, coordinated care. The various AAP chapters could consider writing to the institutions in their states to address these needs.

REFERENCES


SPECIAL ARTICLES 1059
INFANT SUFFOCATION IN LONDON (1879)

The description below of infant suffocation in London, published in the *Lancet* a century ago, bears a striking similarity to current epidemiologic characteristics of SIDS.

The deaths of no less than 503 infants aged less than one year were referred to suffocation within registration London during last year [1878], equal to 3.9 per 1,000 children born. In the two preceding years [1876 and 1877] the deaths of infants from this cause were 488 and 486 respectively. Previous to 1876 the causes of death among infants aged less than one year were not separately distinguished in the Registrar-General's Weekly Return. The deaths from suffocation in London, at all ages have, however, shown a considerable increase in recent years, and, as during the three years 1876-7-8 no less than 88 per cent of the deaths from this cause were of infants under one year of age, it may be assumed that the increase has mainly occurred among infants. Of the 503 deaths of infants from suffocation in London last year, 140 occurred in the first, 147 in the second, 88 in the third, and 128 in the fourth quarters of the year. These infant deaths from suffocation are almost twice as numerous in cold winter weather as in summer; for instance the fatal cases in August did not exceed 24, whereas they were 43 in December.

Noted by T.E.C., Jr, MD

REFERENCES