

H. Goffman

CONFERENCE REPORT

EDUCATION OF PEDIATRICIANS FOR THE ONGOING CARE
OF CHILDREN WITH SPECIAL HEALTH NEEDS*

July 26-28, 1983

Arden House
Harriman, New York

Department of Pediatrics
Albert Einstein College of Medicine

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April 2, 1984

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Dear Dr. *Helen* Gofman:

Enclosed is a copy of the proceedings of our conference on "Education of the Pediatrician for the Ongoing Care of Children with Special Health Needs."

I hope it reflects our discussions adequately and that you will find it useful in your present and future efforts to improve pediatric education.

May I take this opportunity to thank you again for your participation in the conference and many contributions of it.

Sincerely,



Ruth E.K. Stein, M.D.
Director, Division of
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REKS/lr
encl.

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INTRODUCTION

The care of children with special ongoing health needs and of their families is a problem that calls for sustained national attention. Throughout the country, a variety of research and service programs have begun to address this concern and its attendant issues. Although those knowledgeable about child health have begun to chart the manner in which pediatricians can and must be involved in the provision of services to these children and their families, existing pediatric training programs appear inadequate to the task of preparing physicians to deal optimally with the challenges that such care poses.

With these concerns in mind, the Department of Pediatrics of the Albert Einstein College of Medicine organized a conference entitled "Education of Pediatricians for the Ongoing Care of Children with Special Health Needs." The conference, supported by the Division of Maternal and Child Health of the Bureau of Health Care Delivery and Assistance of DHHS, was held at the Arden House Conference Center in Harriman, New York, on July 26th to 28th, 1983. It brought together approximately 40 individuals, primarily pediatricians, who were in a position to make substantial contributions to changing the nature of pediatric training within the broad area of care for children with special health care needs.

The general purposes of the conference were straightforward: to provide a chance for these persons to generate and discuss ideas about improving pediatric education in this area and strategies for implementing such changes as appeared to be needed.

Specifically, the conference aimed to achieve the following objectives:

- (1) Recognize the need for the education of pediatricians to address ongoing care of children with special health care needs.
- (2) Identify the range of roles of pediatricians in the ongoing care of children with special health care needs.
- (3) Recognize the abilities and skills needed by pediatricians in order to assume these roles and provide ongoing care of children with special health care needs.
- (4) Recognize obstacles to the development of these skills in current pediatric education.
- (5) Recognize strengths of current pediatric education in preparing pediatricians to acquire these skills.
- (6) Identify changes that need to be made a) within the current system, b) outside current programs.
- (7) Encourage implementation of needed changes by stimulating educators and policymakers to strengthen pediatric education with respect to children with special health care needs.

Because this conference emphasized the generation and sharing of ideas among participants, it was structured quite differently from most conferences. Formal presentations were not planned (except for the opening and summary session). Instead, the plan was to bring together individuals whose own contributions would form the substance of the conference through an active process consisting of a series of discussions by small working groups with rotating memberships. At well defined points, the small groups (composed of six to eight persons) reported back to the full assembly of participants. At the beginning of the conference, the five small groups worked on exactly the same topic; at later stages, as the problem solving became more refined, they worked on different aspects of the same problem or question. Thus, the conference was participatory in nature. (For a complete description of the model for the conference see Brune, Williams, and Fitzsimmons, 1979.) It focused heavily on the informal generation of ideas in the crucible of a small group process. These ideas were then presented to and discussed by all the participants reassembled into a large group.

The opening session of the conference included a videotape of a group session of parents of chronically ill and handicapped children and of a similar group session held by a Home Care team at the Albert Einstein College of Medicine/Bronx Municipal Hospital Center. This videotape served as a collective point of departure for the rest of the conference. The nature of the tasks that the small groups subsequently considered are listed in the Table of Contents. The subsequent chapters of this report are organized around the sessions identified in this table.

Reference

Brune, J., Williams, J. and Fitzsimmons, E. Self-Responsibility for Health: Focus on the Child and Family. Conference Report, University of Texas Medical Branch at Galveston, Texas. July 19-31, 1979.

OUTLINE OF THE CONFERENCE

Opening Session

Introductory remarks: Ruth E.K. Stein, M.D.
Michael I. Cohen, M.D.
Vince L. Hutchins, M.D.

Videotape

Commentary: Dorothy Jones Jessop, Ph.D.

Small groups discussing the videotape and the overall purpose of the conference.

Small Group Session 1:

Major question: What should pediatricians be doing (e.g., what are the roles of pediatricians) in the care of children with special health care needs?

Group format: All groups discuss this same question.

Small Group Session 2:

Major question: What abilities and skills are needed in executing these roles?

Group format: Each group discusses one of the following roles:

- (1) Coordinating
- (2) Educating
- (3) Advocating
- (4) Providing continuity
- (5) Counseling

Small Group Session 3:

Major question: In what ways does current pediatric education foster and/or obstruct the development of individuals to carry out these roles?

Group format: Each group discusses one of the following roles:

- (1) Coordinating
- (2) Educating
- (3) Advocating
- (4) Providing continuity
- (5) Counseling

Small Group Session 4:

Major question: What needs to be done to enhance preparation of pediatricians and to what extent can it be done within the current system or in an ideal world?

Group format: Each group discusses one of the following themes:

- (1) Special body of knowledge

- (2) Interactions with patient and family
- (3) Communication: Team member vs. leader
- (4) Dealing with the changing boundaries of information/research/
knowledge units
- (5) Advocacy and involvement with community and politics

Small Group Session 5:

Major question: What changes are needed at each of the following levels
and how can they be made?

Group format: Each group discusses one of the following levels:

- (1) Residency
- (2) Fellowship
- (3) Faculty
- (4) Practitioner

Closing Session:

Comments by: Morris Green, M.D.
William B. Weil, Jr., M.D.
Merle McPherson, M.D.
Michael I. Cohen, M.D.

OPENING SESSION

In the opening session, Ruth Stein greeted the participants and spoke briefly about the context and content of the conference. She was followed by a welcome from Michael Cohen and a charge to the conference participants from Vince Hutchins. The opening session also included an edited videotape of mothers of children with chronic illness discussing their concerns, and of the members of the Pediatric Home Care Team who provide care to them. Dorothy Jessop introduced and commented on this videotape.

Opening Remarks by Ruth E.K. Stein, M.D.

I am delighted to welcome you to the Conference on Education of Pediatricians for the Ongoing Care of Children with Special Health Care Needs. The Conference is an outgrowth and culmination of a project we have been doing with the support of the Division of Maternal and Child Health for the past six years. This project known as the Pediatric Ambulatory Care Treatment Study (PACTS) is a prospective randomized trial of a Pediatric Home Care (PHC) program that provides service for children with a wide range of chronic illnesses. Both the PHC program and the evaluation project that MCH has sponsored have been unusual in that they focus on commonalities among ongoing childhood conditions and their effects on the child and family, rather than on specific diagnostic groupings.

This research has led us to two findings which are the conceptual underpinnings of this conference.

1) It has provided data to confirm the notion that children with ongoing special health care needs have a great many similarities regardless of their specific diagnoses, and that they can be viewed generically as a group and collectively offered services.

2) It has demonstrated that the forms of delivery of services to these children and their families can and do make a difference that can be measured in improved outcomes, and therefore it becomes increasingly urgent that we examine the ways we prepare physicians to accomplish the task of providing effective care.

These two points, the generic approach to special health care needs and the benefits of integrated comprehensive services form the context for this conference. The content of the meeting, except for this first hour, will be largely determined by you. It was our notion in organizing the conference that we would bring together individuals with expertise, interest, and a variety of points of view who collectively might grapple with the issues. What you bring in the way of your own experiences and personal resources will form the content of our discussions and reports back to the conference as a whole. We expect to have you interact with one another, to put your heads together, and problem-solve as a group.

Opening Remarks by Michael I. Cohen, M.D.

I am pleased that you could come and wish to extend a warm welcome from our faculty department. We are privileged to have had Vince Hutchins grant us this opportunity to act as hosts for this special conference.

The environs of Arden House are lovely and lend themselves to relaxation and good fellowship. The work of the conference, however, is very serious. Chronic illness, its impact on children, on their families, and on their immediate environment (schools, camps, peers, etc.) press hard against us. Chronic childhood disease is indeed a burgeoning problem. There are 10-20 million children in this classification. As technology advances, it will become an even bigger problem in the late 1980's and the 1990's. Thus, the education of the child's physician in this area is also critical.

I hope that you all come to participate actively and to contribute to this effort. This is meant to be a working conference and not passive learning.

Charge to the Workshop by Vince L. Hutchins, M.D.

On behalf of the Division of Maternal and Child Health, I welcome the participants to this Workshop and extend a special "thank you" to Ruth Stein, Dorothy Jessop, Michael Cohen, and Henry Ireys. It is appropriate that these individuals planned this Workshop on "Education of Pediatricians for the Ongoing Care of Children with Special Health Needs."

Ruth Stein and Dorothy Jessop have carried out pioneering research on care at home of the child with special needs, highlighting the commonalities across disease states. This research has made us more aware of the need for developing and enhancing the community resources to support families of these children. These research findings will assist us in emphasizing the subtleties of care at home.

Michael Cohen has provided national leadership in adolescent health for many years before assuming the Chair of Pediatrics at Einstein. Adolescent health care, as defined by Dr. Cohen and his peers, includes major collaborative work with other disciplines and agencies -- public, private and voluntary.

Henry Ireys has been a key figure in the Vanderbilt University Study on Public Policies Affecting Chronically Ill Children and their Families. Prior to this work, he completed a major review of Crippled Children's State Programs. From these two perspectives, he has a unique view of the organizational needs of children with special needs.

The House Select Committee reminds us that:

"...dramatic changes in the living situations of families and children are taking place, creating new pressures on families and new demands on our institutions. It seems likely that our children will be shaped by environments much different than our own."

The changes for children with handicaps and chronic illness are especially rapid. Our focus for this conference must be these changes and their implications for service delivery.

These children are no longer in institutions (Heart Hospitals, Rehabilitation Institutions, Institutions for the Retarded, etc.); rather they live in their own homes and attend regular schools (as a result of P.L. 94-142 and the 504 regulations). There are also changes in attitude evidenced through increased demand by these individuals for a productive, participating role in society. It has been said before but we are hearing it again: "I am a person -- even with a disability."

As a result of these changes, role changes are required of pediatricians that may be more important than knowing the latest scientific information about low prevalence conditions. These role changes require the pediatrician:

- to understand these children and families generically;
- to have the counseling skills to talk comfortably with parents and the child with a handicap or chronic illness;
- to learn to work collaboratively with other professionals in health, social service, education, the political and legal worlds; and
- to learn to work productively with other agencies.

Two or three decades ago, when there were fewer medical schools, the Division of Maternal and Child Health had training projects in most Pediatric Departments, supporting the training of pediatricians, or other physicians with a pediatric focus, e.g., radiology, surgical subspecialties, or at the interfaces between disciplines, e.g., child psychiatry and pediatrics. "Multidisciplinary," then, was a reference to a variety of medical disciplines.

Later in the late 1960s, and growing out of the Mental Retardation movement, funds became available for interdisciplinary training in University Affiliated Facilities (UAFs). Subsequently, two training programs were developed on this interdisciplinary model, the Pediatric Pulmonary Centers and the Adolescent Health Projects.

Interdisciplinary training in these contexts has the following characteristics: faculty are drawn from many health disciplines and function at a peer level, jointly planning curriculum development, expected outcomes of training programs, and evaluation of those outcomes; they function as a clinical team in order to provide exemplary care, usually at a tertiary care level, and also to serve as role models for trainees.

Trainees in these programs understand that attitudinal changes may be as important as gains in knowledge and skills. They learn to collaborate with other health professionals and to learn from them, and to work in an interdisciplinary team, participating as a member, leader, recorder, and case manager.

Now in the 1980's to meet the service needs, where should the emphasis be: At Pre-Service levels (i.e., student and residency level?) or in In-Service at the level of the faculty, practicing physicians, pediatricians or others?

A review of some recent statements is helpful in answering this question.

In (1979) the Task Force on Pediatric Education reported that seventy-three percent of surveyed pediatricians felt insufficiently trained for work involving community programs and programs for disabled children. Five broad areas of contemporary pediatric care are strikingly underemphasized in pediatric training:

1. developmental, behavioral, biosocial pediatrics
2. handicapping conditions and chronic illness
3. adolescent medicine
4. nutrition
5. interdisciplinary matters: effective skills in working with other agencies and professionals in various settings - schools, private practice, etc.

According to Guralnick and Richardson (1980) in Pediatric Education and the Needs of Exceptional Children, major content areas that appeared with great frequency included training issues related to long-term management, the nature of the interdisciplinary involvement, essential knowledge of child development, the varied and changing role of the pediatrician, and sensitivity to the complex problems of exceptional children and their families.

Recently the Report of the Select Panel (1981) stated that training programs must be enlarged in scope so that individuals not only acquire skill in coping with disease processes, but also gain a firm foundation in human growth and development, and understanding of the influences of genetic, familial, environmental, and social factors on the health status of children.

There is a word of caution from Forrest Bennett in "The Pediatrician and the Interdisciplinary Process" in Exceptional Children (January 1982). The pediatrician may not have a natural interest in interdisciplinary work, such an interest is not usually nurtured during medical school education, internships, residency experience, or fellowship training. In fact, quite the opposite.

The Report of the Surgeon General's Workshop on Children with Handicaps and their Families (1983) found that there is a need for the incorporation of clinical experiences relating to the care of disabled infants, children, and

young adults into all levels of preservice and inservice education for health professionals. Utilization of interdisciplinary methods in the training process encourages coordinated clinical care. Teaching models should enhance professional satisfaction in caring for disabled children. Methods to improve communication skills among patients, parents, and fellow workers must be inherent components of the training program.

Highlights of the Vanderbilt University Report on Public Policies Affecting Chronically Ill Children and their Families (Hobbs, N., Perrin, J. and Ireys, H., 1980) include the identification of basic principles which should underlie public policy: children with chronic illnesses and their families have special needs which merit special attention, beyond that provided to the health needs of able-bodied children. Families have the central role in caring for their own members, and the goal of policy should be to enable families to carry out these responsibilities to the fullest. Services should be distributed in an equitable and just fashion, especially excluding from the distribution formula such nonfunctional characteristics as race, sex, and socioeconomic class. Policy should ensure that a broad array of services is available to families with chronically ill children -- beyond the usual medical-surgical or health services. Policy should encourage professional services of a highly ethical nature. Key elements include truth telling, confidentiality, maintenance of dignity and respect for family preference, professionals' recognition of limits of their own effectiveness and emphasis on collaboration. Chronically ill children should stay on task in school to the greatest degree possible.

In case all of this sounds easy to accomplish, we find in the new text, Developmental-Behavioral Pediatrics (Levin, Carey, Crocker, Gross; 1983), a definition of "Pediatric Role" by Paul Dworkin. He notes that any description of pediatric roles must be specific enough to consider the unique features of problems of development and behavior and flexible enough to take into account their heterogeneity.

With all this advice on what to do, our agency -- and we think the field -- is looking for direction and advice on how to do it. This is your task during the Workshop.

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Videotape Introduction and Comments by Dorothy J. Jessop, Ph.D.

As a point from which to start our discussions and in an attempt to have the conference participants see the problems of giving care to chronically ill children from the perspectives of those most involved -- the parents who care for their children and the health providers who provide services on a day-to-day basis to the children and their families -- we have prepared a videotape. This videotape is based on a group meeting of parents at which they were invited to let "it all hang out" about their problems and about getting medical care, and a meeting of the Home Care team from Jacobi Hospital, Bronx Municipal Hospital Center, in which they were invited to describe what it is like to give care to chronically ill children. This team consists of generalist pediatricians, pediatric nurse practitioners, and a social worker who work closely with the appropriate subspecialists and service agencies.

(AFTER TAPE) Interviewers usually come away from an interview in which people have had a chance to explain themselves with new respect for the people involved. One certainly comes away from this tape with the feeling that these are quite a group of people. Both parents and staff come across as sensitive and caring. The parents, most of whom come from groups often devalued in our society, are articulate, knowledgeable, and resourceful. The staff are concerned about patients as persons, respectful of their capacities and those of their families, and are able to work in a collegial and interdisciplinary fashion as part of a team.

It is striking that both parents and staff are ambivalent. They are doing a hard job and doing it without all the supports they could use. And, for the staff especially, without preparation which would have been relevant and useful.

It is interesting that the parents, when asked how things could be better, could only report concrete things -- someone to provide respite care and give them a break, a patient-held record which would allow them to get care at any nearby facility or emergency room with the assurance that the doctors would know all the necessary facts about their child's current medical problems and care. However, the parents could not conceptualize how the medical care system could be different. Even the staff cannot conceptualize this -- they are too close, too involved in the nitty-gritty, and are trying not to be overwhelmed. That is perhaps the reason for a group such as this to come together for two days to a place removed from other pressures.

We come to consider:

- a) ways of educating pediatricians to care for children with special needs;
- b) educational programs which will develop in individuals the kinds of skills needed, which will support them in learning these skills and facilitate some of the very human qualities seen on the tape; and

- c) educational programs which will train providers to provide care and thus enable parents to care for their children with special health care needs.

Small Group Session 1

ROLES OF THE PEDIATRICIANS IN
THE CARE OF CHILDREN WITH SPECIAL NEEDS

Following the presentation of the videotape, the participants broke into their first small group session. In addition to responding to the videotape, the participants in each of the five groups focused on the same central question: What should be the roles of pediatricians in the care of children with special needs?

The initial task of each group was simply to "brainstorm." Out of this process came a shower of ideas, a flood of proposed roles. A summary listing is included in Table 1.

Each of the working groups of 6-8 people was also asked to choose from all the potential roles identified by their group, the five roles that the members considered to be most important. Each group's choices differed.

Group A agreed that the following five roles of the pediatrician were most crucial: (1) Providing comprehensive health care, including well child care and care for specific health needs with continuity of health care a priority; the physician, it was felt, should know his/her limits in this regard and be able to delegate care appropriately; (2) being a leader in identifying and providing for the specific needs of the child; (3) knowing available resources; (4) advocating for a broad range of services for chronically ill children and their families; and (5) being a teacher and researcher.

Group B developed the following major roles: (1) Coordinating care, i.e., being a "case manager" for the child over both the short and long term; (2) being a counselor to the patient and family; (3) teaching and research; (4) knowing the political system and "political action," and (5) serving as consultant to the community.

Group C listed five major roles in this way: (1) providing ongoing care not necessarily involving the pediatrician alone; (2) coordinating care, including knowledge of community resources, working with subspecialists, etc.; (3) assessing child development and utilizing developmental knowledge in the management of the patient, which encompasses a) early identification of the problem, b) family assessment, and c) a neuropsychological/behavioral assessment; (4) assessing the family's development and adaptation regarding the child and his/her special needs; and (5) being a teacher/advocate to a) the patient and family, b) the community (particularly in helping to promote early identification of at risk children), c) colleagues, and d) oneself through CME.

The five roles of the pediatrician stressed by Group D were (1) being a source of authoritative and competent care; (2) understanding that the child and family are a unit; (3) assuring the coordination of care; (4)

interpreting health care issues to the patient and family; and (5) advocating in the community for the child with special needs.

Group E listed five major roles as follows: (1) providing treatment for medical and psychosocial issues; (2) assessing needs of the child with chronic illness; (3) coordinating all aspects of the patient's care; (4) advocating for the patient and family; and (5) teaching and doing research.

During the report back to the full assembly by Groups A-E, five roles most frequently mentioned by the groups were identified. These five main roles were:

- 1) Coordinator -- A "case manager" in both long and short terms, assuring that all areas of care for children with special needs are covered (including medical, psychosocial, and community issues).
- 2) Educator -- Pediatricians should not only educate patient and family regarding the child's disease and particular needs, but also serve as educator to the community regarding these issues, and as a role model to colleagues and pediatricians in training.
- 3) Advocate -- The pediatrician should serve as an advocate for the child with special needs and his/her family, assuring that medical, psychosocial, behavioral, educational needs are being addressed.
- 4) Provider of Continuity of Care -- The pediatricians should provide continuity within the myriad of health related services and institutions that the family of a child with special needs will find themselves. The generalist pediatrician will be seen as the orchestrator while subspecialists, nurses, psychosocial behavioralists, schools, community, and government groups all play an instrument.
- 5) Counselor -- The pediatrician should be adequately trained in counseling patients and families not only as to their needs, but in adequate listening, in order to discover their needs.

There were unresolved issues in determining the role of the pediatrician in the care of the child with special needs. First, it was the opinion of some group members that to be adequately prepared for all of the above roles was unrealistic. They argued that the general pediatrician with an office practice could not properly afford the time for such extensive responsibility. Therefore, many believe that the major roles, while comprehensive, are realistic only if the physician works with other professionals (nurses, social workers, psychologists, occupational therapists, etc.).

Second, there was questioning of whether the pediatrician should be simply a member of a diagnostic/therapeutic team or need be the leader of it. The groups as a whole supported coordination as a major role of the pediatrician but did not resolve this issue specifically. In addition, for

the pediatrician, these major roles were seen as time consuming. Priorities of residency programs are also not necessarily geared to the types of care the child with special needs must have.

Once the multiple roles of the pediatrician in the care of children with special needs were discussed and debated, the five major themes noted above took shape. It was then the task of each of five newly constituted groups to address the skills and abilities needed by pediatricians to perform these major roles.

TABLE 1

LIST OF PROPOSED ROLES OF THE PEDIATRICIAN

- 1) Providing authoritative, competent care of the patient;
- 2) assessing function for children with special needs;
- 3) serving as a case manager;
- 4) educating the patient and parent regarding realistic expectations;
- 5) assuming supplementary and/or primary responsibility for care of children with chronic illness;
- 6) serving as advocate for the patient with other team members, i.e. nurses, social workers;
- 7) coordinating care, involving a knowledge of community resources, subspecialists, and an interdisciplinary approach;
- 8) knowing how and when to use other resources;
- 9) assessing child development and utilizing knowledge in management including a) early identification of the problem; b) family assesement especially the parent's psychological functioning; c) evaluation of the patient's behavioral status, gross motor functioning, and temperament;
- 10) assessing family development and adaptation regarding: a) response to medical care environment; b) response of family members to each other (e.g., is family falling apart when one member is under stress); c) response of family members to illness (e.g., understanding the grief reaction to chronic illness repeat with each phase of development); d) counseling (M.D. to provide by him/herself or refer);
- 11) advocating and teaching advocacy a) for patient and family so that the patient can be a more effective participant in health management taking more responsibility regarding own health care; b) in community to promote early identification of at risk children and service to them; c) among colleagues; d) for self-education (CME);
- 12) developing an understanding of an expanded role and an acceptance of it;
- 13) providing continuity and assuring comprehensive medical and psychological care;
- 14) being a leader in identifying and providing for the child's and family's needs (both normal and special needs);

TABLE 1 (Cont'd)

- 15) educating the child, family, community, medical student, residents;
- 16) becoming involved in political action on behalf of children with special needs;
- 17) acting as liaison between parents and subspecialists;
- 18) taking responsibility for research in health care delivery.

Small Group Session 2

SKILLS NEEDED FOR EXECUTING IDENTIFIED ROLES

Having identified five major roles appropriate to the pediatrician who cares for children with special needs, the conference continued by charging each of five groups to delineate the abilities and skills needed to execute one of these roles. The sections below summarize the deliberations of each of these groups.

I. Coordination of Care

As the primary provider for a child with a chronic illness, the pediatrician must recognize that coordination of services is a crucial and an appropriate function for the physician to perform in order to meet the multiple needs of the child and family. To serve effectively as a coordinator, the pediatrician, must recognize and accept this role, and must understand the need for flexibility: there must be respect for the contributions that the family, other professionals (medical and nonmedical), and the child him/herself each make in meeting the child's needs. Flexibility is also paramount in appreciating that it may not always be appropriate for the pediatrician to function as the leader in coordinating a child's care. There may be times when the focus of a child's care will shift from medical needs to other concerns (educational, psychosocial, vocational, etc.), and thus make the pediatrician's role less central.

The role of coordinator demands specific skills on the part of the pediatrician:

- 1) An understanding of the child's illness or handicap, and of the range of life history it implies, as well as the awareness of whether the child's growth, behavior, and development are appropriate for the child's age and illness.
- 2) An ability to tolerate the uncertainty and ambiguity involved with chronic illness, as well as a sensitivity to the problems that this uncertainty creates for the child and family.
- 3) An ability to remain in touch with the child's and family's needs, to respond to them, and to support hope.
- 4) An ability to prioritize needs, define and obtain appropriate services, evaluate services provided for the child, and maintain an overview of the child's status and progress.
- 5) An understanding of the range of resources (medical and nonmedical) available to the child and family, and an ability to negotiate effectively among them to assure their provision.

- 6) An ability to communicate effectively, to speak, hear, and understand the languages of other service providers, of the family, and of the child.
- 7) An ability to be self-aware, and cognizant of one's own limits.

II. Educator

To assure that children with special needs receive appropriate care it is crucial for pediatricians to function as educators on several levels:

- 1) Self-education -- the pediatrician must have an adequate understanding of the biomedical processes involved in disease(s), from the points of view of both pathophysiology and development, as well as an adequate level of the interpersonal and technical skills needed to deal effectively both with people and with diseases.
- 2) Patient-education -- the pediatrician caring for a child with a chronic illness must be able to help that child learn about his or her potentials and limitations, and to do so must command an appreciation of child development as well as an awareness of the impact of illness on the developing child.
- 3) Family-education -- the child grows within the context of the family, and all family members, parents and siblings as well as the child with chronic illness, need the pediatrician's help in understanding the illness and its implications. To meet this need, the pediatrician must understand family dynamics and the cultural context within which the illness is experienced.
- 4) Collegial-education -- the pediatrician is uniquely placed, as the primary medical provider for children with chronic illness, to educate other physicians and allied health professionals about the special needs of these children and their families. In turn the pediatrician learns from all of these people as well.
- 5) Resident and Student-education -- the pediatrician has a responsibility to assure that physicians-in-training acquire the skills needed to provide care for children with chronic illness.
- 6) Community-education -- as an expert professional, the pediatrician is well suited to participate with other professionals in providing the public with information about the special needs of children with chronic illness.
- 7) Research -- fundamental to the concept of education at all levels is the discovery of new knowledge. This includes research about these children, their illnesses, their families, and how best to provide care for them.

III. Advocate

Children with chronic illness have special needs, and for these needs to be met the community must recognize them and be motivated to appropriate action. To assure optimal care for these children the pediatrician must function within the community as an advocate by developing:

- 1) Knowledge of current public policy, with an understanding of policy formation (the who and how), and of what in its turn public policy determines (availability of services, public opinion, etc).
- 2) Ability to judge what can and should be done to influence public policy at all levels: local, state, and federal.
- 3) Ability to work cooperatively with other advocacy groups.
- 4) Ability to read social issues critically and to speak about them effectively.
- 5) Awareness of the risks of becoming involved in public advocacy.

IV. Provider of Continuity Care

All children benefit from continuity of care, but in the case of a child with special needs this benefit is intensified. To assure that children with chronic illness receive the best care possible the pediatrician must:

- 1) Learn to follow children longitudinally.
- 2) Be exposed during training to a wide cross section of patients -- seeing patients with a given disease at different stages and ages, and patients with a variety of different diseases and conditions.
- 3) Learn patience and perspective, understand that these problems, both medical and social, are not solved in the short term but that both the child and illness develop over time.
- 4) Appreciate the interaction between normal developmental processes and chronic illness.
- 5) Understand that health care must be provided within the context of other human needs.
- 6) Learn to participate on a team, knowing how, when and which other specialists (medical and nonmedical) can provide services to the child and family.
- 7) Become expert in the management of clinical disease entities, and develop resources for continuing education.

V. Counselor

Because children with special needs are likely to receive services from a variety of sources, the pediatrician who is coordinating the child's care and providing continuity of care is in a unique position to serve as a counselor to the child and family as the child's needs change. To satisfy this role, the pediatrician must:

- 1) Accept the role of counselor and be willing to acquire appropriate information before offering advice.
- 2) Develop the ability to listen -- to the child, the parents, to other professionals -- and to identify nonverbal cues and hidden complaints.
- 3) Develop techniques that make counseling effective, such as the ability to be nonjudgmental, to remain flexible, to develop a relationship based on trust, to communicate with people at different levels of sophistication
- 4) Develop a base of knowledge about psychosocial processes and the common vulnerabilities of families with a child with an ongoing health problem.
- 5) Accept the slow pace and tolerate the slow and uneven progress intrinsic to much long term care.

Small Group Session 3

HOW CURRENT ARRANGEMENTS FOSTER AND
OBSTRUCT THE DEVELOPMENT OF NEEDED SKILLS

The groups formed for Session 3 remained the same as those for Session 2. Having delineated the abilities and skills needed to perform the role of the pediatrician in caring for children with special needs, these groups next examined the ways in which current pediatric education fosters and/or obstructs the development of individuals to carry out these roles.

The groups as a whole identified many of the same problems, regardless of the particular aspect on which a single group was working. Seven obstacles were identified as pervasive impediments to the development of needed skills:

1. The relative paucity of role models/leaders with interest in this area.
2. The lack of a formal body of knowledge of the skills needed and a curriculum to teach them.
3. The lack of money both for research and for primary care in general pediatrics.
4. An emphasis in medical training on acute care programs and inpatient services as opposed to chronic care and ambulatory services; an emphasis on a biomedical training model as opposed to a psychological and social model.
5. The lack of evidence that programs caring for children with special health care needs can be effective.
6. The lack of support and recognition for work in this area especially from department chairmen.
7. A failure to identify and recognize those physicians currently performing these roles and a failure of these physicians to articulate their ideas and experiences.

There are, however, factors within pediatric education that foster the acquisition of the special skills needed. The groups all identified three factors:

1. Some models already exist (programs, faculty members) and should be publicized.
2. There is an increasing awareness by subspecialists and generalists of the broad impact of chronic illness on the child and family and the need for a special approach to their management.

3. The recently increased requirement by the Board of Pediatrics of three years of general training rather than two.

In addition to the aforementioned factors, other specific factors exist that may foster or obstruct acquisition of skills needed for each specific role. The five groups detailed these factors in their respective areas.

I. Coordination of Care

To this group fell the task of identifying the factors that obstruct the acquisition of skills needed to coordinate care effectively. Six items were emphasized.

1. Emphasis on individual clinical decision-making in training programs.
2. Lack of role models and a lack of formal training in these areas.
3. Inability to communicate well with others (with subspecialists and other professionals) and/or a disinterest in learning how to communicate more effectively.
4. Unwillingness to accept the role as coordinator or to accept its importance.
5. Poor understanding of the roles of other professionals and how to utilize their skills effectively.
6. Impracticality of the team model for those in private practice.

Factors fostering the acquisition of the skills, according to this group, include:

1. Exposure to teams that currently exist in some training programs,
2. The increasing awareness of the multiple problems and needs of these children and of the need for a team approach.
3. Frustration and dissatisfaction over handling all the myriad problems individually.

II. Educating

The importance of educating professionals and parents about chronic illness in childhood was affirmed strongly by this group. Factors seen as obstructing the development of relevant skills include:

1. House staff are often drawn into the acute management issues during subspecialty experiences.
 2. Lack of curriculum/funding/research for targeted programs.
-

3. Lack of time within existing curricula.
4. Lack of education directly relevant to these skills.
5. Follow-up with subspecialists is an ambulatory experience, while house staff time is still based primarily on inpatient service.

Factors fostering these skills include:

1. Extensive exposure to chronic disease which could be utilized to improve the nature of the pediatricians education about children with such conditions.
2. Three years in general pediatric residency.

III. Advocacy

Advocating for more attention to these children is not an easy task. Factors that obstruct learning skills in advocacy include:

1. Lack of a formal course or introduction to political and social science issues.
2. Lack of interest in sociopolitical issues and a lack of expectation that these issues are appropriate or important for pediatricians.
3. Emphasis on the physician as technician, rather than as a consultant to policy makers.
4. Lack of knowledge of political process.
5. Disillusionment regarding political process and ability to make changes in existing system.

Factors fostering learning skills as an advocate include:

1. Organized bodies of pediatricians do have some public policy activity.
2. Professional organizations produce publications that review current public policy issues.
3. Some formal teaching occurs on sociopolitical issues.
4. House staff are exposed to political issues in other areas simply by virtue of treating patients with conditions with major social concomitants (e.g. lead poisoning, child abuse, malnutrition) and this could be made more conscious.

IV. Providing Continuity of Care

Factors obstructing the development of skills in providing continuity of care include:

1. Subspecialists are sometimes unwilling to relinquish or share care.
2. Achieving continuity with house staff is difficult. As training programs currently exist, continuous contact with chronically ill children is rare in many training programs.

The following factors that foster skills in this area were identified:

1. The basic concept and acceptance of continuity exists.
2. Some medical school curricula exist that have special teaching programs for medical students to be one-on-one with handicapped children (i.e. some models exist).

V. Counseling

How can pediatricians learn needed skills in counseling? Several obstacles need to be overcome, including:

1. Poor role definition as to who should counsel.
2. Negative physician attitude towards counseling.
3. Lack of training in communication skills.
4. Absence of published data on the effectiveness or outcome on patient care of counseling efforts.
5. Lack of positive feedback for providing counseling service or recognition for having an interest and making an attempt in this area.
6. Lack of time (within house staff curriculum) to learn the necessary skills.
7. House staff "burnout" with "difficult" families, who must need counseling.

Factors fostering the learning of counseling skills include:

1. Existence of physician role models with interest in this area.
2. Increasing presence of pediatric psychologists and behavioral pediatricians committed to training in appropriate interviewing and counseling skills.

Small Group Session 4

ENHANCING THE PREPARATION OF PEDIATRICIANS
FOR THE CARE OF CHILDREN WITH SPECIAL HEALTH NEEDS

In the previous session, the small groups focused on different aspects of current training structures and the ways in which they foster or obstruct the acquisition of skills needed by pediatricians who care for children with special health needs. In Session 4, the small groups focused on what now must be changed. Each of the five groups was organized on the basis of the conclusions from Session 3, and concerned itself with the following general question: what needs to be done to enhance preparation of pediatricians and to what extent can it be done in an ideal setting or in the actual world? The responses to this question are discussed within the context of each group, thus yielding solutions specific to the different topics assigned to each group.

I. A Specific Body of Knowledge

This group considered issues regarding the emergence of a special body of knowledge that should be mastered by pediatricians who care for children with special health needs. Much discussion in the group centered on the definition of this knowledge, and whether in fact there is such a body of information. There was a sense, not universally shared, that the research evidence did indicate that children with diverse chronic illnesses and their families share common burdens, face many similar problems, and have many of the same service needs. Yet, it is also true that different disease categories do have differing consequences, to some extent, for the child and family.

One approach that was suggested as a means of communicating the body of knowledge relevant to the care of these children involved teaching at different sites. Possible sites mentioned included:

- 1) A home care team, where care is delivered outside of the tertiary care centers;
- 2) Primary care clinics;
- 3) Health maintenance organizations;
- 4) Continuity clinics with special emphasis on chronic illness;
- 5) Private practice sites;
- 6) Chronic disease services or centers;
- 7) Child development units.

In addition to training at these sites, pediatric interns and residents should have experience:

1. living in special camps, schools,
2. working with families who actually care for a chronically ill child,
3. working in public programs or agencies that serve these children.

The group also considered the valuable function of role models, and the importance of exposing the pediatrician-in-training to various approaches in delivering care to chronically ill or handicapped children and their families. Such models would include:

1. the general pediatrician within a subspecialty clinic of tertiary care institution,
2. special chronic illness program, e.g. home care,
3. continuity clinic,
4. private practice.

Part of the discussion regarding private practitioners as role models brought a recognition of community resources, including disease-oriented voluntary associations, parent groups, and school programs.

The group also devoted its attention to research and stressed the importance of encouraging research projects and, possibly, nurturing specialized faculty in this area through:

1. fellowships in chronic illness,
2. consortia of investigators, or
3. the formation of a new professional organization.

Such developments may help to counter the negative characteristics often associated in medical training with this field.

In any event, educational objectives should be developed and evaluation methods designed.

And finally it was noted that part of any body of knowledge requires an understanding of other health care providers, and of oneself.

In summary, Group 1 considered advancing a special body of knowledge; and it was discovered that defining such a body of knowledge precisely is in itself difficult. It was suggested that a core curriculum be established with defined educational objectives, and that a specialized faculty be formed for teaching and research in this area. The possibility of establishing a post-doctoral fellowship in the area of "chronic disease" was discussed. The development of non-institutional experiences (i.e., camps, schools, HMO's, private practices, specialty clinics) for house officers was considered important, as was the teaching of counseling, interviewing and communication skills.

II. Interactions between Physician, Child, and Family

This group considered the nature and importance of interactions between the physician, the child, and the family. One major factor that it stressed involved the establishment of a relationship over time so that communication around acute crises as well as counselling over longer periods could both be accomplished. The influence of money and time was seen as a severe obstacle to conducting this process during the pediatric training period (on both housestaff and faculty).

The group emphasized several basic skills for understanding the physician-patient-family interaction and stressed the importance of attending to them in a sustained, if not constant, manner. The basic skills are

1. an articulated ethical framework,
2. an appreciation of ethical and cultural differences,
3. fundamental respect for the dignity of the patient,
4. an awareness of the need for humanizing experiences -- too rarely fostered in the demanding and dehumanizing process of medical school.

Such experiences could include participating in the life of the child outside of the health care setting, in parent support groups, or family discussions.

In addition to these basic skills, the group recognized that fostering attention to interactional aspects of care can be helped substantially by:

1. a chairman who is committed to this area,
2. experiences that permit continuity of care,
3. faculty role models,
4. close and sensitive supervision (in which "caring" is felt by the house staff),
5. and certain personality characteristics of the trainee, characteristics that may be hard to predict or define.

Ultimately, many aspects of hands-on care and theoretical information must be integrated and sustained over time.

To sum up, Group 2 dealt with interactions between physicians, parent and family. A curriculum focusing on family dynamics, response of the child to chronic illness, and development of "listening skills" was suggested. Involvement of pediatric trainees with other health care professionals, and outside agencies might supplement didactic teaching in this area. The fact that the medical environment is a dehumanizing one was seen as a specific obstacle. Formal support systems, open communication, and an emphasis on continuity of care was suggested as a particular solution.

III. Enhancing Communication (Team Member vs. Leader)

Initially, Group 3 concerned itself with communication within a team model. It began by defining the possible roles that a pediatrician might play within a team approach. These roles include:

- Modeling of comprehensive focus by pediatricians within a team setting.
- Involvement of trainee in actual team setting to develop understanding of roles played by a variety of care providers.
- Teaching about the interdisciplinary team to students, house staff, pediatricians.
- Awareness of the available body of knowledge about team functioning, and contribution of increasing that knowledge.
- Joint training with individuals of other disciplines.

The group also discussed aspects of communication with other medical/surgical specialties and noted that the following tasks are especially important:

- Delineate expectations for each party and the institution.
- Teaching other specialists to listen and share (implicit is the concept of the generalist as a practitioner with special knowledge, skills and abilities that make him/her a peer, not an underling).
- Learning how to use a consultant -- how to ask a question and how to understand the answers consultants give (implicit is the notion that the specialist is a consultant, not "the final word").

Having delineated these points, the group began to consider whether or not the "team model" is in fact entirely appropriate. Concern was expressed that the "team" may be an outmoded structure that in practice has failed to deliver what once it was thought to promise. Furthermore, the "team" was felt to be a model inapplicable to the great majority of pediatricians in private practice.

The discussion of "communication" turned toward the responsibility of training programs to maintain relevant and responsive contact with its graduates. The sense developed through the course of the discussion that residency training's most important goals are to teach pediatricians how to learn and how to approach a problem reasonably -- that the vast body of pediatric knowledge cannot be taught, or learned, during residency, that learning must be a life-long endeavor, that a training program must extensively involve itself as a resource in the ongoing learning of its graduates. This involvement must be at several levels:

- a) Individual -- the availability of the academician as a consultant to the practitioner in the community, and thus the need for the academician to learn how appropriately to communicate with the pediatrician practicing in a community (telephone, letter, personal communications).

- b) Formal instruction -- seminars, workshops, etc. designed to be relevant to the needs of the practitioner within the constraints of limited time available for such sessions (need for the academician to hear them correctly and respond appropriately).
- c) Informal lines of communication to be maintained between the "center" and the "community," each contributing to an ongoing evaluation of the other's effectiveness in meeting its responsibilities.

Overall, the group emphasized the importance of a pediatrician's development of a stable and confident professional self-image. Only with this sense could a pediatrician be able to respond flexibly -- as a leader, consultant, consultee, conductor, player, or observer -- depending on the needs of the patient.

Thus, enhancing communication (multidisciplinary, multisource, multisite) was the charge of Group 3. Implicit in this discussion was the role of the pediatrician as a team member. Enhancement of the self image of the generalist and his contribution to team functioning was discussed, as was the importance of exposure of the trainee to the team setting, and his or her learning to use the network of medical/surgical subspecialists, paraprofessionals, etc. was stressed. Ongoing communication between institution and community practitioners was also considered necessary.

IV. The Changing Boundaries of Information

Information relevant to children with chronic illnesses is expanding rapidly in many directions. Group 4 addressed this issue and examined how pediatricians can become and remain informed about an area with ever-broadening boundaries. The group recognized that the pediatrician's vision must be broadened to include new knowledge not only in the technological area but in other areas as well. In essence the pediatrician must become aware of developments in "social technology" that have relevance to his or her skills as a pediatrician -- developments such as a generic approach to understanding chronic childhood illness, the creation of individual service plans, and so on.

Group members proposed several vehicles for accomplishing this goal. They included:

- Creative use of CME courses which allow experiences with nontraditional settings (camps, day care, schools, etc.). In such interface settings new knowledge may emerge and much systematic training is potentially available. Continuing and frequent case conferences should be available.
- The development of academic faculty and other appropriate role models to encourage research and to lend stronger professional "legitimacy" to this area. Out of this cadre of individuals with a career commitment to this area could come more chronic illness clinics and opportunities for training, research, and publication.

- The development of "protected time" during residency training, in which house staff would have the opportunity to become engaged with chronically ill children and their families, and thus to understand the consequences of such an illness. During this time, curiosity about researchable problems could be nurtured and teamwork skills fostered.
- The designation, formal or informal, of this area as a "subspecialty" area for general pediatricians, though not in exactly the same manner as a medical subspecialty.
- The continued co-mingling of generalist and specialist, including social workers, educational or clinical psychologists, and other allied health professionals, around issues of curriculum development, service programs, faculty development, and needs for new knowledge and skills.

The group also reached consensus on a number of needs, including:

- Need for research-motivated faculty with interest in primary care.
- Need for case management and case planning and formal teaching of (a) organizational/managerial skills, (b) teamwork.
- Need to teach "process" to residents (e.g., problem-solving, team approach with subspecialists, multispecialists, paraprofessionals) and to provide experiences with children with chronic illness in many settings.
- Need for a well defined curriculum, including new information regarding individual behavior and family dynamics:
 - (1) specifically create awareness of these problems and how to deal with them, i.e. how to evaluate research findings, gain tools related to assessing changing boundaries;
 - (2) learning how to validate information;
 - (3) creating an atmosphere that fosters curiosity;
 - (4) admitting to uncertainties, giving license for people to admit lack of knowledge.

In summary, Group 4 dealt with the changing boundaries of information and research. A need for continuing research in the area of chronic illness was recognized. The development of an academic faculty and subspecialty training in this area was suggested in order to develop expectations similar to those of "hard core" scientists. A systematic approach is needed to teach residents, exposing them to the changing nature of chronic illness. It was suggested that the house officer be assured "protected time" to have a

continuity experience, and to stress acquisition of skills in case management and teamwork. The role of continuing medical education and involvement of community practitioners was also considered.

V. Involvement with Advocacy and Public Policies

Group 5 addressed itself to the question: What needs to be done to enhance preparation of pediatricians to enable them to become effectively involved with community resources, advocacy efforts, and public policy development? The group pointed out that medical students, interns, and residents now receive no exposure in this area. Several issues were identified and proposals made to enhance knowledge around each of them. These included:

- becoming familiar with maternal and child health programs; learning about the state's MCH program, for example, would give house staff a better sense of the "big picture;"
- becoming involved in some political activity, possibly with AAP or with some advocacy organization such as the Children's Defense Fund;
- becoming familiar with policies of schools, day care programs, and disease-oriented voluntary associations.

The group suggested a series of strategies for implementing these educational goals. These included:

- Finding a good role model and exposing students consistently to him or her.
- identifying a faculty member and providing funds for her or him to be responsible for this area;
- involving house staff in home visits, school visits, etc.

To sum up, Group 5 dealt with involvement of the pediatrician with the community, with advocacy efforts, and with public policy. The need to formalize a body of knowledge addressing these issues and its incorporation into pediatric training was discussed. Awareness of the organizations that exist on the national and local level with participation in group activities should be part of pediatric training. Dynamic, credible role models including faculty and private practitioners involved in public policy issues, and examples of their successes in influencing policy decisions should be stressed. This knowledge could be incorporated in longitudinal and cross-sectional follow-up of a small panel of chronically ill patients.

Unresolved Issues

The primary unresolved issue that emerged from this meeting concerned the definition of a body of knowledge relating to children with special health care needs. There was much discussion on the extent and nature of this body of knowledge -- a discussion that did not reach a universally endorsed conclusion. In a desire to begin to define this knowledge, however, several members of the group met in order to list areas that might fall within such a definition. This list, intended to be simply a starting point, is included in Appendix A. Although many of these topics are relevant to other areas of pediatrics, they were all felt to have special importance to the care of children with ongoing illness.

Small Group Session 5

WHAT CHANGES NEED TO BE MADE

Session 5 of the Conference addressed changes that need to be made within the current medical system that would improve training in pediatric health care of children with special health care needs. In addition the group was asked to enumerate needed changes outside the scope of medical programs as they now exist.

It was clear that this would be a multifaceted project, and that the most efficient approach would be to consider each level of medical training separately and identify changes particular to each group. The levels identified were 1) residency, 2) fellowship, 3) faculty, and 4) practicing pediatricians. The participants then split into four groups, each to consider one level of training and propose appropriate changes at their particular level.

I. The Residency Training Level

The group considering this level of training first outlined "starting points" in this undertaking. The following key elements were emphasized:

- The group felt it mandatory that departmental chairmen be involved, and that the faculty and chairmen jointly identify that body of knowledge particularly important to the care of chronically ill children which should be transmitted to house staff.
- Chronically ill children in a given health care system also need to be identified, so that any special care or services can be targeted to them.
- Sites with strengths or especially strong needs in this area should also be identified. Teaching and services can then be tailored as needed at each institution, and good teaching sites maximally utilized for residency training.

All participants felt it crucial that both the "ideal and real" be considered in these discussions, and that every effort be made to devote initial efforts to those goals that could reasonably be attained. It was felt that placing too much emphasis on unreasonable expectations could sabotage early efforts to bring attention to and effect change in this area.

The last important starting point was the need to provide for evaluation of changes made, i.e. attempt to quantify the outcome of efforts. Two aspects of this were mentioned:

1. the need to measure changes in attitude on the part of physicians in training and practice and
2. the need to measure changes in practice patterns that come as a result of new efforts.

Regarding substantive changes in residency training, the group felt the first mandate must be a declaration of commitment on the part of the faculty to continuity of care for the chronically ill. From this certain changes in the program would naturally flow. For example, arrangements would be made so that residents could follow a number of chronically ill children over a prolonged period, optimally through their entire residency. In addition, certain generalists and subspecialists would be identified as interested and skilled in the care of the chronically ill, and these people would serve as role models for physicians in training. Longer time periods would be allocated to clinic visits for these children, as their care is time and labor intensive. For the same reason "capitation rates" should be set for the care and clinic visits of these children, so that centers can afford to care for them properly. Finally, efforts would be made to involve the resident in health care delivery in sites other than the traditional tertiary care center. Satellite centers and special facilities in the community could serve as sites of training for residents in training.

II. The Fellowship Training Level

The group considering changes in training at the fellowship level had a rather broad discussion, which started out with an attempt to identify the real purpose of a fellowship. In summary, they felt the state of fellowships in general was fraught with risks of exploitation of the trainee and the system. They emphasized that no clear consensus could be reached about the true goal of fellowships; some felt they functioned mainly to prepare people for academia; others felt that the training and development of a special interest or expertise in a person who subsequently functioned in a generalist capacity was a valid outcome of fellowship training.

When discussion focused on the function of a chronic illness fellowship specifically, controversy ruled again. Many felt there was no underlying concept for this type of fellowship, and that there would be "turf issues" or competition with subspecialists over spheres of influence. The issue of whether training should emphasize categorical versus generalist interests was also discussed at length.

Consensus was reached on a few issues. All felt appropriate attitudes toward the care of the chronically ill should be disseminated into already existing subspecialty and generalist fellowships. It was also emphasized that training in and emphasis on research interests should be an integral part of any chronic illness fellowship design, and that scientific rigor should be emphasized in any program instituted. Mentors should be identified within the system who would be available to serve as advisors and role models for the fellows in training. The group finally agreed that there is a body of knowledge on chronic illness and that this needs to be systematized, prioritized, and transmitted to house staff and fellows alike.

The exact nature or function of a fellowship, particularly one in chronic illness, still remained an essentially unresolved issue. It was felt that further discussion would need to take place in the future on the

relative importance of the fellowship as a producer of academics versus practitioners with a special interest in the field. The importance of producing physicians capable of serving in administrative positions and with the skills to implement change in the political arena was also mentioned. The group seemed to be moving toward the concept of the fellowship as a hybrid of the roles mentioned; however, more discussion appeared necessary to clarify this issue. Another serious concern materialized; this was the relationship of any new chronic illness fellowship to already existing generalist and subspecialty fellowships. Many mentioned the importance of identifying one fellow as representing the particular needs of chronically ill, while others felt it sufficient to emphasize the concerns of the chronically ill to those in existing subspecialty and generalist fellowships.

III. The Faculty Level

The group considering changes necessary at the faculty level chose to consider the question in terms of short and long term implementation. Those short term goals thought to be most important touched on three basic areas: education, career development, and resources. Short term goals in education revolved around development and implementation of a core curriculum. They agreed that a certain body of information existed that must be identified and offered to faculty and house staff. In addition, faculty caring for the chronically ill must be effective role models who are competent in general pediatric care and involved in interdisciplinary patient care so that other house staff and faculty will elicit their opinions and respect their judgment. This would then lend credibility to the endeavors in the field of chronic illness.

Those faculty involved in care of the chronically ill must maintain visibility and participate in the mainstream of the department in order to focus attention on their area. In addition, visiting faculty with expertise in the field should be invited to share their knowledge with local faculty. Just as crucial, faculty must be aware of public policy issues impinging on funding of care for the chronically ill and provide support for appropriate legislation.

As short term goals in career development, the group felt it essential that a "mentor" be identified within the department who could provide guidance and leadership in this area. Course opportunities and research skill development must be provided for junior faculty and efforts should be made to "protect" these junior faculty from the pressures of overwhelming clinical responsibilities. Short term resources available to support faculty were identified that included allotment of existing institutional money, involvement on committees within the medical school, and the assignment of summer medical students with research interests in this area.

In summary, the major goals that should be implemented on a short term basis were thought to be the following:

- a) develop an awareness within the faculty of the importance/priority of training house staff in the care of the chronically ill;
- b) identify those with a special interest;

- c) approach the American Academy of Pediatrics regarding recognition of the field as a special interest group.

It became clear that many of the long term goals for implementing changes at the faculty level were extensions of short term goals already mentioned. However, it was more difficult to reach consensus on some long term issues, such as the need for development of separate facilities for care of the chronically ill. Likewise, the issue of whether it is advisable to develop a separate chronic illness faculty (rather than identifying existing faculty members who have a special interest in the area) was debated. In each instance, participants felt there were both gains and risks to be dealt with encouraging development of an individual specialty, including the risks being that facilities and faculty might assume "second class standing" within the community and that communication and participation with subspecialists might be inhibited. On the other hand, developing separate facilities and faculties would allow for efficiency and directedness of effort, along with the ability to have a faculty leader free to "steer the course" of the field.

This issue was still under discussion at the close of the session, with supporters on either side of the issue. The need for the development of research skills in chronic illness has already been alluded to under short term goals. The participants felt that long term ability to develop scholarly productivity and to procure grants was essential. Sabbaticals should be offered so that faculty can continue to expand their body of knowledge, and in turn invigorate their home institution with this information. Once again, the need for the faculty to be educated in political issues pertaining to the care of the chronically ill was emphasized, along with the need for the faculty to work in concert with legislators to attain their goals. In addition, the important contribution made by nonphysicians (e.g., rehabilitation, social service) was emphasized, and all agreed that faculty appointments should be available for outstanding contributors in these areas.

IV. Practicing Physicians

This group first acknowledged that practicing physicians are providing care to the chronically ill, but not at an optimal level. They next discussed how one could implement change to achieve better skills in the practicing physician and thus better care of the chronically ill.

Crucial to the success of any effort is the ability to tie what is taught (via CME) in a region to what practicing physicians are motivated to learn. It was suggested that one start with "Complete Pediatricians" across the country who are respected by local pediatric policymakers. Armed with the body of knowledge crucial to the care of the chronically ill, these pediatricians through their contacts with local clinicians can attract the proper audience and disseminate knowledge. The CME curriculum chosen must be fluid, so that as needs at local levels change, the curriculum can change with them.

Teaching strategies that were suggested included:

- 1) the information has to be clinical and immediately understandable;
- 2) it must be relevant;
- 3) it should not try to engage all pediatricians, but rather those motivated in the area;
- 4) the presentation should be tailored to the developmental stage of the practicing physician;
- 5) the practicing physician should be offered "educational tenure" to ensure that CME is not simply episodic;
- 6) local means of disseminating information i.e. teleconferencing, local small groups, should be utilized;
- 7) resources available to the family and physician in the care of the chronically ill (i.e., government groups, local facilities) should be publicized so that local pediatricians can take advantage of services.

VI. Summary

It is evident from the preceding discussions that there are specific changes that need to be implemented at each level of pediatric training or practice to assure quality care for the chronically ill. What is even more striking, though, is the number of goals that were mentioned by all of the discussion groups; these goals crossed specific group interests and reflected the major concerns of the participants as a whole. The most crucial of these were:

- 1) the recognition by physicians at all levels that the care of the chronically ill is a problem increasing in scope and complexity that touches all pediatricians;
- 2) the need for faculty, chairmen, and institutions to address this issue by providing faculty, funds, and targeted training programs in this area;
- 3) the importance of collecting and prioritizing that body of knowledge specific to the care of the chronically ill;
- 4) the importance of dealing with how best to expedite cohesive, efficient interdisciplinary care for these children;
- 5) the need to develop programs that will meet the needs of these children comprehensively within local institutions through reallocation of existing resources;

- 6) the need to recognize and tap existing resources at the local and federal level;
- 7) the need to familiarize care givers with the political and legislative process so that it can be effectively used to attain the needs of the chronically ill child.

A few central unresolved issues remained, the most important of these being:

1. the issue of whether a separate faculty or division of chronic illness was preferable to merely identifying certain faculty as having a special interest in chronic illness;
2. the exact nature of that body of knowledge necessary for the care of the chronically ill;
3. the need for and substance of a specific chronic illness fellowship.

Though the groups appeared to be moving toward consensus on each of these issues, further discussion at a future date appeared necessary to resolve these issues.

CLOSING SESSION

Comments by William B. Weil, Jr., M.D.

There is a twofold outcome of the conference: Process and Content. I will, focus on the first question. Morris Green will speak in some way to the second question, although I think we will both bring some of our personal views into our closing remarks.

Before speaking to the issue of fitting things together, there are three specific items I would like to address.

The first is confrontation. Although there is, in interviewing jargon, an appropriate place for confrontation in human interactions -- as a means of identifying for the other person the nature of their behavior, the kind of confrontation that concerns me is the negative form, one which is aggressive in character. This kind of confrontation is involved in the common usage of the term compliant and noncompliant, referring to a patient's or family's behavior. Generally when one is tempted to label behavior in this manner, one needs to explore the probability that the provider and the family (or patient) never reached agreement on a common set of goals and a common set of means to meet those goals. For me it has become a warning that I have not perceived the real priorities of the patient and his/her family.

Similarly when confrontation occurs because the specialist, the generalist, or the practicing physician is not meeting our expectations, it signifies for me that we have not arrived at an honest agreement with these individuals about our respective roles in providing health care to a child or a group of children.

The second issue I want to raise is the lack of any discussion about Traditional Medicine -- not the kind we provide that is contemporary medicine -- but the medicine of the family, social group, or ethnic group which is the medicine that they are practicing and have for generations. Whether we acknowledge it or not, it is being carried out. If we acknowledge this, respect it and accept it, this traditional medicine can be a powerful ally in the provision of care -- and especially in the case of chronically ill or handicapped children.

Now let me turn to fitting things together. Generally if there is an identifiable body of knowledge about a subject, that body of knowledge can be defined and made explicit only if we have some conceptual model of the subject areas. In this conference we have talked at length about models of care but we have not identified a model of chronic illness in childhood, and I would like to propose such a model into which we can fit most of what we have discussed. Further, I believe it is a model that we can use to explore many other relevant issues -- some of which we know a little about and many of which we know nothing or very little about. Figure 1 illustrates my model.

The model is a dynamic one and assumes the interaction of five elements -- each of which is developing or changing over time. The essence of chronic illness is that there is a condition which exists over a long period of time. Further, over that time the illness itself is changing -- progressing, regressing and sometimes varying almost randomly. So the first element is the illness itself, which is different today than it was a year ago and different from what it will be a year from now.

This illness is part of a child -- a host that is changing -- often rapidly and dramatically over time. Moreover the interactions between the child and his/her illness will differ as the illness and the child change. The differences between diabetes in a child of two and of fifteen are both biological and behavioral.

Next the child is a member of some kind of family unit. And the family changes with time. Cystic fibrosis in the first child of 20-year-old new parents will generate a very different set of problems and needs than cystic fibrosis in the fourth child of a well established family that has been married for fifteen years. Further, as the new family develops, matures and has other children, the interactions between the family, their first born and his/her cystic fibrosis will also change, creating new problems and new needs.

The fourth element in my model is the health care provider (or providers). These individuals also change with time. The responses of a resident or fellow to the disease, the child, and the family will be quite different from the responses of the 60-year-old physician to these same elements. And the disease, the child, and the family will respond differently depending on the developmental stage of the provider.

The last variable in my model is society which has its own patterns of change with change in technology and values. As Figure 1 suggests, each interacts with the others - changing the others and changing itself from the interaction.

Summary Comments by Morris Green, M.D.

In the form of an interview with a fictitious science writer from a metropolitan newspaper, Dr. Green provided the following dialogue:

Question: Accepting that society confers upon professionals special privileges with the expectation that the professions will remain responsive to the changing needs of times, is a deliberative process being established in pediatrics for the identification of such needs in child health?

Answer: There is no formal established process.

Question: Should there be?

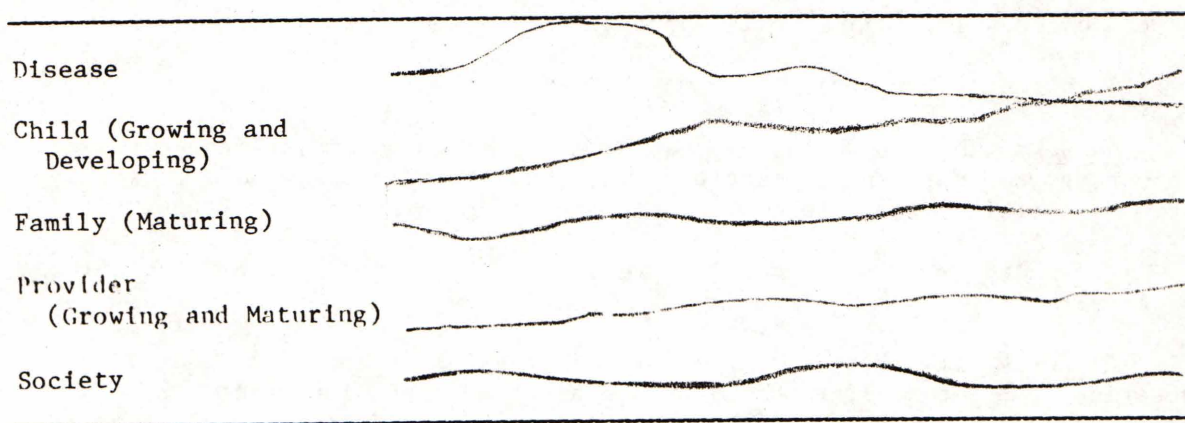
Answer: Yes, urgently.

Question: Putting aside for now how that process could be implemented do you believe that children with long term illnesses/handicaps constitute a group with unfulfilled needs?

Answer: Yes. I believe that most pediatricians would concur.

FIGURE 1

MODEL FOR STUDY OF CHRONIC ILLNESS



Question: Recognizing that there are many other incompletely met needs, e.g. in adolescence, emotional disorders, etc. what would you suggest as the next step in relation to children with chronic illness/handicaps?

Answer: In my judgment, the next step would be to decide what portion of those needs should and could appropriately be met by pediatricians.

Question: What next?

Answer: Then it would be a matter of 1) defining educational goals and objectives for residents, practitioners, faculty, and fellows and 2) seeking ways to facilitate such education in different programs and settings.

Question: What would you like to see as the outcome of that educational process?

Answer: Time obviously does not permit a full response to that question, but let me list what I regard as some of the important characteristics of the complete pediatrician for children with long term illnesses/handicaps. Such an individual:

1. is highly secure as to personal pediatric competence, including comfort in dealing with uncertainty;
2. communicates well and projects personal warmth without becoming personally engulfed;
3. offers child and family a long term commitment in sickness and in health;
4. recognizes, understands and is comfortable in dealing with patient's and family's feelings;
5. is aware of his or her own feelings;
6. is comfortable in sharing the child's care with other professionals, assertive in seeking the best services available and articulate in advocating for the new resources that may be needed;
7. is interested in persons as well as disease;
8. has well developed personal and professional support systems;
9. believes that his or her personal and professional life is meaningful; and
10. has the ability to really care.

Question: Could you summarize that answer in two words?

Answer: Yes - Professionalism and personal freedom.

Question: Can these characteristics be acquired?

Answer: Yes and No. It depends on the clinician's personal strengths, potentialities, resiliency, vulnerabilities, problems, cognitive ability, and so on. The learning process has to be highly personal.

Question: What do you see as happening in general pediatrics that might be relevant to the care of children with chronic illness/handicaps?

Answer: To answer quickly, I see general/ambulatory pediatrics as differentiating vertically into areas of special interest (general pediatrics plus adolescence; general pediatrics plus psychosocial, general pediatrics plus developmental disabilities, etc.) and horizontally (Level I, Level II and III care, defined by the skills, time and personnel required). All general pediatricians will deliver Level I care, some will offer Level II and a few will provide Level III general pediatric care. The future growth areas in ambulatory pediatrics, in my judgment, lie in sophisticated anticipatory guidance, adolescent medicine, chronic illness, sports medicine and in Level II and III care related to a special interest.

Question: What about research?

Answer: Society rightly expects academicians to add to our body of knowledge. Scholarly activity is a proper academic expectation. Rather than constituting a barrier, it offers an important source of professional gratification and is the real key to improved care. Clinicians who care for children with long term illnesses/handicaps have multiple opportunities to derive meaningful generalizations from their daily individual experiences and many chances to identify substantive research questions to which answers may be sought. The frontiers are all about us.

Comments by Merle McPherson, M.D.

My task today is the simple but pleasant one of expressing our appreciation for your participation in this Conference. We struggled in the Conference discussions to determine if there was a body of knowledge regarding pediatric management of chronically ill and disabled children that needed to be incorporated into medical school, residency and post residency curriculums. Early in the Conference it seemed that we were being assured that pediatricians were receiving adequate training and that training monies could be better spent on nurses, social workers, and other health fields. I am relieved at this point to learn that you expect your share, indeed, all of you have done an excellent job of articulating the training needs of pediatricians.

As Vince noted in his introduction there have been dramatic changes in the past two decades as people with disabilities and their families seek fuller participation in society. We are experiencing changes in our service delivery programs related to changing caseloads which include more children with behavioral problems and lifetime chronic illnesses; escalating costs of

the technology for diagnosis and treatment and the widening gap between costs and available resources; the significant changes in socialization of children with disabilities and the need for cost-effective care and support services in the communities in which they reside. These changes must be reflected in the training programs that prepare pediatricians to work with these children and their families. The report of this Conference will be a valuable first step as we seek ways to effect the necessary changes.

Thank you all very much for your hard work and excellent contribution to this worthwhile effort.

Closing Remarks by Michael I. Cohen, M.D.

Just 45 hours ago I welcomed you and now I say goodbye. Arden House has been relaxing, full of good fellowship - deer feeding, running, boating, horse shoes, swimming, tennis, basketball, and baseball. We had some of it all. We came to work and engaged not in passive learning, but in active participation. I believe that the process allowed novel ideas to surface. We did not reach consensus, but the process worked well. We did not simply listen to a prepared text and only react. We focused not on service or research but on specific changes in the education of pediatricians. We asked the question: what is the role of the pediatrician in caring for children with special health needs? We identified 25 or so roles and a synthesis was forged. Then we listed 40 or so skills and abilities plus a host of obstacles and factors that foster development of those skills. Finally, 45 or so strategies for addressing these issues emerged. Finally we considered educational techniques specific to different training levels. In all, over 100 ideas surfaced and we can all be pleased at this outpouring of thought. I am sure that some of these ideas will be brought home and over time will bear good fruit.

APPENDIX A

Elements of Education of Pediatricians for Care of Children with Chronic Illness

Child Development and the Effect of the Chronic Illness.

Family Theory

The Cultural Context of Illness.

Modifications of Primary Care for the Chronically Ill:

- Health Care Maintenance,
- Acute Intercurrent Illness.

Educational Needs of the Chronically Ill and Handicapped.

Health Education.

Prevention of Mental Health Problems and Other Consequences.

Community Resources and Social Services.

Public Policy - Governmental and Non-Governmental.

Introduction to Research Methodology - Biostatistics,
Epidemiology, Research Design, Computerized Record Keeping.

Multiple Models of Organization of Care - Teams.

Long Term Institutionalized Care.

Parent Groups.

Categorical versus Non-Categorical Issue.

Interviewing Techniques.

Problem Solving Skills.

Dealing with Uncertainty.

Self-Knowledge and Care for the Physician to avoid "Burnout."

Care Plan Development - Assessing Alternative Care Plans,
Knowing Alternatives.

Sexuality of Children With Special Health Needs.

Technical Skills to Address the Medical Problems.

Rehabilitation and Durable Medical Equipment.

Behav. style middle child. look - Carey how is the what of behav
 Behav style ^{manners} synonymous $\bar{c}$ Temperament
 congen. components of behav style arent separable
 from environmental influences at any point

①

40% $\bar{c}$ D+ cluster - calls "intense"

What is hard to manage by parent.
 diff. ages

4-8 mo neg mood
 high act
 lo. distract (soothably)

middle neg mood
 lo. adapt
 lo. persistence - (school)

(MBD
 Hyper
 ADD)

Carey
 20%
 10% difficult
 + count $\bar{c}$
 rather
 Diff temp count $\bar{c}$ hi act.
 lo. att
 hi dist
 hi act
 as normal variable
 75% All def. disorder
 "disorder state"
 diff from
 normal

at risk $\bar{c}$
 contenders 15-90%
 could be given
 D+ MBD

Ch i handicaps

(4)

Don't miss to look at temp.

Measurement of Temperament

(3)

parent interview + ?
prof. observations

parent + teacher 68
Thomas & Chess 1977
McDev & Carey 1977

8-12 yrs. 8 char 44 items
middle ch. 1-6 range

Hypert - McDev. Carey. 3th. predictability
replaced
sufficiently

506 children st. sample
hi rel. v. 88

* significance
middle

Thom. Ch. et al.

last soc. adjustment

School + perform
physical health + dev

poor fit
ch + parent's
values,
expectations

* French study

infant temp reg mood
hi int hi comul

> Hosp admissions
for hospital
accidents

physical
normal

low - cog.

temperament

behav adjustment

(2)

Attention - temp
vs
cog. skill.

Reynolds Temperament
factor
+
environment

unfolds like eg eye color
musical talent

Stability of behav style:

middle childhood most stable > than earlier

most stability

for 8 charact of temperament
correl
0.42 mean

189 age 5.1 yr
children age 9.5 yr
in pub.

0.40 - 0.59 - range

Behav style becomes > stable as get older

physical
 CNS-processing
 Temperament
behav. } Learning Style
 } coping style

family system - culture

Chess et al
 Burns, Breitzer
 Brazelton
 Kanner

N.Y. Long Study

Eschola
 Bill Carey - India, Pa