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# Home Care for Life-Supported Persons: the French System of Quality Control, Technology Assessment, and Cost Containment

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## Synopsis .....

*Home care for persons who require the prolonged use of life-supportive medical technology is*

*a reality in several nations. France has had more than a quarter of a century of experience with providing home care for patients with chronic respiratory insufficiency and with a system to evaluate the patients' outcomes. The French approach features decentralized regional organizations which offer grassroots involvement by the beneficiaries who participate directly in the system. Since June 1981, a national organization has provided patients, professionals, and others concerned with direct access to national funding authorities and governmental officials and has created a data base for evaluation of the experience. This system permits direct input by current users of the services and creates informed opinion among members of the general public, governmental officials, and others involved (health care professionals and service providers). This is essential for the development of responsive public policy and for the determination of the relevancy of programs.*

*In the United States, increasing demands are being made upon expensive hospital services by patients with diseases such as AIDS and other catastrophic, long-term care conditions. Cost-saving, community-oriented home care models serving complex medical-societal needs abroad are worthy of study to discern possible applications to health and social problems in our nation.*

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**H**OME CARE FOR PERSONS who require prolonged use of life-supportive technology for breathing is a reality in many nations (1, 2). The initial home care programs for ventilator-assisted persons were established at regional polio centers during the poliomyelitis era (3, 4). In the United States, the poliomyelitis era ended in 1956 when the Salk vaccine came into common use. However, the era continued into the 1960s in France, where vaccine use was not mandatory. Beds in evolving intensive care units in France were occupied by polio patients with respiratory insufficiency. In the respiratory centers (and the ICUs that evolved from them), care at home programs were designed for survivors of poliomyelitis with severe chronic respiratory insufficiency who could benefit from returning to their families and communities. Over the years, extensive programs derived from these original centers of expertise evolved to serve patients with other life-threatening conditions who could be treated

successfully because of advances in critical care and rehabilitation medicine.

## Overview

Although home care can be accomplished for ventilator-assisted persons, concerns have been raised by U.S. public policy experts about the expanding practice of the prolonged use of the mechanical ventilator, a "halfway technology" (5). In addition to cost-benefit issues, questions asked included the performance reliability of life-sustaining medical devices designed for use in the home, the adequacy of patient and equipment surveillance, and the appropriateness of health care services provided in the community. Quality control, technology assessment, and cost containment all require a system to determine if care delivered and technology applied are medically necessary, appropriate to the individual patient, and reflective

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of cost-consciousness while maintaining quality.

Current concerns about the organization, data collection, and quality assurance of medical care in the United States encourage efforts to evaluate experiences abroad that might be applicable to our nation. France has had more than a quarter of a century of experience with a community-based system of regional home care programs for ventilator-assisted persons (6). The original program was established by the Association of the Lyon Region for the Fight Against Polio (Association de la Region de Lyon Pour la Lutte Contre la Poliomyélite = A.L.L.P.). The A.L.L.P. began in 1960 as a collaborative effort among concerned physicians, regional governmental officials, funding authorities, and patients who could not leave the hospital because of their prolonged need for mechanical ventilation. The second program was established in Paris in 1967 by the Association of Mutual Aid for Polio and Handicapped (Hospitalized) People (Association d'Entraide des Polios et Handicapés (Hospitalisés) = A.D.E.P.). A.D.E.P. modeled its home care service after the A.L.L.P. and added two concepts of major relevance: a documentation center and an alternative community-based living arrangement (foyer) for those who could not return to their families.

During the 1970s, many other regions developed programs modeled after the A.L.L.P. and A.D.E.P. for providing mechanical ventilation at home and in response to increased demands for home respiratory support with oxygen. As a result, a study was commissioned in 1978 by the Ministry of Health and the major national health care funding authority of France, the National Health Care Finance Authority for Salaried Workers (Caisse National de l'Assurance Maladie des Travailleurs Salariés = C.N.A.M.). The dual purpose of the study was to evaluate the initial experience and determine options for the future.

Two outcomes of the study were the development of many more regional programs and the creation of a national organization, the National Home Care Association for Chronic Respiratory Insufficiency (Association Nationale Pour le Traitement à Domicile de l'Insuffisance Respiratoire Chronique = A.N.T.A.D.I.R.). A.N.T.A.D.I.R. was established in June 1981 to accomplish tasks more appropriately managed at the national level. The association was an outgrowth of 20 years of program evolution and one specific recommendation that this experience be carefully evaluated.

The components of the French system, as well as their interaction at the local, regional, and national levels, reflect the needs of multiple parties: government officials, reimbursement authorities, health professionals, service and equipment providers, and patients and their families. In addition to the direct services provided, mechanisms are in place to control quality, assess technology, and contain cost. The focus of this communication, taken from my 1986 WHO Fellowship Report, is to describe the operations of the French solution to the care of patients with severe chronic respiratory insufficiency. The purpose of the report is to determine if this approach is useful for other complex medical-social problems and applicable to the United States or other nations.

## **The Regional Level**

**Historical evolution.** France, a nation of 55 million inhabitants, had 28 regional associations serving 10,000 patients who were ventilator-assisted, oxygen-dependent, or both, in 1985. Each regional association had evolved at the grassroots level after initiation by an individual or small group of concerned persons: health professionals, patients and family members, and community leaders. Each organization had grown out of a "base unit" in a designated regional center of expertise at a university affiliated medical center. In each region, a growing number of medically stable, technology dependent patients with chronic respiratory disorders had accumulated in expensive intensive care units, blocking more appropriate use of such acute care facilities. Prompted by both social concerns and financial constraints, the associations were created to develop the mechanisms for the proper selection, preparation, and training of patients and families for discharge to home. They were designed to provide the clinical and technical surveillance required for safety; to monitor psychosocial, financial, and health-related issues;

and to manage overall care coordination in the community of these candidates for complex home care.

Regional associations were originally conceived as social support systems. Since the turn of the century, the French have had associations "according to the law of July, 1901" as a legal "nonlucrative" entity available for any social purpose. Such organizations are available to any group that functions to benefit its constituencies. Statutory requirements define the structure of their governing bodies and specify accountability and oversight mechanisms.

**Organizational structure and function.** The regional associations for chronic respiratory insufficiency are incorporated "according to the law of July, 1901." As such, they must serve a social, not-for-profit purpose, and they must be controlled by representatives of the universal constituency who are beneficiaries of the services provided.

Each regional association has a general assembly made up of representatives of the government (ministries), reimbursement authorities (caisses), health professional disciplines (physicians, nurses, physical (respiratory) therapists, social workers), and patients and their families. The general assembly is an open membership body for all persons involved. For example, local primary care physicians, community agency representatives, governmental officials, and patients and families are among members who can vote and affect policy. The size of the general assembly varies with each association. The general assembly of the A.L.L.P. has 60 voting members; some have as many as 200. General assemblies meet annually. The decisions they make by voting are enforced by members who represent the "public powers" (ministries, caisses) who must sign all contractual terms for reimbursement of services provided by the association.

For operational convenience, each general assembly elects members of a working administrative council who prepare budgets and propose policy and procedures for approval by the general assembly. The administrative council elects its own president who appoints other officers. By law, the council must have 4 persons; most councils consist of between 4 and 12 members. In addition, a committee (commission) structure is in place to review financial, medical, technical, and social issues of importance to the constituency. By means of studies authorized by the committees and conducted by subcommittees, concerns about quality of services, assessment of technology, containment

of costs, funding of programs, and appropriateness of health care practices can be raised, opened for discussion, and brought to resolution. The regional associations can meet and monitor effectively the technological and care needs of the beneficiaries with the input of those affected by or receiving services. Regional associations also work closely with the regional medical centers from which they draw both expertise and human and material resources.

Program criteria and services and the means to implement and evaluate them at the local level are clearly defined by legal contracts executed between the regional associations and the regional reimbursement authorities. Each regional association functions within clearly defined protocols to prepare patients and their families for home and to provide the means to assure patients' safety once in the community. Administrative, technical, and professional staff, including physicians, provide both surveillance and support to assure patients' well-being. They collect data in a broadly defined computerized data base that covers the total experience of each patient in the home care. This information system is almost universal among the regional associations. Its components include health status, service delivery, device experience, and cost-accounting data. Such a management information system permits a comprehensive review of each patient's situation and the comprehensive experience of each region for the purposes of managed care, quality control, and program evaluation.

## The National Level

**Historical evolution.** The magnitude of the current system in place in France targeted to chronic respiratory insufficiency has evolved over nearly 30 years. The expansion over the past decade reflects awareness that the numbers of persons requiring long-term oxygen support were growing and that costs could only be contained and quality assured if the system that was then in place was evaluated now.

France already had the benefit of pioneering regional home care programs for mechanical ventilation (6). A special study authorized by the Ministry of Health and the National Health Care Finance Authority in 1978 evaluated past experience for future planning. Since 1985, the number of the beneficiaries of the system has grown to more than 20,000 persons with chronic respiratory insufficiency. An additional 3,000-4,000 people are served by proprietary organizations outside the

associations. Most patients that are eligible are known to the C.N.A.M. because they require a standard procedure. In France, there is a standard prescription that must be filled out by the patient's physician in order to obtain approval for mechanical ventilation or oxygen in the home. This prescription is required when public monies are used whether the services are provided by the association or a proprietary organization.

The French way of doing things requires that decision-making and implementation of services administered regionally and delivered locally with monies collected "for the common good" are overseen and approved by public authorities at the national level (7). The authors of the 1978 study recommended that A.N.T.A.D.I.R., a national association "according to the law of July, 1901," federate the regional associations, evaluate their collective experiences, and involve national level leaders from the government, funding authorities, and scientific societies in making decisions about the criteria for services and technology appropriate for this target population. With such participants, commitment is obtained at the "action level," and public policy is established based upon informed opinion.

#### **Organizational structure and function.**

A.N.T.A.D.I.R. at the national level reflects the regional association model. A.N.T.A.D.I.R. has a broad-based constituency whose members represent a cross-section of society (governmental, financial, scientific, and professional), sections that should and must be involved for such a system to work in France. Governance is via a general assembly, administrative counsel, and committee structure that provides authority to and demands accountability from the staff of the national program. Since membership in this national body is open to all regional associations, issues raised reflect local and regional realities as well as national priorities. A national data base provides access to an information registry that is required for a variety of purposes: public policy formation, capital budget planning, review of operations, materials management (including procurement, inventory, and distribution), cost containment analysis, technological assessment, and quality control. All of these tasks concern individual members and organizations that provided input into the design of the system. Information exchange occurs daily between regional associations and A.N.T.A.D.I.R., and monthly reports and quarterly meetings of many subcommittees enhance communication. As a result, members at every level

are aware of issues that affect quality, technology, and cost.

**Health care financing.** The home care system for chronic respiratory insufficiency is financed by contracts for services authorized by funding authorities (caisses) and the government (social security). In France, all citizens must contribute as workers or employers to "caisses" which are defined by the nature of the work and geographic location. More than 75 percent of workers in France have obligatory payroll deductions designated for social and health programs that are reviewed by the National Health Care Financing Authority for Salaried Workers for its regional (C.R.A.M.) and local (C.P.A.M.) branches. Although there are many minor funding authorities for other defined categories of worker groups and the remaining population, most of them (the caisses) have agreed to abide by policy formulation made by the major general organization. C.N.A.M. policy also requires approval of the Ministries of Health and Social Security. Thus, there is a mechanism for consensus which has resulted in a national public policy in France regarding reimbursement and the establishment of focused programs for persons with chronic respiratory insufficiency.

**Information registry.** In addition to monitoring the services provided to this growing population, A.N.T.A.D.I.R., A.D.E.P., and A.L.L.P. maintain continuous mechanisms to collect and exchange information necessary to improve the system's functioning. These management information mechanisms make it possible for any concerned person or organization to obtain both quantitative data and qualitative information pertinent to this target population.

To prepare my 1986 WHO Fellowship Report to the Surgeon General, I requested and received within 10 working days statistical data according to the following categories on patients with severe chronic respiratory insufficiency in France:

- national population served, 1982 and 1986 (A.N.T.A.D.I.R.)
- global home care costs, 1986 (A.N.T.A.D.I.R.)
- home care costs and experiences by etiology and therapeutic categories, 1983-86 (A.D.E.P.)
- home care costs and experiences by etiology and therapeutic categories, 1983-86 (A.L.L.P.)

These data were presented in tabular form in my

report (copies may be requested from the author).

In addition, biannual publications of the Medical-Technical Subcommittee of A.N.T.A.D.I.R. review major studies that evaluate the appropriateness and quality of medical practices and technological applications (8). Similar studies of relevant social issues and financial concerns are conducted by the social and finance subcommittees. These consensus reports incorporate grassroots input which validates the system in place and empowers it with effective mechanisms.

### **Applicability to the United States**

The general purpose of a WHO Fellowship is to determine how one nation has responded to complex public health issues in ways that might be applicable to health and social problems in other countries. My 1986 WHO Fellowship built upon my 1985 study of life-sustaining technologies and the elderly performed under contract with the U.S. Congress, Office of Technology Assessment (5). Specifically, my 1986 WHO Fellowship was designed to determine the applicability of France's regional organization of home respiratory care to the United States: Could it work? Who would administer it? What would be the specific barriers to setting up such a system in our own country?

What is put in place to meet the health needs of a nation is a reflection of its political, economic, social, and cultural realities (9). The associative system legislated in 1901 works in France because it is "the French way" of meeting social needs outside of governmental bureaucracy, and it is appropriate to the culture. Many characteristics of the regional associations demonstrate the French people's traditional determination to respect the "equality, fraternity, and liberty" of all citizens. However, the uniqueness of each association also "fits" the local scene; France is far from a homogeneous nation (10). Furthermore, the organizational components and the evolution of the French regional system are remarkably similar to those of the Responaut regional program in England (11). I have already described the common elements for a successful program in these two very different countries in my 1983 World Rehabilitation Fund Fellowship Report (12). Both nations' programs reflect the willingness of key individuals and committed organizations to work together to the benefit of the same target population; to understand local, regional, and national requirements; and to respond to these demands.

The United States is a very different nation from France (13). Inherent in our differences are both barriers and opportunities for establishing a program modeled after the French. Our founding fathers were determined to foster individualism and broaden the opportunities for everyone. We are a pluralistic and increasingly specialized society that encourages diversity. Our nation values entrepreneurial initiatives and the pioneering spirit. Our frontier tradition rewards the strong but also helps those in need of assistance at a time of crisis. As a result, our health care reimbursement system is geared to acute care.

The United States also is far from uniform; its various regions comprise several "nations" (14). Although there exist Federal laws and administrative regulations determining public policy for health care financing and the provision of services, implementation of many laws and regulations is discretionary at the State and local levels. Our nation has a highly fragmented public and private reimbursement system, multiple payers, and complex channels of supply and distribution which makes it difficult to put in place a coordinated health care delivery system. American medicine is undergoing a social transformation that will profoundly alter the traditional system of providing health and medical care (15).

A comprehensive home care program for persons requiring life-support systems could be established in the United States, but its creators would have to understand certain realities. Americans resist being registered and accounted for and prefer to use their own resources before seeking public support. These attitudes have hampered attempts to collect needed information. In 1982, Surgeon General C. Everett Koop requested an indication of the magnitude of the need for home care programs for technology dependent children (16). Since then, multiple attempts have been undertaken to obtain information and increase understanding of the issues. As a result of the way we organize services, fund programs, and prioritize concerns, there is yet no consensus for a uniform approach to the development of "a system."

Respiratory care at home transcends medical needs. It represents a social problem that cannot be solved in the customary ways we budget, finance, and deliver services. The varied needs of patients with chronic respiratory insufficiency at one time or another impact all sectors of society: private, public, governmental, and voluntary. What is put in place must manage all the sectors and reflect cultural differences and regional peculiarities within

our country. It must value the central roles of the family, self-help, and alternative care providers.

A cost-effective and operationally successful program in the United States must generate a minimum patient volume, work within constraints of local public health care financing, and serve all political and business entities with which it must interact. The program should operate primarily at the local and State levels.

Since these patients often travel to special centers to obtain medical care, regional arrangements should be considered for interstate financing and service delivery. A national component should also be established to collect and disseminate information and to capitalize on learnings from regional experiences. In addition, a national association is needed to work with other national organizations. A national association could realize economies of scale that would lead to improved quality and cost reduction.

Does "the association" fit the American way? Alexis de Tocqueville noted associations in place in the United States many decades before France developed them and predicted their vital role (17). He observed (18): "Americans of all ages, all conditions, and all dispositions constantly form associations. . . . Wherever at the head of some new undertaking you see the government in France, or a man of rank in England, you will be sure to find an association." Furthermore, de Tocqueville saw the importance of the association in replacing the powerlessness of the individual with the collective force of people voluntarily helping each other (18): "Governments, therefore, should not be the only active powers; associations ought, in democratic nations, to stand in lieu of those powerful private individuals whom the equality of conditions has swept away."

Whether we in the United States approach the care of patients with chronic respiratory insufficiency in the private or voluntary sector is a question of finance. A not-for-profit organization would have financial advantages over a commercial enterprise: tax exempt status, fund raising options, and no payback requirements to equity or debt investors. However, due to the complexity of the required service components, the approach must incorporate the latest organizational development and management practices to compete for available resources and be credible with participants (19). It must be run "as a business" to achieve the economies of scale that a private company would if it decided to target this population as a product line. The profits that it could capture would be

available for reinvestment in service delivery for social needs that are today hard to fund. A not-for-profit company would invite representatives of all beneficiaries to serve on its board of directors, advisory councils, and committees. It would "work in a glass house" and be accountable to all stakeholders, including public and private payers.

Leadership and management are major issues inherent in establishing a systems approach to patients with chronic respiratory insufficiency in any nation. The task to be accomplished is the same in every country; the difference is how it is done. The central role of culture and tradition must be respected. In Drucker's view (20), "Because management deals with the integration of people in a common venture, it is deeply embedded in culture. . . . One of the basic challenges managers. . . . face is to find and identify those parts of their own tradition, history, and culture that can be used as building blocks."

The key to success in France was the recognition that chronic respiratory insufficiency was an issue of enough significance to warrant specific action. Programs resulted from the determination of concerned leaders to put in place an operational system that works in France's unique political and cultural setting. As a result, both quality and cost savings have been realized. Information can be obtained to develop programs and evaluate outcomes.

In the United States, the fragmentation of "unbundled" services and partial regulation has resulted in uncoordinated delivery and rising home health care costs that have approached and exceeded fixed prospective payment rates to hospitals for these patients. Some ventilator-assisted persons have been denied the choice of the home option due to regulations and statutory requirements. This lack of choice is contrary to the values of our heritage. It has also resulted in patients remaining needlessly in institutions, blocking beds required for those with other acute care problems. Hospitals have faced rising costs and increasing losses due to limited funding for these patients. We can no longer afford, financially or ethically, the absence of a rational approach to the solution of this problem.

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## Does the Average Cost of Home Health Care Vary with Case Mix?

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### Synopsis .....

*The relationship between the average cost of home health care and the case mix of patients served by the home health agency is investigated using 1983 data from Wisconsin's home health care agencies. In contrast to previous work, case mix is shown to have a significant effect on the home*

*health agency's average costs. The methods used in the previous work are evaluated, and differences between the earlier study and the present study are discussed to explain the divergent results. Also, average costs are shown to decrease with output, to increase with the proportion of private patients served by the agency, and to be higher if the home health agency is located in an urban area or if it has a proprietary charter.*

*The implications of this research for the design of an appropriate home health reimbursement policy are discussed. Primarily, it is argued that, although future research might confirm the relationship between average costs and case mix for home health agencies, we cannot necessarily conclude that reimbursement rates must be adjusted to account for differences in case mix as many States are now doing for nursing home reimbursement. Policies must take into account the fundamental differences between home health agencies and nursing homes, and their respective markets, in order to be effective.*

**A**LTHOUGH A LARGE NUMBER of articles have investigated the determinants of average costs of nursing homes, the health services literature has

almost totally neglected similar "cost function" research with regard to home health agencies. This neglect is somewhat surprising since many of the