

1993 Report on Home-Based Long-Term Care

Prepared by the Polio Survivors Association

INTRODUCTION

The purpose of this report is to acquaint the reader with issues relating to long-term care, and enlist support for programs that provide home-based long-term care. As survivors of the polio epidemics of the 1940s and 1950s, the authors feel that they have a unique perspective on this part of the health care spectrum. We hope to provide insights into this area that will become increasingly important as our nation's population ages, and as technology allows more people to survive catastrophic illness and injury.

We will show that home-based long-term care can be both safe and cost effective. It can provide the elderly and disabled with the means to avoid unwanted institutional placement. With home-based long-term care individuals remain more independent and often continue to be actively involved in their communities.

We feel that it is in the interest of all Americans that their disabled fellow citizens live with dignity, and as much independence as possible. This should be the goal of all government agencies; local, state, and federal. When one person's life is improved, we are all enriched. If an opportunity to help is missed, it is a denial of the best in all of us.

*Richard Daggett, President
Polio Survivors Association*

BACKGROUND

Many health care issues appear in the news. In the last few years we have read headlines announcing, "Trauma Centers Close For Lack Of Funds," "AIDS Brings Health Care Crises," "Health Care Reform Tops Agenda." These and similar health related issues will have an impact on every American. In the 1992 presidential campaign, all of the major candidates issued statements about how they would deal with the increasing cost of health care.

The people of the United States, individually and collectively, spend about 800 billion dollars on health care annually. Experts predict that we will be spending twice that amount by the end of the decade.

The broad spectrum of health care can be loosely divided into four general areas.

- **Primary Care:** Preventive medicine and health maintenance, usually provided in the doctor's office or clinic.
- **Acute Care:** Serious illness and post trauma care, usually provided in a hospital.
- **Trauma Care:** Immediate care of major injury, usually provided in the emergency unit of a hospital.
- **Long Term Care:** Extended period health care and supportive services, too often provided in a skilled nursing or board and care facility.

Rehabilitation medicine is also an increasingly important part of health care, and can take place separately or concurrently with these four groups. No single aspect should take precedence over any of the others. This report, however, will concentrate on long-term care.

Most news coverage of long-term care emphasizes skilled nursing facilities, e.g. convalescent hospitals, nursing homes, and similar institutional settings. This industry consumes nearly 50 billion dollars annually. About \$22 billion of this is taxpayer money, mostly through Medicaid and Medicare. The remainder is a mix of private insurance, and the assets of individuals who reside in these settings and their supportive family members.

It is estimated that one person in twelve will become permanently disabled before the age of sixty. According to *Parade* magazine, eight out of ten American families will be faced with a long-term care dilemma due to the frailties associated with advanced age or a disability. A study published in the *New England Journal of Medicine* (Vol. 324, No. 9, Feb. 28, 1991) shows that 13 percent of all women and 4 percent of all men will spend at least five years in a nursing home. Thirty-three percent of all people who reached age 65 in 1990 will spend at least three months in a skilled nursing facility, and 25 percent will spend at least a year. The number of people using nursing homes nearly tripled between 1964 and 1985.

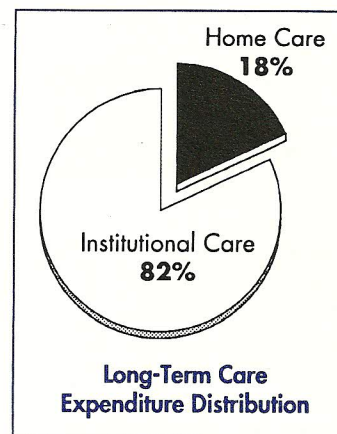
In addition, a study published by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research estimates that 9.5 million non-institutionalized Americans experience difficulty in performing basic activities of daily living or ADLs. These include bathing, dressing, toileting, transfer, feeding oneself, and getting about the home. This breaks down to about 5.6 million Americans over the age of 65 and 3.9 million younger Americans who are living at home with disabilities, defined as functional limitations in basic ADLs.

In 1988 the American people spent over 53 billion dollars on long-term care, but only 18 percent of this went to fund

home-based care programs. These figures indicate an under-utilization of home-based long-term care; the most cost effective and humane form of long-term care (see graph).

Polio survivors were the first disability group to attempt the transition from hospital to home, despite very severe functional limitations, often including respirator dependence. This was in the late 1940s. Home-based care delivery systems were rare, and assistive devices were primitive by today's standards. Most day-to-day tasks were performed by family members.

Slowly, the system began to see the benefits of home-based care. Cost savings was the most obvious of these, but social and psychological factors were also evident. Some hospitals and most rehabilitation centers started to encourage this transition



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for their patients. Today these same factors are even more obvious to anyone who cares to look. Unfortunately, many of the government agencies who should be supporting this community-based form of long-term care are stuck in a mind set. They equate long-term care with institutional settings. They will approve charges of \$1,000 a day, or more, to provide care in an institution but will not approve one-tenth of that to provide care at home.

The medical establishment has often been obstructionist, too. Many doctors and nurses, and their professional associations, still feel that any medical procedure has to be done by a licensed medical professional. This overlooks the fact that thousands, probably hundreds of thousands, of individuals are doing what are often referred to as medical procedures. Many diabetics check their own blood sugar level several times a day and administer their own insulin shots. Many other non-licensed individuals regularly change dressings on themselves or family members, clean ostomies and tracheostomies, monitor oxygen therapy, and insert and remove catheters. These could all be described as medical procedures.

Even individuals with respirator dependence can be assisted by non-licensed care givers. Dr. Allen Goldberg, writing in the December 1990 issue of *Chest* states, "People requiring prolonged home mechanical ventilation have utilized personal caregivers to augment self-care and family efforts since the poliomyelitis era." He added, "Such attendants, properly trained, are safe and completely satisfactory, and accomplish a remarkable degree of cost savings at a time when we are looking for ways to bring down the costs of medical care."

Doctors and nurses who work full time in rehabilitation hospitals know this. They support the idea of care in the least restrictive environment, done by ordinary lay people who have been shown how to do these procedures.

In the forward to *Hospital to Home: A Patient Teaching Guide to Nursing Procedures*, published by the Nursing Department and Professional Staff Association of Rancho Los Amigos Medical Center, Mary Pratt, R.N. writes, "Rising hospital costs and utilization review committees have dictated that hospitalizations be shortened, and experience has shown that this can be done successfully. However, the shortened hospital stay may mean that some nursing procedures must be done at home until convalescence is complete or, in some cases, for the rest of the patient's life."

Even in cases where periodic monitoring of a patient by a physician or other licensed professional may be necessary, home-based care can be a cost effective alternative. Joseph Keenan, M.D., past president of the American Academy of Home Care Physicians writes in the *Academy's Newsletter* (Vol. 4 No. 4, 1992) "Modern home care is not only good medicine it is often qualitatively better than care provided in other settings. As we have greater technological and ancillary provider support available for care in the home, the main reasons for taking the patient out of the home will diminish."

There are thousands of individuals who are now receiving care in hospitals and skilled nursing facilities who could receive the same level of care at home. Most are not "sick." They just have functional limitations and require assistance in activities of daily living. They could receive this assistance at home with safety, and at much less cost.

There are, undoubtedly, individuals who have conditions where immediate access to specialized medical staff warrants hospital-type settings. There are others who are not self-directing and need close supervision. The unfortunate truth is that a significant number of long term care institutions fail to meet either of these needs.

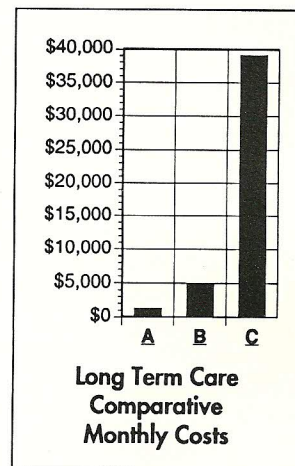
As indicated, home care is the least restrictive, most cost-effective mode of care delivery for those with long-term, severe disability. For example, California's In-Home Supportive Services (IHSS) program provides a maximum amount of \$1,203 per month. In contrast, a competent, skilled nursing facility costs \$4,712 per month and an acute care facility can cost \$1,298 per day, or \$38,940 a month (see chart). These figures may differ by region and as the quality of care varies, but the cost ratio will remain constant.

A. In-Home Supportive Services maximum

B. Bel Vista Convalescent Hospital. Bel Vista is located in Long Beach, CA and is one of the very few skilled nursing facilities that will accept a respirator dependent person.

C. Rate for a respirator-dependent person at Rancho Los Amigos Medical Center.

Rancho Los Amigos is located in Los Angeles County and is the world's largest acute care rehabilitation facility. Respirator dependent IHSS recipients have re-entered Rancho Los Amigos when there was a failure in the IHSS delivery system.



PROPOSAL

We urge that a fully-funded home care program be included in any reform of our nation's health care system. Several states have home-based care programs in place. Some are better than others. We will examine one of these programs, and note changes that should be made to improve this existing model. With these improvements, this model could easily provide a base for a national program for home-based, long-term care.

In California, one of the greatest aids to home care and independent living is the In-Home Supportive Service program.

IHSS provides funds that allow qualifying persons to hire home care attendants. The program serves about 165,000 people state-wide.

To qualify for IHSS, the recipient must be aged, blind, or disabled and meet the income and resource restrictions that apply to recipients of Supplemental Security Income (SSI). For a single individual, resources must be less than \$2,000 and gross earnings must be less than \$300 a month. Individuals

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with earnings above that amount may still qualify for IHSS with a share-of-cost which they must contribute on a monthly basis.

IHSS is funded from a mix of federal dollars under Title XX of the Social Security Act, state dollars and county dollars. *NOTE: In 1992, approval was obtained to use funds from Title XIX of the Social Security Act to underwrite the personal care portion of IHSS.* State legislation sets the maximum limits on how much can be authorized per recipient. The current monthly maximum is \$829 for non-severely impaired recipients and \$1,203 for severely impaired recipients. A severely impaired recipient is one who requires 20 hours or more per week of paramedical and non-medical personal services. About 12% of the case load is severely impaired.

California allows three modes of service delivery for IHSS; county employees, contract providers, and individual providers. The most cost-effective of these is the individual provider mode. It is also the mode favored most by self-directing disabled adults.

In the individual provider mode, non-severely impaired recipients have their providers paid in arrears, e.g. after the work is done. Severely impaired recipients have the option of receiving their IHSS paid in advance and directly to the recipient. It is the responsibility of the recipient to recruit, hire, train, supervise, and fire his/her own provider. Providers of service are paid minimum wage, and no funds are allowed for health insurance, sick leave, vacation, or pension. *NOTE: Minimum wage is inadequate to attract reliable home care providers. Many providers work more hours than are "authorized" by IHSS, consequently, they are working for less than minimum wage. We recommend in-home service programs be funded at a level commensurate with the duties performed.*

Determination of how many hours of IHSS is needed for a particular recipient is made by an eligibility worker in a face-to-face interview in the recipient's home. This is done at initial intake, at an annual reassessment, and whenever a significant change in the recipient's condition or living circumstances is brought to the attention of the eligibility worker.

The current maximum allowed is 238 hours. No recipient may receive payment for more than this state-mandated maximum. If the assessed need is greater than the maximum, then these hours should be documented as an unmet need.

Depending on the functional limitations of the recipient, hours of IHSS may be assessed for a variety of domestic, personal care, and paramedical services. These services are broken down into eight categories:

1. **Domestic Services.** Tasks include: Sweeping, mopping, cleaning, making beds and changing bed linen, etc.
2. **Related Services.** Tasks include: Meal preparation and clean-up, menu planning, laundry and mending, shopping for food and heavy cleaning.
3. **Non-medical Personal Service.** Tasks include: Respiration, bowel and bladder care, menstrual care, feeding, bathing and dressing, oral hygiene, grooming, skin care, aid in ambulation and assistance with prosthetic and/or orthotic devices.
4. **Transportation.** Tasks include: Accompaniment to medical appointments and alternative care resources.

5. **Yard Hazard Abatement.** Tasks include: Removing grass, weeds, rubbish and snow.
6. **Protective Supervision.** Tasks include: Prevention of hazard or injury. *NOTE: Protective supervision is currently limited to recipients with mental impairment.* Those charged with writing the regulations for IHSS believe protective supervision is warranted if mentally impaired recipients may cause themselves bodily injury, but they refuse to acknowledge the possibility of hazard or injury to a self-directing, severely disabled recipient; e.g., failure of mechanical life support systems. We feel very strongly that this is shortsighted, and contrary to the intent of IHSS.

7. Teaching and Demonstration

8. Paramedical Services. Ordered by a physician

The vast majority of disabled IHSS recipients have a medically stable diagnosis. Even respirator dependent quadriplegics can live safe, productive lives if assistance is available. An impressive number of severely disabled IHSS recipients have received recognition for their contributions to society.

On April 2, 1992, the Los Angeles County Commission for Public Social Services held public hearings on Governor Wilson's proposals to reduce funding levels for Aid to Families with Dependent Children (AFDC), General Relief (GR), In-Home Supportive Services (IHSS), and a variety of other "safety net" programs. Following the hearings, the Commission members issued their report. While the Commission members expressed differing opinions on most of these programs, they agreed unanimously on IHSS. The report concluded, "This is a very cost-effective program which has a straight forward and humane goal of allowing the elderly and disabled to remain in their own homes as long as possible...the small wages paid out to in-home caregivers pale in comparison to the cost of institutionalizing people unnecessarily."

The California IHSS program is based on a social service model. Assistance is provided for tasks that the recipients would do for themselves except for their functional limitations. A significant percentage of those residing in skilled nursing and board and care facilities are there because they do not have access to this assistance at home. They have no actual need for daily nursing services.

A medical element could easily be added to this model. Medical services could be provided by home care physicians and visiting nurses. This would raise the cost of the program, but costs would still remain substantially below institutional care. Including a medical element would avert needless hospitalizations and unwanted institutional placement.

We propose that a program based on this IHSS model be included in the reform of America's health care system. The program should be funded at a level that will allow recipients to remain at home with safety, and encourage honest, capable home care providers. Every dollar spent on home-based, long-term care will save from four to thirty dollars that is now being spent on unnecessary institutional care. ■

For more information, contact:
Richard Daggett, President
c/o Polio Survivors Association
12720 La Reina Ave.
Downey, CA 90242
(310) 862-4508