



Polio Survivors Prove The Value Of Home Care Services

by Gini Laurie

It is a privilege to be here with so many persons dedicated to home care services. I hope that we will be able to make history repeat itself. I hope that by directing attention to ventilator-dependent persons, all disabled persons will benefit in the same way that the earlier nationwide systems of home care services benefited all of them.

That system, which existed from 1953 to 1959, freed hundreds and hundreds of ventilator-dependent polio survivors from custodial care in hospitals — freed them to live self-directed and productive lives in their communities for 30 years. That system was the genesis of the independent living movement. Those polio survivors have been the role models of the spinal cord injured and all other severely disabled persons since the early 1950s. The lives of those polio survivors prove the value of home care services.

I was directly involved with the system because my volunteering started in 1949 and coincided with the development of the regional

respiratory polio centers which created that home care system. The centers were developed by the National Foundation for Infantile Paralysis to reduce the costly custodial care of 400 ventilator-dependent polio survivors of former epidemics who were scattered across the country in hundreds of hospitals. Sixteen regional centers were established at medical school/teaching hospitals to accept groups of those chronic ventilatory patients and to develop a positive approach to their care.

They were established just in time for the very severe polio epidemics of the early 1950s which filled all the 16 centers. Since no one had had experience with such numbers of seriously disabled persons on ventilators, the centers were a team learning experience for everyone. The patients and their families were important members of that learning team from the very beginning. The centers had weekly patient-staff conferences, which were the key to the integration of the program. Here,

all of the services working with the patient met to discuss with the patient his or her present status, treatment plan, anticipated goals, and time factors.

The first organized home care system was created by Dr. John E. Affeldt, who was the medical director at Rancho Los Amigos Hospital in Los Angeles County in 1953. At that time, Rancho had the largest number of patients in the country — 158 who were ventilator-dependent.

When Los Angeles County realized that these long-term patients were unnecessarily occupying \$37/day hospital beds when they could be cared for at home for \$10/day with attendants, equipment maintenance, and other supporting services, a home care program was set up and 152 went home.

A semi-trailer, with a complete workshop, made the rounds regularly — maintaining and repairing the ventilators. The hospital functioned as an information service to the polio survivors and to their personal physicians — an al-

most umbilical cord relationship.

The transition from hospital to home was gradual and meticulously planned and scheduled. The staff made home evaluations and the necessary adaptations for ventilators and accessibility. The first visits were for hours, then a day, then overnight, then weekends, with emphasis on training the family and the disabled individuals in the use and maintenance of the ventilators and in assisting each one to resume his/her own place in the family and the community.

At our center, the disabled individuals signed out when they left for a trial visit and signed in when they returned. In the interval, they were on their own.

At first, attendants were trained at the hospital. But it was soon found that attendants changed so often, it was a waste, and families and the disabled individuals were much better at training another person to take care of personal needs.

Each disabled individual and the parents or the spouse had to become experts in medical, personal, and equipment needs and had to be able to delineate those needs to the changing attendants or to whom ever was at hand.

The centers and their home care systems resulted in tremendous savings of money, and a greater degree of self-sufficiency and independence for ventilator-dependent people than had been thought possible.

As of 1959, the National Foundation reported the following savings: The average hospital time was cut from one year to seven months; home care costs were 1/10 to 1/4 of hospital care.

As of January 1959, the National Foundation reported that there were 1,756 ventilator-dependent polio survivors in the United States. Of these, 1,271 were at

home. The Foundation study estimated that 40% of those at home would have remained in custodial care for the rest of their lives if the center's service systems had not been the means of making the transition from hospital to home care. Unfortunately, the centers lasted less than a decade. The programs became too costly for a voluntary organization when the public lost interest in polio after the vaccine. By 1959, the National Foundation had to change its emphasis from polio to birth defects, and to curtail the polio programs.

After the centers and the attendant care programs stopped, the polio survivors scrounged on their own. Some found funds for attendants from welfare or churches or relatives. Others found foreign or other relatively inexpensive live-in attendants or part-time students or retired neighbors. Later, some moved to California, New York or one of the few other states with attendant care.

Fortunately, there were no special segregated residences built for ventilator-users. They solved their problems as individuals, not as a group of ventilator-users. Remarkably few had to go to nursing homes or VA hospitals.

Polio survivors have been among the founders and the leaders of the nationwide independent living centers, which are sources of information on attendants. For attendant care is the linchpin of independent living.

Throughout its 25 years, the *Rehabilitation Gazette* has been a proponent of home care and attendants and a force for independent living. It has documented the lives of severely disabled persons around the world and acted as an international clearinghouse on polio and ventilator dependency.

(For a brochure on its information services and a list of the back

issues, write to Gazette International Networking Institute (GINI), 4502 Maryland Avenue, St. Louis, MO 63108 (314)361-0475.)

Among the ventilator-dependent readers who have recounted their family lives and their careers in the *Gazette* are attorneys, clergy, computer programmers, engineers, physicists, professors, physicians (who changed to such no-hands fields as radiology, dermatology, psychiatry and allergy), rehabilitation counselors, therapists, teachers, and writers. Their casual/careful approach to travel is typical of their adaptation to life with a ventilator. More than 40 ventilator-dependent persons from around the world were among the 439 registrants at the *Gazette's* Second International Post-Polio Conference and Symposium on Living Independently with Severe Disability held here at this Sheraton in May of last year. We expect even more at the third conference which will be here in May 1985.

Many of the polio survivors have been ventilator-dependent since they were children. Some went to grade and high school by tutor or telephone. Others attended with their ventilators and then went on to college and graduate school. Some were disabled while they were students and others after they had married and had children.

One example, is an Indiana physician who contracted polio in 1955, shortly before he graduated from medical school. He received his medical degree while he was still hospitalized. After rehabilitation, he completed his internship and residency. He practices dermatology fulltime. He is married and has two children. He uses oral positive pressure continuously by day and sleeps in an iron lung. He has traveled widely, including a recent trip to a medical meeting in Australia. He rents or borrows an

iron lung when he travels and he is working on a portable lung so that he can travel extensively in Europe.

Another example, a Minnesota adoption specialist, was disabled in 1950 at age 27. She and her husband, a psychologist, have adopted 13 children, most of them disabled. She uses a pneumobelt by day and a trach-connected ventilator at night.

She is one of the few polio survivors in the United States who uses a tracheostomy. Most of the tracheostomies that were performed at onset were later closed and other means of ventilation used. They include many permutations and combinations, such as:

- Cuirass by day and rocking bed at night
- Glossopharyngeal breathing by day and lung or positive pressure by night
- Oral positive pressure by day and lung at night

Our panel will share more personal experiences to *emphasize* the safety, economy, and satisfaction of home care and to *demonstrate* the educational, vocational, and productive potential of severely disabled individuals, including those who have been ventilator-dependent for more than 30 years.

Finally, a few observations based on almost a lifetime of volunteering with persons who are severely disabled . . .

The most important contributions of the service system created by the regional centers were:

- The *team approach* that included the disabled persons and the family in the planning
- The *positive attitude* toward discharge home
- The *training of disabled persons to train attendants* and to be experts in their own care
- The *treating of each disabled person as an individual*. No group solutions. No mini institutions. Each individual was seen as having the right to make decisions as to the way in which to lead one's life.

This is absolutely fundamental to the *dignity and integrity* of each individual human being, and includes the right to place one's self at risk and the right to make mistakes — in other words — the right of persons with disabilities to live as do all people in society. ●