

1993
Report on
Home-Based
Long-Term Care

Prepared by the
Polio Survivors Association

1993
REPORT ON
HOME-BASED
LONG-TERM CARE

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Prepared by the
POLIO SURVIVORS ASSOCIATION
12720 La Reina Avenue
Downey, California 90242

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.

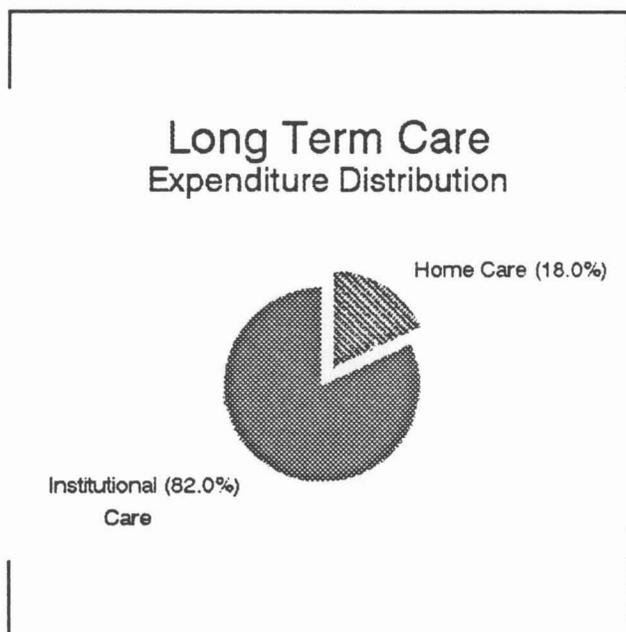
Rehabilitation medicine is also an increasingly important part of health care, and can take place separately or concurrently with these four groups. No single aspect should take precedence over any of the others. This report, however, will concentrate on long-term care.

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. 33 percent of all people who reached 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 chart at left)

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 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."

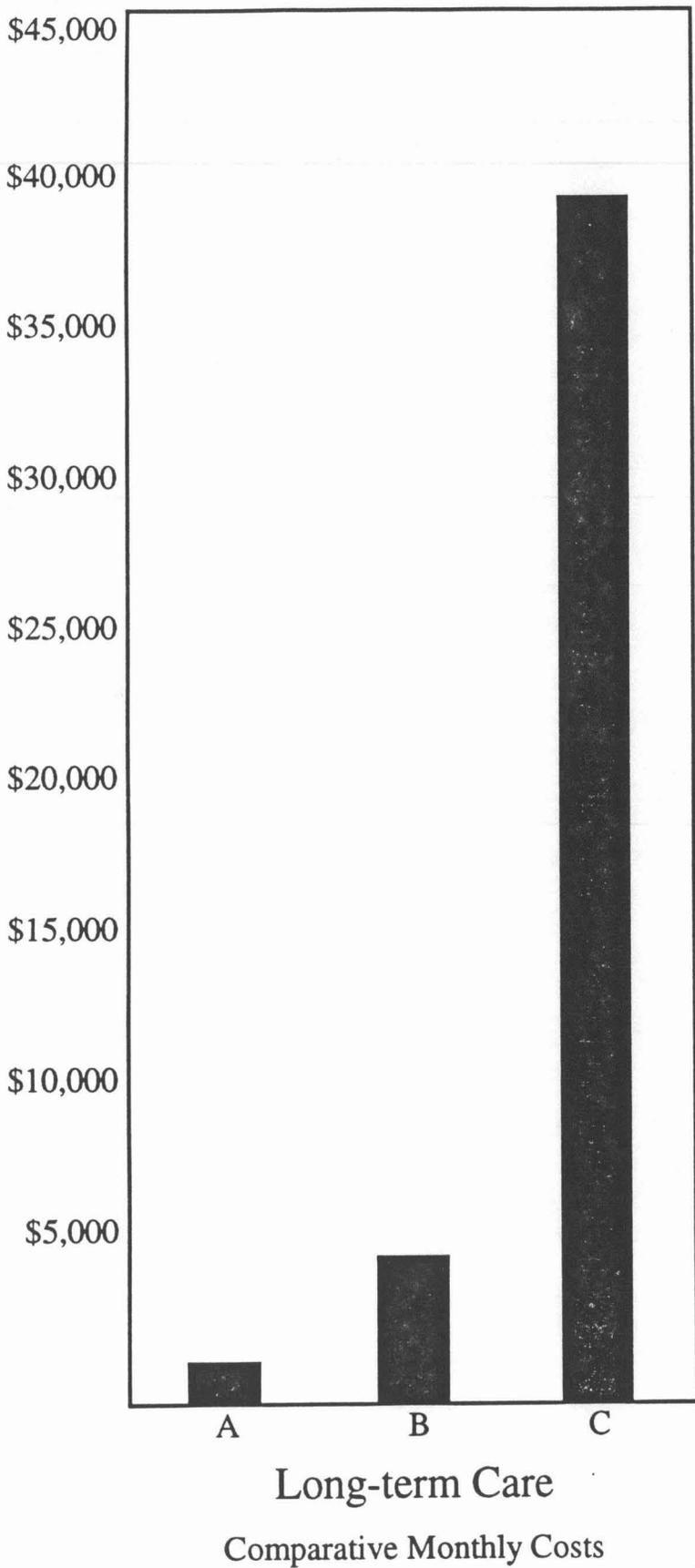
Doctors and nurses who work full time in rehabilitation hospitals know this. They support the idea of care in the least restrictive environment, done by ordinary lay people who have been shown how to do these procedures.

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 \$1,203.00 per month. In contrast, a competent skilled nursing facility costs \$4,712.00 per month and an acute care facility can cost \$1,298.00 per day, or \$38,940 a month. (see chart at left) These figures may differ by region and as the quality of care varies, but the cost ratio will remain constant.

(A) IHSS 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 Services program, commonly called IHSS. 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 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.

NOTE: All dollar and hour amounts listed are previous to the October 1, 1992 IHSS budget reductions of 12 percent. This short-sighted action by California has caused pain and anguish to the IHSS recipients, and has produced turmoil in those charged with in-home care delivery.

California allows three modes of service delivery for IHSS; (1) county employees, (2) contract providers, and (3) 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 283 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 SERVICES 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, 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.

SUPPORTING DOCUMENTATION

Includes a representative
sample of letters from
organizations and individuals
supporting home-based long-term care.



ASSOCIATION

Hope through research

Support through caring

The Amyotrophic
Lateral Sclerosis
Association

February 22, 1993

21021 Ventura Blvd., Suite 321
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Telephone: 818/340-7500
FAX: 818/340-2060

Mr. Richard Daggett, President
Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242

Dear Mr. Daggett,

Board of Trustees

Thank you for the opportunity to express our support
for home-based, long-term care.

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ALS is a degenerative disease of the nervous system for
which there is currently no known cause, treatment or
cure. As the disease progresses, patients lose their
ability to move, speak, breathe, and eat, yet through
it all the mind remains completely intact.

Although we cannot yet change the course of the
disease, much can be done in terms of symptomatic
management ultimately improving the quality of life for
the patient. And home is the place where the treatment
can be administered best!

The ALS Association believes it is important for PALS
(Persons with ALS) to learn to LIVE with ALS, rather
than sit around and wait to die from it. We try to
instill the thought they are a person first and have
ALS second. It is vitally important to maintain a
quality of life and sense of "normalcy" at a time when
they feel powerless over the course of their lives.

Being cared for in one's own home provides both patient
and family a chance to participate and make decisions
about their care. Many ALS patients, though ventilator
dependent, continue to lead full and productive lives,
something they would not be able to do in a hospital
setting. Being home provides a sense of independence,
not to mention maintaining a sense of dignity, the one
thing ALS cannot take away, but being institutionalized
can and will!

The ALS Association is the only
national not-for-profit voluntary
health organization dedicated
solely to the fight against Amyo-
trophic Lateral Sclerosis (Lou
Gehrig's Disease) through
research, patient support, infor-
mation dissemination and public
awareness.

Member National Health Council

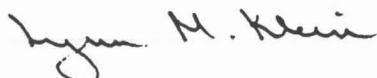
Mr. Richard Daggett, President
February 22, 1993

Page Two

In addition, repeated studies over and over again show that the cost of home care is much more cost effective than hospital or nursing home care. Long-term, home-based care must be an integral part of health care reform.

Home-based, long-term care should be every American's right, not privilege. We strongly support your efforts on behalf of all Americans.

Sincerely,



Lynn M. Klein
Vice President, Patient Services

LMK:jg

International Polio Network (IPN) 福

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Saint Louis, Missouri 63110 USA
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Joan L. Headley, editor

February 16, 1993

Richard Daggett
Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242

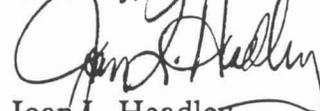
Dear Richard:

Your concise report on home-based, long-term care definitely warrants the support of the International Polio Network.

As you state, polio survivors were the pioneers of living at home with a significant disability and documented the cost benefit of such an arrangement. Additionally, by graduating from schools and colleges, holding jobs, and raising families, they documented the contribution individuals with disabilities can make to their communities and to society.

Reform in our health care system is a must. We concur that a fully funded home care program should be included in any future national plan because of the cost benefit and because the social benefit makes it the right thing to do.

Sincerely,


Joan L. Headley
Executive Director

**International Ventilator
Users Network (I.V.U.N.)**

4635 Larwin Ave.
Cypress, CA 90630 USA
(714) 761 - 4503

1 February 1993

Richard Daggett
Polio Survivors Association
12720 La Reina Ave.
Downey CA 90242

Dear Richard:

Congratulations on your home-based longterm care report. It is excellent, and clearly addresses the problem, the needs, and the solution. You have focussed well on one major point: most people with a disability and most older persons have nothing physically wrong with them - they simply need an extra pair of hands to help them live independently in their own homes. This is especially true for ventilator users, who usually are medically stable, and who live and work in their communities - with the aid of that extra pair of hands.

The cost of home care is so obviously less than that of institutional care that it must be a cornerstone of any health care reform. Your report provides critical information about the absolute necessity of longterm health care, and it will be welcomed by government and health policy reformers.

Sincerely,

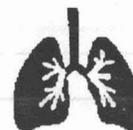


Judith Raymond Fischer
Editor, *I.V.U.N. News*



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Michael Bronstein, M.D.
Thomas G. Mahrer, M.D.
E. A. Oppenheimer, M.D.
James E. Wight, M.D.

Regional Home Care Program for KFH Ventilator-Dependent Patients

Monday, February 8, 1993

Mr. Richard Daggett, President
Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242

Dear Mr. Daggett:

It is a pleasure to strongly support your "Report on Home-Based, Long-Term Care".

Home care has been an integral part of comprehensive health care in the Kaiser Permanente Medical Care Program since its inception in the early 1940s.

In 1985 we started a demonstration home care program for Kaiser Foundation Health Plan members who are severely disabled and also need mechanical ventilation for more than 12 hours a day for long-term life support. 158 people have been able to be at home, previously unable to leave the acute care hospital, due to support from this program in California. Their age ranges from less than a year up to age 87. They require on average 22.5 hours of mechanical ventilation daily. Compared to hospital care the quality of their life at home has been much better, and the quality of care has been equal or better. Their care at home is supported by our Home Health program with RN care coordinators and a team including physicians. The cost is high due to the use of nurse shift care (LVNs) to assist family caregivers when they are at work, or sleeping. But the cost is less than hospital care. If attendant-level caregivers could be used instead of LVNs, the cost would be more reasonable and we believe that the care might be better.

-Page 2.-

These people and their families have been able to reestablish a life at home and in the community. A brief abstract report of our program is attached.

We strongly support the importance of long-term care and home care that is integrated using a combined health care *and* social service model.

Sincerely,



Edward Anthony Oppenheimer, M.D., FACP
Chief, Pulmonary Medicine
Regional Physician Coordinator
Associate Clinical Professor of Medicine, UCLA



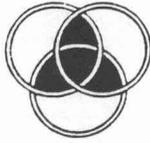
Adrienne Baldwin-Myers, RN, MSN
Regional Nurse Coordinator

Enclosure

**REGIONAL HOME CARE PROGRAM FOR VENTILATOR-DEPENDENT
PREVIOUSLY HOSPITAL-TRAPPED PATIENTS, 1985-1992.**

E.A.Oppenheimer, MD and A.S.Baldwin-Myers, RN, MSN, Southern California Kaiser Permanente Medical Care Program, Los Angeles; J.A.Fuller and P.Tanquary, DSW, Northern California Kaiser Permanente Medical Care Program, Oakland, California, USA.

158 long-term ventilator-dependent (LTVD) patients were discharged to home mechanical ventilation (HMV) from two regional California Kaiser Permanente home care programs for hospital-trapped LTVD children and adults, 1985 to 1992. Ventilator support was initiated non-electively during emergency hospitalization and intensive care. 90 patients were discharged from ten Southern California Kaiser Foundation Hospitals (KFH), with a coordinated program using defined standards, policies and procedures. Standardized data is collected as part of a research and demonstration pilot program. 68 LTVD patients were discharged from a similar program from 13 KFHs in Northern California. After intensive hospital care and rehabilitation, these patients require on average 22.5 hours mechanical ventilation daily. 90% require assistance for most care and activities, or are totally dependent. A multi-disciplinary team process is used for teaching, discharge preparation, and for coordinated management of home care. Families provide at least eight hours of ventilator care daily. Licensed vocational nurses (LVN) paid caregivers provide an average of 14.5 hours of care daily. One and two year survival rates were: 80% and 75% for neuromusculo-skeletal etiologies; 64% and 55% for COPD; and 0% for interstitial lung disease and malignancy. Almost all previously hospital-trapped LTVD patients were able to continue care at home with support from this program. Over 65% are alive. Those who died at home or hospital had no evidence of adverse medical care, and their families felt positively and would do it again. Quality of care and safety at home was found to be similar to hospital care. Quality of life was judged by patients as better at home. The 1991 average daily cost for these patients was \$405, which is beyond the capability of most families. Home care costs for some of these patients are higher than operational non-critical care hospital costs, but on average home care costs are lower than in a hospital or nursing home. 87% of the costs are for LVN paid caregivers. Attendant-level alternatives to LVN care should improve quality and cost. Other patients who start HMV electively, or who require 12 or less hours ventilator support daily, are usually able to arrange hospital discharge more easily without needing paid caregiver assistance; and then have substantially lower HMV home care costs.



Rehabilitation Research and Training Center on Aging

Rancho Los Amigos Medical Center • University of Southern California
7600 Consuelo Street, Downey, California 90242 • (310) 940-7402

March 2, 1993

Richard Daggett, President
Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242

Dear Mr. Daggett:

I want to extend my support to your organization for its efforts to acquaint policy makers, health professionals and the public at-large of the need for home-based long-term care for those aging with life-long disabilities.

As has been true in the past, polio survivors are once again serving as pioneers in the rehabilitation movement to maintain the dignity and independent living status of those with severe physical disabilities. Your report is well-written and timely. It does an excellent job of summarizing both the cost effectiveness and quality of life benefits of home-based long-term care.

I strongly endorse the need for more investment in home-based supportive services as an alternative to institutional placement and I applaud the Polio Survivors Association for advocating on behalf of this critical new health care issue of the 1990s.

Sincerely,

Margaret L. Campbell, Ph.D.
Senior Research Associate
Los Amigos Research and Education Institute
Rancho Los Amigos Medical Center



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of Los Angeles, Inc.

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Caroline Johnson

Jesse L. Jones

Gary K. Koch

Myra W. Markle, Jr.

Paul V. Martin

Carol Matos

Robert M. McDevitt

Robert G. Miller, III

Marie Morse

Pat Penney

Ron J. Pille

California Penney

R.N., M.S.N.

Joseph W. Roopp

Bonnie Ross-Smith

Robert Sachs, M.D.

William Siderman

Richard E. Strong

Robert J. Tatum, M.D.

Peter A. Towes

Janet L. Wood

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Alan J. Swartz, Ph.D., D.

Robert J. Tatum, M.D.

February 25, 1993

Richard Daggett, President
Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242

Dear Richard:

I am happy to send this letter of endorsement for the value of long-term care provided to help individuals remain independent in their own homes.

The Visiting Nurse Association of Los Angeles is the largest provider of home care in California, and I am acutely aware of the benefits to both patients and families when costly hospitalization is avoided, and effective and professional in-home health services are utilized. In these times of curtailed state funding, home-based primary medical care is clearly the most cost effective means of serving patients.

I support with enthusiasm your efforts to provide home care for all.

Sincerely,

Sharon

Sharon F. Grigsby
President

SFG:rl



Westside Center for Independent Living, Inc.

February 16, 1993

To Whom It May Concern:

The Westside Center for Independent Living provides advocacy, support services and training to assist people with disabilities and seniors to explore alternatives to institutionalization and to make their own decisions about how they will live. The essence of the Independent Living philosophy and movement is the concept of "consumer control". This concept is unique in that the consumer is the **primary decision-maker** about any plans or activities that may affect his or her lifestyle.

With this as a foundation, the Westside Center for Independent Living wholeheartedly **supports** the conclusions and proposals set forth in the Report on Home-Based, Long-Term Care prepared by the Polio Survivors Association. Home-based long-term care is the most cost effective way (for persons with disabilities and seniors) to maintain self-sufficiency and independence while concurrently maximizing the quality of our lives.

If you wish any additional information, please feel free to contact me Monday through Friday between 9:00 AM and 5:00 PM at (310) 390-3611 (voice) and (310) 398-9204 (TDD).

Sincerely,

A handwritten signature in black ink that reads "Stanley Greenberg". The signature is written in a cursive, slightly slanted style.

Stanley Greenberg, Ph.D., Executive Director
Westside Center for Independent Living

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12901 Venice Blvd.
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510 SIXTEENTH ST
SUITE 100
OAKLAND
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VOICE OR TDD
510 763 4100
FAX 510 763 4109

March 3, 1993

Richard Daggett
President
Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242

Dear Richard,

Your report is excellent. The World Institute on Disability's extensive research confirms your conclusions. It is a particularly critical time as there is careful consideration to include home-based long-term care as an integral part of our nation's health care reform. I believe and can demonstrate that IHSS can be both safe and cost effective.

In California we must prevent further cuts in the IHSS program. I believe this report will help in that quest. We hope that by Californians adopting the Medicare Personal Care Option which incidently could provide as much as 180 million to our IHSS program - another step could be made in preventing cuts.

Certainly as a person who uses personal assistants's help, I tully believe that home-based care must be available to people with disabilities who need it.

Thank you for your important contribution.

Sincerely,

A handwritten signature in cursive script that reads "Ed".

Edward V. Roberts
President

MOVING TOWARD EQUALITY

CHARLES WOLFINGER

ATTORNEY AT LAW
4652 CASS STREET
SAN DIEGO, CA 92109
TEL (619) 272-8115 FAX (619) 272-0069

February 8, 1993

Richard Daggett, President
Polio Survivors Association
12720 La Reina Avenue
Downey, CA 90242

Re: California's In-Home Supportive Services program: lay
home care alternatives to professional institutionalized care

Dear Mr. Daggett:

I have been involved in the administration of California's In-Home Supportive Services program since the late 1970s. My role has been as a lawyer for recipients seeking to eliminate administrative restrictions on the scope of care available under IHSS.

IHSS is quite simply the least expensive, safest, home health maintenance program in California, particularly for recipients with severe physical or mental impairments. The IHSS program has four features which make it the most cost effective program of home health care.

First, the IHSS program expressly allows lay persons to provide health care, including paramedical services so long as a doctor certifies that it is safe for them to do so. The paramedical services provision of the IHSS program constitutes an exception to the Nursing Practices Act and Medical Practices Act, which artificially increase the cost of health care by restricting who may provide it. I am not aware of any litigation from unsafe health care under the IHSS program. Without lay care recipients would require more expensive professional care, which generally can only be provided in a nursing home.

Second, the IHSS program creates economically stable households for the aged, blind and disabled poor by allowing relatives and friends living with recipients to be paid for their care. Indeed, most recipients need far more care than paid under the IHSS program. However, it at least provides sufficient financial resources to allow relative providers to give uncompensated care at home. Without such care, recipients would be forced into nursing homes.

Richard Daggett
February 8, 1993
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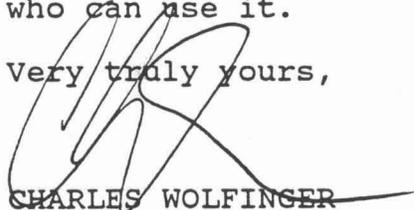
Re: California's IHSS program

Third, the IHSS program eliminates the costly bureaucratic system of oversight required for congregate facilities like nursing homes. Most providers are sufficiently alert that they can control and watch out for their care at home. It is simple and uncomplicated. There are far more vulnerable in large health care settings with others controlling the care.

Fourth, the IHSS program gives recipients control over their lives. They live in the familiar setting of their home where they decide when they need care. In nursing homes they live in setting where care is dictated by the needs of the institution.

By any measure - cost, effectiveness, and individual dignity, IHSS far exceeds institutionalized care as a method of health care. It has one major drawback - funding limitations and bureaucratic preference for institutionalization have substantially limited its expansion to all the State's residents who can use it.

Very truly yours,



CHARLES WOLFINGER

dagt1

