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To: Participants in the conference, "The Role of the
Primary Care Provider in the Provision of Services to
Handicapped Children"

FROM  James M. Perrin, M.D.

Enclosed is a copy of the report of the conference on the role of primary care providers in the care of children with handicaps and chronic illnesses that was held at Vanderbilt University a few years ago. We are very pleased to forward this written record of the findings and recommendations of the conference. Additional copies are available from:

National Maternal and Child Health Clearinghouse
3520 Prospect Street, N.W. - Ground Floor, Suite 1
Washington, D.C. 20057

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PRIMARY PROVIDERS IN THE CARE OF HANDICAPPED CHILDREN

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Conference Report



Vanderbilt University

Primary Care Center

and

Department of Pediatrics

July, 1985

*after HFG's
formal
presentation*

PRIMARY PROVIDERS IN THE CARE OF HANDICAPPED CHILDREN

Conference Report



Vanderbilt University
Primary Care Center
and
Department of Pediatrics

July, 1985

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Conference held 15-17 September 1981, Nashville, Tennessee. Supported by the Tennessee Department of Public Health (GR 3268) and the Division of Maternal and Child Health, U.S. Department of Health and Human Services.

The Division of Maternal and Child Health is not necessarily in accord with certain comments about Federal policy. In addition, certain statements are no longer a propos, since the Conference took place in 1981.

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THE ROLE OF THE PRIMARY PROVIDER IN THE TREATMENT OF HANDICAPPED CHILDREN

INTRODUCTION

GOALS AND OBJECTIVES OF THE CONFERENCE

Sponsored by the Division of Maternal and Child Health, U.S. Department of Health and Human Services, and the Tennessee Department of Public Health, Division of Maternal and Child Health, a national interdisciplinary conference on "The Role of the Primary Care Provider in the Treatment of Handicapped Children" was held 15-17 September 1981 in Nashville, Tennessee. The conference was designed to define key issues in providing primary health care to handicapped and chronically ill children and to develop specific guidelines for improving the quality and extent of primary health care available to these children and their families. The main theme of the conference was primary care providers' responsibility for coordination of care and assuring access to necessary specialty care. The specific objectives were:

- 1) to describe the ideal nature and scope of quality primary care services for handicapped children;
- 2) to discuss the issues involved in the provision of quality care;
- 3) to develop ideas and guidelines for model programs to be implemented on a state or regional basis.

THE PARTICIPANTS AND THE PROCESS

The thirty-two participants were selected with the assistance of the Federal Office of Maternal and Child Health to represent a diverse sample from various national regions of professionals involved with handicapped children and their families. Eleven states ranging from the heavily urban to the very rural were represented. Physicians and nurse clinicians providing primary care to handicapped children joined physicians providing subspecialty medical care (e.g., hematology, neurology) and other health professionals such as psychologists, physical and speech therapists, and social workers to address the conference objectives. Administrators of Crippled Children's programs in seven states shared their perspectives with those of representatives of Federal agencies concerned with child health and with primary health care.

To meet the stated objectives, the conference process used small working groups drawing on the expertise and creativity of conference participants. Initially participants brainstormed in small groups to define issues that either promoted or impeded the provision of primary care to handicapped children. Five priority issues emerged and provided

the basis for further discussion. Groups for each topic area then met to clarify the importance of the topic area, to identify factors as facilitators and/or barriers in the area, to develop an ideal model for service, and to make recommendations for implementation of new approaches. The five topic areas were:

- 1) Family involvement
- 2) Training issues and provider skills
- 3) Coordination of care and communication
- 4) Financial concerns
- 5) Legislative issues and values

DEFINITIONS

For the purposes of the conference, the term handicapped children was defined broadly to include physically handicapped, chronically ill, and developmentally delayed children. This broad definition was formulated because the issues of providing quality primary care were perceived as more similar than dissimilar for these groups of children. Children with physical handicaps, chronic illnesses, and developmental disabilities have similar needs for frequent primary health care as well as for subspecialty services with their resultant high cost to the family. All of these conditions limit activities of normal daily living, generate common problems of secondary adjustment in the child, and impact significantly upon the family. A functional definition that includes orthopedic handicaps as well as other childhood chronic illnesses has been used. Perhaps the best definition is a modification of that used in P.L. 95-602 (1978):

A severe chronic disability of a person that:

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. is manifested before age 22;
3. results in substantial functional limitations in three or more of the following areas of major life activity:
 - a. self-care
 - b. receptive or expressive language
 - c. learning
 - d. mobility
 - e. self-direction
 - f. capacity for independent living
 - g. economic self-sufficiency;
4. reflects the need for a combination and sequence of special, interdisciplinary, or generic care treatment, or other services that are:
 - a. life-long or of extended duration
 - b. individually planned and coordinated.

Chronic illness has a similar, although more restrictive definition of handicapping condition than the above since we include only physical conditions. The definition also imparts a temporal quality.

Chronic illness is a physical, usually non-fatal condition that:

1. Lasts longer than three months in a given year, or necessitates a period of continuous hospitalization for more than one month (Pless and Pinkerton, 1975);
2. will not resolve spontaneously and completely (thereby excluding resolvable trauma);
3. is manifested before age 22;
4. reflects the need to the family or patient, on a frequent and chronic basis, of any of the following:
 - a. specific medications
 - b. specific therapies or procedures
 - c. the utilization of specialized equipment for the maintenance of the medical condition or for the performance of normal function and activities.

Primary care provider was defined as any health professional responsible to the child and family for assuring access to comprehensive, longitudinal care. This individual is often the initial source of care and usually has the most frequent contact with the child and family. The primary care provider as a regular source of care offers, between provider and patient or parent, a relationship that lasts over time regardless of the presence or absence of particular health problems or diagnoses. The provider may be generalist or specialist, physician or other health professional, and may work in a community or specialty setting.

Similarly, the definition of family includes the cluster of people caring for the daily needs of the child and responsible for him or her on a continuous basis. Our definition encompasses unrelated people living together and thinking of their household as a family and is not limited to relationships of blood, marriage, or adoption. Also included are those who think of themselves as family members and maintain social, emotional, or financial ties, but may not live together. The definition of family focuses on the needs of the child and views the family as responsible and capable in managing the child's needs.

PROCEEDINGS

The proceedings of the conference are documented in this volume. The first chapter outlines the conference process and its implementation. The next chapter examines the common concerns developed in the initial home group discussions. The next five chapters present the discussions and recommendations of the topic groups. The final chapter provides an overview of the conference and guidelines concerning the roles of families, primary care providers, and governmental agencies in the care of handicapped and chronically ill children.

THE CONFERENCE PROCESS

Mary C. Cerreto, Ph.D.

PLANNING FOR THE CONFERENCE

The conference focused on the role of the primary care provider in the treatment of handicapped children. During the conference, participants were asked to concentrate on the questions: "What do we know?" "What don't we know?" and "Where do we go from here?" The answers generated the innovations comprising the final report. The conference format needed to be conducive to the free flow of ideas and an open exchange of knowledge among participants. Conference planners sought a format that would encourage participants to generate the content areas they felt important, to delineate the issues within content areas, and to develop concrete recommendations regarding an effective role for the primary care provider in the treatment of handicapped children.

The planners believed that a traditional format of individual paper presentations or panel presentations would encourage a passive role for the participants. The participants had been invited because of their knowledge and experience in the areas of primary care and children with chronic conditions. In order to provide an atmosphere for a truly working conference, the conference staff adopted a process successful in a previous conference entitled "Self-Responsibility for Health: Focus on the Child and the Family." (For a detailed description of this process, the reader is referred to the conference final report [Bruhn, Williams, and Fitzsimmons, 1980].) The following description of the adaptation of that methodology will explain why and how we arrived at the content and final recommendations of this conference. It will also provide a replicable model for adaptation to other content areas.

THE APPROACH

The conference philosophy provided the foundation for the process. The process was based on the assumption that the participants are the content of the conference. Even though the last paper written, the last article read, or a recent goal accomplished by a participant is important, the conference placed its emphasis on the participants as sensitive and creative persons with unique training experience and personal reflections applicable to the complex issues of the conference.

Participants worked primarily in small task groups with periodic general group sessions. By providing opportunities in both formal and informal gatherings for creative interaction, the format allowed participants to learn from each other and to generate ideas for future planning.

CONFERENCE DESIGN

The conference emphasized interaction in small working groups balanced by sharing, in general plenary sessions, the ideas generated in the small groups. To provide for both types of interaction, each participant was assigned to a "home group" at the beginning of the conference. Assignment to home groups was based on heterogeneity in participant's experience, disciplinary background, and current employment. These home groups enabled participants to know one another and to explore ideas together, both from the viewpoints of their particular disciplinary backgrounds and from their own personal experience and orientation. These groups set the participatory tone for the conference and served as a home base for dissemination of conference information.

During initial sessions, the home groups used brainstorming and priority-setting techniques to generate a list of key topics pertinent to the conference focus on the role of the primary care provider in the treatment of handicapped children. Participants then elected to join one of five topic groups. These groups were asked to discuss the importance of the topic area, to examine current knowledge about that topic, to develop an ideal model, and to make recommendations regarding implementation of their ideas. During the plenary sessions, reporting panels presented a summary of each group's discussion and an outline of recommendations to the conference.

The conference process fostered cross-fertilization of ideas, individuals, and groups. Home groups provided continuity and linkages among the topic groups, while topic groups enabled participants with special interests or expertise in specific areas to work together on tasks. The conference design was formulated in such a manner that delineation of the content areas, in-depth analysis of these areas, and recommendations for the future in these areas unfolded as the conference progressed.

HOME GROUPS: FACILITATORS AND BARRIERS TO PRIMARY CARE PROVIDERS' INVOLVEMENT IN THE TREATMENT OF HANDICAPPED CHILDREN

Carolyn Keith Burr, R.N., M.S., and Mark J. Merkens, M.D.

On the morning of the conference's first full day, the initial task of the home groups was to brainstorm about factors that are either facilitators or barriers to the primary provider's role in caring for handicapped children. Each group then identified and categorized its perceptions of the most important factors. The five to ten themes generated from these categories were then stated in the plenary session. The recurrent common themes from the home groups were selected as the focal points for the topic groups.

Many factors, the home groups noted, could be either facilitators or barriers depending on one's perspective as parent or provider, as primary provider or agency administrator. The home group's task was not to seek solutions but to raise the issues to be discussed in depth in the topic areas. Some areas of concern from home groups did not fit into a topic group's scope and were not pursued. Other topic areas overlapped and were discussed by more than one topic group. This chapter on the home groups documents briefly the concerns raised in the initial sessions.

PRIMARY PROVIDER ISSUES

In the home group discussions, the skills and training of primary providers were viewed as facilitating in some cases, and impeding in others, the primary provider's role with handicapped children. For example, the importance of a pediatric generalist physician to comprehensive, coordinated care was stressed in many groups. However, the group perceived the barriers for primary physicians as their training in the care of handicapped children, their attraction to -- but discomfort with -- an ombudsman role, and financial disincentives in coordinating the care of handicapped children.

Because of the emphasis in training on tertiary and acute care and on curing, primary providers--both physicians and other professionals--often lack experience in long-term management of chronic disease and understanding of its impact on the child and family. They may have limited skills in case management, in work with a multidisciplinary team, and in identification and utilization of community resources. The failure of specialty physicians to communicate with primary physicians after referral was seen as a contributing factor both to primary physicians' reluctance to stay actively involved in the care of handicapped children and to the perception of the primary physician's role as less valuable than that of the subspecialist. The groups interpreted as a positive trend the growing number of physicians entering primary care specialties with increasingly sophisticated training. The value of the primary physician's personal relationship with the child and the family in the context of a community was stressed.

FAMILY ISSUES

Much of the discussion within the home groups revolved around the central role of the families of handicapped children. Recent research in many fields has been concerned with the impact of chronic illness and disability on the child, his siblings, and his parents. The health care given to handicapped children must include a recognition of these impacts. Primary care providers need to know about family functioning and family resources. They need to gain skills in using tools of family assessment. The participants voiced concern about the possibility of the providers' medical model view emphasizing a family's weakness and pathology, as opposed to building upon its strengths.

Groups noted that the family is the essential primary caregiver for a handicapped child. Parents may become specialists in the care of their particular child and may know more about the specific disease--certainly about their individual child's treatment needs--than their primary provider. In fact, ideally families are the most appropriate case managers. Hence, they need to know more about resources, medical systems, and interfacing agencies. A great deal of time needs to be spent teaching families about the illness and its treatment, but there is no specific funding for professional time spent helping families become knowledgeable.

Groups noted the changing demographics of families as both potential barriers and potential facilitators to handicapped children's care. Fathers are becoming more involved with children; an increasing percentage of mothers are working outside the home. The health system is often oblivious to these changes. Children are often scheduled for multiple daytime appointments, and providers assume that only the mother provides care. Families are mobile, and this condition requires communication between professionals in different locales and reinforcement of the family's role as caregiver. Family composition is changing with single-parent and blended families on the increase. Health care for handicapped children must reflect these changing realities.

As those primarily responsible for the handicapped child, parents must have a voice. The current system for delivery of health services to handicapped children has many barriers to family involvement. We must create systems that allow parents to be advocates for themselves and their children and that promote autonomy.

FINANCING ISSUES

Families of children with handicapping conditions are burdened by specialty services which, although usually of high quality, are extremely costly. Present funding mechanisms are biased toward technological services, often to the exclusion of other special services such as genetic counseling, psychological support services, respite care, and vocational planning. No financial incentives to primary care providers exist to encourage spending the extra time needed by these families. Fee-for-service mechanisms, in particular, provide disincentives. Society seems to value high- technology interventions rather than long-term involvement with families. There are economic incentives to having the children return frequently to the physician for specific procedures and acute care, but not for preventive services. Primary providers may not be procedure-oriented, but the health promotion services they can provide are often not reimbursed.

Benefit packages of funding mechanisms encourage hospitalization and discourage home care. Failure of third parties to pay for coordination activities adds to fragmentation of services and leads to unequal access to services. Services aimed at primary and secondary prevention need more investment. Follow-up care of high risk populations (for example, infants discharged from intensive care nurseries) presently receives insufficient funding.

The availability of Federal and state dollars to pay for care that otherwise would not be financed was seen as an important facilitator in the care of handicapped children. Title V, for example, pays for case coordination. However, Title XIX does not reimburse sufficiently for medical services rendered. The Federal titles have inflexible financing criteria. A decreasing percentage of Federal dollars is devoted to the care of children, and huge cuts are pending. State programs will have to increase their share of the health-care dollar, and each program will have to reevaluate program priorities. States will need to find ways to provide more quality services with fewer dollars. Methods also need to be devised to overcome the interstate service and payment barriers that particularly affect sparsely populated states with fewer sources of specialized care. Improvement in financing mechanisms can have far-reaching effects on the care of handicapped children.

ORGANIZATION OF SERVICES

Each home group generated much discussion regarding the barriers and facilitators to the delivery of care to handicapped children. barriers and facilitators resulting from the present organization of services within our contemporary medical and political structures. Many technical, support, and community services have been devised to respond to the varied

needs of these children and their families. Historically, efforts have centered around the technical care of the specific illness; the result in the last few decades is the extension and improvement in the life of children with many of these illnesses. More recently, psychosocial needs have become increasingly apparent. Families now seek the services of many providers functioning within multiple private offices, agencies, institutions, foundations, and service organizations. Although patient and family needs are better understood and better met, there is greater likelihood of duplication of some services, inattention to other services, and overall fragmentation through multiple agencies trying to care for one child. Each agency has different guidelines, conceptual approaches, and values. Attempts at comprehensiveness expose problems of communication among providers and between providers and families. Families need to know who is steering the case through the maze of services, where to go for a service, and how to interface with the appropriate agency or provider. Providers, funding agencies, and programs often do not know or do not uniformly understand the various services available. In short, a need has become apparent for case management and coordination for every child. The present organization of services includes neither financial nor professional enhancement incentives for monitoring and coordinating such care. Coordination by one individual of a multiplicity of providers and sources of services is difficult, and has not yet been proven efficacious. Interagency agreements help to clarify roles and obligations but may inadvertently weaken protection of privacy and confidentiality.

Historically, health care to handicapped children has emphasized the technical, subspecialty, and tertiary care services (particularly surgical and medical procedures). Because that model of care persists, many families do not have a source of primary care. The organization of services does not encourage the provision of primary care to these children. The recent trend toward primary care and family practice and the development of expanded nursing roles have improved the system's response to the generic needs of handicapped children. System reorganization must include better coordination of services and a stronger role for the primary provider.

THE FAMILY

Susan McCammon, Ph.D.

ASSUMPTIONS

The members of "The Family" topic group shared the assumption that attempts to aid children with handicaps should focus on the child in the context of the family. Respect for the family generates an approach to care through a partnership between professional health care providers and family members. This relationship should be directed toward promoting the family's independence from the health-care system.

The evolving process to decrease professional involvement relies heavily on three principles. First is the issue of reciprocal education. The child with special needs, his/her siblings, and his/her parents must be educated as to the course, treatment options, disease-specific management skills, and long-term consequences of the handicapping condition. Group members emphasized the importance of health care providers learning about ecological issues from the families. Providers can fill their proper roles by enhancing already existing coping and adjustment mechanisms rather than by simply grafting on another prescription. Second, family members must be involved in planning and evaluating interventions. While the degree of parental involvement and desire for participating in decision-making varies among families, involvement can be strengthened by understandable presentation of diagnostic and treatment options, discussion of risks and benefits, and joint choice making. The topic group's caveat to providers was to refrain from "doing to" parents and from taking away responsibility that parents can handle. The third principle is the need for coordination of services so that service provision is efficient and is implemented with the least possible disruption in the family's normal life.

CURRENT STATUS AND ISSUES

Inherent in the conference working definition of "family" is the recognition of a variety of family constellations. These may include foster parents (permanent and temporary), grandparents, aunts and uncles, step-parents, siblings, and even governmental entities (in cases of protective custody or residential institutions). The multiplicity of family arrangements calls for flexibility on the part of care providers in assessing and collaborating with the family system.

"The Family" topic group recognized possible complications from its emphasis on promoting familial involvement. Usually, parents are

the proper advocates for their child. There are situations, however, in which the providers' desire to share responsibility for making decisions may lead to giving responsibility to parents unable or unwilling to share that obligation. In other situations, capable parents may need help in sorting through conflicting needs, advice, and recommendations. Finally, because of the dependent nature of children, it may be very difficult to decide upon a course of action when professional and parental views are at variance about what is the best interest of the child and/or the family.

GENERAL GUIDELINES

Education

When parents are informed about specific issues and needs (e.g., immunization, time range for developmental milestones), they are better advocates for their children and set more realistic expectations for them. A focus on educational needs for families with a chronically ill or handicapped child should include attention to the following:

- (1) cognitive understanding of the nature and course of the illness or condition;
- (2) psychosocial aspects (guilt, grief, etc.) and coping mechanisms;
- (3) the effect on siblings;
- (4) appropriate child-management strategies related to medical compliance and family living;
- (5) developmental tasks and role changes as the child matures;
- (6) teaching treatment and self-management methods where appropriate (to parents and ill child); and
- (7) aiding parents to serve as advocates for the child in school and community programs.

The main educators for the family are likely to be the primary health care provider, the specialist, parent groups, and community groups organized around specific diseases or conditions.

The topic group strongly recommended promoting parents' contact with other parents and developing support groups. They saw emotional support and problem-solving among parents and informational exchange between parents and professionals as especially valuable. Such communication is helpful in raising the consciousness of professional service providers regarding their impact on families.

Parental involvement

A goal for health care providers is promotion of family autonomy by maximizing the potential for independence at each successive stage. Increasing family members' ability to ask questions was one recommendation to enhance their understanding and coping. The group saw the teaching of intervention skills (self-treatment, triage), which allows the family to assume the appropriate level of responsibility, as a confidence-raising and competence-building intervention.

The participants viewed diseases or conditions requiring a great deal of treatment as especially relevant for home involvement. A specific single problem (e.g., hemophilia) may establish a set of needs and treatment tasks very different from those of multiple handicaps.

The topic group discussed the high level of involvement and sophisticated learning of some parents to the point that they become more expert in their child's condition than the health-care provider. At times, such involvement results in the family's withdrawal from the medical system. The consensus was that improved communication between parents and professional health-care providers was the most likely method of promoting optimal parental involvement to reduce professional intrusion and to include appropriate professional care.

Coordination of care

Coordinated care was viewed as more efficient and less intrusive on the family than fragmented care. The topic group observed the need for a lead person or care coordinator/manager. An advocate and coordinator aware of the total picture of the family's needs and available resources can avoid the problems of multiple treatment plans lacking coordination. See "Communication and Coordination," pp. 23-28.

Identification of lead person

The lead person role can be filled by any of several service providers: primary care provider, public health nurse, social worker from a social service agency, nurse coordinator or social worker from a specialty care center, or other specialty care team member (speech or physical therapist, school personnel, etc.). The orientation of the lead person (specialist or generalist) should be determined by the needs of the family and the nature of the illness.

The topic group felt strongly that the identification of the lead person should be based on the family's service needs rather than on their financial situation. Drawing on intact agencies and staff with already existing responsibilities for children and families would enhance the feasibility of this concept. The delineation of roles, including identification of the lead person and functions of other team members, could be established through cooperative agreements among helping units or lead agencies. However, it is imperative that the identified person have the authority base (through the family) for taking the lead in the team.

Functions of the Lead Person

Activities of the lead person can include the following:

- (1) assessing family strengths and coping abilities, including appreciation of:
 - (a) the family's material and financial resources,
 - (b) interpersonal support networks,
 - (c) spiritual/religious resources,
 - (d) the condition, perceptions, and expectations of the child, and
 - (e) complicating factors affecting the family's situation (another ill child, single parent, etc.);
- (2) remaining informed about community resources and linking the family with resources;
- (3) coordinating health-care provider and agency efforts, ensuring that necessary follow-up work is scheduled and that the overall treatment plan is periodically restructured as necessary;
- (4) providing information to the family and serving as an interpreter when necessary to family and to service providers;
- (5) offering financial counseling;
- (6) providing care or expertise in the assigned area.

Among the necessary characteristics of the lead person are skills in team functioning and team building, knowledge of family relations and functioning, and skills in human-relations counseling.

IMPLEMENTATION

Financial feasibility was emphasized as an essential feature of any recommendations developed by conference participants. The lead-person concept can be financially feasible because it simply enlarges the role of team members already present in the health-care and social-service systems. The topic group recommended a policy of ensuring that a lead person or advocate for each family be funded and that a mechanism be available for locating a lead person for families not qualifying under agency financial guidelines. Financial incentives must be developed for providing comprehensive, coordinated care.

The funding of educational interventions was discussed. Group members observed that hospital funding is not likely to be allotted for teaching home treatment or for primary prevention efforts--private insurance may be a possible source.

Finally, although within the province of another topic group, the family group addressed the issue of professional training. The group identified learning to focus on a child within a family rather than on a medical problem, attending to the family's need to be listened to and be heard, and learning to offer interventions responsive to the family's perspective and ecological situation as vital components in the training of health-care providers.

TRAINING AND PROVIDER SKILLS

Gerald S. Golden, M.D.

ASSUMPTIONS

Under the broad definition used in this conference, primary care can be provided by any health-related professional working at any institutional level. This individual may provide direct service to the handicapped child, may facilitate entry into the health-care system, or may carry out both functions simultaneously or at different points in time. The training given primary providers to enhance their role with handicapped children, therefore, must include specific disciplinary skills, a knowledge of families and psychosocial impact, a knowledge of the roles and abilities of all other relevant disciplines, a knowledge of institutional structure, and a knowledge of community resources.

The physician, by early and frequent contact with the child and family, is often thrust into the role of primary care provider, whether he or she is a tertiary care subspecialist or main provider of primary care. Unfortunately, the majority of medical school graduates have had little or no education or training in the care of handicapped children. Postgraduate (specialty) training may or may not increase skills in this area, as there is a good deal of variation among programs and no broadly accepted external standard.

The educational experiences of other health care professionals and paraprofessionals also vary widely. Usually, specific disciplinary skills, which can be generalized to the problems of the handicapped child, are well taught, but lack content about the specific problems of handicapped children. In most disciplines, the training is also insufficient in the areas of institutional structure and function, and community resources. A common method of teaching the content and skills required for handicapped children has been to use an interdisciplinary setting. The model has been assumed to be effective, but expensive. In addition, individuals trained in such a setting may have difficulty carrying over the skills when a different model of practice is entered.

With this background, the conference participants agreed that a focus on training was essential. Two complementary features were identified:

1. Improving the skills of primary care providers in the treatment (broadly defined) of handicapped children.
2. Improving understanding of the community and of families of handicapped children in relation to the role of the primary care provider.

The Topic Group procedure was used to delineate and agree upon six major issues. The group outlined methods of meeting the defined problem, formulated a series of guidelines for improvement of provider skills, and developed recommendations based on these concepts.

MAJOR ISSUES

1. We now have the methods/techniques to teach the skills primary providers need. We need to introduce these skills to more providers earlier in their training.

The majority of training for the care of handicapped children currently takes place in medical institutions. Traditionally, most activity has been carried out in child development clinics housed within departments of pediatrics. The growth and maintenance of these clinics were assisted by the Division of Maternal and Child Health through funding for demonstration projects. This assistance allowed the building of interdisciplinary staffs and development of interdisciplinary training programs, neither of which had been items of high priority in traditional medical schools.

The development of University Affiliated Facilities was extremely important, but has had a mixed effect. On one hand, an impressive amount of training related to the handicapped child has been carried out. On the other hand, the development of separate facilities, often isolated from the medical school itself, has led to isolation and insulation of UAFs. Students in health-care professions might be exposed to these programs, but perceived the clinical activities as highly specialized and capable of being performed only in such a setting. They saw little relevance to their eventual career and practice.

Despite these issues, the methods and techniques for training now exist and are in use in child development clinics and UAFs. The problem has been to get to the student early in his career and to make a lasting impact.

The first approach would be to share training resources within medical settings. Liaisons should be developed, for instance, between such departments as pediatrics, family medicine, and nursing. The interchange would allow a broadening of the number and kinds of professionals and students exposed to the patients and their families and the important aspects of their care. A student would also perceive that the care of handicapped children really was appropriate for practitioners in all these areas. The student would clearly see that the skills could be generalized and were not applicable only to specialists. Finally, those liaisons would permit efficient sharing of personnel, training materials, and facilities.

Every training and service unit has felt compelled to develop its own training materials. A national survey would allow cataloging of the materials (videotapes, self-instructional units, etc.) and techniques that exist and have been proved useful. Needless duplication could be avoided; more staff time would become available for direct training. The cost of individual materials would also decrease through volume production.

The training must be brought to the students. Rather than the concentration of training in special centers where certain "mystic rites" (the interdisciplinary team processes) are carried out, the emphasis must be on the student's perception of how primary care can be provided in a primary care setting. Specialists in all disciplines must be trained to consult with health care providers in the general clinics and on the wards. Consultation skills must be introduced early in training.

Well-developed programs for continuing education already exist and can be incorporated into professional training programs. An example is the Society for Teachers of Family Medicine. In addition, highly structured and well-planned courses (such as those offered by the American Academy of Pediatrics and training programs in developmental diagnosis sponsored by the University of Colorado) are available on a regular basis. Pressure for including this material in the curriculum could be brought to bear through organizations such as the American Medical Student Association. Students have, for the past 15 years, been demanding a role in shaping educational practices toward their perceived needs. This sort of pressure could be developed and used positively if sound arguments could be developed.

In order to foster the development and continued existence of training programs, people in key positions both within the institution (such as departmental chairpersons and deans' office staff) and in critical outside agencies must be convinced of such programs' worth. Agencies such as the American Board of Pediatrics can have a tremendous impact by requiring skills in the care of handicapped children for general, not subspecialty, certification.

As more maternal and child health activities are being turned over to state Crippled Children's Services (CCS) agencies, it becomes increasingly important to develop creative relationships between CCS agencies and academic institutions. The state must be convinced that the training-service model can be carried out efficiently. Subspecialty service can be given at an excellent level while training is simultaneously carried out, and as a relatively inexpensive fringe benefit, specialists and primary-care providers can be trained in the issues of care to handicapped children.

2. We need field in-service and community-based education for providers.

There are three major elements that must be addressed in relation to in-service education: maintenance of skills; development of new skills; and imparting new information as guidelines, procedures, and concepts change. Skill maintenance is less of a problem in certain working environments with daily exposure to other professionals. However, the individual practitioner is totally dependent on his own efforts in this area and does not have the same access to feedback about his performance.

The development of new skills and the acquisition of new knowledge are issues for all practitioners, although access to relevant educational activities is easier in an institutional setting than in individual practice. In any case, the need for in-service education is clear. Carrying out this process in the community provides access to all individuals needing the education by eliminating the barriers and expense of travel and time lost from practice. It also allows the program to be more clearly geared to specific regional or local needs (e.g., urban vs. rural).

Several approaches were suggested in discussion of this problem. The least costly would be the development of self-paced instructional materials for providers. This method allows an active approach to learning that is educationally sound. An incentive can be built in through the granting of continuing education credits when the units are completed. This approach can be supplemented with videotaped materials or closed-circuit TV. These audiovisual approaches can stand alone, but they provide only passive learning--educationally less effective.

Professional associations (e.g., American Academy of Pediatrics, American Nurses' Association) should develop mechanisms for obtaining and distributing educational materials in their disciplines. They also have the prerogative to set standards and define continuing education requirements and thereby provide the impetus for participation in in-service programs. Organizations with a broad base and generic approach (e.g., Association for the Care of Children's Health) should be encouraged to develop interdisciplinary programs and to go beyond narrow interests of specific disciplines.

A more costly but important approach is to have consultants go into the field to increase a number of services unavailable through any of the previously discussed techniques. These would include, but not be limited to, assessment of individual or group performance, introduction and initiation of educational programs, and consultation in teaching around specific patients. The on-site consultant could introduce a degree of quality control into educational programs and could provide highly focused and personalized educational experiences.

States can take an active role in bringing together maternal and child health and Crippled Children's Services agencies, parents, and community providers to develop educational programs. This function would help assure that these programs meet the actual and perceived needs of the agencies and individuals.

3. We need role clarification and multiple models for training; different approaches are needed in different locales.

The group generally agreed that standardized training models are not necessarily appropriate for all locales and all professional groups. Sparsely populated rural areas and major urban areas have different

problems that need different solutions. Analysis of needs could best be done on-site, and it was recommended that CCS take the responsibility to ascertain these needs by placing consultants in the field. The consultants should attempt to develop plans to make the maximum use of available resources, including professionals such as school nurses and public health nurses, as well as parent associations. If local resources do not exist or cannot be adequately mobilized to meet the needs, CCS should then take the lead in developing programs.

4. There are few incentives to carry out training; in particular, financial incentives are lacking.

Costs of training have often been hidden in the costs of providing clinical service, and in many clinics the two are virtually inseparable. Third-party carriers are now closely scrutinizing this issue and are refusing to reimburse training activities beyond direct service provision. We see that didactic aspects of training programs, the development of educational materials, and a good deal of in-service training have not been demonstrated to improve outcome and hence would not be reimbursable.

One major source of training funds has been through the UAF and other projects funded by the Federal Maternal and Child Health program. These funds will continue to come directly from Washington rather than to be channeled through block grants to the states. Each year will probably see a major and progressive decrease in these funds for the foreseeable future. Cutbacks make imperative the development of new funding sources.

Private foundation funding has always been available to a limited degree. It would be appropriate to make foundations aware of the training needs before the financial needs are acute, since these organizations must develop policies and decide on areas of interest years in advance. An omnipresent problem, however, is that foundations are anxious to provide funds for the initiation of innovative or experimental programs, but will rarely pick up the burden of ongoing support.

Insurance companies have become interested in disease prevention and health maintenance. Support for training might be available as it has impact on these areas. In the past, drug companies have been willing to provide limited support for educational activities, but generally only if the conditions discussed were related to their product line.

It is also necessary to examine the other side of the coin--the cost effectiveness of current training and training/service models. The interdisciplinary team is an example of a widely accepted and commonly used model. It probably is not cost effective in terms of an individual professional's time, however, and restricts the volume of patients that can be seen. In areas underserved by professionals, it is even less efficient. A fresh look at the costs and benefits is required. Creative modification of current methods may reduce training costs without compromising the goals of current approaches and practices.

5. We need more research into the efficacy and cost effectiveness of training models.

In addition to rising concerns about the cost of interdisciplinary teams, one does not know the effect of team care on the quality of care for the handicapped child. The assumption is that an interdisciplinary team process gives the best functional outcome for the parent and child, but this assumption has not been rigorously tested.

A new trend has been to educate trainers to teach skills to others; thus we can achieve a multiplier effect in the training process. The American Academy of Pediatrics course and the course in developmental diagnosis given by the University of Colorado are examples of this model. The cost effectiveness of this approach has not been studied. In addition, there is no way of assuring the continuing competence of the second generation trainers.

6. Parents and families also need training.

There has been a tendency to treat parents of handicapped children as passive implementors of professional recommendations. Obviously, families are the major decision makers and in the best position to provide a major portion of the child's primary care.

Parent training has become an accepted method of providing parents with the skills necessary to become active and semi-autonomous participants in the care of their child. The approach has usually been highly problem-specific and thus applicable only where a sufficient number of families and a skilled trainer could be brought together. The development of a generic, rather than categorical, approach to parents' groups needs to be developed. Generalized skills, applicable to a broad range of handicapping conditions, would also benefit by being able to monitor and develop a fuller understanding of parents' concerns. These groups would produce a dynamic interchange to the benefit of all parties, especially the children.

GUIDELINES FOR IMPROVEMENT OF PROVIDER SKILLS

After the achievement of consensus on the major training issues, the group concurred on the need for a focus on specific skills required by the primary care provider. The educational processes used to develop these skills are paramount. The content, most easily determined, must be detailed and complete. The context in which the training is given is also important, and there was general agreement that supervised work with children and families was the most meaningful and the most educationally appropriate. Finally, the process of the training was considered. Clinical supervision allowing for a gradual assumption of responsibility was the favored approach. The content, context, and process are, therefore, closely interwoven.

A long list of necessary skills was developed. They can be divided into three major categories: intrapersonal, interpersonal, and content skills.

1. Intrapersonal skills

Development in this area requires the trainees to be able to assess their own reactions to given situations and to function professionally despite any anxiety or negative feelings that might be raised.

These skills include:

- a. Ability to overcome fears in dealing with emotional issues, the chronic nature of the condition, and the concerns of the disabled;
- b. Ability to handle one's own stress;
- c. Understanding of ethical issues and of personal values;
- d. Techniques to allocate and utilize time most effectively.

2. Interpersonal skills

The majority of the skills in this area are interpersonal competence skills that are needed to work with families and children, including:

- a. Counseling and interviewing;
- b. Understanding of family dynamics;
- c. Understanding of family systems;
- d. Familiarity with normal and abnormal family development;
- e. Understanding of cultural, religious, and socioeconomic differences;
- f. Familiarity with values clarification techniques;
- g. Knowledge of different patterns of coping and methods of dealing with loss and grief;
- h. Communicating with children about their own conditions;
- j. Knowledge of differences in learning styles and skills.

Another group of interpersonal skills is needed to work with other professionals involved in the child's care including:

- a. How to collaborate and work effectively with persons from other disciplines;
- b. How to share the burden of care and avoid duplication of services;
- c. How to make effective referrals and provide consultation.

3. Content skills

Although some content areas are quite specialized and vary according to setting and health problem, certain skills were identified as being important (although often lacking) for all primary providers:

- a. Knowledge of specific disease entities;
- b. Knowledge of the health care delivery system;
- c. Knowledge of community and funding resources;
- d. Knowledge of normal and abnormal growth and development;
- e. Understanding of prevention issues;
- f. Skills in genetic counseling or knowledge of referral sources for genetic counseling and screening;
- g. Ability to evaluate research findings.

RECOMMENDATIONS FOR IMPLEMENTATION

The participants in this work group agreed on a number of recommendations to assist the development of appropriate training for primary care providers and to facilitate the implementation of this training. The recommendations were divided into those to address now and those to be the focus of future efforts.

1. Recommendations for immediate implementation:

- a. Set priorities for training needs;
- b. Identify the training content needed to better prepare primary providers to care for handicapped children, such as those skills listed in the previous section
- c. Recommend curriculum changes to facilitate teaching these skills, including:
 - i. Use of role models;
 - ii. Training in the "natural setting," i.e., community agencies, pediatricians' offices, handicapped children services;
 - iii. Use of advanced technology such as video and audio tapes in educational institutions and continuing education programs;
 - iv. Longitudinal experience with individual chronically ill children;
- d. Use methods that will attract providers to the educational programs, such as:
 - i. Attractive titles for lectures;
 - ii. Reward system for provider participation;
 - iii. Pressure from parents;
- e. Identify key people to teach, such as influential community providers;
- f. Change the reward system in medical education to reward those skills necessary in the primary care of handicapped children;
- g. Utilize parents in the education process.

A number of additional recommendations for immediate implementation require the active participation of state Crippled Children's Services (CCS):

- a. State CCS should insist on multidisciplinary training sessions;
 - b. State CCS should recommend that physicians and other primary care providers attend the AAP course on handicapped children;
 - c. State CCS should incorporate outreach programs to primary care providers.
2. Recommendations for future implementation:
- a. Explore new technologies for training, e.g., video/audio tapes, multiple media, etc.;
 - b. Develop a central source for training materials;
 - c. Investigate new funding sources for training;
 - d. Conduct research on the effectiveness of training approaches;
 - e. Conduct research on the outcome of the effects of coordinated health-team care;
 - f. Develop ways to apply the results of research;
 - g. Consider an amalgam of parent and professional groups in the area of chronic illness in children.

Implementing the above recommendations for training new providers and upgrading the skills of practicing providers could dramatically improve the quality of primary care available to handicapped children and their families.

COMMUNICATION AND COORDINATION

Mark J. Merkens, M.D.

Of the numerous factors described as facilitators or barriers in the provision of high quality care to handicapped children, the topic group discussed issues of communication and coordination of care most frequently. After clarifying assumptions and setting a research background, the group constructed general guidelines for the components of an ideal model, and developed specific recommendations for the implementation of programs to improve communication and coordination.

ASSUMPTIONS AND PHILOSOPHICAL BASE

Communication and coordination are essential to meeting the special needs for wide ranging treatments and psychosocial support of children with chronic illnesses and their families.

A primary assumption of this topic group asserted that certain components of communication must be inherent in the delivery of any service, particularly health care. These are: the gathering and returning of information about the problem (specific disease or handicap), the action to be taken (treatment to be given), the system to be used (health care delivery system), and the expected results (course of illness). If any of these components is omitted, care will be incomplete, and patient and family insufficiently informed.

A second assumption was that children with chronic illnesses have many special problems including long-term care of life-threatening illnesses often involving many organ systems and requiring complicated and expensive therapies. In addition, these children and their families may have a higher prevalence of secondary psychosocial adjustment problems than has the healthy population. We must work not only for resolution or stabilization of the biological condition, but also for the enhancement of the family's understanding in order to facilitate their participation in the care of the illness and the development of coping skills. A multiplicity of providers may be involved in the care of the child. Social agencies must also be drawn into the plan. Finally, community institutions (such as schools, church, day care, sport facilities) need accurate information about the capabilities of the child, about treatments to be delivered under their care, and about acute problems for which to be prepared. The topic group believed strongly that the complexity of the problems facing chronically ill and handicapped children and their families demands that delivery of services be coordinated.

Coordination of care is defined here as regular communication by various professionals about their observations in order to integrate their decisions and actions in relation to their separate goals for and with the patient and family. The main function of coordination is to maximize communication and thereby minimize fragmentation. Resultant efficiencies will limit cost and prevent duplication. These efficiencies can be achieved by the identification of roles of all providers (individuals and institutions), the recognition of the importance of the coordinator's role, and the designation of the specific person to fill that role. Finally, coordination will not only insure comprehensiveness of care by maximizing communication and integrating goals, but can be used as a mechanism to emphasize the support of families.

We also assumed that all our activities must be with the family and must encourage its independence and self-advocacy. The ethical principles of justice, utility, and benevolence must lead us from paternalism to promotion of the autonomy of the child and family. This philosophical precept underlies all aspects of our care of handicapped children, and is discussed more fully in "The Family" section of these proceedings. In that light, the term "case management" was interpreted as authoritarian by its lack of input from families and by its failure to promote their autonomy.

The philosophical base of efforts on behalf of chronically ill and handicapped children must include a holistic approach to the child and family. The needs of children with chronic illness are of greater importance than the technical and diagnosis-oriented aspects of the specific disease. This holistic approach facilitates access by other providers (such as social workers, nurses, psychologists) who have skills in health promotion and habilitation. This approach also facilitates an ecological approach, which considers functional abilities and psychosocial needs of the child, family dynamics, financial issues, cultural environment, and community interactions with the handicapped child.

CURRENT KNOWLEDGE

In an attempt to form general guidelines for the composition of the ideal model, we made use of current knowledge about communication and coordination of care. The impact of the grief process on a family's ability to communicate interferes with understanding; multiple contacts with parents are required before they comprehend their child's disease process, impact, and treatment requirements. It has been shown, however, that the patient's level of understanding is not related to the length of time in communication--that is, longer is not necessarily better. Effective communication leads to better patient satisfaction and increased compliance with medical regimens. Although parents want to understand their child's problems as specifically as possible, labeling may impede communication and understanding and perpetuate jargon and fragmentation.

Many approaches to coordination of care have been investigated. Collegial interdisciplinary care improves illness outcome in numerous settings. However, from the viewpoint of parents, handicapped children receive incomplete care with insufficient coordination, whether in a multidisciplinary tertiary disease-specific clinic or a primary care pediatrician's office. Families desire more advice, more help with future planning, and more genetic counseling than they are receiving even from subspecialty clinics. Local comprehensive care may lead to lower cost of care, increased patient and provider satisfaction, and better compliance with treatment protocols by primary providers. Coordinated comprehensive care improves--or prevents deterioration of--functional activities, disease processes, and economic independence. Such care also leads to better school attendance, to decreased hospitalization, and to decreased emergency room utilization for some illnesses. In some instances, non-professional coordinators have been shown to improve outcome and parent satisfaction.

The role of primary physicians in the care of handicapped and chronically ill children has also become more clear. We know that physicians follow no pattern of referral for consultations, nor of use of community agencies and other local providers. Very few physicians know of funding sources for child support services, even within their own communities. Understanding these gaps in the existing system, we must construct a model ensuring comprehensive care and complete communication.

GENERAL GUIDELINES

At the outset, we noted that there are many delivery models that can be used in different settings. No one model fits all needs; needs vary. Guidelines for implementation must be tailored to fit local needs.

Any system promulgated must facilitate the involvement of primary care providers. Their indirect care activities, such as phone consultations, should be reimbursed, as should nonmedical activities such as counseling, liaison, monitoring, and advocacy. The system should encourage primary care providers to know community, regional, and state resources such as agencies, funding sources, support groups, and volunteer groups (particularly disease-oriented organizations and foundations). Provider skills should be constantly improved through continuing education programs and incentives (see the section on Training and Provider Skills).

When possible and useful, interdisciplinary activities should be fostered. Teams should be collegial, not hierarchical. Interaction should be organized around the problem to be solved, as is done in the matrix organization approach used in industry, rather than around

traditional hierarchical rank. A collegial approach should emphasize interprofessional relationships based on each professional's contribution to the particular case-management problems. Ideally, if there is interprofessional respect with no fear of intrusion when roles overlap, team members feel secure. However, roles must be clearly established so that responsibilities are understood and fulfilled.

The role of Care Coordinator must be defined, delineated, and carried out by some specified provider in every case. The major activities are: (1) communication with consultants, (2) coordination among numerous providers as well as the patient/family, (3) interpretation of consultants to the family, (4) assistance to families in gaining access to health care, (5) liaison with community agencies, and (6) monitoring to ensure the provision of all necessary care. To ensure easy access to the patient, the individual filling the position of Care Coordinator should be based in the local community. The Care Coordinator must have ready access to all team members. The professional role of the person fulfilling these tasks should meet the changing needs of the patient. For example, the Care Coordinator could, but need not necessarily, be a pediatrician or other primary physician. It is paramount, however, that the Care Coordinator be someone acceptable to the patient and his/her family.

Although it may appear that the role of Care Coordinator is contrary to the collegial approach described above, the function of the Care Coordinator is not to evaluate directly, but to carry out the service program agreed upon by the many professionals and to be the family's interface with the health-care system.

Some functional components of this ideal model facilitate the role of the Care Coordinator. His or her activities should be financially supported, including reimbursement for indirect and non-patient services. There should be incentives and rewards, including financial and intellectual, for filling the role of Care Coordinator. The job description must include the person's authority, responsibility, and accountability and thereby facilitate the person's effectiveness. There must be continuing education, including ongoing skill improvement for the Care Coordinator, as well as continuing education for other providers about the importance of the role to them and their patients. Finally, research into the effectiveness of the Care Coordinator model is necessary to demonstrate efficacy and identify components needing improvement.

IMPLEMENTATION

Steps for implementation of this model include recommendations to make practical the general guidelines--specifically the processes of referral, consultation, and coordination.

Recommendations regarding referral and consultation include the following tenets. All contacts between referring provider or agency, and the evaluator or consultant, should facilitate communication and continuity of care. To ensure that specific questions by the patient or referring provider are answered, the reason for referral should be specified. The referrer should clearly state whether he and the family wish the consultant to provide specialty opinion or to assume care of the patient. Establishing a date for reply to the referring provider, regardless of source of ongoing care, will clarify and expedite lines of communication. The referring provider will continue to act as case manager and primary provider until the evaluation has been completed. After evaluation, there must be timely communication to the referring provider or agency and other appropriate providers.

Innovative programs generating contact between consultants and primary providers should be instituted. These programs should financially support subspecialty medical providers for consultant activities that develop personal contact with, generate referrals from, and provide educational services for primary care providers. By paying for visits to provision sites of primary care, such programs will expose the consultant to the issues of primary medical practice. The visits will also inform potential referring providers about the consultant's agency. These programs should also help improve overall provider skills by funding subspecialists to deliver educational services informing primary providers about regional resources, service models (e.g., care coordination), and current therapies. The topic group recommended that the process of coordination include a care plan for each child, developed in concert with the patient and family as well as the primary care providers. The care plan should be written and delivered to all providers and should contain specific recommendations, role delineations (particularly that of Care Coordinator), and follow-up plans. The goals should be measurable with projected dates of achievement. A date for reviewing and monitoring service delivery should be set. (The Individual Service Plan used by the SSI/Disabled Children's Program is one such process which has been successfully used in some settings.) The family should also receive a copy of any such plans, perhaps in summary form, in simple language. Requiring the patient or parents to sign the care plan will demonstrate that they understand it, have received a copy, and agree with its contents and goals; this will also ensure that they can consult the plan for clarification at any later time.

The local Care Coordinator should provide follow-up care of the handicapped child. Frequently primary physicians do not wish to act in that role, which other professionals--such as social workers, public health nurses, or physical therapists--might assume more appropriately.

Rarely, a physician who is a subspecialist, practicing at some distance from the patient's home and community, may be the most skilled professional to be the Care Coordinator. All children with chronic illness and all handicapped children should have a generalist primary care provider with pediatric skills at least involved in, preferably coordinating, their care. Several recommendations were made to facilitate care coordination. First, interagency agreements should designate responsibilities of involved parties; these agreements should include:

- a) a structured referral process,
- b) an individualized care plan,
- c) funding for the remuneration of the Care Coordinator,
- d) funding and provision of necessary related services.

The agreement is particularly important when clients are referred from one large institution to another. Second, reimbursement systems should reimburse for Care Coordinator activities. Third, to ensure responsiveness to the Care Coordinator's activities, the role must be given authority of enforcement, perhaps in the form of funding control or access to services. Finally, local agencies, such as state handicapped children's programs (e.g., CCS), should take an active role in developing coordinated health care systems using a Care Coordinator model.

We recognize that no one plan can be universally applicable. However, the care coordination model will facilitate better communication through the establishment of specific programs--tailored to local needs--for handicapped and chronically ill children.

FINANCING

Henry T. Ireys, Ph.D.

PRELIMINARY ASSUMPTIONS

To keep the discussion within reasonable bounds, the financing group identified several underlying premises. First, we agreed that public monies are necessary for adequate care of handicapped children. Without reimbursement for care-coordination activities, for example, pediatricians and other primary care providers are not likely to undertake these time-consuming activities. Since private insurance companies and other private sources are not likely to reimburse care-coordination activities, public monies will have to be used--although they could be used in a wide variety of strategies. The essential point is that public programs are necessary for these children in order to activate existing resources or to generate new ones.

Second, we agreed that solutions must differ among states, and between rural and urban areas. While we wanted to avoid debate on issues of federalism and on urban needs versus rural needs, we emphasized that regional resources and regional politics shape the universe of options--often quite dramatically. Any broad scale recommendation must take account of this reality.

Third, out of a desire to remain optimistic, we noted that periods of transition from relatively plentiful resources to relatively scarce resources--and the crises that ensue--are historically quite frequent. Such periods provide opportunities to shift patterns of care radically and to structure a system based on a critical review of priorities. Such periods also have wide-ranging and often subtle implications. For example, decreasing resources for maternal and child health in general can particularly alter the nature and breadth of the population of low income, chronically impaired children.

Fourth, we proposed that, in the face of severe cut-backs, the most important question to address is: How can agencies marshal their efforts to preserve both important services and a degree of authority? This question was the primary fulcrum for the group's discussion.

CURRENT STATUS AND DILEMMAS

Several major issues now face state agencies traditionally responsible for providing services to chronically ill children. (The term Crippled Children's Services agency will be used to represent these state agencies

with the understanding that many CCS programs are operated under a Maternal and Child Health agency.) The task of financing primary care services for this population must be seen in the context of these larger issues which can be summarized as follows:

First, many CCS agencies have either not attempted or have not been successful in utilizing other sources of funds for services provided to patients under the care of the program. CCS agencies in many states could much more aggressively pursue Medicaid or private insurance plans to help support services.

Second, many state CCS agencies have failed to make existing private providers (both specialists and primary care providers) an integral part of the program. Private providers are often referred to as vendors, a term suggesting that they dispense services and send a bill with no real sense of control over or participation in the decision-making process. One of the major challenges for many state CCS programs, therefore, is to build relationships with the private sector.

Third, as the Maternal and Child Health block grant is implemented, most CCS agencies face a severe cut-back in Federal support and perhaps in state support (because of altered matching requirements). Many CCS programs, resting on their 35-year-old Federal mandate, never developed any mechanism for advocacy at the state level. Now these programs need to learn advocacy skills and to mobilize their original constituents and supports--parents. However, several group members believed that it would be better for some state CCS programs to collapse entirely with the likelihood of resurrection at some later date.

Fourth, CCS agencies would have never succeeded if they had had to pay usual and customary rates for all services delivered to these children. Therefore, CCS agencies have developed a variety of mechanisms to permit physicians to deliver services at low cost. These mechanisms include: quick but lower payment, no paper work, and professional recognition. Those CCS programs using these mechanisms have been more successful in stretching dollars.

IDEAL MODEL

The financing group identified a variety of ideal characteristics of a state agency providing financing and coordinated care for handicapped and chronically ill children. We grouped the attributes into three areas: policy guidelines, organizational structure, and use of funds.

First, an ideal CCS agency would have clear policy guidelines. In particular, explicitly stated criteria would lead to priorities for allocating funds. Furthermore, there would be both formal and informal--but above all, effective--working relationships with other funding sources (both public and private) at the Federal, state, and local levels.

The organizational structure of the agency would permit: (1) a balance among tertiary, secondary, and primary care; (2) clear and rapid payment, payback, and data collection systems; and (3) equitable salaries for any person providing a given service. In essence, the structure of the agency would ensure consistent involvement of and support from the private sector providers and from parents--both of whom could advocate for funds and special programs when necessary.

The agency must be able to control funds in such a way as to stimulate good care, and simultaneously to provide incentives for timely reductions in the level of medical care. Furthermore, the agency must use funds to ensure coordination of care, follow-up, and regular check-ups for preventive purposes.

IMPLEMENTATION

The financing group believes that state CCS agencies must preserve their authority and their ability to fund or provide services. Without some authority backed by public funds, the ability to implement an idea pales quickly. Thus, the major goal is to maintain some visibility and some hold on the decision-making process at the state level. We propose three specific strategies accompanied by ideas for implementation.

First, make the argument strongly and often to the legislature and to the entire health care system that these children need a type of care fundamentally different from well child care programs:

1. Identify the opinion-makers and the power base and begin to influence it;
2. Put legislators or other opinion-makers on the advisory board;
3. Gather existing research data and facts;
4. Organize special interest groups into a lobbying force;
5. Establish a governor's task force to look at the problems.

Second, the existing health care providers in the private sector must become actively involved in the CCS program:

1. Invite private providers into the planning process;
2. Give professional recognition to program providers;
3. Develop quick reimbursement, even if it is below cost;
4. Become a fiscal intermediary for private providers;
5. Remove the prior authorization requirement for certain services that exists in some states.

Third, keeping a focus on the child and family, the CCS staff must become active promoters, seek finds and ideas from many sources, and become advocates in many different communities and at many different levels:

1. Establish a network for dissemination;
2. Keep in touch with other CCS program;
3. Work on reimbursements through Medicaid;
4. Hire a financial counselor to work with patients to use available private third-party insurance policies;
5. Establish liaison with the state Insurance Commissioner to promulgate innovative insurance programs such as high risk pool;
6. Use financial incentives as a lever for ensuring appropriate care. For example, pay hospitals for five days beyond the authorized limit if they develop an appropriate plan for home care;
7. Establish very specific criteria for CCS payment.

PUBLIC POLICY AND VALUES

James M. Perrin, M.D.

BACKGROUND COMMENTS AND ASSUMPTIONS

Four key assumptions underlay the work of the group on values and public policy. The first is: in the development of programs for children with chronic handicapping conditions, the focus should be on the child and the family broadly, not just on the medical condition. Chronically ill children need access to cost-effective, high quality medical services offering the best of new technology and knowledge of specific conditions. Although the child's illness can be viewed independently, it and its treatment often have profound effects on other family issues, including the jobs and productivity of parents, the adjustment and school performance of siblings, and the intactness of the family itself. Illness occurs in a family context. Many problems facing children and families with chronic illnesses are common to essentially all chronic medical conditions. These generic demands include the need for early identification and referral to appropriate tertiary care providers and attention to issues of schooling, financial support, counseling regarding genetic and psychological issues, family respite, and quality nursing care. The presence of any chronic condition places stress on the child and family, and often interferes with the child's ability to participate effectively in school and peer activities. Attention to a broad spectrum of child and family needs will extend the application of medical therapy and improve the child's ability to participate as effectively as possible in daily life activities.

The second assumption is: child health needs its own focus in policy and legislation, a focus that should be separate from other health and related services. When combined with other service priorities, child health issues tend to be obscured. For example, although children represent roughly 47 percent of Medicaid recipients, they receive about 17 percent of Medicaid expenditures. Similarly, children with chronic handicapping conditions have special needs, often beyond those of other children. Access to quality tertiary care, to special counseling and support, and, at times, to special education, are all requirements of chronically ill children. Thus, although the development of comprehensive children's health services is likely to improve the lot of children with chronic illnesses, the need for special programs for children with chronic handicapping conditions will continue. Vigorous advocacy for these special needs is crucial. Usually, when setting priorities in health fields, the "squeaky wheel" is most likely to receive attention and public support.

The third assumption is: Any response to the special needs of chronically ill children in the 1980s requires a creative partnership of private and public resources. Although children of different socioeconomic classes may receive care from different sources, the special needs of children with chronic illnesses relate more to their chronic illness than to their financial status. Major advocacy for children with chronic illnesses has come both from public agencies, including state and Federal Maternal and Child Health agencies, and from many private groups, for example, the March of Dimes, United Cerebral Palsy Association, and the Cystic Fibrosis Foundation. Times of financial crisis suggest the need for pooling of limited resources. Joint efforts also reflect the different skills and abilities of these public and private resources that can complement each other in developing the best possible support for chronically handicapped children and their families.

The last assumption concerns the development and diffusion of new technology in the medical and surgical care of chronically handicapped children. The need for careful evaluation of new technology and its cost-benefit ratio is important. New programs have often developed merely as a result of the availability of new technology. Such programs may not always be in the best interest of the child, and the availability of new technology is not in and of itself an indication for the delivery of services or the development of new programs.

CURRENT STATUS AND ISSUES

Many programs are faced with the complex task of deciding how to set priorities among age groups of children, types of procedures, or categories of illnesses. Often priorities related to the classification of handicapping conditions reflect an historical attachment to certain diagnoses, rather than an analysis of cost-effectiveness or equity. More effective prioritization systems take into account cost or equity criteria. They recognize that limited resources must be carefully parceled out to spend wisely and for greatest effect. If it is felt that treatment and support services will improve the condition of children and their families, obviously they should be provided. The existence of a problem, however, does not justify the delivery of services, if there is little evidence that the services will provide effective remediation.

In line with the assumption that programs should reflect the needs of children and their families, effective programs stress prevention. Prevention in the area of chronic handicapping conditions has three main forms. Primary prevention is the prevention of the handicapping condition itself. Examples include the prevention of crippling disorders through the control of accidents and the prevention of premature births through improved prenatal care. Secondary prevention involves slowing the

progress of physiological consequences of the illness. The potential decrease of vascular disease in juvenile diabetes mellitus through better glucose control is an example of secondary prevention. Tertiary prevention is the prevention of associated problems of chronic illness. Examples are the problems of psychological adjustment more prevalent among chronically ill children, and the problems of family functioning and disruption, also more common among families with chronically ill children. The evaluation of programs for chronically handicapped children and their families presents special problems. Good measures of outcome and functional status are not widely available. Documenting metabolic and physiologic changes has always been easier than measuring changes in a child's participation in school, usual childhood activities, or daily home tasks. Recent progress in the development of broader family and functional status measures is encouraging. Effective programs improve functional status; functional measures should be keys to assessing programs and therapeutic impact.

Families with chronically handicapped children face special issues with respect to incentives in the provision of health care. Fee-for-service payment has been the general mode through which medical services have been provided. This mode has encouraged an entrepreneurial spirit, likely a causative factor for technological advances in the improvement of the lives of chronically ill children over the past quarter century. On the other hand, present reimbursement systems encourage an emphasis on high technology care to the relative exclusion of family support and child development services. The systems discourage the extra professional time needed by stressed families that assures meeting their varied and complex needs. A comprehensive view of the needs of families with chronically ill children requires balance between technological services and other family services. Prepayment may help in some circumstances, mainly by discouraging the use of inappropriate or unnecessary technology and by encouraging attention to important preventive activities. On the other hand, prepayment programs have a real incentive to discourage enrollment of chronically ill people because they may be frequent users of resources in the prepayment plan. Thus, if broadly implemented, prepayment plans need financial incentives to attract, enroll, and care for chronically ill children.

GENERAL GUIDELINES

An ecological approach should characterize services and programs for chronically handicapped children. Programs and interventions should be designed to take into account the child in his/her family environment. Legislation should reflect a comprehensive view of family needs. Programs should be organized to meet a basic minimum of family service needs. These needs should include access to quality primary and tertiary care,

access to schooling in the least restrictive environment, financial support, respite services, psychological support, and family counseling. Because of the tremendous diversity of illnesses, children, and families, individualized care plans should be developed. Individualized plans should include assessment of present functional status and periodic review to assess their impact on functional abilities of the child. This individual planning for each child and family begins with an initial status review, proceeds with the development of optimal (and measurable) status goals, continues with the determination of limitations and problems for implementing programs to achieve these goals, and culminates with timely receipt and monitoring of services.

Financial rewards for providing comprehensive, coordinated care should be developed. At the very least, financial support should exist for the very important role of coordination of care. From a functional-status view, coordination of care is generally more important than any specific service, yet it frequently is unreimbursed. This pivotal activity merits recognition and requires compensation. More creative approaches to developing incentives for providing comprehensive care should be developed.

IMPLEMENTATION

Basic research activities merit continued funding. First, as indicated above, functional-status research remains crucial. Development of reliable measures of functional status of children will be a tremendous step forward in the ability to assess programs and the progress of individuals. Second, the historical evidence of the success of basic research, coupled with the long-term commitments and the uncertainties of research efforts, confirms the continued funding of basic research as a high priority. Third, to reflect the complex and comprehensive nature of the problems affecting children with chronic handicapping conditions and their families, research should be multidisciplinary. Service and research resources should be allocated to take into account all of the existing modalities, including medical/surgical, psychosocial, educational, and financial. As an example, research into the physiology and therapeutics of many chronic illnesses has been of extremely high quality and has been very productive of important therapeutic advances. Similar standards of quality should apply to the study of psychosocial interventions and mechanisms, and support for the development of similarly high quality research in new areas is a high priority.

In implementation, the identification of political power bases supporting particular policy areas is important. In the past, the scientific community has been a central power base, encouraging the development and distribution of new technology for the care of chronically ill children and their families. To enhance this advocacy, complementary power bases must be developed towards a comprehensive and ecological approach to children with chronic conditions.

CONCLUSION

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PARTICIPANTS

The diverse characteristics of the conference participants shaped the final recommendations. Many specialists and professions were present; thus the recommendations were interdisciplinary. Participants represented numerous areas of private, academic, public health, and governmental endeavors; diversity led to recommendations applicable to many settings and yet flexible enough to be implemented according to programmatic needs. Because participants came from urban and rural settings from all regions of the country, they were aware that recommendations must be tailored to local needs. The creative conference process allowed the participants to utilize their extensive combined experience to learn from each other and to contribute to the final conference product.

COMMON THREADS

Many of the same areas of unmet needs, of deficiencies and strengths of agencies, of process difficulties, and of policy concerns were brought up repeatedly throughout the conference as facilitators and inhibitors to the role of the primary provider in the care of handicapped children. The topic groups, although having different missions and perspectives, arrived at many of the same guidelines and recommendations. These common threads underlie the issues and recommendations.

Certain values can be discerned as woven through the fabric of the workings and recommendations of the conference. Among these threads was an ecological approach, which considers the handicapped child as living within a community, evaluates the impact of each upon the other, and emphasizes the centrality of the family. Participants were also aware of the impact of the illness on the child and family. Because these children's needs extend beyond medical care, the guidelines include recommendations regarding psychosocial support services. Responses to the multiplicity of child and family needs often result in a multiplicity of funding mechanisms and delivery systems. Thus warned, systems serving chronically ill and handicapped children must emphasize simplification and commonality of effort and must seek to promote the autonomy of the child and his family.

The format of the five specific topic group chapters does not sufficiently underline the importance participants have given to the role of primary care provider. In addition to providing longitudinal care, the primary provider can facilitate access to services and help ensure comprehensiveness of care for the child with a developmental disability, chronic illness, or handicapping condition. The scope of the primary care provider's role cannot be underestimated. After illness detection, the primary care provider often guides the patient through the referral process. The primary care provider can help assure that a care plan meets the individual needs of the patient and can help shape local implementation. Finally, this provider's relationship with the family and knowledge of available services and technologic advances can avoid excessive or inappropriate utilization of medical services in the long-term care of the handicapped child and his family.

Participants were aware of the importance of research. Basic science and applied medical research will lead to dramatic improvements in the treatment of various diseases and result in finding the cause and cure of some. The participants stressed the need for studies of the efficacy of interventions, both medical and psychosocial, and the importance of studies evaluating outcome. Groups also urged consideration of the financial practicability of innovative programs before recommending wider implementation. There remains much to learn about the impact of chronic illness in general and of specific diseases on the child, his family, and his community.

IMPLEMENTATION

Fiscal pressures, recent change in governmental involvement at the state and Federal levels, and ensuing programmatic cutbacks are having a serious impact on the financial support for programs for handicapped and chronically ill children. Additionally, recent research has also changed the understanding of the impact of these conditions.

Assumptions, background, components of ideal models, and specific recommendations from the five preceding topic chapters are summarized in the format of GUIDELINES FOR IMPLEMENTATION. The Guidelines promote the role and function of three concentric levels of services for handicapped children: the family, the primary care provider, and governmental programs.

APPENDIX

GUIDELINES FOR IMPLEMENTATION

The Role of the Primary Care Provider in the Treatment of Handicapped Children

I. Guidelines to promote the role of the FAMILY in the care of
chronically ill and handicapped children:

- A. Governmental, university, foundation, and private programs
and professionals serving handicapped and chronically ill
children should:
 1. Promote family autonomy by encouraging family
participation in decision-making, such as:
 - assuring parent involvement in and approval of an
individualized care plan for their child
 2. Provide reimbursement to professionals for time spent
educating families regarding:
 - a. their child's specific illness
 - b. their child's functional abilities
 - c. utilization of the health care system
 - d. services available through community agencies
 3. Provide reimbursement to professionals for time spent
counseling families
 4. Make interventions that promote coping available to
families, such as:
 - a. Parent support groups
 - b. Counseling regarding psychosocial adjustment
problems
 - c. Behavioral interventions

5. Provide services and reimbursement for care provided in the home, including:
 - a. Home health nursing and physical and occupational therapy
 - b. Supplies and drugs for care given by family members
 - c. Technical equipment for specialized care given at home by family members and/or home health nurses and therapists
 6. Develop resources, and improve families' access to information and services in the community, such as:
 - a. A parent bank: names of those willing to share information and experience with other parents of a child having a similar health condition
 - b. Parent support groups
 - c. Community resources library: a directory of agencies and services
 - d. Chronic illness library: current literature about specific illnesses
 7. Include parents as members of advisory panels to agencies and programs
 8. Make available to each family one professional who is responsible as the Care Coordinator for having a holistic view of the child and family, serving as their advocate, and helping them gain access to needed resources
 9. Provide financial counseling to the family so they make use of all eligible funding sources
 10. Fund or provide continuing education programs for professionals regarding family issues such as the grief process, the impact of the illness, secondary adjustment issues, and coping strategies
- B. Families of handicapped and chronically ill children should:
1. Learn about their child's health problem and assert their needs for continued education about the illness

2. Take an active role in decision-making regarding their child's care; this role includes the development of an individualized plan of care
3. Assume a role as essential members of the health care team
4. Become involved, as family resources allow, in parent support groups, advocacy groups, and advisory panels to agencies and programs

II. Guidelines to promote the role of the PRIMARY CARE PROVIDER:

- A. Governmental agencies that serve chronically ill and handicapped children should:
 1. Assure that every chronically ill and handicapped child has a generalist primary care provider, by such mechanisms as:
 - a. Developing interagency agreements between state handicapped children's agencies and community health centers, health maintenance organizations, local public health departments, and other primary care agencies that delineate responsibility for primary care and specialty services
 - b. Maintaining close communication and structured referral patterns with private medical providers
 - c. Including primary care providers in the development of the child's individualized plan of care
 2. Promote continued involvement of primary care providers by having a structured communication process that assures feedback to the primary care provider and includes information such as:
 - a. The reason for referral
 - b. An agreement on the continuing responsibilities of the primary care provider and consultant, e.g., who will provide which services to the patient
 - c. A time frame and method (copy of notes, copy of care plan, telephone call) for reply to the primary care provider from the consultant

3. Provide reimbursement through state agencies or private insurance for activities that improve comprehensiveness and coordination of care, including:
 - a. Patient and family education
 - b. Counseling
 - c. Contacts with other providers and community agencies, including telephone contact
- B. Governmental, university, foundation, and private programs serving chronically ill and handicapped children should:
 1. Provide resources to primary care providers to help them keep their knowledge of current treatment and available services up to date, for example:
 - a. Chronic illness library that includes current literature regarding specific illnesses
 - b. Community resource library: a directory of agencies and services
 - c. Community-based continuing education programs
 2. Include primary care providers in policy-making bodies, such as advisory panels to agencies and programs
 3. Include primary care providers as providers of services within their programs, as:
 - a. Medical and nursing consultants
 - b. Medical and nursing staff
 4. Provide continuing education opportunities for primary care providers in the following areas:
 - a. Specific conditions and illnesses
 - b. Generic aspects of handicapping and chronic illnesses
 - c. Service delivery issues such as care coordination and interdisciplinary activities

5. Support research examining the role of the primary care provider in improving the health and functional status of handicapped and chronically ill children, including:

utilization of primary care providers in various delivery systems

- C. Primary care providers for handicapped and chronically ill children and their families should:

1. Follow a structured process that includes:
 - a. The reason for referral
 - b. An agreement on continuing roles of the primary provider and the consultant in the care of the child and his family
 - c. A time frame and method for reply by the consultant to the primary care provider
2. Be involved, when possible and appropriate, in the development of an individualized plan of care for his or her patients
3. Keep a copy of the individualized plan of care in order to be aware of the services the child is receiving, the integrated program, and the specific goals that have been agreed upon
4. Be aware of the family issues, commonalities, and values involved in the care of these children
5. Seek continuing education through programs as described in B. 4 above

III. Guidelines to enhance the function of GOVERNMENTAL AGENCIES serving handicapped and chronically ill children

- A. Governmental agencies should:

1. Help to assure continued financial viability of programs by the following:
 - a. Use all available sources of payment for services, including Medicaid and private insurance
 - b. Develop mechanisms of graduated family co-payment with higher maximum income eligibility, in order to spread the impact of programs

- c. Develop incentives for lower cost, high quality services such as:
 - 1. Prompt reimbursement
 - 2. Incentives for developing early discharge and home care plans
 - d. Provide financial counselors to assist families and agency professionals
 - e. Maintain visibility to public and legislative bodies
- 2. Promulgate clear policy guidelines for allocation of funds for services
 - 3. Regularly evaluate how funds are allocated, based upon:
 - a. Changing technologies in the care of specific diseases
 - b. Changing service priorities
 - 4. Establish the care coordination model including the following components:
 - a. Require that every child with a handicapping condition or chronic illness has an available Care Coordinator
 - b. Include in the job description of the Care Coordinator responsibility for:
 - 1. Communication and liaison with all providers of care and services, such as primary care providers, tertiary care providers, and community agencies
 - 2. Establishment and implementation of an individualized plan of care
 - 3. Monitoring of the individualized plan of care
 - 4. Interpretation of care plan and consultation to the child and family
 - c. Reimbursement for care coordination

- d. Assuring care coordination and compliance with the individualized plan of care by giving the Care Coordinator authority to control disbursement of funds
- 5. Establishment of an individualized plan of care for every handicapped child that includes:
 - a. Diagnosis
 - b. Present functional abilities
 - c. Specific, measurable goals including:
 - 1. Anticipated outcomes
 - 2. Time frame for evaluation of outcomes
 - d. Services to be provided to reach the goals, including:
 - 1. Agencies providing specific services
 - 2. Manner of child's participation
 - 3. Statement of cooperation between agencies
 - 4. Date of initiation, duration, and frequency of recommended services
 - e. Monitoring activities with statement of methods, criteria, and projected date
 - f. Consideration of:
 - 1. Primary and tertiary medical care
 - 2. Psychosocial support services
 - 3. Financial issues and counseling
 - 4. Future planning regarding long-term goals and capabilities of the child
 - g. Parental involvement and acceptance of the plan
- 6. Establishment of a data collection system that maintains information about:
 - a. Diagnoses of children served

- b. Services delivered
 - c. Cost of services paid for or delivered by agencies
 - d. Providers of services
7. Establish interagency agreements that designate:
- a. Responsibilities between funding agencies and providers for funded services
 - b. Responsibility for services provided and by whom among providers such as community health centers, local health departments, health maintenance organizations, tertiary medical centers, and other primary care agencies and providers
 - c. Source of funding for care coordination
 - d. Provider of care coordination
 - e. A structured referral process, including:
 - 1. Who is responsible for primary care?
 - 2. Who is responsible for consultation?
 - 3. What is the pathway of referral and consultation?
 - 4. What is the time limit and the method of communication to referring primary provider?
 - 5. Who shall pay for consultation?
 - 6. Who is responsible for longitudinal care?
 - 7. Who shall pay for longitudinal care?
 - f. Responsibilities regarding establishment, implementation, and monitoring of an individualized plan of care
8. Continue funding research, particularly:
- a. Basic science and applied medical research that may produce continuing improvements in treatments of various diseases

- b. Studies that examine the efficacy of interventions, both medical and psychosocial, and their impact on the course of the illness, the cost of care, patients' coping, and functional outcomes
 - c. Demonstration projects of innovative service programs
9. Identify and work with coalitions that support policies promoting comprehensive and ecological approaches to children with chronic conditions

THE ROLE OF THE PRIMARY CARE PROVIDER IN THE
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