



COFO

Consortium of
Family Organizations

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FAMILIES AND LONG TERM CARE: AN ISSUE FOR THE 1990'S

Long-term care is a major issue commanding increasing national attention. "As many as 4 million people are so severely disabled they cannot survive without substantial help from others. Millions more know the physical, emotional, and financial burdens of caring for relatives or friends who need such care."¹ The parents of technology-dependent children, adult children of the elderly, and the relatives of chronically disabled adults all face the burdens associated with providing home care, yet resist having their loved one placed in an institution.

Policymakers are aware of the need for a national long-term care policy but are paralyzed by the specter of the accompanying costs. Yet, as the Pepper Commission Report has recognized, the issue will not go away.

The Consortium of Family Organizations (COFO) believes that the debate needs to be reframed. The focus of policy needs to shift to those individuals, usually family members, who provide the bulk of long-term care. The key element to controlling costs and improving the quality of care is to address the central policy question: *How can we support, supplement, and strengthen family caregivers?*

This issue of the *Family Policy Report* examines a promising new initiative to support home-based long-term care—the Comprehensive Health Care Act, H.R. 4253, introduced by Rep. Mary Rose Oakar (D-OH) on March 13, 1990. Our brief analysis of the bill's section on home and community-based care is conducted from a "family perspective" using the key family criteria and questions developed by COFO (See *Family Impact Questions Insert*.)

COFO encourages readers to use this analysis when evaluating other legislative proposals on long-term care, including the recently released Pepper Commission recommendations.

H.R. 4253

The Comprehensive Health Care Act would provide universal access to health care and long term care for all Americans, funding for state-administered public health education and prevention programs, and funding for research and development for the prevention and cure of diseases that result in the need for long-term care.

A major section of H.R. 4253, Section B, addresses the issue of long term care. It builds upon other long term care proposals, including H.R. 3436, sponsored by Rep. Claude Pepper in 1988.

THE LIFE CARE LONG TERM CARE PROTECTION PROPOSAL

The Life Care Long Term Care Protection proposal of H.R. 4253 would amend the Social Security Act and establish Title XXI—The Life Care Long Term Care Protection Program. The

program would provide a range of benefits under a new federal/state-funded, state-administered program that would provide comprehensive health care assistance in the home and community (i.e., nursing home care) for any person of any age. The proposal is intended to allow states flexibility in developing and implementing a long-term care system based upon the specific needs of the state.

Eligibility for care would be determined by an individual's need for assistance with at least 2 activities of daily living (ADLs) (bathing, dressing, eating, toileting, etc.); or assistance in performing two or more age-appropriate activities; or the need for constant supervision because of a cognitive impairment. Eligibility for benefits would be certified by a screening agency and the determination of services would be based upon an assessment conducted by a case-management team. Eligibility would not be based upon income.

Home care services funded under the bill could include: home nursing care; homemaker/home health services; "heavy chore" services; respite care; dietary aid services; limited mental health services; the provision of medical supplies and equipment for home use; medical social services; and rehabilitative services.

The legislation also includes a strong system of quality assurance for home care, including mandatory training and regular review of paid caregivers, a home care consumers' bill of rights, and community review boards and other mechanisms to ensure compliance.

The bill's cost-containment provision is intended to tightly control costs for the first three years after enactment by limiting monthly payments to 65% of the costs for the same number of days of the monthly Medicaid rate for skilled nursing home services. In subsequent years, the U.S. Secretary of Health and Human Services would determine the cost for services based upon a prospective payment formula.

In addition, the bill would provide up to six months of free nursing home care. It also includes separate authorizations for training and research grant programs and demonstration projects for the seriously mentally ill and the working disabled.

The Congressional Budget Office (CBO) has estimated that Section B would cost \$30 billion in the first year. This amount includes the cost of six months of nursing home care. Although no separate costs breakouts were available for the homecare provisions of H.R. 4253, the Pepper Commission estimates its home care provisions would cost \$24 billion the first year and would serve about 3 million individuals.²

COFO's analysis suggests that H.R. 4253 not only incorporates many of the Pepper Commission's recommendations but is more generous in several areas. H.R. 4253 eligibility require-

ments allow more individuals to apply for assistance and it also allows six months of free nursing home care instead of three.

FAMILY IMPACT ASSESSMENT OF H.R. 4253

Overall, H.R. 4253 is a very important and constructive step forward in providing public funds to support family-based care across the life cycle. It has the potential for considerably easing the physical, emotional, and financial burden on families of providing home-based care, improving the quality of such care, and enabling chronically ill patients to be cared for at home.

From a "family perspective", however, COFO believes that H.R. 4253 should explicitly acknowledge the important and crucial role of family caregivers in the provision of long-term care. This role is acknowledged in the section separately authorizing demonstration projects for the mentally ill (Part F, Sec. 2151) but is not acknowledged in the primary portion of the Life Care Protection Act of H.R. 4253.

Information from research studies and testimony from family experts and caregivers indicate that the way in which a family responds to a relative's long term illness or disability is perhaps the single most important factor in determining how successfully that elderly parent, disabled adult child, or chronically ill child will adjust to their condition and whether they will have to be institutionalized or can remain living in the home. Moreover, the caregiving experience can be positive or negative, depending on the family's relationships, resources, support systems, and ability to cope.

On the plus side, H.R. 4253 includes funding for respite care and adult day care, two very important services needed by family caregivers, especially those who are employed.

Unfortunately, however, it does not include funding for other services needed by caregivers such as information and educational services and family counseling and/or therapy except under the mentally ill demonstration project.

The bill is also silent with respect to how professionals, especially case managers, are to work collaboratively with families. Our analysis suggests that some additional language in the bill or in the resulting committee report is required to provide guidelines and resources for training that will encourage health care and other social services providers to treat family caregivers as true partners in providing home and community-based care.

FAMILY IMPACT QUESTIONS (SEE INSERT)

1. FAMILY SUPPORT AND RESPONSIBILITIES

Does H.R. 4253 support and supplement parents' and other family members' ability to carry out their caregiving responsibilities?

Yes, H.R. 4253 would provide an array of medical and important nonmedical services that would partially support and supplement the care already provided by families. Two new, very important benefits are included: adult day care and respite care (720 hours per year). The inclusion of these benefits recognizes that it is the family caregivers who provide the bulk of care to their ill or disabled relatives. Although these benefits provide assistance to all families, they are especially helpful to families in which the primary caregiver is employed. Previous and current long term care proposals have not included or have significantly limited the scope of these benefits.

H.R. 4253 also provides funding for homemaker services and heavy chore services. Such services, for example, make it possible for an elderly couple, where one spouse is very frail, to remain in their family home and receive help with routine tasks, like cleaning, cooking, or fixing the faucet. Such services may also give

more support to a family trying to help their disabled adult child live more independently.

Very few private and public insurance programs reimburse for these services. Only 18% of the \$53 billion spent on long term care in 1988, went for home care, despite the fact that most disabled and severely disabled individuals live at home or in the community.³

Regrettably, H.R. 4253 restricts reimbursement for information and education services and counseling services for caregivers to Part F, Sec. 2151, the demonstration project for the mentally ill. Family counseling and education and information services are essential supports for caregivers given the psychological and physical strain of prolonged caregiving. This legislation needs to address this larger need.

Does H.R. 4253 provide incentives for other persons to take over family functioning when doing so may not be necessary?

Unfortunately, yes. COFO applauds the inclusion of funding for case management services but, as currently drafted, these provisions largely ignore the role and needs of family caregivers. There is no explicit language that requires case managers to work in partnership with families in the coordination and management of services needed by the ill or disabled relative (Sec. 2101(5)). Yet, in the majority of cases, families are already carrying out these responsibilities.

COFO suggests using language here similar to that which is contained in the mental illness authorization, which states that services provided under this authorization shall "*be responsible to family needs and concerns and appropriately involve and consult family members*" (Sec. 2151).

On the other hand, the section outlining the requirements for homemakers expresses an expectation that the professional is to work in conjunction with the family in the provision of services (Sec. 2101).

What effect does H.R. 4253 have on adult children's relationship with their elderly parents?

Although the bill does not directly address the emotional issues involved in providing long-term care, research and polling data indicate that adult children with ill or disabled parents experience much anxiety and conflict when decisions must be made regarding a parent's long-term care needs. Moreover, elderly parents are often concerned about becoming a burden to their children.

In addition, findings from studies conducted to date indicate that the situation is greatly improved when sufficient support is available to caregivers from both case managers and other professionals. When the patient receives care at home (either in a child's home or his or her own home), both caregivers and the parent apparently experience less stress and tension. Overall improvement in the parent-child relationship is a by-product as well.

2. FAMILY MEMBERSHIP AND STABILITY

Does H.R. 4253 encourage and reinforce marital and family commitment and stability especially where children are involved?

Yes, indirectly, H.R. 4253 is likely to have a positive effect on marriages and family commitment. Studies have shown that in many cases the burden of caring for a very ill child, disabled adult child, or a frail spouse for long periods of time places enormous strain on a marital relationship, which may cause it to breakup or deteriorate to behavior involving neglect or abuse. The availability of respite care, adult day care, homemaker services and home

health care, which provide some emotional, physical, and mental relief for couples and parents, contribute to the quality of marriage and family life.

3. FAMILY INVOLVEMENT & INTERDEPENDENCE

To what extent does H.R. 4253 recognize the influence of the family context upon the individual's need for long term care?

In several instances, H.R. 4253 partially recognizes the impact of the family upon the health of the individual but, for the most part, the legislation largely disregards this influence. The comprehensive needs-assessment provisions (Sec. 2101(7)) somewhat recognize the family situation in determining the level of services. For example, "*The [comprehensive needs] assessment shall address the functional status of the individual...instrumental activities of daily living...mental status...and the availability of caregiver support.*"

In addition, in Sec. 2101(13), homemakers are to report "*...changes in the condition of the family situation of the individual...*" to a registered nurse supervisor, reflecting an awareness that the family situation has an impact upon the individual's need for care.

How does H.R. 4253 assess and balance the competing needs, rights, and interests of various members of the family?

To some degree, H.R. 4253 recognizes that a balance needs to be struck between the interests of the chronically ill/disabled individual and other members of the family.

Presumably, the adult day health care benefit would allow a previously employed daughter, now taking care of her frail parent full time, to return to the work force in order to financially support her family.

Additionally, respite care benefits might allow parents of a terminally ill child an opportunity to spend time with their other children.

On the other hand, the bill is less clear about balancing the rights of various members of the family. Although H.R. 4253 explicitly recognizes the rights of the individual through the provisions of the Consumer's Bill of Rights (Sec. 2118), the rights and role of the family caregiver are not made fully explicit and need to be. Even though the bill of rights "*may be asserted by the home care consumer or his or her representative*", it is not clearly stated who the representative may be.

In the implementation of this component of the bill, regulations or administrative memoranda should define the procedures for designating the patient's representative in the case of adult and elderly patients who are considered unable to exercise their rights themselves. For example, the issue of who should take care of the ill person's finances is not addressed. Although this issue is normally resolved on a case-by-case basis, any statutory language that spells out the consumer's rights should be careful to protect the rights of parents and family caregivers as well.

4. FAMILY PARTNERSHIP AND EMPOWERMENT

In what ways does H.R. 4253 involve parents and family representatives in policy and program development, implementation, and evaluation?

H.R. 4253 seems to involve family caregivers in the program development, implementation, and evaluation of programs, both at the national and the state/community level. States must "*establish and appoint members to an advisory board for each Case Management Agency [which] shall be composed of consumers of services and their families*" (Sec. 2118). Although the mission of

the Advisory Council is not totally spelled out, presumably it would include assisting the Case Management Agency in identifying the long term care needs of individuals and their caregivers in the community. At the national level, a Home and Community-based Care Advisory Council would be established to advise the Secretary of Health and Human Services in the implementation of H.R. 4253. The Council would include "*home and community-based consumers and their representatives.*" Again, it is presumed that family members would be considered "representatives" in this case.

In what ways are professionals required or encouraged to work with the families of their clients?

As mentioned in the second question under #1 above, there is very little specific language that requires professionals to work collaboratively with family caregivers. Basically, only homemakers are directed in the bill to work with families. Otherwise, the bill does not indicate to the other helping professionals that the family needs to be treated as a partner in the provision of long term care.

Committee report language or the regulatory process could encourage this collaboration by requiring that the standards for education, training, and experience that must be met by case managers (Sec. 2101(6))—and other professionals as well—include training in family systems and experience in working with the whole family.

5. FAMILY DIVERSITY

How does H.R. 4253 affect various types of families?

One of the primary strengths of H.R. 4253 is its recognition that long term care is a problem that faces families across the life cycle and families coping with different chronic diseases and disabilities. Other aspects of family diversity and complexity however, are not addressed in the bill. As an example, the bill does not reflect an awareness of the specific issues and/or problems of different types of families, such as single-parent families or stepfamilies. In addition, language is needed that requires health and social service professionals, "*to be sensitive to the needs of racial and ethnic minorities*", which is a requirement under the demonstration project for the mentally ill.

6. TARGETING VULNERABLE FAMILIES

Does H.R. 4253 identify and target publicly supported services for families in the most extreme economic or social need?

No. The bill does not base eligibility for services upon an individual's ability to pay nor does it require payment—either full or on a sliding scale fee—for services. Everyone, regardless of their ability to pay, can apply for the same long-term care benefits. On the other hand, the bill recognizes different levels of need based upon the individual's physical and cognitive abilities.

¹ A Call for Action, (The Pepper Commission, U.S. Bipartisan Commission on Comprehensive Health Care, 1990), p. 10.

² Ibid, p. 17.

³ Ibid, p. 11.

NOTE: COFO wishes to thank the legislative staff of Congresswoman Mary Rose Oakar for their cooperation and help with this report. They report that H.R. 4253 will be reintroduced in the 102nd Congress and will address many of the issues raised in this Report.

The next issue of the Family Policy Report will focus on substance abuse legislation and families.



Increasingly, policymakers and their staff at all levels of government ask: **What effects does (or will) this program (or proposed policy) have on families? Will it help or hurt, strengthen or weaken family life?** These questions sound disarmingly simple. In fact they are very complex. A policy may have different effects on different types of families and on various dimensions of family life. Research may determine what these impacts are. But evaluative criteria are needed as yardsticks to decide what is meant by the terms "strengthen" and "weaken."

COFO has developed a tool to serve as a basic framework for such investigations: a set of six guiding principles to serve as the criteria and a checklist of basic family impact questions. These tools, when used together, guide the research.* COFO believes that these principles, or family criteria, represent a general consensus on goals for family policy. The relevant family impact questions listed under each principle should be adapted and fleshed out to incorporate specific program content. This tool can be used to:

- Help prepare questions for legislative hearings.
- Review a policy proposal, draft regulation, or draft bill.
- Study the implementation and assess the outcomes of an existing program.

Often the answers to these questions are not readily available because the research has not yet been conducted. **But the first essential step is to ask the right questions.** Only then will the necessary research follow.

CHECKLIST: A TOOL FOR ANALYSIS

✓ Check those principles and questions that apply to the particular program or policy.

1. FAMILY SUPPORT AND RESPONSIBILITIES: Policies and programs should aim to support and supplement family functioning and provide substitute services only as a last resort.

- ✓ How does the proposal (or existing program) support and supplement parents' and other family members' ability to carry out their responsibilities?
- ✓ Does it provide incentives for other persons to take over family functioning when doing so may not be necessary?
- What effects does it have on marital commitment or parental obligations?
- ✓ What effects does it have on adult children's ties to their elderly parents?

2. FAMILY MEMBERSHIP AND STABILITY: Whenever possible, policies and programs should encourage and reinforce marital, parental, and family commitment and stability, especially when children are involved. Intervention in family membership and living arrangements is usually justified only to protect family members from serious harm or at the request of the family itself.

- ✓ What incentives or disincentives does the policy or program provide to marry, separate, or divorce?
- What incentives or disincentives are provided to give birth to, foster, or adopt children?
- What criteria are used to justify removal of a child or adult from the family?
- What resources are allocated to help keep the family together when this is the appropriate goal?
- What services are provided to help family members living apart remain connected and, if appropriate, come together again?

3. FAMILY INVOLVEMENT AND INTERDEPENDENCE: Policies and programs must recognize the interdependence of family relationships, the strength and persistence of family ties and obligations, and the wealth of resources that families can mobilize to help their members.

- ✓ To what extent does the policy or program design recognize the influence of the family context upon the individual's need or problem.
- To what extent does it involve immediate and extended family members in working toward a solution?
- To what extent does it acknowledge the power and persistence of family ties, especially when they are problematic or destructive?
- ✓ How does it assess and balance the competing needs, rights, and interests of various members of a family? ➔

*Adapted from *A Strategy for Strengthening Families: Using Family Criteria in Policymaking and Program Evaluation*. T. Ooms & S. Preister, Eds. A consensus report of the Family Criteria Task Force. Washington, DC: Family Impact Seminar, 1988.

4. FAMILY PARTNERSHIP AND EMPOWERMENT: Policies and programs must encourage individuals and their close family members to collaborate as partners with program professionals in the delivery of services to an individual. In addition, parent and family representatives are an essential resource in policy development, program planning, and evaluation.

In what specific ways does the proposed or existing program provide full information and a range of choices to individuals and their close family members?

In what ways do program professionals work in collaboration with the families of their clients, patients, or students?

In what ways does the program or policy involve parents and family representatives in policy and program development, implementation, and evaluation ?

5. FAMILY DIVERSITY: Families come in many forms and configurations, and policies and programs must take into account their different effects on different types of families. Policies and programs must acknowledge and value the diversity of family life and not discriminate against or penalize families solely for reasons of structure, roles, cultural values, or life stage.

How does the proposal or program affect various types of families?

If the proposed or existing program targets only certain families, for example, only employed parents or single parents, what is the justification? Does it discriminate against or penalize other types of families for insufficient reason?

How does it identify and respect the different values, attitudes, and behavior of families from various racial, ethnic, religious, and cultural backgrounds that are relevant to program effectiveness?

6. TARGETING VULNERABLE FAMILIES: Families in greatest economic and social need, as well as those determined to be most vulnerable to breakdown, should have first priority in government policies and programs.

Does the proposed or existing program identify and target publicly supported services for families in the most extreme economic or social need?

Does it give priority and preventive services to families who are most vulnerable to breakdown?

THE CONSORTIUM OF FAMILY ORGANIZATIONS

Formed in 1977, the Consortium of Family Organizations (COFO) is composed of five national organizations working together to promote a family focus in public policy and social programs. In addition to other activities, COFO sponsors monthly family policy seminars held in Washington, DC, by AAMFT's Family Impact Seminar.

Member organizations of COFO are:

The American Association for Marriage and Family Therapy (AAMFT) is the professional association for nearly 17,000 credentialed marriage and family therapists in the United States, Canada and abroad. The AAMFT Research and Education Foundation conducts research, education, and other activities that promote the well-being of marriage and family life. The Family Impact Seminar is the policy unit of the Foundation. Mark R. Ginsberg, Ph.D., Executive Director, AAMFT, 1717 K Street, NW, Suite 407, Washington, DC 20006, 202/429-1825. COFO Representative: Steven Preister, D.S.W., AAMFT Deputy Executive Director.

The American Home Economics Association (AHEA) is an educational and scientific association of more than 26,000 professionals from various disciplines that comprise the field of home economics. Karl Weddle, Ph.D. Interim Executive Director, AHEA, 1555 King Street, Alexandria, VA 22314, 703/706-4600. COFO Representative: Kathleen Sheehan, Director of Public Policy.

Family Resource Coalition (FRC) is a national organization representing thousands of community-based family resource and support programs across the country. Bernice Weissbourd, President, 230 N. Michigan Avenue, Suite 1625, Chicago, IL 60601, 312/726-4750. COFO Representative, Frank Farrow, 202/371-1565.

Family Service America (FSA) is a network of more than 290 private, nonprofit, voluntary agencies in the United States and Canada dedicated to providing a wide range of services to families in crisis or with specific problems and needs. Geneva Johnson, President, FSA, 11700 West Lake Park Drive, Milwaukee, WI 53224, 414/359-1040. COFO Representative: Patricia Langley, Director, FSA Office on Governmental Affairs, 1319 F Street, NW, Suite 606, Washington, DC 20004, 202/347-1124.

The National Council on Family Relations (NCFR) is the professional association of scholars and practitioners engaged in research, dissemination, and practical application of the multidisciplinary study of marriage and family life, family life education and counseling, and public services for families. Mary Jo Czaplewski, Ph.D., Executive Director, NCFR, 3989 Central Avenue, NE, Suite 550, Minneapolis, MN 55421, 612/781-9331. COFO Representative: Margaret Feldman, Ph.D., 1311 Delaware Avenue, SW, Washington, DC 20024, 202/554-0242.

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COFO FAMILY POLICY REPORT

The *COFO Family Policy Report* is a publication of the Consortium of Family Organizations (COFO), consisting of the American Association for Marriage and Family Therapy (AAMFT), the American Home Economics Association (AHEA), the Family Resource Coalition (FRC), Family Service America (FSA), and the National Council of Family Relations (NCFR). Formed in 1977, the nonpartisan Consortium is committed to the promotion of a family perspective in public policy and human services. Collectively, COFO comprises nearly 50,000 family professionals working with families in every state of the union, faculty members in every major university in the nation, nearly 300 family agencies and more than 2,000 family resource programs providing services to millions of families annually, and more than 10,000 volunteer board members.

The *Report* is published quarterly in the spring, summer, fall, and winter and addresses current legislation and programs that affect families. Correspondence and requests for subscriptions and back issues may be addressed to COFO Coordinator, c/o FSA Office on Governmental Affairs, 1319 F Street, NW, Suite 606, Washington, DC 20004,

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