



**COFO**

Consortium of  
Family Organizations

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## PRINCIPLES OF FAMILY-CENTERED HEALTH CARE: A Health Care Reform White Paper

### SUMMARY

Two urgent goals shape the majority of current health care reform proposals: broadening insurance coverage and controlling costs. Yet these goals do not address the long-run concerns about how to make health care more effective and more responsive to consumers' needs. **This issue of the *Family Policy Report* uses a family perspective to analyze the basic components of the health care system and outlines a vision for the future.** There is growing agreement among many professionals, advocates, and consumers that health care systems must be restructured and become family-centered in order to be more effective. Many also believe that family-centered care has the potential to help reduce costs through redirecting resources into more preventive, coordinated, and community-based services.

Over the past two decades, studies have documented the numerous ways in which families have a powerful influence on individual member's health, upon the course of medical treatment, and the management of chronic illness and disability. Family members are both providers and consumers of health care. Clearly, the family has a vital role to play in partnership with health care providers in any effective health care system. **Yet the way health care is currently financed, organized, and delivered makes it very difficult to practice family-centered health care and to support and strengthen family caregiving.**

The role of parents in their children's health is generally acknowledged, but the family is also very important to the health and treatment outcomes of its members at every age. Family members—parents, spouses, adult children, siblings, grandparents, and significant others—are the people who promote the health, safety, and well-being of their members, who seek out health care services, monitor treatment, provide follow-up care, and encourage or ensure compliance with treatment regimens. It is family members who provide the bulk of daily nursing care and support for adults and children with chronic illnesses and disabilities. (Note: It is usually women family members who assume the major

responsibility for promoting health and coordinating health care services for family members.)

Importantly, some promising preliminary studies are documenting that a family-centered approach to health care is considerably more cost-effective than the present approach which focuses solely on individuals. Thus, it is vitally important that the role of families be acknowledged, supported, and strengthened by the formal health care system.

**A growing number of health care professionals, researchers, advocates, and consumers are convinced that an ideal health care system should be family-centered and family-friendly.** By these terms they mean that: (i) Family members need to be recognized as full partners with professionals in planning, providing, and evaluating care; (ii) The family system often needs to be the focus for support, services, and/or treatment; (iii) Health care services must be provided in ways convenient to families and respectful of family-identified needs and preferences. (See sidebar box, p. 2.) At present most health care systems are neither family-centered nor family-friendly.

This issue of the *Family Policy Report* presents principles, preliminary guidelines, and specific recommendations to help promote a family focus in health care. It is designed as a discussion document—a white paper—to be used by health care consumers, advocates, professionals, and policymakers as they develop and implement proposals for shaping the future directions of health care. The scope of this report is very broad and cuts across the usual age and program categories and both public and private sectors. We believe the issues we raise go far beyond issues of financial access and cost. They have implications for restructuring many interrelated components and levels of the health care system. Importantly, family-centered health care helps to integrate physical health, mental health, and social services. COFO hopes that these suggestions will be incorporated into the discussions at federal, state, and local levels on how to improve our current health care systems.

## WHAT IS MEANT BY THESE "FAMILY" TERMS ?

The use of these "family" terms can be confusing; they mean different things to different people using them in different health contexts. Some people use them interchangeably, as they do convey overlapping concepts. Essentially, they all convey the constancy of the family as the organizing concept in health and social services policy and practice. The family is viewed as the focus of study and analysis, intervention, and support (Snyder and Ooms, 1991).

Specifically, a **family systems perspective** is based upon a theoretical framework that integrates the biological, psychological, and social/environmental aspects of development. It does not view individuals, their behavior, or illnesses as existing in a vacuum, but as connected to and affected by larger "systems," their family being the most important and influential system. Family members — their beliefs and behaviors — are affected by their interaction with each other and their interaction with the external environment, i.e., schools, churches, neighborhoods, government, etc.

The terms **family-centered** and **family-friendly** are derived from a family systems framework. A **family-centered** approach to policy and practice recognizes the pivotal role of the family and is based on the assumption that the best way to help individuals is to view them holistically, within the context of their family, neighborhood, and community. At the service delivery level this means viewing the family, not just the individual, as the constant factor in that person's environment and often as the appropriate focus of service, consultation, empowerment, and support. At the policy level this refers to active support for family involvement in the financing, policies and procedures, staffing, training, record keeping, and the structure and organization of a program or agency. At all levels family members need to be viewed as a resource and a partner with health care professionals.

**Family-friendly** refers to the manner in which health care and other institutions and professionals interact with families. For example, do they give them the information they need in a manner that they can understand and use to make choices and follow treatment? Do they respect and treat them as consultants and partners? Do they offer services in a convenient, attractive place and at convenient times?

In general, for policy purposes, COFO uses the term **family** to refer to two or more persons related by blood, marriage, or adoption. However, health care professionals need to acknowledge that in some situations — such as a foster child, an elderly frail adult or an individual with AIDS — other persons are often much closer to the patient emotionally and physically than a blood or legal relative. These caregivers and companions function as surrogate or "foster" family and need to be involved by health care providers in most of the ways outlined in this Report.

The report first outlines three broad principles for family-centered health care and then develops specific guidelines for separate components of health care systems, suggesting some of the questions that should be asked of any proposal for improving health care. (The reader is invited to add additional questions.) The final section includes a summary of the emerging research on the relationship of families and health and recommends a major investment in studies that investigate the cost effectiveness of a family-centered approach to health care.

## PRINCIPLES OF FAMILY-CENTERED HEALTH CARE

COFO recommends that the following three broad principles guide the development of a family-centered and family-friendly health care system: **family support, family partnership and empowerment, and family diversity.** (These principles are drawn from COFO's list of family criteria and family impact questions. See COFO, February 1990.)

### 1. FAMILY SUPPORT

- Health care financing, organization, and delivery should support and strengthen, not undermine, the constructive role of families in the promotion of healthy life-styles, in the prevention of disease, and in the care, support, and treatment of their members with illness or a disability.

- In addition, incentives should be provided that encourage health care providers to consider the family, when appropriate, as the focus of support, services, and/or treatment, and to require third party payors to provide the option of family coverage.

### 2. FAMILY PARTNERSHIP AND EMPOWERMENT

- Health care policies, services, and providers should recognize the expertise and central role of families. Health care providers need to treat family members with respect as key consultants and partners when providing health-related services to an individual family member. In child health care they should recognize and respect parents' key decisionmaking role.

- Parents, spouses, and other relatives or caretakers should be offered a range of levels of involvement depending on the individual patient's and family's wishes and situation. But in all cases it needs to be explained to the individual and family how important and helpful family members can be.

- Families need to be empowered to carry out their health-related responsibilities. They should be provided with clear, unbiased information, a maximum degree of choice and decision-making, and access to the resources and support that they need to carry out these responsibilities.

- Health care policies and programs should take into account the complex, multiple responsibilities and schedules of families today. The financing, organization, and delivery of services should be designed to help, not hinder, family members ability to manage and coordinate their various relationships with health care systems and with their other work and family responsibilities.

### 3. FAMILY DIVERSITY

• Health care policies, services, and providers need to recognize, understand, and respect the diversity of families in order to provide effective health services. Families differ a great deal in terms of their structure, resources, stages of development, racial, religious, and cultural backgrounds and beliefs, and the setting in which they live (urban, rural, suburban). All of these factors strongly shape families' needs for health services, response to illness, and their utilization of health care services.

• Health care providers need to be open-minded about which members of the family need (and want) to be involved in the care, treatment, and support of an individual as this can vary a great deal. In pediatric care, fathers as well as mothers may play a critical role or it may be the maternal grandparent. Non-custodial parents, an adult sibling, or a life-long adult friend or close companion may be the most significant person to involve.

### KEY COMPONENTS OF A FAMILY-CENTERED HEALTH CARE SYSTEM

The following section provides specific guidelines to implement these broad principles through addressing family issues in the major components of health care: financial and physical access, types of benefits covered, staffing and staff training, health care practices, quality assurance, cost containment, and cost effectiveness.

#### FINANCIAL ACCESS

**Problem:** Too many families have no health care coverage at all. In other cases some members of the family have coverage and others do not. Over 35 million Americans, including 8.3 million children under age 18, are currently without health insurance protection. Many others, due to changes in job situation, residence, or age, are without coverage at some time during the year. (In 1987, 50 million were without health insurance coverage for at least one month during the year.) Many others are underinsured. They may have coverage for catastrophic or acute care, but not for primary and preventive care.

Another problem is that some members of the family may be covered while others are not. In many cases private insurance covers only the employed member and is either unavailable or unaffordable for other family members. Increasing numbers of employers are either dropping dependent coverage altogether or have increased the employees premiums for this type of coverage. In addition, some are increasing the deductibles and reducing the scope of benefit coverage. Once children reach age 18, most are no longer included in their parent's coverage, yet they are seldom stably employed in jobs that offer affordable insurance. Young adults are the least covered of all age groups. There is an additional problem for children of divorced parents, since the cost of health insurance is often not taken into account in the divorce agreement or in calculating child support awards.

On the other hand, public programs such as Medicaid may pay for the costs of medical care for pregnant mothers and their infants and young children but often not for older children, fathers, or other important family caregivers. Yet the health of parents often negatively affects the health and well-being of their children. For example, when a mother has a strep throat that goes untreated, her children will repeatedly get strep throats. Or when parents are not able to get treatment for serious depression or substance abuse they may not be able to properly care for their children.

Additional barriers to adequate insurance coverage are the exclusions for pre-existing conditions (which can restrict a family member from changing jobs and improving the family's economic situation), and the lack of portability of coverage when a family moves out of state or a parent changes jobs.

*Proposals that expand insurance coverage should ensure that all members of the family household are covered, not just the employed member (when the insurance is employer-based). Children of the non-custodial parent also need to be covered if the custodial parent does not have coverage. Coverage should be extended to young adults until they are covered by an employer. Insurance should be available independent of pre-existing conditions and be portable.*

#### Assessment Questions

— Is private or public insurance available and affordable to all families, without regard to pre-existing conditions or employment status?

— Are all members of the family able to be included in the coverage, including those who may not live in the household but are still partially dependent (e.g., the child of a non-custodial parent, the young adult)?

— Does the insurance assure continuity and portability if a family changes location or employment?

— In employer-based plans, how is coverage to be assigned in two-earner families?

— Other questions?

#### SIMPLIFICATION OF THE CLAIMS AND REIMBURSEMENT PROCESS

**Problem:** The present system of processing claims for reimbursement from third parties imposes enormous stress and burdens on families, especially those least able to cope. The administrative waste and inefficiencies involved in the present system have been much discussed and various calculations have been made of the administrative costs that could be saved by improved coordination between insurance companies, such as using a single claims form or by moving to a single payor system. Once again, the consumer perspective is missing in much of this discussion. The costs in terms of time and stress to consumers have never been calculated.

Endless hours are spent by family members trying to claim reimbursement even when they simply consume an average amount of health care services. But those families who have a member with

a severe, or complex, chronic illness or disability are very seriously burdened by the paperwork at a time when they are already under heavy emotional, economic, and physical stress. One study of 48 such families in New York reported that in nearly all the families surveyed the paperwork required several hours each week, and in some families it was a daily task. In addition, families reported incredible duplication of effort in filing claims and reports for different sources of public and private insurance (Knoll, 1989). Families with little education or who do not speak English are often at a total loss when confronting the claims process, and may fail to claim benefits they are owed.

In 1986, tax simplification was one of three key criteria underpinning tax reform. Simplification of the reimbursement and claims process should be one of the key criteria in assessing any new proposal for financing health care. Indeed one of the major benefits for consumers of many managed care models such as the health maintenance organizations is the reduction or virtual elimination of paperwork. At a minimum, patients themselves should not have to bear the confusing burden of the paperwork. (In what some see as a positive step forward, since 1989, Medicare providers have been required to submit all claims on behalf of patients.) Reducing the paperwork burden on health care providers should also be a goal as it would not only save costs but could release time for them to spend directly with their patients.

*Any health care proposal needs to be carefully scrutinized with regard to the extent to which it simplifies and expedites the process of obtaining reimbursement for patients, their families and providers alike. At a minimum, a universal, easily understood claims form needs to be developed and required for use by all insurers. In addition, each insurer could be required to offer a 24-hour, toll-free number that families can call to clarify claims-related questions.*

#### Assessment Questions

— To what extent will this proposal add to, or lessen, the time and hassle families experience in obtaining reimbursement for their health care expenses from third party payors?

— Will it increase or reduce the time and burden of paperwork imposed on health care providers?

— Will the proposed system result in uniform enrollment and claims forms, appeal processes, and benefits descriptions?

— Other questions?

### PRACTICAL ACCESS TO SERVICES

**Problem:** Even when financial access is assured, families often experience a great deal of practical difficulty getting needed health services. In certain areas — particularly rural areas — appropriate primary care services do not exist or are in very short supply. Specialized services — e.g., tertiary care hospitals — are often located at a considerable distance. This is especially a problem when a child or relative has to be hospitalized. In metropolitan or inner-city communities health care facilities may exist but are often not located in areas accessible by public transportation.

Most doctors' offices and clinics are not open at times convenient for working families. Employers usually do not provide leave to take a child or other ill relative for health care appointments during working hours. Families may thus go without preventive or basic care services and wait until the situation becomes acute and they have to seek emergency care. Emergency rooms are also used, inappropriately, for treatment of mild illness or well-child care, especially in rural and some inner-city areas for want of access to a source of preventive and primary care. This pattern of use greatly contributes to the escalating costs of care.

In a number of existing state and local demonstration programs effective alternative service delivery models exist — such as mobile health units, outreach through home visits, providing occasional evening or weekend hours, all-night outpatient health clinics (for shift workers), volunteer transportation networks, and so forth.

*Health care reforms must address the issue of families' practical/physical accessibility to needed health-related services. This includes providing more outreach services in homes and neighborhoods, and more services offered in a single location. For low-income families, subsidizing the costs of transportation for patients and their families may be needed. Increasing access also requires increased flexibility in scheduling, and accommodation to the special needs of families with a member who has disabilities or of those for whom English is not their primary language.*

#### Assessment Questions

— To what extent does the reform proposal address issues of equalizing physical access? What incentives exist to improve the geographic distribution of health care services and health care providers?

— What incentives or other initiatives are included to help promote service outreach, more flexible hours of operation, and more community-based primary health care?

— Is reimbursement available for health-related services that are provided in non-medical settings?

— What incentives or requirements are included to co-locate related services and to use a single point of entry?

— What accommodations are made for persons with physical, cognitive, sensory, or language difficulties to have equal access to needed services?

— Other questions?

### TYPES OF BENEFITS COVERED

**Problem:** Too often, third party insurance severely limits families' choices of services and of the type of treatment they can receive for a condition. In general, benefit coverage is biased in the direction of high-cost and acute care services. For example, most policies cover emergency/acute care, services provided by specialists, and inpatient care (catastrophic coverage). Many policies do not cover preventive and primary care such as physical exams, health screening for children and adults, immunizations,



eye exams and glasses, and dental care to name a few. Alternatively, large deductibles effectively prevent many families from seeking these primary, preventive services. When these primary care services are funded, overall medical care costs are often reduced.

Research now provides plentiful evidence of the strong connections between physical, mental, and social health. Thus, providing mental health treatment and social services can often be the route to improving physical health and vice versa. This knowledge provides the rationale needed to support and integrate the provision of physical, mental, and social services. Yet, too often, vitally needed mental health and social services are considered a luxury or "frill" and are not covered by insurance.

Mental health coverage and coverage for alcohol and other substance abuse is consequently very limited. Moreover, studies have shown that outpatient substance abuse services are equally or more effective than inpatient treatment. Yet benefits for expensive, inpatient services are much more adequately provided than for the less expensive, outpatient services. In addition, compensation is rarely available to health providers for the time spent in providing education and prevention services, or for family supportive and follow-up services such as educational counseling, family therapy, and respite care.

Coverage is also frequently unavailable for the range of early intervention, rehabilitative services, and social supports needed by families with infants, children, and adults with serious injuries, disabilities, or chronic illness in order to function in the community (for example, physical therapy, speech therapy, and personal assistance services). When benefits are available for these services they are capped at unrealistic levels.

*Benefit coverage should provide families with access to a comprehensive continuum of services beginning with preventive and primary care services, including outpatient mental health and substance abuse services such as family therapy, and support for family caregivers as well as for the more specialized, institution-based care to handle acute and complex health problems. Patient cost sharing should not create barriers to use of primary care services. The coverage should provide incentives and rewards for families who are caring for their members with chronic illness and disability, including supporting education and home- and community-based services and supports.*

#### Assessment Questions

— Does the financing system ensure coverage for a comprehensive range of benefits?

— Does the financing provide incentives towards preventive and community-based services or towards high-cost, institution-based treatment?

— Are there extended benefit packages for children and adults with chronic illness and disabilities?

— Are outpatient and inpatient mental health and substance abuse treatment benefits included in the coverage?

— Does the financing system include payment for supports, education, and respite services for family caregivers?

— Other questions?

## HEALTH CARE PROFESSIONAL STAFFING

**Problem:** There are two main problems with the staffing of the U.S. health care system that make it difficult to provide family-centered care: overspecialization and limitations on the categories of providers who receive reimbursement. First, the balkanization of medical care into sub-specialties is very confusing for patients who often do not know which specialist they should seek help from for a particular symptom or problem. The resulting overuse of specialists is costly for patients and the payors, and can lead to misdiagnoses and poor or ineffective treatment.

Generalists, that is general practitioners or those trained in the specialty of family medicine, treat the physical health of all the members of a family and are often trained to understand how the health of one member can affect the others. They also treat the whole person. They understand how different body functions relate to each other, how the mind and emotions can affect the body. They can coordinate and integrate the patient's and family's use of specialists. Family-focused generalists can also provide critical support and coordination for families who are caring for a person with serious disability or chronic illness.

The United States is unique among developed nations in that nearly 70 percent of physicians practice sub-specialties. Only 30 percent of today's doctors in the U.S. are generalists. In other developed countries, who spend much less money on health care, half or more of the physicians are generalists.

The second major problem is that services provided by non-physician health and mental health professionals, such as marriage and family therapists or occupational therapists, whose approach is generally more well rounded and family-centered, are frequently not financed by current insurance. Nor is the health care provided in non-medical settings such as schools or community centers or in the home usually reimbursed. This country's medical education, health care delivery, and health care finance systems, thus, strongly, though unintentionally, discourage comprehensive, preventive, community- and family-based primary care and practice.

*Health care insurance should equitably reimburse a range of health and mental health care providers, including those who provide preventive and primary outpatient health and mental health care, and those who provide rehabilitative and long-term care and support services. In addition, incentives must be developed to encourage more physicians and other health care professionals to practice as generalists delivering primary health care and serving the whole family (e.g., specialists in family medicine, nurse practitioners, marriage and family therapists, and social workers).*

### Assessment Questions

- Do the reform proposals require that consumers are assured access to a full range of providers and settings?
- How do the financing mechanisms affect the types of providers and settings which can be reimbursed or who are willing to accept reimbursement?
- Are approved services that are paid for when delivered in hospital and clinic settings also covered in home or in certified school and community settings?
- What incentives are offered to encourage the training and financing of providers of generalist/family-focused care?
- Other questions?

## FAMILY-CENTERED PRACTICE OF HEALTH CARE PROVIDERS

**Problem:** Families are potentially health care professionals' greatest allies. Because families are the primary, continuous providers of health care and support for their members, they need to be involved as partners with the health care providers to assure the best and most cost-effective care and treatment. Studies document that when health care services are family-centered individual health outcomes improve. Yet family members repeatedly report that they feel as though they are treated as obstacles, or are viewed as irrelevant to effective treatment. The lack of an explicit emphasis by health care providers on working with the family can have several unwanted results. Much valuable information is not obtained. Family members may encourage the patient to ignore the professional's advice. And an opportunity is missed to engage the family in a process of reinforcing and supporting treatment and service goals which can speed up and sustain recovery and prevent relapse.

Health care practitioners are often perceived by family members as being unfriendly to them. Family members need and want information, education, and to be included in decision-making. They need and want recognition and respect for their knowledge, responsibilities, and situation. Yet the reality is they are too often ignored by health care professionals. When they do talk with family members, professionals may only focus on how family members hinder a patient's progress instead of identifying family strengths and resources which can help a patient recover or adopt a healthier life style.

The communication and other problems in the relationship between patient, family, and health care provider are usually exacerbated in the case of low-income and minority families, especially those who speak little or no English and in the case of families coping with chronic illness and disability.

*Health care professionals must treat families as partners in health care. Parents, spouses, adult children, and others usually choose, or help the individual choose, the doctor or health care facility and are responsible for making major health care decisions if the patient is a child or dependent adult. Even when the patient is the decisionmaker, family members can profoundly*

*influence that patient's decisions and the extent to which the patient cooperates with the prescribed regimen. (Indeed, studies have found that the most important reason that many patients discontinue treatment or go against medical advice is upon the urging of their family.) Thus, families need to be involved by providers in the ongoing care of most individuals.*

### Assessment Questions

- What policies spell out the roles and rights of patients and their family members in health care decisions and in the provision of treatment?
- How does the health care delivery system provide families with the information, advice, and support to enable them to work in partnership with health care professionals?
- What support and incentives are provided to health care professionals to get them to work in partnership with the patient and family in health promotion and disease prevention, in diagnosis, treatment, and management of chronic illness and disability?
- What institutional policies and practices facilitate the family's involvement in patient care, especially for the child or dependent adult who may be hospitalized?
- Are there any incentives or requirements to develop mechanisms that help coordinate services provided by different specialized providers?
- Are there incentives or requirements for health care programs or institutions to hire health care professionals who speak languages spoken by their non-English speaking patients and families in communities in which there are large numbers of such families? For example, do these professionals get higher salaries?
- What educational programs are offered on issues of prevention, health promotion, rehabilitation, and recovery for patients, their families, and the community?
- Other questions?

## FAMILY-CENTERED TRAINING FOR HEALTH CARE PROFESSIONALS

**Problem:** Most health care providers are trained in an individually-oriented, biomedical, disease-based approach — an approach that focuses exclusively on an individual and his/her disease, i.e., a patient's cancer or disability such as blindness or depression. The individual's accompanying mental and emotional states, his/her family's reactions to the illness or disability, the meaning of the illness or disability to the family, and the influences of the patient's living environment are all incorporated in the systems-oriented, bio-psycho-social approach. Yet these important factors are often ignored in the biomedical philosophy and training of health care professionals. While increasingly these concepts are being included in the academic curricula, they are seldom a part of the clinical, inservice training.

The biomedical approach has contributed to a specialized and fragmented health care system in which a variety of specialized professionals generally serve individual members of families at various offices and locations. Few health care practitioners get to know the entire patient or the whole family. Few are trained to

understand the relationships between family factors and the health of their patient or the effects of their patient's illness, disability, or chronic condition on the health of the rest of the family. Few know how to involve members of the family as partners in health care.

In addition, health care professional training typically fails to include important information about the many different ways in which families from diverse cultures and of different religious faiths respond to illness and their different attitudes towards getting help and treatment. This lack of culturally sensitive training can result in incorrect diagnoses and ineffective treatment. In addition, there is a great shortage of physicians and other health care providers who are themselves members of minority groups.

*Ideally, there should be an expansion of primary care professionals who work with all members of the family throughout the life span (such as specialists in family medicine, family nursing, or marriage and family therapy). At the bare minimum, all health care professionals should receive training in the bio-psycho-social approach to health care, which views the individual as a whole person and as a member of a family and larger social environment. Training should teach providers how to assess the influence of family factors on health, to work in partnership with family members so as to promote the health of their patients. This is especially important for those practitioners who play such a critical role in the care of children with special health care needs (such as pediatric nurse practitioners, nurse midwives). In addition, training for all health care professionals needs to include an emphasis on the cultural dimensions of health, sickness, and disability, and the importance of respecting diversity.*

#### Assessment Questions

— Are there mechanisms built into the reform proposals to require, encourage, and fund pre-service and inservice education and training of health care professionals in family-centered, culturally competent approaches to health care?

— Are there mechanisms to require, encourage, and fund pre-service and inservice education and training of health care professionals in a positive, non-demeaning approach to children and adults with disabilities and their families (consistent with the principles of the Americans with Disabilities Act)?

— Do federal programs for training health care professionals encourage training in a family systems/bio-psycho-social and interdisciplinary approaches?

— Are there increased funds available to support the training of health care professionals representing different minority groups.

— Other questions?

### THE FAMILY'S ROLE IN IMPROVING QUALITY

**Problem:** There is an increasing focus on the need to develop a health care system that is consumer driven. Yet the multi-faceted role of family members as consumers of health care services is seldom acknowledged. While the individual patient is the most direct consumer of health care services, close members of the individual's family are also, indirectly, consumers of these services.

Indeed, it is they who often function as the most effective monitor of, and advocate for, quality of care, especially for children, adults, and the elderly who are chronically ill or disabled. In addition, family members are also direct consumers when they receive health services themselves.

As already suggested, the parent, spouse, or adult child is generally the primary coordinator, manager, and monitor of health care services provided to an individual who is seriously ill or disabled or for the frail elderly. It is these family members, or other close relatives and caregivers, who are most frequently the guardians of quality of care. They are usually to ones who keep track of all the appointments, medications, and contacts with various health care professionals. It is often their informed vigilance during hospitalizations that helps the hospital staff prevent or correct mistakes in treatment. It is often family members constant questioning that helps health care providers improve the coordination of services. It is their insistence on drawing attention to the patients' unmet needs that can call forth additional services or, when appropriate, less intrusive services.

There are difficult, complex issues that arise when family member's views come into conflict with the patient's views or needs or when different family members disagree with each other. But the institutional policies, procedures, and clinical processes that are set up to balance and mediate the various rights and interests involved in such cases must give families due recognition of their rights and responsibilities, and opportunities to be heard.

There is increasing discussion and debate about how to assure that patients' wishes about quality of life are respected in decisions about the medical care they receive at the end of their life. Family members have a critical role to play at this difficult time and in these decisions. Importantly, when they are actively involved in care and treatment — whether in the hospital, nursing home, hospice, or in the home — family members can greatly help to improve the quality of the patient's final days.

Family members are not usually invited to be advocates or to monitor the quality of care for individual patients, they simply take it upon themselves. Regrettably, only a minority of family members have sufficient confidence and/or perseverance to be strong advocates and effective managers in a system that actively discourages such involvement. Since this role seldom receives official acknowledgement and support, many patients of the health care system do not receive the quality of care that they should.

*Family members need to be viewed by health care providers and health care systems as a vitally important resource for achieving improvement in health care quality both, in individual cases and for the system as a whole. Their role in serving as monitors, coordinators, and managers of health care services provided to individuals needs to be given official recognition, encouragement, and support. In addition, family members, as well as patients, need to be invited to provide consumer feedback and to serve on*

*ongoing planning and quality assurance committees at state, county, and local, institutional levels.*

#### **Assessment Questions**

- What vehicles exist for providing information and education to the relatives and other caregivers of individual patients?
- Does the health care institution, agency, and professional association provide recommendations and guidance to health care professionals about ways that patients and their relatives can provide consumer feedback on the services they receive as well as involve these consumers in policy and program development and implementation?
- When services are provided to an ill child or adult, is the parent or close relative invited to serve as the advocate and monitor of the services the patient receives and shown how best to do this?
- When a child or adult requires multiple health-related services, is a professional case manager or care coordinator designated? How does such a case manager relate to the person(s) in the family who are already acting as the informal care coordinator?
- Are family members, as well as patients, invited and supported to serve on national, regional, local, or institutional health care planning and advisory boards and quality assurance committees?
- Other questions?

### **THE FAMILY AND COST CONTAINMENT AND MANAGED CARE**

**Problem:** With the continuing, escalating costs of health care, cost containment has become one of the driving forces for health care reform. Insurance companies, employers, and federal and state governments have utilized different managed care approaches for controlling these expenditures. These include new organizational and financing arrangements such as health maintenance organizations (HMOs), preferred provider organizations (PPOs), or specific cost containment measures such as diagnostic-related groups (DRGs), utilization review, limitations on benefits, higher deductibles, and coinsurance payments for employees.

Managed care and other cost containment measures determine how much health and mental health care is provided and to whom. At times, conflict is generated between controlling costs and providing needed and appropriate health and mental health care and supportive services. Cost containment measures often dictate what services health care professionals can provide, in what manner, and for how long (for example, providers must spend only 15 minutes with a patient or only see her/him for a certain number of visits; baby and mother may stay in the hospital only 24 hours after delivery).

Although the implications of the trend towards managed care for families are not fully known, these arrangements can clearly have a significant impact upon families. In some cases managed care may help avoid unnecessary intervention and promote more preventive, home-based services. These can be cost effective and very welcome to patients and family members. However, in other

cases, attempts to control costs create extraordinary new burdens and anxieties for families and may also result in denial of needed services. This is especially true when families have to monitor the recovery from surgery or carry out highly complex therapy and treatment regimens at home. Most families are willing to take on these new responsibilities if provided with sufficient information, training, support, counseling and therapy, support groups, and occasional respite care. But some families have too many other work and family responsibilities or problems in their home environment which makes it impossible for them to take them on.

Thus, cost-saving measures which do not provide the education and supportive services required by the family/caregivers and do not take into account the specific needs and resources of individual families may result in a rigid, inflexible system and result in poor, ineffective and cost-inefficient treatment.

*Plans for managed care and cost containment measures should include mechanisms to assess the patient's life context and the family's values, resources and needs. With appropriate services and supports, families may often take on considerable, additional responsibilities which will help to contain costs. Without these services to families, the patients will not recover as fast, they may deteriorate and recycle back into the hospital. Alternatively, members of the family may react to the burden and stress by becoming ill themselves. Studies of the cost effectiveness of managed care initiatives are badly needed and should include an examination of their effect on family health, functioning, levels of support, and well-being.*

#### **Assessment Questions:**

- Do managed care proposals limiting hospital stays or requiring out-patient surgery include flexible mechanisms and procedures to assess the social and family context to which the patient is to be discharged ?
- Do cost-saving measures designed to limit high cost, institutional care recognize the importance of providing supports for home-based treatment and family caregivers?
- Do managed care proposals assure access to appropriate specialty care, especially those needed by individuals with disabilities or chronic illnesses?
- Are the gatekeepers of managed care (sometimes called case managers) trained to assess the needs and resources of family caregivers?
- Other questions?

### **FAMILIES' INFLUENCE ON HEALTH: SELECTED RESEARCH HIGHLIGHTS**

Over the last two decades a growing body of research has documented the ways in which families impact the health of their members and how the health of one member affects the health of the family. This research shows what many clinicians and family members have known for years — that the family has a powerful influence on health and that illness, especially chronic illness or



disability, affects family members health and functioning in many ways. A few studies have examined the effects of interventions which involve family members in treatment. To prepare this brief summary of the highlights of this research we have drawn upon a number of references listed at the end of this section, and most heavily upon the useful review and syntheses of this literature in Campbell and Treat, 1990; and Doherty and Campbell, 1988.

#### • Family Factors and Health Status

Families' socioeconomic level, cultural background, overall health status, and family history affects an individual's disposition to certain diseases, degree of health, and access to health care. In fact, family factors are the best predictor for the health status of their members. For example, many research studies document the strong correlation between poverty and health status. Individuals of all ages who live in poverty are at substantially greater risk for acute and chronic physical and mental illnesses than those with higher incomes. In addition, they face greater barriers to adequate health care. Similarly, family structure is a predictor of health status for both adults and children. Individuals who live in families or have other close social networks are healthier than those who do not. Married men are generally healthier than single men. And children living in single-parent households are at greater risk for various negative health outcomes.

#### • Family's Role in Health Care Promotion and Illness Prevention

Nearly 80 percent of diseases in industrialized countries are a result of lifestyle behaviors — diet, exercise, smoking, drug and alcohol use, compliance with medical regimens, etc. — and the family has the greatest influence upon these behaviors. Parents and other family members help promote healthy behaviors and avoid risks to health through health education, modeling healthy lifestyles, and providing safe home environments and a nutritious diet. Research suggests that health-related behaviors such as those mentioned above have a very significant effect on an individual's health and that the family is the primary context in which health promoting activities occur. For example, adolescents are more likely to smoke if they have either a parent or older sibling who smokes. Conversely, family support is an important and determining factor in an individual's ability to change an unhealthy behavior. Involvement of a spouse in weight-reduction programs, for example, significantly improves long-term results.

Studies have documented the importance of acknowledging cultural, racial, and religious factors in health care, and the family is the primary vehicle for transmission of culture and religion. They can influence individual's predisposition to certain illnesses, their understanding of the causes of illness and the importance of prevention, their response to pain, their attitudes towards and use of home remedies and folk medicines, and most importantly whether and whom to go for information and help when ill. The health care system's failure to acknowledge and understand these cultural and racial factors has led to some groups' serious underutilization of available medical services and to much ineffective treatment.

#### • Family's Involvement in Diagnosis and Treatment

Research indicates that families play a pivotal role in defining the nature and seriousness of symptoms in an ill child, spouse, or adult parent; in encouraging use of home remedies; in deciding whether professional medical help is needed; and helping them get access to services. If allowed or encouraged to be present, family members help the patient understand the health care provider's instructions and assist the patient in complying with the treatment recommendations. Failure to comply with health care provider's prescribed treatment is a major, and largely unacknowledged problem in health care. Family involvement has consistently been shown to improve levels of adherence to medical regimens.

Ideally, families are a great source of knowledge for health care professionals who are seeking to determine the cause of an illness or health-related problem. Turning to family members for information becomes even more important when families change doctors or a family member needs emergency care and access to records is not available.

Most parents of young children are clearly the best source of health history and information and the key intermediary with health care professionals. Although seldom acknowledged by health care professionals, parents generally continue to play a strong role in the diagnosis and treatment of health problems of adolescents, depending on the issue and the need to respect privacy and confidentiality. This is especially true for adolescents with substance abuse and mental health problems. But it is also true for teenagers and young adults with chronic illness or disability. While these young people should gradually be encouraged to assume more responsibility for their own health and treatment, realistically, their parents must often continue to be involved.

Parents or siblings of adults with serious mental illness, substance abuse, or mental retardation are also usually very important sources of information for health and mental health professionals, both about medical history and current functioning for adult as well as child patients. They also often participate in systems-based education and treatment programs. In summary, studies show that parents and other relatives are potentially the health care provider's most powerful ally in diagnosis and treatment.

#### • Effects of Family Stress and Support on Health and Illness

Research indicates that stress and social support have a significant impact on the physical health of all individuals and that the greatest source of both stress and social support resides within the family. Stress has the effect of suppressing the body's immune function and, thus, predisposing individuals to becoming ill. Social support positively influences health, both directly and indirectly.

Family stress that is the result of such life events as the birth/death of a child, marriage, divorce or marital separation, death of a spouse, affects the health of all family members. For instance, in the case of children, a prospective study of 1000 preschoolers found that family life events were strongly correlated with

subsequent visits to doctors and hospital admissions for a wide variety of conditions (cited in Doherty and Campbell, 1988, p. 50). The two most stressful life events — death of a spouse and divorce or marital separation — are well documented to have very adverse health consequences. Mortality rates for surviving spouses are much higher than for the general population.

Social support or social relationships also powerfully effect an individual's physical health. Family members, especially the spouse, tend to be the most important source of social support and account for most of the association between social support and health. Marital status and the levels of support available from relatives and friends are the most powerful predictors of health. For the elderly, the presence and number of living children are the most powerful predictors of survival. Family stress and support take on even greater significance for those families caring for members who are chronically ill or disabled.

#### • The Family's Role in Long-Term Care

Family members (parents, spouses, adult children, and adult siblings) are the primary caregivers and care managers of family members of all ages who are chronically ill, disabled, frail, or experiencing a chronic condition (e.g., heart disease, hypertension). This role has become more important as the results of advanced biomedical science and technology and improvements in public health have led to longer life expectancies and greater rates of survival from previously fatal injuries, disabilities, and illnesses. In addition, changes in public policy — the trend away from institutionalization towards home- and community-based services especially — and the steadily growing aging population have led to a greater focus on the family's role in caregiving.

Long-term caregiving places significant stress upon the family and the person with the chronic illness or condition. The prevalence of depression and other symptoms of psychological distress are higher among caregivers of the frail elderly, especially those frail elderly with cognitive impairments, i.e., Alzheimer's disease, than for the overall general population. Preliminary studies also suggest that emotional responses of other extended family members to the primary caregiver also affect the caregiver's depression (Shields, 1992). Besides the emotional stress and strain of caregiving, families must also contend with a medical system designed for acute care, not long-term care. Thus, family stress is compounded when long-term care services (e.g., specialized day care, respite care, home nursing) are unavailable and/or unaffordable or when a family must choose between employment or caring for a family member who is chronically ill. Spouses are the most at risk for the negative effects of caregiving; adult daughters are next at risk.

#### • Effects of Family Involvement on Health Outcomes

Unfortunately, few large-scale empirical research studies have examined the financial costs and benefits of involving family members in the provision of health promotion and treatment. A few small studies and clinical experience suggest, however, that involvement of families in the provision of health services to individuals leads to positive health outcomes for the ill family

member and a few of these have also documented reductions in health care costs.

For example, in the case of children with serious psychosomatic and chronic illnesses, studies have found that family involvement is extremely important in terms of recovery and long-term adjustment (cited in Campbell, 1986). In a recent controlled study, involving spouses and other family members in a program to treat patients with hypertension led to significant decrease in blood pressure levels and in mortality (Morisey, 1983 cited in Campbell and Treat, 1990, p. 103).

Studies of families with a schizophrenic member show that psycho-education, support, and therapy with the family after his or her hospitalization can prevent relapse of the patient and is demonstrably cost-effective. Increased costs due to the family intervention are outweighed by a decrease in usage of the established mental health services — a decrease of 27% in mean costs per patient in one study and 19% in another (Falloon, 1985).

The few hospital-based studies of family involvement that have been done show positive health outcomes for children. For example, when mothers provided the nursing care to their children after tonsillectomies, children recovered faster and went home sooner than those whose mothers did not provide the care (cited in Farkas, 1983, p. 15).

### RESEARCH NEEDED ON THE OUTCOMES OF FAMILY-CENTERED CARE AND TREATMENT

The results of these and other such studies are very promising. The growing body of research documenting the effect of family factors on health provides a strong rationale for a major investment in evaluation research that will examine the effects of family involvement on health outcomes for the individual and family, and the effects of family-centered care on health care costs. There has been a paucity of such studies to date. These studies need to be conducted across many branches of government. Among the questions that should be addressed are:

— How does involving the family in child health services affect children's health?

— What are the effects of family-centered health care on family members' health, utilization of health services, or individual functioning, such as children's school performance and attendance, and family stability and well-being?

— To what extent, and in which situations, does providing family information, education, support, and therapy to families in which a child or adult has a chronic illness or disability help to improve the health of the patient and of family caregivers, and reduce overall medical costs?

— What types of family involvement programs are most effective in improving individual's health outcomes?

— When spouse and family education and therapy are covered by employer-based managed care plans, what are the effects on employee productivity and absenteeism?

— What are the effects of managed care systems, or particular cost containment measures, on family health, functioning, and levels of family support?

— Other questions?

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## COFO Family Policy Report

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