1988 - February 27

Tenth Annual Conference National Network of Graduate Business School Women.
Washington U School of Business. Speaker: "Volunteerism and Non-Profit Organizations."

St. Louis, MO
I'm asked to speak before successful business women.

My business/business very limited.

But my volunteer/business very extensive. Fills my life with excitement & challenge. Learned so many trades (editing, printing, layout, fund raising, marketing, PR, conference mgmt/)

My business experience in depths of depression.

Graduated from college -RMWC- in 1934.

Latin major. No teaching.

no $ for MD .... Father ...

Job at $60 month distributing welfare checks in "bucket of blood"district. Got job because printing neat.

After several years welfare cut back.

Took course in typing & shorthand. Did not finish.

Temporary job...Then decorating shop.

Started $100 month. As depression deepened, cut back to $50....then $0...paid workroom employees.

Married in 1938. Cleaning woman $2.20 day. Could afford only 1/2... $1.20 Meat budget 25¢ a day.

Been volunteering fulltime ever since....Red Cross ...Camp follower USO...then Red Cross again.
1949 moved to Cleveland....polio epidemic. hot packs...

Found my niche in life. Before born...siblings.

Worked 10 yrs at resp ctr. Made friends with & kept up.

Built swimming pool. Became meeting place for disabled.

1958 started newsletter. Mimeographed. 100 local ctr.

Filled universal need of all people: info & other people.

RG.... Still going & growing. Now 40,000 87 countries

International journal. Translated.

All disabilities.


Ramps. W/c. Plywood iron lung. Hobbies (fishing with
elec reel & mouthstick). Painting... Different mouthsticks.
"ticks of the trade."

Advocacy....After vaccine. MofD. Polio without funding.

Attendant care stopped. Organized natl campaign for

natl attendant care. (Still trying....Now bills for

home care.


'84. HCFA.

Disabled/Minority Followed evolvement of blacks & women

& Hispanics. 1st step. ACCD. Token disabled.

Early 70's Active in 504, Bill of Rights.
Early 70's husband retired & moved back to St.L...fulltime vol.. through 70s...Gliding along...once a yr publishing...bought a camper..travelled all over U.S. & Mexico & Canada....

Go to a conference...Denver, or San Francisco...or Boston or whatever and just keep going.


1980...went to Europe on Fellowship from World Rehab Fund.. study indep liv. 5 coutnries.. train...stayed with friends (all used iron lungs or equivalent.. hospitable...)

Suddenly...leisure pace stopped. Since we knew so many polio survivors, we first to notice something happening as people aged....Called it the "late effects of polio." pain, musc w, fatigue

I've been on a merrygoround ever since....

People wrote their young MDs knew nothing about polio... told them symptoms were imagined...


OK...decided to do it without $. Ask everyone to pay own way. No honoraria. Call it a "brown bag" conf. Sent brown bags. 
$6,000 Still do it. Last one: $17,000.

Telephoned MDs and polio survivors. Talked into coming.

So... still doing conf. every other yr... first: 168.
1987: 787. 18 countries. Leading physicians around world.
40 using vents. Incredible gathering & spirit. Disco.

You may have seen articles on late effects of polio. TV.
Kuralt. NYT. NE J of Med. JAMA

We've become more & more absorbed in late effects. Center of
info in world. International PolioNetwork: have director.
Published handbook = bible. Many languages.

Started support groups. Now 200... 55 clinics. quarterly
newsletter & directory.

TRavel all over U.S. to conferences.
"Magnet that has held polios of world together."

Going to Munich in April to give keynote. Germans don't fool around:
45 minutes... summary of polio history, late effects, support grps.

Also coordinate IVUN... moving into computerizing the info
and in setting up support groups by computer. I'm just in
learning stage of computerland... but have some experts on board.

In another exciting stage now... EXECUTIVE SERVICE CORPS....
Monte Throdahl. did 5-year plan. Future looks more exciting
than ever and more fun. Getting some great new people on Board...
more & more people with disabilities.
Recommend if onBoard of non-profit organ...investigate the ExecService Corp (read from broch)

As I said at beginning, I dont have real business experience.... but I know how to do business in reverse: I seem to have a talent to get people to work for nothing, to donate services...

I work hard to be sure they are paid in satisfaction....

You have to make it fun and rewarding. Thanks & praise... and more thanks & praise. Build an esprit de corps. Make it a family. Break bread together...& everyone a part of teh gathering: covered dish...BYOL...

I never asks anyone to do anything I dont do.. I work 7 days wk, fulltime & nights.

Until 1984, had no salaries. Then hired exec dir & secy. But had kept going for more than 25 yrs with volunteers only. ...and some rather odd sources of income: early days: Saamese...tax-deductible..stud fees...... Herb vinegar.....

Instead of business mailing firm, had LSD parties.

Still have penny-pinching habits: especially telephone: figure time on East & West coasts so call them at lunch, then they call back at their expense.

This year is our 30th anniversary. Able to keep going because & generous of volunteering by wonderfully talented people: editors, layout artists, PR, advertisers, lawyers..all ages...all backgrounds.

Two best volunteers: 80 yr old music teacher & 16 yr old h.s. stud
I've brought some slides of our early volunteer parties.... and some of our conferences .... to give you feeling of the ability of people with severe disabilties.... & peopleness!

But first, I want to think with you about the role of dis as a minority......who are discriminated against as we are as women, and as/blacks and other minorities.

As business leaders, you will be in the position to give people with disabilities a chance to prove their abilities. If 2 applicants have equal qualif.. give dis chance.

But above all, people with dis local agencies: the Next time you have an opening, call your state vocational rehabilitatio office, bureau for the blind or vtsually the organization-impaired, and-agency-for the hearing impaired or deaf, and the independent living center.

Don't be surprised if you find hidden treasures.

When you go back to your offices, take a look around to see how you would fare if you were in a wheelchair.

Ask yourself these questions:


The adaptations need not be expensive. Use commonsense.

Drinking fountain too high? Put a holder for paper cups.
Desk too low for w/c? Raise on blocks.
Bathroom stall door too narrow? Remove partition between & hang curtain.
Mirror too high? Hang another at an aggle.
Environmental accessibility...transportation...housing...are important to people with disabilities...

But, more important...and the basic cause of most problems faced is a negative attitude. More handicapping than disability.

As women, we sympathize...have same problems. "although she is a woman she is vice pres thoughts" although dis....
Our attitudes our responsibility. We can change....We can influence others.

First step: watch our words. Use positive words to engender positive thoughts. Language reflects, shapes, and reinforces our perceptions of people.

Say person with dis - not dis person. personhood not dis.
Say dis, not hand & certainly not crippled

We are close to evolvement of words used to describe blacks:
crippled = colored
hand = negro
dis = black

(Regional variations& There are stepnfetchits in dis communit. I'm reflecting the feelings of leaders of dis community.)

down
Watch out for demeaning words: victim, invalid
" " " pedestal words: courage, despite (lonely)
" " " dehumanizing words: the blind, the deaf. (people aren't diseases)
" " " helpless: confined (it is mobility) shut-in (never home)
" " " ugly: disfigured

Think about these words and images if your volunteering includes telethons, like the Jerry Lewis. It typifies everything about dehumanizing, belittling, negative attitudes, demeaning Check the "$
If we have been using the wrong words... if we are uncomfortable with people with dis... We should realize how we've been conditioned by history, the bible, literature... parent's... conditioned to fear... conditioned to think sins visited on children... (Japan..blind man).

And... afraid of being reminded of our vulnerability & mortality. (elderly don't like dis around - housing).

Don't feel guilty... But we can change. We can learn.

The solution is integration... start kindergarten... dis-blind as well as color-blind... Work with... know... then forget disability.

Peopleness is only thing that matters. Dis unimportant.

Dis doesn't change peopleness. If bastard before, b after.

If you're disabled, same person... same family, tastes, abilities, just have to learn new ways of doing & getting around.

As you can gather from my enthusiasm. I've loved my life of volunteering. Interesting... fun... learning... met fascinating people.

Highly recommend you fit volunteering into your lives. Your business skills & talents make tremendous difference to a non-profit.

...If any of you live in St. Louis, we'll welcome you!

Show slides... brought samples... & brochures... and we have time for lots of questions... so I can know your ideas... & try to answer.

Thank you... Wish of the : Foo sign...

Denver, Colorado.
DENVER, WEBB WARING LUNG INSTITUTE

SUPPORT SYSTEMS FOR PULMONARY REHABILITATION AND HOME VENTILATOR PATIENTS.

Thank you. I'm honored to be a part of this important conference.

I am a catalyst - a catalyst of developing information for independence for ventilator users.

I have been one since 1949, when I began volunteering at a respiratory center and met my first ventilator using friends.

Independence for a ventilator user means that one can say, "I use a ventilator. So what? I am in charge of the ventilator. I direct my own life. I choose how I want to live."

For nearly 40 years, I have been observing the awesome power and support of useful information, of shared experiences, and a positive attitude among ventilator users. My closest friends are ventilator users. I know thousands of them around the world - probably more than any other single person.
I learned about ventilator users at one of the Utopias of pulmonary rehabilitation, back in the 1950's — one of the Polio Regional Respiratory and Rehabilitation Centers. There I learned the incredible potential for a full life for ventilator users if their acute care and rehabilitation included a positive and respecting attitude, and if their life at home included support services.

Those wonderful centers did not last long — the average time was between six and nine years — but they are still models of pulmonary support services and I'd like to share a retrospective glimpse of them as a model for the present and future.

The centers were created by the National Foundation for Infantile Paralysis to save money by bringing scattered ventilator users together for treatment by multidisciplinary teams of professionals. They were located across the country at the teaching hospitals of 16 medical schools.

The NFIP or the March of Dimes funded everything — staff, patient care, research, equipment; and, eventually, home adaptations, attendant care, and other home support services.

There was an open-minded, team approach that included the patient and the patient's family. The typical weekly staff
Preparation for going home was extensive. Homes were made accessible and autostart generators were installed. Daylong, then overnight, then weekend trial visits were made. Maintenance and service of all respiratory equipment was provided once a month when a repair truck, large enough for a lung or rocking bed, made the rounds.

At first, attendants were trained by the center. But the turnover was so rapid that it was obvious the most effective method was to train the patient to hire and train his/her own attendants and to train the patient to direct the operation and maintenance of his/her ventilators.

The Rancho home care plan spread so rapidly across the country that only three years later, 92% of those permanently dependent upon artificial respiratory equipment had been discharged to their homes.

The centers and their home care programs resulted in tremendous financial savings and a greater degree of independence and self-sufficiency than were ever dreamed possible for people so severely disabled.

Here are a few cost-effective figures: the average hospital time was cut from more than a year to seven months. The
conference included a medical director (pediatrician-contagious), nurse, physical therapist, occupational therapist, engineer, vocational counselor, teachers, and dietitian.

I'm sure you all noticed that there were no pulmonologists or respiratory therapists, on the staff. Nor was there an intensive care unit. But care was caring and intensive in an area next to the nurses' station. Pneumonia was the most common problem and the treatment was simple: antibiotics, the lung in Trendelenburg, and vaporizers.

Regular conferences at the Centers and National levels resulted in broad-based agreement on total patient-care objectives and a consistent positive attitude toward the patient and family.

When, in 1953, the Los Angeles center at Rancho Los Amigos Hospital set up a home care program to save money, all the other centers set up similar programs.

Basically, the program was based on the concept of independent living with an umbilical cord to the center. The patient remained a patient of the hospital and the patient's personal physician was placed on a panel which made the hospital staff available for consultation.
home care costs were one-tenth to one-fourth of hospital costs.

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In all the careful planning and adaptations there was never any attempt to move the hospital to the home. Even more important, the family was involved in all planning. A "family member" - now with some breathing equipment - returned home to the family. Everyone was casual - but careful. They were at ease with the equipment. The family learned to transfer to battery operation in a station wagon for trips to work or school or travel. They learned to repair and adapt the equipment to their specific needs.

Their experiences demonstrate that ventilator users and their families must be woven into any pulmonary support system whatever the type or amount of professional or nonprofessional care involved. Their experiences are a lesson that should be remembered when overprofessionalism threatens, such as the legislation proposed in Florida that would have made it illegal for anyone except registered respiratory therapists or technicians to provide incidental respiratory care to ventilator users.

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But that utopian period in pulmonary rehabilitation lasted only until 1959. Then the centers were closed and the
attendant care funds were stopped. The centers had not had permanent funding from state or federal government, but only from a voluntary agency dependent upon public largesse. When the vaccines stopped polio, the public stopped giving.

When attendant care funding was stopped, ventilator users had to band together to try to effect attendant care legislation and to generate ideas on how to find inexpensive attendants. (I remember that one such idea that was shared almost immediately was for the employment of illegal aliens.)

The ventilator users needed a catalyst. And, there was one - the publication, Rehabilitation Gazette, which I had started in 1958, and which I am still editing. It has now become an International journal which reaches about 40,000 people (ventilator users and people with all types of disabilities, as well as health professionals) in 87 countries. In it, individuals with disabilities share their experiences with education, employment, equipment, travel, hobbies, sex, marriage, and raising children. Each writer empowers the other readers to live fully and productively.********

But let us return now to more recent history. Since we at the Gazette had become the magnet that held the polio survivors of the world together, we were the first to notice the late effects of polio including those who were
underventilated because they had been overweaned initially or because they were using too little respiratory aid for the increased needs of aging.

The problem was that the younger physicians had not been taught about respiratory polio, and did not know about the noninvasive ventilators used for 30 years - such as the lung, chestpiece, rocking bed, oral positive pressure, pulmo-wrap, pneumobelt, etc. They did not know about polio underventilation, its symptoms of morning headache, depression, and sleep problems, and the renewal of joy that followed the use of night respiratory aid.

Again, we played the role of the catalyst. To educate physicians and provide a forum for polio survivors to share information, the Gazette organized the first international conference on polio and independent living in 1981. We have had them biannually ever since.

At the first conference there were 168 physicians and polio survivors. At the 1987 conference there were 757 registrants from 18 countries, about 3/4ths were disabled individuals and their families or attendants. About 40 were ventilator users who came from all over the U.S. and from Denmark, Sweden, Germany, England, Canada, and Australia. Most used oral positive pressure en route and during the
conference. A few rented iron lungs or rocking beds from Lifecare.

At the 1987 conference, a special session on nasal and face masks for night ventilation was packed with polio survivors and physicians demonstrating masks they had designed themselves. This session typified the essence of the conferences - a spirit of learning and sharing, and a mutual respect between health professionals and polio survivors.

As a result of the conferences, we have become the catalyst again. In 1985 we formalized the International Polio Network and started support groups for those experiencing the late effects of polio. We now coordinate more than 200 polio support groups and 55 polio clinics in the U.S. and we've published a handbook on the "late effects" for physicians and survivors, as well as proceedings of the conferences and a quarterly newsletter - and a handbook on ventilators and muscular dystrophy.

More recently, we have started a network with a newsletter for health professionals and ventilator users, the International Ventilator Users Network (IVUN). We hope to develop it into a national, and international support group that meets continually by computer telecommunication.
There is information on the Rehabilitation Gazette, our ventilator users network, and our next conference in your packets. The conference will be held in St. Louis from May 31 to June 4, 1989 at the Sheraton Hotel. I hope we see many of you there. It will be a memorable learning experience.

Thank you for the privilege of speaking to you. I'll conclude by showing a few slides of the 1950's and of the 1985 and 1987 conferences.

As you look at the people in the slides notice how their support systems and respiratory aids evolve and change.
1988 - April 7-9

International Conference on the Late Effects of Poliomyelitis and Chronic Underventilation. Speaker: Pfennigparade.

Munich, West Germany
PFENNIGPARADE'S INTERNATIONAL SYMPOSIUM

LATE EFFECTS OF POLIOMYELITIS

Munich, April 7-9, 1988

OPENING SUMMATION OF THE SYMPOSIUM'S TOPICS

by Gini Laurie

Thursday, April 7 11:15 - 12:00
ABSTRACT

INTERNATIONAL VENTILATOR USER'S NETWORK (IVUN)

by Gini Laurie

The pioneers of home mechanical ventilation are the polio survivors who have been ventilator assisted since the epidemics of the 1950s. There are many lessons to be learned today by health professionals, other ventilator users, and social planners from their more than 30 years of experience with living fully, independently, and productively at home:

ECONOMY. Individuals were sent home from the hospital to save money. They were able to go home after the hospital set up an "umbilical cord" system of home services that included attendant care and equipment maintenance. (Costs of home care, then and now, were 1/10 to 1/4 less than hospital care.)

CONTINUITY OF ATTENDANT CARE. Individuals were trained to train their attendants. They were funded monthly and made responsible for paying, hiring, and firing.

CONTINUITY OF MEDICAL CARE. Each individual's personal physician was considered "on staff" for that individual and was given access to the records and to an exchange of information.

CONTINUITY OF EQUIPMENT. A semi truck, equipped with a small scale machine shop, made regular monthly rounds to repair and maintain equipment.

RESPONSIBILITY FOR EQUIPMENT. The individual and the family were trained to be responsible for the use and maintenance of the ventilators and taught to explain their operation to whomever might be at hand.
TEAM APPROACH. The staff, patients, and families functioned as a team exploring and exchanging plans and possibilities of treatment and rehabilitation.

THE HOSPITAL WAS NOT MOVED INTO THE HOME. Each home was adapted to the needs of each individual. An attitude of casual carefulness was fostered, based on the knowledge that the home is free of the risks of cross infection that exist in the hospital.

COMMUNITY SUPPORT. The support of each individual's community was sought and encouraged.

GROUP THERAPY. Patients and their families were encouraged to share and assist each other to adjust and to cope.

POSITIVE ATTITUDE. The staff, without precedent or prejudice, developed a contagious positive attitude toward the potential of this unique group of ventilator assisted individuals.

EVLVING VENTILATORY NEEDS. Individuals learned to adapt to new ventilators as they were developed, to respond to their own needs for increased ventilatory assistance as they aged, and to utilize improvements, such as the recent equipment dealers' maintenance systems and respiratory therapists' home services.

SELF-HELP. NETWORKING. Since 1958, the international journal, Rehabilitation Gazette, which evolved into the International Ventilator User's Network newsletter, has provided role models, peer counseling, worldwide networking, information on new commercial equipment and individual adaptations, encouragement to adapt to changing needs, and, most important, a positive attitude.
Dankeschön. It is a great pleasure for me to be here in Munich again with old friends. I have worked with many of you for years, gathering and sharing information on the twin polio problems of the late effects and underventilation.

It is fitting that we meet in Germany, which is again taking the leadership in the area of poliomyelitis with this symposium. You are following the lead of your great orthopaedist, Dr. Jacob Heine, whose 1840 and 1860 treatises were the first proper studies of polio. As many of you know, for a dozen years or so, polio was termed Heine-Medin disease.

It is a privilege for me to share my lifetime of experiences and observations of polio survivors that began when bulbar polio caused the deaths of three siblings.

I began volunteering with ventilator users in the 1949 epidemic. In the years following, I have known many thousands of ventilator users and other survivors around the world, who live fully, productively, and independently at home — many of them using ventilators for more than 30 years.
In medical history, mechanical ventilation is a recent development. The first iron lung was developed in 1927 at Harvard University by Professor Phillip Drinker and Dr. Louis Shaw. Their first iron lung patient was a cat. They paralyzed its breathing and placed it in an airtight box with alternative air pressure from a vacuum cleaner motor. Two years later, Professor Drinker created the first iron lung for human beings.

The first person to live at home and travel extensively with a ventilator was Frederick Snite, Jr., the 25-year-old son of a wealthy Chicagoan. He was disabled by respiratory polio in 1936 in Peking, China. At that time, there were only 222 iron lungs in the world and one just happened to be at the Peking Medical College for use with opium smokers.

Frederick stayed there in that lung for over a year, then came home in it on a 21-day trip via truck, ocean liner and train. (His trans-Pacific party occupied 12 cabins and consisted of a physician, 7 Chinese nurses, a Chinese physiotherapist, two American nurses and his family.)

Frederick's life in a lung fascinated the American press -- especially after he married and fathered three daughters. He traveled by train back and forth between the family homes in Florida and Chicago and went to Lourdes on the Normandie
and crossed France with an entourage of a trailer, a car, and a truck.

He and his team created a variation on an early Swedish chest respirator which was made of steel and heavy rubber.

He knew how to live independently. His biographer wrote, "He governed his own life. He made the decisions. He tackled and solved the problems. He gave the orders."

Frederick lived in the lung at home from 1936 to 1954, when he died of cor pulmonale.

By 1949, there were 400 other ventilator users in the U. S. who were not at home but in custodial care at over a hundred hospitals scattered around the country. They were funded by the National Foundation for Infantile Paralysis (the March of Dimes) which President Franklin Roosevelt had founded. The hospital charges for the 400 were so exorbitant that the March of Dimes initiated a study to find ways to reduce the cost. The study showed that it would be far more economical to move them to regional centers with multi-disciplinary professional teams.

This was done and, eventually, there were 16 polio respiratory and rehabilitation centers at the teaching hospitals of 16 medical schools, ranging in size from 15 to 160 patients.
The first two centers were set up in Boston and Houston in 1950. The lifespan of most of the centers was less than a decade (the average was six years), but their impact on physical medicine, independent living, and vocational rehabilitation of ventilator users, and other individuals with severe disabilities was tremendous.

The timing of the opening of the centers was propitious because they were in place just in time for the devastating epidemics of the early 1950s in which so many young adults were disabled by respiratory paralysis.

During those terror-ridden epidemic years, the money poured into the March of Dimes. It paid for everything at the centers: the professional staff, patient care, equipment, and research. Later it paid for home care, home modifications, and the salaries of attendants.

Although the age incidence of polio had been rising and it was more severe in the older age groups, most of the centers were located where polio and other children's diseases had always been treated -- the contagious wards. There, of course, the medical directors were pediatricians, so they became the medical directors of the respirator wards.
The evolution from "contagious ward" to respiratory and rehabilitation center was effected rapidly and naturally through an open-minded, learning, team approach. The typical staff conference included medical director, nurse, physical therapist, occupational therapist, engineer, vocational counselor, teacher, dietitian, and volunteers.

I'm sure you all noticed that there were no pulmonologists, or respiratory therapists, or rehabilitation engineers on the staff. Nor was there an intensive care unit. But care was caring and intensive in a private room by the nurses' station. Treatment was simple: antibiotics, the lung in Trendelenburg, and vaporizers.

Regular center staff and national conferences resulted in agreement on total patient-care objectives and a consistent attitude toward the patient and family, who were seen as important members of the team.

Underlying the centers' concept of comprehensive care was the recognition of the patient as a whole human being and the perception that physical, mental, emotional, spiritual, social, and vocational problems were all interrelated.

But, though their respiratory rehabilitation was successful, few patients went home until a home care plan was developed in 1953. The plan was created at Rancho Los Amigos Hospital.
in Los Angeles, California, to save money. The plan was effected after a study for the Los Angeles County showed that the 158 quadriplegic polio patients using respiratory equipment were unnecessarily occupying $36 a day hospital beds when they could be cared for at home for $10 a day with trained attendants and supportive service.

Basically, the plan called for independence with an umbilical cord to the center. The patient remained a patient of the hospital and the patient's personal physician was placed on Polio Physician's Panel which made the hospital staff available for consultation.

Before a patient could go home, homes were made accessible and autostart generators were installed. Preparation for going home was extended and careful. Day long, then overnight, then weekend trial visits were made. Maintenance and service of all respiratory equipment was provided once a month and a repair truck, large enough for a lung or rocking bed, made the rounds.

In all the careful planning and adaptations there was never any attempt to move the hospital to the home and the family was involved in all planning. The family member returned home to the family -- with some bulky equipment. There was casual carefulness. Everyone in the family was responsible for and at ease with the equipment. They all learned to
help transfer it to battery operation in a station wagon for
trips to work or school or travel. They learned to repair
and adapt it.

A 3-year old was the best aspirator I've known. She stopped
the rocking bed with the foot lowered, climbed up, then,
hanging upside down like a monkey, turned the bed back on.
She operated the suction tubing like an orchestra conductor
until she located the plug of mucus. I asked her how she
did it. She said, "I watch my mommy's eyes."

At first, attendants were trained by the center. But the
turnover was so rapid that it was obvious that the most
effective method was to train the patient to hire and train
his/her own attendants, to train the patient to direct the
operation and maintenance of ventilators.

The Rancho home care plan spread rapidly across the country
and, by 1956, 92% of those permanently dependent upon
artificial respiration equipment had been discharged to
their homes.

The centers and home care resulted in tremendous financial
savings and a greater degree of independence and self-
sufficiency than was ever dreamed possible for people so
severely disabled.
Here are a few of the cost-effective figures: the average hospital time was cut from more than a year to seven months. The home care costs were one-tenth to one-fourth of hospital costs. Compare those costs to today's: The American Association of Respiratory Therapy estimates it costs $271,000 a year to maintain a ventilator-assisted person in a hospital and $21,000 at home. Without those centers, 40% of those who were at home would have had to remain in custodial care for the rest of their lives.

But no figures, no statistics can measure the magic of the sharing, mutual support, caring, learning, and teaching of each other that existed between patients, families, and center staff.

That learning and sharing was very evident in the gradual evolution of respiratory equipment.

Now, I want to say more about ventilation.

When I started in 1949, there was no awareness of the dangers of underventilation, no understanding that some people would have to be ventilator users for the rest of their lives.

Instead, use of the lung was seen as a failure, a last resort. Patients were threatened with it if they did not
try harder to breathe on their own. If they did use it, they were constantly encouraged to wean themselves from it.

I watched the gradual awakening to the error of overweaning and the acceptance of ventilator-using as a way of life. The awakening began when patients who had been weaned and sent home began to regress, to fail in school or business, to become irritable and suffer morning headaches. They were brought back for reevaluation and sent home again to renewed life with night respiratory aid -- usually a chestpiece or rocking bed.

A later discovery was that some people became addicted to overventilation. They had to be very gradually brought back to the normal range.

Another important lesson was the use of prophylactic tracheostomies rather than waiting until cyanosis set in.

Incidentally, in the U. S. tracheostomies were rarely used for ventilation of polio survivors, but for suctioning during the acute phase. Most eventually let their tracheostomies close, but a few retained them and kept them plugged and ready for the complications of colds or pneumonia.
In the mid-1950s, I watched the first rocking bed roll down the hall and the excitement of staff and patients over the freedom from the lung.

Next came a parade of various types and shapes of chestpieces -- to fit children, a giant basketball player, or one in a special shade of pink for a wedding.

Late in the 1950s, oral positive pressure by mouthpiece was discovered. At first, it was not humidified and there were many dry mouths. Then water was added and they looked like they were smoking hubble-bubble pipes.

Just in time for a big outdoor spring picnic, the engineer at our center developed a wheelchair tray for batteries and the respirator motor. That was the forerunner for travelling ventilator users who now circle the globe.

But the Utopia of the centers and their home care programs came to an end in the late 1950s.

Both concepts -- of regional respiratory and rehabilitation centers and of home care attendants -- had come into being to save money. Both ceased when the money stopped flowing, when the success of the vaccines caused the public to curtail donations.
That precipitous cessation of attendant care funding in 1959 was the "burr under the saddle" that resulted in significant developments in the growth of the disability movement.

In California, the ex-patients and medical directors for the two centers effected state legislation in 1960 that created an attendant care program that is still functioning and which has grown to a multi-million dollar a year home care program for both elderly and disabled persons and which has saved the State countless millions of dollars that would have been spent on institutional care.

That legislation and the successful experiences with independence of the respiratory polio survivors were the foundation for the independent living movement that was started in the 1970s in Berkeley, California.

In Ohio, the cessation triggered a national advocacy effort by respiratory polio survivors for national attendant care legislation. The effort failed, but it demonstrated the power of unified action and the value of networking and mutual support.

That support and networking system of respiratory polio survivors that was started in Ohio has been and is my lifework. It began when I began to volunteer at the hospital in 1949. It grew during my years at the
It was formalized in 1958 when I started a mimeographed newsletter to enable the local survivors to keep in touch with each other and to share information on employment, education, homemaking, equipment, and travel.

It filled the universal need of all people for information and for people. Very shortly, the newsletter grew to a little magazine, then to an international journal, the Rehabilitation Gazette. Its circulation expanded to survivors around the country, then around the world. Today, it reaches about 40,000 people in 87 countries.

Although I have been the catalyst, the Gazette has always been edited and written by people with disabilities.

One survivor called it "The magnet that has held the polios of the world together." Others described it as "an independent living center by mail," and "a mailbox support group."

Survivors in the United States needed a magnet, a center and a support group, for when the centers closed, free medical care ceased. When attendant care funding stopped, there was no other source of payment. They were on their own for many years until Medicare, Medicaid, Social Security Disability,
limited attendant care, and independent living centers evolved.

Of necessity, they became creative, ingenious, and independent. They adapted their own equipment. (The National Foundation continued to maintain the old respirators.) They doctored themselves.

In this connection, one might speculate:
Are the late effects more prevalent in the United States because we do not have national health insurance and survivors over-economized on medical care?

If we had had national health insurance would the late effects have been noticed sooner?
Could they have been prevented if overexercising had been recognized and proscribed sooner?
Has underventilation due to aging been caught earlier in countries with national health care?

Perhaps some of these speculations will be answered at this symposium or in the resulting research.

Thirty years ago, accessibility was accidental or nonexistent at universities. Yet many ventilator users went on to higher degrees and became professors, physicians, engineers, or lawyers. They were carried up and down the stairs of the inaccessible universities. They turned pages with mouthsticks. They taped lectures and borrowed notes.
Others went into sales or business. They married. They became mothers and fathers and are now grandparents. They experimented with the gamut of inexpensive attendants, such as illegal aliens. They travel. They vacation. They are active in their communities.

Not surprisingly, in later years, these pioneers, honed by their experiences, became the leaders of the disability movement. They are well known to many of you. Some of them are here today. It is very special for me to be here with them. They are longtime friends.

Over the years, they and many other polio survivors have shared their creative adaptations, their educational and employment experiences, their travels, and their family life in the Rehabilitation Gazette. It was and is the worldwide source of information on polio.

Consequently, we at the Gazette were the first to be called when they had respiratory problems and we were the first to notice the late effects of polio.

From the 1960s on, underventilation was a problem both for those who had been overweaned initially and for those using too little respiratory aid. Later, it became a problem for those whose aid became inadequate as they aged.
The underventilated wrote or called and told of morning headaches, sleep problems, depression, or frequent pneumonia. Or their families called when they were at a hospital in distress. We referred them to former medical directors of respiratory centers whom their doctors could call for consultation, or to Lifecare representatives who would know nearby polio-knowledgeable physicians, and to others who had been underventilated and who had changed and benefitted.

As a result of increasing underventilation problems with aging, there has been a gradual change in the aids used. Many rocking bed users and some chestpiece users had found that they were being inadequately ventilated and they have changed to positive pressure with a face mask or c-pap. A few longtime chestpiece/rocking bed users have had to change to a lung, then to a tracheostomy.

At the Gazette, we learned to expect to hear from a slowly growing number of ventilator users and nonusers who were underventilated.

But we were totally unprepared for the deluge of letters from less severely disabled polio survivors that followed the printing of a letter in our 1979 issue. The letter was from a survivor whose problems with mobility and breathing were increasing and who could not find a polio-aware physician.
The symptoms reported in these first letters are still the most commonly reported symptoms of what has become recognized as the late effects of polio or the post-polio syndrome. They are:

- unaccustomed fatigue -- either muscle fatigue or generalized body fatigue
- weakness in muscles - both those originally affected and those unaffected
- pain in muscles or joints
- sleep problems
- breathing difficulties
- swallowing problems

But their complaints were more centered on their frustrations with their physicians than on their symptoms. They had outlived their polio physicians. They were being told by their present physicians, "It is all in your head," and given tranquilizers, or exacerbated by orders to exercise over-exercised muscles, or sent for expensive referrals. A frequent complaint was that their physicians did not appear to listen.

The starting point would have to be to educate the medical community about polio. To tackle the problem, I sought the advice of Dr. Dickinson & Dr. Eiben two former respiratory polio-center medical directors, and Dr. Fred Maynard, a
physiatrist at U of Michigan, and an old friend, Dr. Allen Goldberg. The four advised an international conference to educate physicians, to promote research, and to share the information and experiences of polio survivors with other ventilator-users - those disabled by spinal cord injury, muscular dystrophy, amyotrophic lateral sclerosis, etc.

As a result, we organized the Gazette's First International Polio and Independent Living Conference in Chicago in 1981. It was the first coordinated approach to post-polio problems.

The 1981 conference gathered together 168 physicians and polio survivors, 30 of whom used ventilators. Some of those polio survivors are here today: Adolph Ratzka, Audrey King, and Judy Heumann. Among the physicians were Dr. Fred Maynard, Dr. Augusta Alba, Dr. Armin Fischer, and Dr. Geoffrey Spencer of London, who is also here today.

Later, Dr. Maynard said, "Gini was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when? She asked me to give a talk at that first conference; I remember thinking, 'Who am I to talk?' I told them I didn't know if what I was seeing in the handful of people in my clinic was typical or just odd cases. The
audience said yes, they had the same symptoms, knew others with them. After that meeting, I was convinced."

The second international conference in 1983 in St. Louis attracted many more physicians and survivors - a total of 439 registrants. Of these, 201 were disabled. They came from around the world -- 24 from Germany. There were 40 ventilator users, including one from Australia who used a portable en route and rented an iron lung for sleeping in the hotel.

The conference was well recorded on film. The Columbia Broadcasting System filmed a 10-minute feature for "Sunday Morning with Charles Kuralt," one of the country's most popular national television shows. Adolf Ratzka and Hans Peter Meier made part of the documentary which you will see tonight at 19:15.

Following the conference, Dr. Lauro Halstead, who is one of your speakers, took the leadership in promoting research into the late effects of polio and in involving the medical community. He was one of the organizers of the scientific symposia at Warm Springs in 1984 and 1986.

At the 1984 symposium, Dr. Mary Codd of the Mayo Clinic reported that her studies indicated only about 25% of the 200,000 to 250,000 polio survivors in the United States with
residual paralysis may experience the late effects. We hope that with the advantage of your national health care, your research will further Dr. Codd's.

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In 1984, two of the physicians, Dr. Fred Maynard and Dr. Armin Fischer, worked with the Gazette staff to create a concise, easy-to-read booklet, the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. It has become the "bible" of information for polio survivors.

The handbook is in its fourth printing. We have sold more than 30,000 copies in English and it is being translated into other languages. Adolf Ratzka has had it translated into Swedish. Uwe Prehse is having it translated into German. Translations are in process into Spanish, French, and Finnish and it has been excerpted in Chinese.

The Gazette's third international polio and independent living conference in 1985 drew 586 registrants from Europe, Asia, Africa, Taiwan and Australia, as well as the United States, Canada, and El Salvador. Among the speakers were Dr. Albert Sabin, creator of the oral polio vaccine, and Dr. William Masters of the Masters and Johnson Institute.
In 1987, the fourth international polio conference drew 747 registrants to St. Louis from all across the United States and from 18 countries, including South Africa, Mauretius, Zaire, Japan, Brazil, and China.

A special conference session on face masks for night ventilation was packed with polio survivors and physicians demonstrating masks they had designed themselves. Among the most innovative were those designed by Adolf Ratzka, Bruni Bung, and Dr. Newton-John from Australia. This session typified the essence of the conferences - the spirit of learning and sharing and the mutual respect between health professionals and polio survivors.

The conferences have had a significant impact on the medical community. The progressive growth of the conferences reflects the increasing acceptance of the phenomena of the late effects. That acceptance is further reflected by Dr. Halstead's two symposia and by articles by respected scientists published in such prestigious journals as the NEW ENGLAND JOURNAL OF MEDICINE, JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, ORTHOPAEDIC REVIEW, SCIENCE, POSTGRADUATE MEDICINE, ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION, AND CLINICAL PROSTHETICS AND ORTHOTETICS.

Further, the conferences have triggered research into the postulation that late effects may manifest themselves in
other long term disabilities. The United States Veterans Administration is currently funding research into the late effects of spinal cord injury.

The Social Security Administration participated in the 1987 conference and followed up with an investigation of the late effects of polio. As a result, it has issued official guidelines to all its field offices recognizing that these functional problems may limit ability to work.

More important, the conferences have drawn physicians, such as Dr. Dick Owen and Dr. Halstead who are themselves disabled by polio, and who understand the need for both physiological and psychological support.

Psychological support is perhaps the more important. The majority of survivors had been relatively mildly disabled. They adjusted. They compensated. They overcompensated. They exercised. They overexercised. They lived for 30 years with a limp or a cane; they were untouched by the world of disability - by the problems of discrimination and prejudice, untouched by the barriers of steps and inaccessible bathrooms.

Naturally, when these survivors began to experience the late effects and began to use wheelchairs or some of the other
trappings of disability, they faced significant psychological adjustments.

The conferences were the catalysts that brought the survivors together. As a result, a grassroots movement evolved to cope with the psychological adjustments by sharing with others in support groups. It is a movement that is by people for people. During the 1985 conference, our organization formalized our longtime polio network into the International Polio Network (IPN) to link polio survivors with each other and to encourage the formation of support groups. Our IPN acts as the international center of information on polio. We publish a quarterly bulletin, Polio Network News, and maintain a national and international directory of support groups, physicians, and clinics.

In addition to our IPN, we have recently formalized our longtime network into an even more specialized network for all ventilator users and the professionals who work with them. It is the International Ventilator Users Network (IVUN). We have also published a handbook titled, Ventilators and Muscular Dystrophy.

In our computerizing expansion plans, we hope to supplement the present biannual IVUN newsletter with support groups that "meet" by computer.
Presently IPN coordinates about 200 support groups in the United States and 55 clinics. Each support group is highly individual, reflecting local needs and personalities. They are primarily run by and for their members who have a sense of ownership and who help each other by sharing common problems. In most groups, there are three basic types of activity: emotional support, information exchange, and coping strategies.

Support groups and polio clinics work closely together, each making referrals to the other, but functioning quite independently. Support groups are an important adjunct to treatment and rehabilitation. They do not replace professional services, but they supplement them and provide benefits that professionals cannot. Yet, professional human service agencies continue to try to co-opt local polio support groups as they have tried to co-opt many similar groups.

Incidentally, the number of support groups in the United States is growing at an astounding rate; there are now about 15 million persons in more than one-half million groups.

In conclusion,
I want to thank you for the privilege of being a part of this significant symposium. I look forward to every minute of the three days ahead of us.

I would like to extend an invitation and share a few caveats.

I hope that our International Polio Network will see many of you at our next polio and independent living conference in St. Louis on May 31 - June 4, 1989.

A few caveats:

- Beware of professional intrusion in mutual support groups.
- Beware of overprofessionalization of home care and ventilator users. Bringing the hospital into the home increases costs, inhibits individual independence, and intrudes on family privacy and intimacy.
- Beware of astronomical costs for all ventilator users or society will choose the more economical alternative - no ventilators.
- Beware of underestimating the limitless potential of individuals with disabilities. Do not forget the experiences of resourceful, independent ventilator users in the United States who lived productively and independently at home for 30
years, without home care funding and without medical funding, because they had learned to be independent at regional respiratory centers.
COORDINATING OF EXPERIENCES WITH LATE EFFECTS
AFTER POLIOMYELITIS IN THE USA - AN EXAMPLE FOR EUROPE

By Gini Laurie

Saturday, April 9 10:00 - 10:15
The ideal U. S. examples of coordination are still the polio and regional respiratory and rehabilitation centers of the 1950's.

- Their multidisciplinary teams that involved the patients, their families, and other physicians;
- Their location at teaching hospitals of medical schools;
- Their sharing of knowledge through regular meetings of their medical directors;
- Their home care support systems that included home adaptations and payment of attendants;
- Their equipment research programs;
- Their equipment maintenance programs that included a mobile repair truck;
- Their umbilical cord relationship that enabled ventilator users to live independently in the community.

The centers succeeded because they not only empowered their patients with the positive attitude, equipment, techniques, and support systems necessary to their maximum rehabilitation but they resulted in tremendous financial savings.
They failed because their funding was not based on permanent government funding but on emotional appeal to the general public by a voluntary agency.

That responsibility was too great for a voluntary agency. They should have evolved into government supported centers for all types of severe disabilities -- including muscular dystrophy, high level spinal cord injury, amyotrophic lateral sclerosis, etc. They should have continued to research and experiment with respiratory equipment. They should have adapted the variety of ventilators used for polio - lung, chestpiece, pulmowrap, pneumobelt, and oral positive pressure - to other disabilities.

Instead all that experience and medical knowledge were dissipated.

As a result, modern health professionals are unaware of the experiences and equipment of polio survivors who lived independently with mechanical ventilation for more than 30 years.

Therefore, professional education was our first priority in the U.S. and should be your first priority in Europe. In the U.S., the March of Dimes went on to another disability. But in Europe and Canada, your polio voluntary organizations, such as Pfennigparade, did not close but
continued or added other disabilities. So you may not have so much of a problem educating your health professionals. Educating health professionals has not been easy in the U.S. and it will not be easy in Europe:

- They do not know of or do not accept the late effects of polio;
- They are not tuned to look for the underventilation of scoliosis or aging that may occur as a late effect of polio;
- They have not had experience with the rapid recovery from underventilation that may occur when night ventilatory aid is added;
- They do not easily accept that some individuals are unweanable and they can live a good life at home with the assistance of a ventilator;
- They are unfamiliar with the noninvasive ventilators that are so familiar to polio survivors;
- Their experience has been limited to ventilation through a tracheostomy - largely in intensive care.

Of course, basically, most health professionals are not in the habit of being educated by their former patients.

But it can be done - as I told you at your opening on Thursday how our International Polio Network and our International Ventilator Users Network have begun the
process by publications and publicity and by coordinating international, regional and local conferences, clinics, and support groups.

You have a good start with this exciting international conference and your cadre of polio survivors and concerned and cooperative physicians and other health professionals.

In the United States we were blessed from the beginning with such a cadre of polio survivors and of caring and helpful physicians, such as Dr. Fred Maynard, Dr. Armin Fischer, and Dr. Augusta Alba, and with Dr. Geoffrey Spencer and Dr. Lauro Halstead, who are here.

Such concerned physicians will continue the momentum with further conferences, - regional, scientific, and international; will educate other physicians through their publications in scientific journals.

In addition to coordinating the education of health professionals, you will need to promote the education of polio survivors, other persons with severe disabilities, other specialized voluntary agencies, and the general public through TV, radio, and newspapers.

But, most important will be doing more of what you are doing so well as this conference - involving polio survivors and others with severe disabilities, empowering them with
information, and tying them together so they can support each other in accepting lifestyle changes.

You have some advantages in Europe. You can utilize

- U.S. experts - such as those who are here;
- the proceedings of U.S. symposia and conferences;
- U.S. publishings in medical journals,
- International Polio Network's experience coordinating more than 200 support groups and 55 clinics,
- IPN's handbook on polio which has been or is being translated into German,
- and Rehabilitation Gazette's 30 years of subjective experiences of ventilator users.

Further, with national health insurance, you should have better records of early treatment and, without financial impediments, it should be easier to convince polio survivors to get baseline examinations for comparison and to uncover unrecognized underventilation.

You have some disadvantages, too. European professionals may find it more difficult to accept the mutual support group and team spirit because it will seem too independent, too individualistic, too American.
But your polio survivors will evolve a European variation on our support groups, just as the support groups around the U.S. reflect their varied locales.

Eventually, you will develop a European network, working with existing polio and other disability voluntary agencies - but not being co-opted by them.

Whatever you do, wherever you go, our International Polio Network and International Ventilator Users Network will work joyously with you in every way we can.
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Whatever you do, wherever you go, our International Polio
Network and International Ventilator Users Network will work
joyously with you in every way we can.
1988 - October 20

St. John's Mercy Rehabilitation Center dedication. Speaker.

St. Louis, MO
ST. JOHN'S POOL DEDICATION.  Oct 20, 1988

Thank you, .... This is a touching moment for me to be at the dedication of this pool and expanded rehabilitation facilities which will be so helpful to my friends who are polio survivors. It is touching because I have such sad and glad memories intertwined with St. John's and polio.

My father, Dr. Robert E. Wilson, was a surgeon and on staff at the old Euclid Avenue St. John's. In 1912, the year before I was born, four siblings were struck by polio: a 12-year old sister was mildly disabled, a 6-yr old brother very severely disabled, and two sisters, aged 3 and 9, died within days at St. John's. In their memory, my mother painted a mural on the ceiling of the St. J. chapel depicting them as angels.

16 yrs later, I watched my brother die of pneumonia and underventilation at St. John's. His funeral Mass was in St. John's chapel, underneath the mural of our sisters.

But I have many glad memories, too. When I was a child, my father sometimes took my younger sister and me on his Sunday morning hospital rounds. Our favorite hospital was St. John's because one of the nuns always us cookies and milk and, occasionally, took us to see the guinea pigs in the labes in the back.

Now, 70 years later, I can still remember that big entrance hall - the enormous curving wood stairway, the clunking
2-St. John's

elevator, the awesome formal parlor on the right, and the telephone/cloak room on the left. Most of all, I remember the fun of watching the switchboard operator put and take those plugs attached to the cords that jumped back into their holes. When someone telephoned for a doctor, she looked at the coat and hat hooks to see if he were there. (Now, I wonder if there were names on those racks or if she memorized the garments. In those days, we can be sure she didn't have to memorize any feminine hats or coats.)

Perhaps later, one of the older nuns or nurses can solve that coatroom mystery for me.

Meanwhile, it is with great pleasure that I congratulate St. Johns on this addition to rehabilitation arena of Greater St. Louis.
1988 - October 28

Meeting of Rehabilitation Nurses at Deaconess Hospital. Speaker.

St. Louis, MO
INDEPENDENT LIVING - REHABILITATION

Have lived history of IL & polio & rehab. 1912.

INDEPENDENT LIVING .......... HISTORY
IL not just happen. Quads Berkeley not just wave mouthsticks.
Interdependent. Not isolated. Part of its time.

Influences:
1. Importance of individual.
2. Rights of individuals & minorities, blacks & women.
3. Medical advances, penicillin, healthy & long-lived.
   Elderly - nursing homes, pneumonia = friend.
5. Preceeded by other organizations. Canadian Para Assoc after WWII govt agency. PVA info & lobbying.
6. Existing legislation for attendants. Calif started IL. Why?

GL volunteered 10 yrs. By 1958 vaccines. Started TJC which became RG - all dis. 87. Forerunner of IL = by mail, peer models & counseling. Forum. WILL COME BACK TO RG AND REHAB... FINISH IL STORY FIRST.
When vaccines stopped polio, MofD stopped funding. Shock of stopping attendants. Calif organized. Legis. RG rest of country. Showed could work together.

8. NPF trained present leaders.
10. ACCD - all disabilities. NSE & W know each other.

First thought of COMMUNAL. Said NO - fortunately. Instead
set up office to provide services. Same now. Not residential. Their mothers.
Worked so well, other nonstudents wanted to copy.
Then spread through Calif. largely because of legis.
Funded first 10. Then accepted as part of VR & funded.
NCIL.
Essentials: 51% disabled control.
peer models
peer controls
service system - transp, attendant, housing, +

Proceedings. Started formal IPN. Now 253 support groups. 50+ clinics. Wice at StJ. Local support group. Publications.

INTERNATIONAL VENTILATOR USERS NETWORK...Mysc dys handbook & problem of ventilators. Polio experience.
Noninvasive. 30 yrs at home. Knowing own equipment. Hiring own attendants. Living full & productive lives.

Briefly, CONFERENCE in 1989.

FINALLY.....REHAB OF PERSONS WITH SEVERE DISABILITIES & HOME CARE......
RG...30 yrs....BI list for everyone. Next issue.
Genskow...Susan...Gloria Finkel.
1988 - October 28

President's Dinner. Annual meeting of Ohio Easter Seal Society. Speaker.

Cleveland, Ohio
I'm delighted to be here, to be back in Ohio, to be with so many old friends, and to be here for such a gala occasion as your annual banquet.

And, of course, I'm happy to talk about my favorite subject - polio. My favorite because it has played such an important part in my own life and because I have lived and contributed to the history of polio.

I'll start at the beginning....76 years ago....before I was born, when four of my siblings were struck by polio. It caused the deaths of two sisters immediately and one brother some years later. I was born to replace the two sisters and given their names.

Consequently, when the epidemics started in 1949 and the contagious ward of the Cleveland City Hospital (now Metropolitan General) called for volunteers to learn hotpacks, I volunteered and I have never stopped.
For 10 years, I worked there at the Toomey Respiratory Polio Center once or twice a week. I made close friends with the survivors and their families and we kept in touch after they went home.

In 1958 we did more than keep in touch. At our home in Chagrin Falls, my husband and I built a heated swimming pool with a hydraulic lift and it became the gathering place for polio survivors and, eventually, people with other disabilities from all over northern Ohio.

That same year, at the suggestion of Dr. Eiben, the medical director of Toomey Pavilion, I started a little newsletter to keep people in touch with other, to share ways of adapting to living at home and of going to school or work. I called it the TOOMEY GAZETTE.

Are there some of you here who read that little newsletter and who came to the pool picnics and helped write the old Toomey Gazette?

That little newsletter changed to the REHABILITATION GAZETTE and became an international journal written by people with all types of disabilities - not just polio survivors.

The GAZETTE now reaches about 40,000 people in 87 countries and is translated into several languages, including
Japanese. It grew because it filled our universal human need to share problems and solutions, our need to have role models and, above all, to know that we are not alone. In other words, the GAZETTE became a support group, an independent living center by mail, and most importantly, it became a family - the Gazette family.

And, because we kept in touch with our polio family through the GAZETTE, we were the first to notice the late effects of polio and the first to take action to educate physicians, survivors, and the public through publications and international conferences. We were the first to coordinate and act as a clearinghouse for polio support groups and clinics. We have become the world's center of information on polio - the International Polio Network.

Now, the International Polio Network has a full-time director, Joan Headley, a polio survivor. She coordinates 255 polio support groups and 55 clinics in the United States, maintains a national and international directory of support groups and clinics, edits the quarterly newsletter, POLIO NETWORK NEWS, organizes a biennial Support Group Leaders Workshop, acts as a clearinghouse and an information and referral service for the flood of survivors and health professionals who call and write for information, and edits the proceedings of our biennial international polio and independent living conferences.
Those unique conferences are the pivot of our information and education services and the birthplace of the present concern with the late effects of polio.

I'd like to share the beginnings with you in a quick flashback.

Back in 1979, the REHABILITATION GAZETTE published an article describing the problems a reader was having with polio as he aged and with the younger physicians whose education had not included polio. The letter triggered a flood of letters from others with the same problems. This, coupled with the increasing underventilation I had been observing, made me realize that the most urgent problem was the education of physicians.

In 1980, I discussed the late effects and the need for education with old friends, Dr Robert Eiben of Cleveland, Dr. Allen Goldberg of Chicago, and Dr. David Dickinson of Ann Arbor. Dr. Dickinson referred me to Dr. Frederick, a physiatrist, who had seen a few polio survivors who were having problems of some sort. They agreed the best way to start educating both physicians and survivors was an international conference and they all offered to help me organize it.
The Gazette's first international polio conference in 1981 drew 125 survivors and physicians. There began the unique partnership of lay and professional persons working together to solve an undocumented problem, the special spirit of polio togetherness that characterizes all the Gazette's international polio conferences.

Six years later, Dr. Maynard reported in an interview in the ST. LOUIS POST-DISPATCH, "Gini was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?"

Isn't that shivery to think that the late effects might not have been noticed?

But they were noticed because of that first conference. And that conference set the pattern. The leading polio physicians of the world were there because they were old friends through the GAZETTE. About three-fourths of the registrants were polio survivors and their families or attendants. The speakers were divided equally between medical experts and the polio experts who had lived productively at home for more than 30 years.
There was the extraordinary spirit of a family reunion, of learning and sharing, of mutual respect between health professionals and polio survivors. The conference was such an outstanding success that we have continued to convene international conferences on polio and independent living every other year since 1981.

The number of registrants has increased every year. We expect about 1000 at our 1989 conference. The international representation also continues to increase and now includes physicians and survivors from every continent. As honored guests and keynote speakers, we've had some prestigious persons - the Surgeon General, Dr. C. Everett Koop, Dr. Albert Sabin, Dr. William Masters of Masters & Johnson, and Ted Kennedy, Jr.

The conferences continue to bring together physicians and polio survivors to share information and to enable survivors to give mutual support to each other by sharing problems and solutions.

We invite you all to attend our Fifth conference which will be held in St Louis, as usual, at the Sheraton Hotel on May 31 to June 4, 1989. Once again, the polio experts of the world will gather for an exciting program that includes research, treatment, psychological adjustment, underventilation, ethical challenges, and independent living
worldwide. A new feature will be EXPO Midwest - a display of all kinds of equipment - at the convention across the street. A superb opportunity to try on wheelchairs and three-wheelers and to meet all sorts of new equipment.

While some of you are very informed, by now, some of you must be wondering just what are these "late effects of polio?" If you want to be informed quickly, get a copy of our handbook, HANDBOOK ON THE LATE EFFECTS OF POLIOMYELITIS FOR PHYSICIANS AND SURVIVORS. It is in dictionary style and in plain English and summarizes all the aspects. It is the "bible" of polio information. If you want more technical information, you will find it in the proceedings of our conferences.

But to save your time, I'll try to summarize the information in the handbook and the conference proceedings:

The symptoms are unaccustomed fatigue, muscle weakness, pain in muscles or joints, sleep problems, and breathing and swallowing difficulties.

The diagnosis is one of exclusion. Your physician will first determine that it is not ordinary aging, arthritis, or some other neuromuscular problem.
Research seems to indicate that the late effects may affect only 25% of the 300,000 polio survivors in the United States, that they occur about 30 years after onset, and that they are treatable if the prescribed procedures and common sense are followed.

The following recommendations are so universal that we would all be healthier if we followed them:

Don't overexercise
Don't overuse
Rest when you're tired
Watch weight gain
Don't smoke
Don't overindulge in alcohol
Avoid narcotics
Listen to your body
Pace yourself; slow down.

You can cope with the late effects of polio by staying informed, using commonsense, and sharing with other polio survivors through support groups.

The sharing with other polio survivors in support groups is the essential psychological support that is needed to make the lifestyle adjustments to continue a life of dignity and independence.
There is eternal comfort in the clubbiness that members of tribes and villages have extended to one another for millenia. There is comfort in knowing one is not alone and that others share the same problems and have found solutions. This comfort is essential in the aloneness of our mobile, urban society of small and scattered families.

To fill that universal need for sharing, the number of support groups in the United States is growing at an astounding rate: there are now about 15 million persons in more than one-half million groups. The variety of those one-half million groups is even more astounding. They range from AA, which was established more than 50 years ago to the Zellweger Syndrome and they cover addictions, disabilities, illnesses, parenting concerns, bereavement, and other stressful life situations.

They are so successful because they offer very real relief from isolation and fear, in ways that even the most sympathetic physician or the most skilled therapist cannot approach. They offer vast experiential knowledge and practical coping skills, not only for the individuals but often for their spouses and families. They recognize and nurture members' strengths and competence.

They provide rare opportunities to learn from positive role
models - those who have been there. Members often experience an increased sense of needed self-worth and self-esteem when their own experiences enable them to help others in the group.

Briefly, the typical polio support group, like all other groups, has a common health concern, governs itself, provides emotional support, gathers and shares specialized information, increases public awareness and knowledge, is nonprofit and voluntary, charges small or no fees, and is constantly struggling to survive. Attendance at meetings is fluid and small, though membership may be large.

Ever since our organization first began to nurture the development of support groups, we have encouraged them to govern themselves, to be autonomous and to reflect the needs of the individual members and of the local community. Consequently, there is great variety in the support groups. Some meetings are structured, others casual. Some have achieved nonprofit status, others are disinterested. Some meet in each others' homes or by phone or mail, others meet in independent living centers, rehabilitation centers, churches, hospitals, senior centers, or local March of Dimes or Easter Seal offices. Some have asked one or more of these institutions to provide mimeographing or postage as well as meeting places, others are totally self-sustaining. Some
have co-sponsored valuable local and regional conferences with their local institutions.

To seek help or not to seek help from a local institution is a dilemma for many support groups. Either choice presents problems for both the group and the institution.

Total independence is the surest way to remain true to the purpose of a self-help group, but it is slower and more work. Seeking help from an institution is faster and less work, but there is the risk of losing control and of diluting the real purpose of the group - to provide mutual support.

I have been reading everything I could find about self-help groups and last summer I was privileged to be selected as a member of Surgeon General's Workshop on Self-Help and Public Health. There I learned how universal these dilemmas and problems are. Following are three of the most common:

- Historically, professionals have sometimes tried to co-opt self-help organizations, and they are often regarded as intruders.
- When support groups turn to the institutions for assistance, a struggle for control and inherent tension may result.
- Conversely, when the success of support groups has led
professional institutions to sponsor groups of their own, choosing the participants and convening the meetings themselves, even more tension results. Since members do not control resources and direct policy, they are not technically self-help groups and do not accomplish the same ends. The more professionals are involved, the more likely it is to resemble group therapy and lose the essence of self-help.

Yet, sometimes, collaboration can work.
As you seem to be making it work here in Ohio.

Apparently, your Ohio polio support groups and your Ohio Easter Seal have worked out a collaboration that benefits you both. Easter Seal recognizes when it may be extraneous and has learned to follow, not to lead, and the support groups have learned that you are both part of the helping systems that exist in a community.

Best wishes on your rare, mutual collaboration!

To give us all a chance to give ourselves a pat on the back, I'd like to close with a trio of examples of what can be done when we all cooperate and network together.
The first was back in the 1960s, when a polio survivor who could not use her hands or arms saw someone who was blind using Talking Books. She wrote to us at the Gazette and suggested we try to get Congress to change the laws from blind only to include people who were unable to turn pages. Wonderful idea! We asked survivors all over the country to write to their congressmen. They flooded Congress. Mrs. Cyrus Eaton, here in Cleveland, whose husband owned the Chesapeake & Ohio, added her influence and the legislation was passed. One good idea and a lot of cooperating people.

The next was in the early 1980s. One Friday, we started to receive frightened phone calls from ventilator users saying they had just received a letter from HCFA (Health Care & Financing Administration) advising them that henceforth they could have only one ventilator. That meant not only being without a portable to go to school or work, but also being without one in case of emergency. For the next four days, we did nothing but telephone all around the country, asking people to write or call their congressmen, news media, President Reagan, and HCFA. We called individuals who used ventilators, their physicians, therapists, Easter Seal and other national organizations, and equipment manufacturers. They all responded so effectively that by the following Thursday night we had a call late in the evening from the White House saying that the order had been rescinded.
The last one climaxed our 1987 conference banquet. Simon Levin thanked all the polio survivors for securing the release of his wife, Tamara, a polio survivor, and their son, Mark, who had been kept in Russia as Refusniks for seven years after he had left. He attributed their release to the letters written in response to our request in the POLIO NETWORK NEWS asking polio survivors to write Mikhail Gorbachev, President Reagan, and Dr. Armand Hammer. When Simon thanked everyone, he said, "If you can get Gorbachev to change his mind by working together, then you can accomplish anything you want by working together."

Thank you and my best wishes for the continued success of your working together.
1988 - November 2

"Beyond the ICU" - Community Living Options for High Level Quadriplegics and Ventilator Dependent Individuals.
Hugh MacMillan Centre. Speaker.

Toronto, Ontario
Gini Laurie

Involved by polio all life. 4 siblings. Brother under ventilated.

Working as volunteer with people on vents since 1949. 10 yrs at respiratory polio center.

Have followed lives of 1000s around world since then through our publications, RG and IVUN, and our international conferences.

Early 50s, 17 resp ctrs in U.S. Thought had to stay in hospital rest of life. But, in 1953, Rancho in LA had 153 in iron lungs. To save money, did study on home care support services. Found instead of $30 day, could do for $10 day, including attendant care and equipment maintenance. Same ratio today: 1/10 to 1/4 less at home.

The way people were trained to go home applies today. Based on common sense and on recognition disabled are people first and they have a right to make choices and to be informed about those choices.

Attitude is the key. "I'm on a vent, so what?" Positive attitude is vital!

Home Care System - umbilical cord to hospital.

   Equipment maintenance. Semi made rounds.

   Own physicians access to hospital staff & records.

   Team approach from beginning. Family & survivors.


   (March of Dimes stopped. Calif legislation. $300 month to individuals who hired, trained, & fired. Still in effect in legislation.)


   Of course, everyone can't go home. Everyone can't take charge of his/her equipment and attendants. Of course, some will be too ill.
But more could, IF staff had a positive attitude, if staff knew role of role models...if staff knew how to train.

Society has tendency to smother with care. Instead, teach the individual to be careful.

You may be saying, all very well for the 50s, but not today. But I spent a week in a center in London this spring that is a modern day version.

Center is Phipps Respiratory Center. A part of St. Thomas' Hospital. Prestigious. Has been in wing of South Western Hosp. New space in St. Thomas' first of yr.

Dr. Geoffrey T. Spencer, anaesthetist, consultant at St.T. Director of unit since 1968. Now provides hospital unit of 16 beds and home service for ventilator users with all types of disabilities in England, Scotland, Wales, and Northern Ireland.

......going to take 5 minutes to read Dr.Spencer's talk at a polio conference in Munich this April.........(Read from "In England" on....)

Last paragraph fits with English paternalistic English attitude, rather than with more liberated Canadian and American.

Same essential service system that made US respiratory centers work: hospital base, umbilical cord, attendant care, and equipment maintenance.

The unit has a large equipment repair and maintenance area, two ambulances which are used to make regular visits and to bring survivors in for treatment......Superb head nurse available to answer questions.

I'd suggest that Ontario respiratory service should start by a visit to Phipps Respiratory Unit and then to Concepts in New York City to study the attendant care system and then to Western Canada to study the home care systems in Alberta & BC.

Here are more details about those programs and more examples. Incidentally, I've brought a copy of my book on HOUSING AND HOME SERVICES, published by Harper & Row.

DENMARK...1960, most at home. Expenses paid by Natl Fdn Against Polio. Survey indicated 6 wanted to live with families and also have help from an institution. At time, large housing project. 170 flats at rehab center for
disabled & staff. Top floor turned into nursing annex. 14 flats reserved for families. In theory, would have place for emergency care or could go there to sleep. But, plans and people are rarely copacetic. Eventually, became longterm chronic care unit for all types of disabilities requiring ventilators.

Visited there in 1980, when on study tour for World Rehabilitation Fund. Stayed a week in the apts. Depressing ghetto. No curb cuts. Never saw disabled in nearby shops or restaurants. At that time in Denmark, if needed more than 3 hrs of attendant care (cost about $18), you went to a young chronic sick home costing $125 a day. UBI - Universal Bureaucratic Idiocy.

Shortly afterwards, Danish laws changed to allow payment of full attendant care so people with severe disabilities could live at home. Example: met young woman in 1980 with muscular dystrophy living there. When law changed she moved to own home. In 1987 came to our conference in St. L & went on in rented car to Grand Canyon, Pikes Peak, etc.

Incidentally, '89 CONFERENCE brochures.
GOLDWATER... NYC. One of original resp ctrs. Again, as in London, leftovers from 1950s. When public housing nearby, many moved out because NY state had attendant care legislation.

Concepts, system to recruit and screen attendants set up by one of the ventilator users. They are given $ and taught to hire, train, and fire. One or two who did not wish to leave and still in hospital.

Again, the combination of attendant care monies and the umbilical cord to one of best respiratory centers in country.

ALBERTA'S UNIVERSITY HOSPITAL.....Most moved out years ago when attendant care and living expenses provided. Very few preferred to stay on. Flexible approach to hospital life. Survivors owned a race horse, ran a computer business, and took trip to Hawaii.


One, David Young, said "I was at Pearson from 1955 to 1976 when I left to get married...Life outside an institution is so much better. Life in an institution is staying alive. Isn't living.....After 20 years of institution, it takes quite a while to become strong of spirit to handle any given situation.

ENGLAND'S GROVE ROAD HOUSING SCHEME....Six-family flat in local community. 3 on first for disabled, 3 on 2nd for nondisabled helpers. Sounded great. But shortly afterwards, disabled tired of being so "special" and wanted to move into ordinary housing. One couple said, "It looks super, but it is another isolated mini-institution."

ENGLAND'S CHESHIRE HOMES.....Visited Le Court several times. The model home, the leader. First to work with Cheshire Homes Foundation to set up an attendant care system so could move out into community. Many out under this scheme.

AMERICA'S CHESHIRE HOMES.....In 1980 I had a long talk with Group Captain Cheshire in the British Embassy in Washington. He asked me how he should start a Cheshire Home in the U.S. I told him to put it in:
1. California, because there is attendant care legislation there.

2. Not to buy and not to build a specially adapted home, but to rent a house or apartment in an ordinary neighborhood and make whatever adaptations are necessary.

3. Keep the number small and homelike. No more than 5 or 6 or whatever is the maximum number of unrelated people allowed in one home to keep it from being termed an institution and being forced to conform to local laws.

He took all of my suggestions and followed them literally. Now there are several Cheshire Homes in California set up along those lines.

SWEDISH FOCUS. Visited them in 1980. Very disappointed. Had thought I would find the perfect answer. Large housing complexes, 2 apts on each floor for disabled and congregate dining & meeting rooms, with attendants on call. That was the plan. But that is not the way it worked out. The dining & meeting rooms were not used. It is a myth that people with disabilities want to be with others with disabilities - whether they have anything else in common or not.

Attendants went around from apt to apt. They became an ambulatory institution. No privacy. Favorites picked. If not liked, you were last.

EASTERN PARALYZED VETERANS OF AMERICA... Excellent system of transition living for many years. Organization owns one apartment in an ordinary apartment building. Couples or individuals, with attendant care, live there for weeks or months while they are learning.

Much more normal way than lumping 10 or 12 together in a so-called "transition" home.

You learn to live independently only by living independently.

Discharge planning and home care planning start on the day of admission.

Recommend "transition" or "living practice" apartment in the in the hospital, similar to the one at Lyndhurst.

Practice lifting and transferring and working with ventilators while there are experts on hand to help with the learning process.

Go home gradually.
Don't try to build the perfect place. Don't fall victim to the EDIFICE COMPLEX.

People need service systems, not bricks. People need people.

People need as much control over their lives as possible.

People need freedom of choice and they have a right to information to help them make informed choices.

People have the right to live as independently as possible and with as much control as possible.

They should be informed as to their potential and be given the opportunity to learn and to experiment with independence and make choices.

These are not idle platitudes. The experiences of ventilator users in the United States who lived productively and independently at home for more than 30 years without any special entitlements or funding prove the cost-effectiveness of independent living over institutionalized living.

I have spent 30 years documenting the lives of ventilator users in the REHABILITATION GAZETTE.

They are proof of the cost effectiveness and people effectiveness of home mechanical ventilation.

To name a few who have lived at home and managed successful careers as physicians, lawyers, professors, teachers, engineers, scientists, business men, entrepreneurs, salesmen, etc. To them, a ventilator is an inconvenience, not a deterrent.

A FEW CAVEATS...

Beware of overprofessionalization of home care. It may make home care more expensive than hospital care.

Don't bring the hospital into the home. It is unnecessary because homes do not have the cross infection of the hospital. It increases costs. It inhibits individual independence and intrudes on family privacy and intimacy.

Beware of astronomical costs for ventilator users or society will choose the more economical alternative - no ventilator.
Beware of underestimating the limitless potential of individuals with disabilities

Do not forget the experiences of resourceful, independent ventilator users in the United States who lived productively and independently at home for more than 30 years because they had learned to be independent at the regional respiratory care centers.
1988 - November 3-5

National Conference on the Late Effects of Polio. Ontario March of Dimes.

Speaker.

Toronto, Ontario
Thank you... I am delighted to be here at this important Canadian polio conference. And, I'm happy to talk about polio and the history of the late effects of polio because I have lived the history.

To give you a quick glimpse of my part in the history of the late effects of polio, let me quote Dr. Frederick Maynard of the University of Michigan in a newspaper interview in 1987. Speaking of our first post-polio conference in 1981, he said, "Gini was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?"

Of course, I would notice that polio survivors were having problems because I had been working with them so closely as a volunteer since 1949. 10 years in a respiratory polio center, and, since 1958, editing an international journal, the Rehabilitation Gazette, corresponding with survivors all over the world, and creating a "Gazette family." For more than 30 years, the Gazette has been the lifeline of information on polio and the center of that large family of about 40,000 readers in 87 countries.

During the 1970s, I had noticed the increasing incidence of underventilation of long-time ventilator users as well as of those who had been weaned soon after onset. I had so many calls that I kept a list of the physicians who had been medical directors of the former respiratory polio centers by my phone for referral. But it was not until 1979 that I realized nonrespiratory survivors were having problems too. That year I published a letter from a survivor who was having problems with weakness, pain, and fatigue and even more problems with physicians who were untrained in polio. The letter caused a flood of letters from others with the same problems.

Therefore, it seemed the first step was to educate physicians. How to do that? I consulted some of my special physician friends - Dr. Robert Eiben of Cleveland Metropolitan General, Dr. Allen Goldberg of Children's Memorial Hospital in Chicago, and Dr. David Dickinson at the University of Michigan, who introduced me to Dr. Frederick
Maynard. They all suggested an international conference and they all offered to help me organize one.

The Gazette's first conference, titled "International Conference on Respiratory Rehabilitation and Post-Polio Aging Problems," was held in 1981. About 125 physicians and survivors attended. Most of them were old friends whom I had known during my years of work with polio. The physicians included Dr. Geoffrey Spencer of St. Thomas' in London, Dr. Augusta Alba and Dr. Matthew Lee of Goldwater in New York City, Dr. Ernest Johnson of Ohio State, Dr. D. Armin Fischer of Rancho Los Amigos in Los Angeles, Dr. Henry Betts of Rehabilitation Institute of Chicago, and, of course, Dr. Dickinson, Dr. Maynard, and Dr. Goldberg. Dr. Goldberg brought his friend, Dr. C. Everett Koop, the present Surgeon General.

About three-fourths of the registrants were polio survivors and their families or attendants. The speakers were divided equally between medical experts and the polio experts who had lived productively at home for more than 30 years. About 30 of them were ventilator users. Audrey and Joe were there. Audrey had been a GAZETTE reader for several years. I seem to remember spending a lot of time on the phone tracking Joe down and persuading him to come.

As at all our conferences, there was the extraordinary spirit of a family reunion, of learning and sharing, of mutual respect between health professionals and polio survivors. The conference was such a success that we have continued to convene international conferences on polio and independent living every other year since 1981.

The international representation continues to increase and now includes physicians and survivors from every continent. The number of registrants has increased dramatically every year. We expect about 1000 at our 1989 conference. It will be another extraordinary gathering and we invite you all to attend. The dates are May 31-June 4 at the Sheraton Hotel in St. Louis.

I was the catalyst for the first conference. The conferences, in turn, have been the catalysts for post-polio research, publications, support groups, clinics, regional and international conferences, and scientific seminars.

Regional polio conferences followed soon. They continued the pattern of cooperation between health professionals and polio survivors. The first was organized by Renah Shnaider, a polio survivor, and Dr. Stanley Yarnell in Oakland, California. There are now so many in the United States that we publish a calendar so they will not conflict. Local and regional conferences are an invaluable way of educating
physicians and other health professionals, as well as polio survivors and the general public.

By the second conference, it was apparent that psychological problems were as important as physiological problems and that the natural way of coping with them would be through sharing in support groups. Consequently, we became involved in their development.

Our organization, International Polio Network (IPN), now has a full-time director, Joan Headley, a polio survivor, who coordinates 255 polio support groups and 55 clinics in the United States, maintains national and international directories of the support groups and clinics, edits the quarterly newsletter, POLIO NETWORK NEWS, organizes a biennial Support Group Leaders' Workshop, acts as a clearinghouse and an information and referral service for survivors and professional personnel, and edits the proceedings of our international conferences.

Since our organization first began to nurture the development of this grassroots movement of support groups, we have encouraged them to be autonomous and independent, to meet local needs, and to concentrate on mutual support.

Our polio support groups are certainly not an isolated movement. There are now about 15 million persons involved in more than one-half million different support groups.

Clinics, too, were started shortly after the second conference and there are now 55 clinics in the United States. The typical clinic is located in a hospital or rehabilitation center. It is in operation one day a week and is usually directed by a physiatrist. Most of them are so heavily booked that appointments are being made six months ahead. Clinics and support groups work closely together, each making referrals to the other and both work with researchers.

The early conferences triggered informative publications, such as the HANDBOOK ON THE LATE EFFECTS OF POLIOMYELITIS FOR PHYSICIANS AND SURVIVORS. The handbook, in a concise dictionary format was edited by Dr. Maynard, Dr. Fischer and my assistant and me. It is another example of the unique collaboration of professional and lay persons. We have sold more than 40,000 copies and it has been translated and published in Swedish, Chinese, and Finnish, has been adapted in German, and is being translated into Italian and Spanish.

In addition, we edit the proceedings of the conferences and publish a biannual newsletter, INTERNATIONAL VENTILATOR USERS NETWORK, for ventilator users and health professionals.
concerned with home mechanical ventilation. The newsletter is a unique source of information on the experiences of ventilator users who have lived at home for more than 30 years.

And, of course, we continue our international journal, REHABILITATION GAZETTE. The latest issue, to be published at the end of 1988, is a special double issue celebrating its 30th anniversary. It is an extraordinary collection of reflections on motivation and rehabilitation by individuals with disabilities, looking back, as I have just done with you, to see how they got here from there.
THE INTERNATIONAL PERSPECTIVE OF POST-POST POLIO SUPPORT
GROUP NETWORK

Gini Laurie

I've had a lovely time being with so many. I'm coming from Canada with my friend. Three days with so many. It's a privilege to be here with so many of my old and new friends and to relive the last 30 years with you. Thank you. It is a great pleasure to be here with so many of my old and new friends and to relive the last 30 years with you.

When I founded our international journal, the REHABILITATION GAZETTE, in 1958 I picked a most fortuitous year.

On the local scene, all my polio friends, whom I had known during my 10 years of volunteering at the Cleveland respiratory polio center, were at home and eager to find a way to keep in touch with each other. That year, my husband and I built a heated swimming pool with a lift at our home. It was such a powerful magnet that our garden immediately became their meeting place. Consequently, throughout the swimming season, we had a garden full of volunteer writers who were experts on respiratory polio.

On the national scene, the March of Dimes was stopping its support of polio because the success of the vaccines had stopped public contributions. Consequently, the centers were closed and attendant care funding stopped. This affected all the ex-patients from the 16 respiratory centers around the
country and left them in need of a national publication and a national advocate.

Internationally, unlike the March of Dimes, the national polio organizations in other countries continued so there were publications and staff to help reach individuals. The proceedings of The Fourth International Poliomyelitis Congress held in Geneva in 1957 were published in 1958. I bought a copy and badgered the Congress staff until I received the mailing list of all the registrants. Then I sent a copy of our fledgling publication and a letter asking each one to share it with a polio survivor and to send us the names of others. We not only heard from polio survivors but they sent us the names and addresses of their friends who had been in the hospital with them. In no time, we had a worldwide mailing list of polio survivors eager to exchange experiences in the Friends Around the World Section of our GAZETTE and our pages were soon filled with their photos and stories. (For the first few years, the GAZETTE was free, then we had to start charging a little.)

By 1960, we had discovered so many talented artists around the world who painted with the brush held between their teeth that we announced in the GAZETTE our First International Paralyzed Artists Exhibition. We were overwhelmed by the 400 entries we received. They came from 22 states and from Argentina, Canada, England, Finland,
France, Germany, Nairobi, and Sweden. We held the show at the Town Hall in our village of Chagrin Falls. To guarantee a good crowd on the opening day, we asked about 300 people to our home for a picnic after the exhibit. We had a big crowd and good sales, with all the monies going to the artists. The show continued on the road for over a year then we gave our list of artists to the Kenny Institute and they have carried on with it.

In 1960, we made more international friends when my husband and I went to Europe and called or visited many of our readers. In Paris, we went out to the respiratory center at Garches and bumbled along in our school days French. In England, everyone we talked to told us to get in touch with their favorite doctor, the director of the Portsmouth Respiratory Center, Dr. Brian Sandiford. So, I called him one morning. I was told, "Dr. Sandiford is in the theatre." I thought this was a rather frivolous doctor to be in a movie theatre at 10 in the morning. Of course, I learned eventually that he had been in the operating theatre. When he called back, he said that he and his wife were going to Canada the next year to visit his brother. Of course, we invited them to visit us and thus began a long and warm friendship. They visited us many more times and their daughter lived with us for months. She was a great volunteer typist.
Several years later there was a fascinating incident involving Dr. Sandiford and the Ministry of Health. The latter wanted the addresses of all the polio survivors who were using respirators in England. Dr. Sandiford said no one had this information, but that he knew a publication in Chagrin Falls, Ohio, that would have them. So his daughter went through our files and typed the list and sent it to her father to give to the government.

Over the years, we continued to increase our international readership, reaching not only polio survivors and their physicians, but people with all kinds of disabilities. (Currently, we reach about 40,000 people in 87 countries.) Along the way, different issues have been translated into German, Portuguese, Spanish, and French and, for more than a decade, every issue has been translated into Japanese. When I was in Japan in 1986, I met many GAZETTE readers who told me that it had taught them both English and rehabilitation.

For years and years, we have answered many many questions from our friends overseas and exchanged blueprints for portable iron lungs and rocking beds and sent information on accessible universities and travel across the States. Some came to visit us and we suggested others for them to visit around our country. Others traveled around Europe and visited other readers whose stories they had read in the GAZETTE. The photographs and life stories made deep and
lasting impressions. The people on its pages became close friends. We were gradually building a worldwide GAZETTE family - an international polio support group network.

This feeling of family, of a quarter of a century of trust in us and in our organization is very important because it is the foundation on which we have been able to build our conferences, our International Polio Network, and all our other involvements with the late effects of polio.

Thus, in 1981, when we wondered what to do about educating physicians about polio, we asked our friends who had been the medical directors of the former respiratory centers. They not only advised us to convene an international conference, they also offered to help. And, when I telephoned Dr. Geoffrey Spencer, a consultant at St. Thomas's Hospital and director of its respiratory center, whom we had visited in London the year before, and asked him to come and speak, he agreed. We also had old friends there from Sweden and from Germany, as well as Canada. Probably, about 95% of the physicians and survivors at the first conference were long-time GAZETTE friends. The ratio has changed little at subsequent conferences as the GAZETTE family evolved into the International Polio Network family and broadened to include nonrespiratory survivors who were experiencing the late effects of polio.
In the States, the response to the problems of the late effects was a grassroots movement that created independent, self-governed support groups coordinated by the International Polio Network (IPN). IPN now coordinates about 255 support groups and 55 clinics. As we will learn at this conference, a similar movement has been occurring in Canada.

No network of independent polio support groups, similar to that in the States and Canada, has developed elsewhere in the world. This is quite understandable because nowhere else has the support group movement burgeoned so rapidly as in the States. (There are now about 15 million persons in more than one-half million different groups.) Further, most existing European national organizations devoted to polio have been too structured for too long to welcome such a grassroots, North American-type movement. The service systems in most European countries are professionally run and delivered unto the user, not directed by them.

The very existence of the late effects of polio is still questioned by some Europeans, who label it a "North American phenomenon."

The knowledge of the late effects has been spread largely by those survivors or physicians who attended our conferences.
and returned to their homes as "missionaries" to spread the word.

The one exception is Denmark whose polio society has maintained its Outpatient Clinic for Physiotherapy since 1952. Home adaptations, aids, and conservative weekly treatments have always been available to any survivors who faced increasing weakness and degenerative changes.

Judge Kallehauge, chairman of the board of The Danish Anti-Polio Society, is a long-time GAZETTE friend. He was unable to attend the 1987 conference because of his wife's illness but they have registered for the 1989 conference.

The British Polio Fellowship has continued its system of services to polio survivors since the 1950s. It has published only a trickle of information on the late effects and has not attended a conference in the States or Europe. When I visited the headquarters this spring, I ran into a wall of indifference. However, even their published trickle has spurred many individuals to write to IPN for information about their problems and we shall continue to invite them to the conferences.

A much more open-minded approach is apparent in Sweden - among both the scientists and the survivors. The second Scientific Symposium at Warm Springs included reports by
Swedish scientists on muscle morphology with reference to muscle strength and strengthening exercise programs.

The Swedish survivors are well organized by Dr. Adolf Ratzka, whose doctorate is in urban planning. A ventilator user and a long-time friend, he has attended all our conferences. With the scientific community, he organized a polio conference in Sweden several years ago and he arranged to have our handbook translated and printed in Swedish.

Kalle Könkolla, a member of the Finnish parliament, a ventilator user, and another long-time friend, is a strong advocate for his fellow survivors. The Finnish society, Suomem Poliohuolto, is having our handbook translated and printed in Finnish.

France has a number of organizations and clubs concerned with polio and the motor impaired. We have been in contact with them for years and they print our press releases and information about the late effects. Consequently, we hear from individuals with problems but we have had any only one official representative, Monsieur Dessertine, who came to the first conference.

The German contingent of polio survivors and health professionals at our conferences has been one of the largest and the most articulate. They have made significant contributions to the development of a face mask. The leading
advocate of the group, Uwe Frehse, organized an important international polio conference on underventilation in Munich in April of this year. The conference was sponsored by the Pfennigparade, which has continued its service to polio survivors. Because Gertrud Weiss, a researcher, and so many other sensitive polio survivors have participated in our conferences and understand the psychological value of support groups, they hoped the conference would hasten their development in Germany. I spoke on the American experiences and led a two-hour workshop with Dr. August Ruggeberg. Afterwards, they said they felt the development of support groups will be very gradual, for such independence and self-direction are not typical of the German system of health services.

Health professionals from Austria and The Netherlands have attended conferences and we correspond with and send information to individuals in many other European countries, including Czechoslovakia, Hungary, Italy, and Spain, but they have not been represented at the conferences. However, we hope to change this, as the handbook is being translated into Italian and Spanish.

In Taiwan, a Jesuit priest, Fr. Ronald, who is a polio survivor, has translated the relevant parts of the handbook into Chinese for the network of persons with polio and other
disabilities in Taipei. A long-time friend, he has attended most of the conferences.

Both China and Japan are interested in the late effects. The Chinese government sent two orthopaedic surgeons to speak at the 1987 conference. A group of about 30 Japanese attended the 1987 conference and several hundred are coming to the 1991 conference.

The director of the Australian respiratory centre at Fairfield Hospital, Dr. Hugh Newton-John, is a regular participant of the conferences. Other health professionals and survivors have attended. One of the survivors, Anna Young, who attended the 1987 conference, went home fired with enthusiasm for setting up American-style support groups. She reports very slow progress. But she is a very determined lady. A group of about 20 New Zealanders combined a tour with the 1987 conference. They are also working toward American-style support groups and are planning to return to the 1989 conference.

I met many polio survivors from Third World countries when I attended the 1985 World Congress of Disabled Peoples' International in the Bahamas. I organized a "Polio Breakfast" when I discovered how interested they were in the late effects. As a result, survivors from Zaire, Mauretius, El Salvador, Brazil, and India have come to our conferences.
We are planning a session on the late effects and support groups at the next meeting of the DPI Congress in Bogota in 1989.

For all of us, international polio work must go on and on in the Third World. Rotary and the World Health Organization hope to have everyone in the world immunized by the end of this century. But, meanwhile, it is estimated that every year there are 250,000 new cases of paralytic polio. With the backup of cases from previous years, that's an astronomical number of people who may meet the late effects - some day - and need the expertise we are sharing at this conference.
1988 - November 18

Rancho Los Amigos Medical Center
Centennial Dinner honoring Dr. John E. Affeldt, Citation.

Downey, California
RANCHO DINNER; Nov 18, 1988

I am happy to add my congratulations to Rancho's anniversary celebration. This is a touching occasion for me. It brings back warm memories of the regional respiratory and rehabilitation centers of the 1950s and loving thoughts of my Rancho friends of those days...many of whom have created the Polio Survivors Association and are here tonight...

The 16 centers of the 1950s were bright landmarks in medical history. The pioneering spirit, the creativity, the mutual respect and the teamwork between the staff, the patients, and the families resulted in extraordinary rehabilitation.

The caring and creative medical directors set the tone. Their names are a litany of love and dedication. I'd like to recall them for my own nostalgia and for those here who moved to California to be near Rancho after their own centers closed: Drs. Affeldt, Anderson, Batson, Benton, Dickinson, Eiben, Ferris, Lewis, Loeser, Oliver, Plum, Saxton, Sweet, and Spencer.

Before the epidemics, most of them had been pediatricians and directors of contagious wards. Suddenly, the epidemics filled their wards with adults in iron lungs.

Unfettered by tradition, the directors invented disciplines, they became on-the-job pulmonologists, rehabilitationists, and respirator engineers.

Equally unfettered by tradition, the polio survivors invented their own in-hospital mutual support systems. In the open wards of iron lungs, each individual found friends, peer counselors, and role models.

From their inception, the centers provided superb medical and psychological rehabilitation but, until 1953, most of the permanent respirator users seemed doomed to remain in hospital for the rest of their lives.

That year, in order to save money by avoiding lifelong hospitalization at the high per diem rate of $37, Rancho pioneered a system of home care that cost only $10 per diem. That system revolutionized the rehabilitation of persons with severe disabilities, prepared the way for attendant care legislation in California, and, thus, was the catalyst and the model for the independent movement worldwide.

The home care system succeeded because it respected the right of each individual to make choices and to take charge of his or her own life, and provided the attendant care necessary to be free to live life to the hilt and to make the impossible possible.
For 30 years, I have proudly documented the life stories of thousands affected by the Rancho home care system. Written in their own words, their stories have filled the pages of our publications, the old TOOMEY J GAZETTE and the present REHABILITATION GAZETTE.

It is a joy to be here, where that liberating system started, and I am happy to share in honoring one of those very special medical directors. Dr. Affeldt, and the director of all the centers, Dr. Landauer...... I thank you.
1988 - November 19

Eero Saarinen Award
St. Louis Society for Crippled Children.
Acceptance:
Mr. Caldwell, members of your Award Committee, I thank you for this prestigious award.

And, thanks to the hundreds and hundreds of other volunteers, with and without disabilities, here in St. Louis and around the world, with whom I have shared almost 40 years of joyous and loving work - work that has always seemed more like play.

Together, we have created a worldwide "family" - a living network of individuals with disabilities who help each other by sharing life experiences through our publications and conferences.

Our unique network has motivated countless thousands to achieve productive and independent lives.

Many of those individuals were the pioneers of independent living. They were the first to overcome the attitudinal, environmental, financial, and technical barriers to living and working in the community.
In the 50s, 60s, and 70s their environmental barriers meant being carried to the fourth floor of law school in a wheelchair.....or wrangling to carry batteries for a portable respirator on a flight from Europe.....or dodging traffic in the street because there were no curb ramps to the sidewalks.....or living on the second floor of an apartment building and being dependent upon people power.....or being frustrated and delayed by unbrailled reference material or lectures without an interpreter.

In recent years
In the past, these and many more of society's environmental barriers made life difficult for people with disabilities.....but now, many of these barriers have been eliminated by legislated accessibility.

Still remaining and much more insidious, restrictive, and dehumanizing are society's attitudinal barriers. The poisoned tentacles of negative attitudes touch the lives of all who are "different" or who do not fit into the mold of the herd.

At times in our lives, all of us have experienced negative attitudes. Some of you have unpleasant memories of the way the office personnel sneaked furtive glances at you when they learned that you were about to be a former employee, or
the way people stared when you wore a cast and crutches after a ski accident or a patch to cover a stye.

But those transient incidents are trivia compared to what you would face daily if you were an individual with a longterm disability: the patronizing pat on the head, the waitress asking your companion what you would like, the questioning child snatched away, the simpering smile, the hasty glance that zaps you into an invisible, nonperson.

How do we change those negative attitudes into positive ones? Start by watching our words - both written and spoken. Words not only reflect our thoughts but they influence them.

If you weren't such a disability-sensitive audience, I'd list the specific words and phrases that are pejorative, demeaning, and dehumanizing.

But you know them.

And because you know them, you are even more personally responsible for changing those negative attitudes.

May I suggest a specific project for all of us here tonight? Let's concentrate on the media and watch and listen for the words that mean negative attitudes.
let's praise the media with a note when the dignifying "person with a disability" is used and remonstrate when the demeaning "handicapped" is used. We might call attention to page 100 of the Associated Press Stylebook which states, "The term 'handicap' should be avoided in favor of 'disability.'

And let's all write to the POST-DISPATCH - just a postcard - expressing our appreciation for the excellent Saturday morning column, 'Living with a Disability,' by Dianne Piastro.

With the people power here tonight, we can make a dent in those negative attitudes that are far more than disabling than disability.

Thank you........
COORDINATING OF EXPERIENCES WITH LATE EFFECTS
AFTER POLIOMYELITIS IN THE USA - AN EXAMPLE FOR EUROPE

By Gini Laurie

Saturday, April 9       10:00 - 10:15
The ideal U. S. examples of coordination are still the polio
and regional respiratory and rehabilitation centers of the
1950's.

- Their multidisciplinary teams that involved the
  patients, their families, and other physicians;
- Their location at teaching hospitals of medical
  schools;
- Their sharing of knowledge through regular
  meetings of their medical directors;
- Their home care support systems that included home
  adaptations and payment of attendants;
- Their equipment research programs;
- Their equipment maintenance programs that included
  a mobile repair truck;
- Their umbilical cord relationship that enabled
  ventilator users to live independently in the
  community.

The centers succeeded because they not only empowered their
patients with the positive attitude, equipment, techniques,
and support systems necessary to their maximum
rehabilitation but they resulted in tremendous financial
savings.
They failed because their funding was not based on permanent government funding but on emotional appeal to the general public by a voluntary agency.

That responsibility was too great for a voluntary agency. They should have evolved into government supported centers for all types of severe disabilities -- including muscular dystrophy, high level spinal cord injury, amyotrophic lateral sclerosis, etc. They should have continued to research and experiment with respiratory equipment. They should have adapted the variety of ventilators used for polio - lung, chestpiece, pulmowrap, pneumobelt, and oral positive pressure - to other disabilities.

Instead, all that experience and medical knowledge were dissipated.

As a result, modern health professionals are unaware of the experiences and equipment of polio survivors who lived independently with mechanical ventilation for more than 30 years.

Therefore, professional education was our first priority in the U.S. and should be your first priority in Europe. In the U.S., the March of Dimes went on to another disability. But in Europe and Canada, your polio voluntary organizations, such as Pfennigparade, did not close but
continued or added other disabilities. So you may not have so much of a problem educating your health professionals. Educating health professionals has not been easy in the U.S. and it will not be easy in Europe:

- They do not know of or do not accept the late effects of polio;
- They are not tuned to look for the underventilation of scoliosis or aging that may occur as a late effect of polio;
- They have not had experience with the rapid recovery from underventilation that may occur when night ventilatory aid is added;
- They do not easily accept that many individuals are unweanable and they can live a good life at home with the assistance of a ventilator;
- They are unfamiliar with the noninvasive ventilators that are so familiar to polio survivors;
- Their experience has been limited to ventilation through a tracheostomy - largely in intensive care.

Of course, basically, most health professionals are not in the habit of being educated by their former patients.

But it can be done - as I told you at your opening on Thursday how our International Polio Network and our International Ventilator Users Network have begun the
process by publications and publicity and by coordinating international, regional and local conferences, clinics, and support groups.

You have a great start with this exciting international conference and your cadre of polio survivors and concerned and cooperative physicians and other health professionals.

In the United States we were blessed from the beginning with such a cadre of polio survivors and of caring and helpful physicians, such as Dr. Fred Maynard, Dr. Armin Fischer, and Dr. Augusta Alba, and with Dr. Geoffrey Spencer and Dr. Lauro Halstead, who are here.

Such concerned physicians will continue the momentum with further conferences, regional, scientific, and international; will educate other physicians through their publications in scientific journals.

In addition to coordinating the education of health professionals, you will need to promote the education of polio survivors, other persons with severe disabilities, other specialized voluntary agencies, and the general public through TV, radio, and newspapers.

But, most important will be doing more of what you are doing so well as this conference—involving polio survivors and others' with severe disabilities, empowering them with
information, and tying them together so they can support each other in accepting lifestyle changes.

You have some advantages in Europe. You can utilize

- U.S. experts - such as those who are here;
- the proceedings of U.S. symposia and conferences;
- U.S. publishings in medical journals;
- International Polio Network's experience coordinating more than 200 support groups and 55 clinics,
- IPN's handbook on polio which has been or is being translated into German, Swedish, Finnish, Italian, Spanish, and Chinese.
- and Rehabilitation Gazette's 30 years of subjective experiences of ventilator users.

Further, with national health insurance, you should have better records of early treatment and, without financial impediments, it should be easier to convince polio survivors to get baseline examinations for comparison and to uncover unrecognized underventilation.

You have some disadvantages, too. European professionals may find it more difficult to accept the mutual support group and team spirit because it will seem too independent, too individualistic, too American.
But your polio survivors will evolve a European variation on our support groups, just as the support groups around the U.S. reflect their varied locales.

Eventually, you will develop a European network, working with existing polio and other disability voluntary agencies - but not being co-opted by them - but maintaining your ownership.

Whatever you do, wherever you go, our International Polio Network and International Ventilator Users Network will work joyously with you in every way we can.
Whereas,

The problems of the late effects of polio are complex - involving medical, psychological, and sociological solutions - and can be solved only by the interaction and cooperation of the medical community, polio survivors, and voluntary organizations, and government, be it therefore

Resolved,

That the medical community:

- Educate itself by capitalizing on the wealth of information published since 1981 in the United States in journals and proceedings of international scientific symposia by the medical community and publications and international conferences by the International Polio Network, all of which should be translated;

- Disseminate information to physicians and therapists;

- Promote the development of polio clinics;

- Encourage research, not only on the cause and treatment of the late effects of polio, but on the effects of aging on all disabilities.

That polio survivor leaders concentrate on:

- Acting as the catalyst and coordinator of support
groups;
- Acting as the center of self-help information and people networking;
- Educating families and friends;
- Creating a quarterly newsletter;
- Maintaining and publishing a directory of support groups and clinics;
- Organizing a biennial training workshops of support group leaders.

That the existing and historical national voluntary polio organization in each country redesign itself to deal with the late effects of polio by creating an equal and participatory partnership between its professional personnel and the cadre of polio survivor leaders, and that the organization's professional personnel concentrate on:

1. Educating and working with the medical community;
2. Educating the general public;
3. Working with the polio survivors to educate other polio survivors;
4. Facilitating the newsletters, workshops, and other projects of the polio survivors.

If such a voluntary organization does not exist, or is too bureaucratic to work with polio survivors, then the support groups assume these responsibilities.

That the government accept the late effects of polio as a disability which may limit employment potential and the activities of daily living and require workplace and home adaptations, equipment, and additional home services. This means a legal acceptance of the late effects of polio as a disability.
That, with an attitude of mutual respect, the medical community, polio survivors, voluntary organizations, and government maintain an active interchange with each other and with their counterparts in Europe, throughout the world, and with the International Polio Network by:

- Funding and translating publications and reprints both for the medical community and polio survivors, such as the Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors.
- Funding and cooperating on the continuation of an international conference in Europe, such as this, in even years, and participating in the International Polio Network's international conference in the United States in odd years;
- Pooling their resources to solve the complex medical, psychological, and sociological problems of the late effects of polio.

Call for papers to come up with this volume.

Push the publisher to publish the medical volume.

Regime now access to data to be the recipients of grants to regimes that people with disabilities to continue working on the work of this conference.
The Conference notes that
the only studies on the late
effects of Polio have been
reported but in the United
States of America and some
European countries.

It therefore urges the members
to the World Health Organization
to take the necessary steps to
initiate further research on
the subject and

1) to tackle the late effects of
Polio problem as a global
issue which will in future
effect in developed and
under-developed countries.

Dr. Peter Porritt, Malta
No. J.R. Kavanagh, Malta
1988 - May 13

Post-Polio Syndrome Conference. Spaulding Rehabilitation Hospital and The March of Dimes. Speaker: "The Role of Networking and Support Groups."

Dedham, Massachusetts
THE ROLE OF NETWORKING AND SUPPORT GROUPS

by Gini Laurie

We've all been networking all our lives, without calling it that. It is a new word for the ancient system of support services supplied by the family and neighbors and friends.

But organized self-help groups are new and rapidly growing. Now in the U.S. 15 million people are in one-half million different groups.

I've been studying the new wave of self-help to see what we could learn for our International Polio Network. Here is a summary of the typical support group. As you will see they are very much like the polio support groups which you created all over the country.

Typical self-help groups are run by and for group members. Professional providers may participate in the self-help process at the request of the group and remain in a consultant role.

Activities focus on social support through discussion and sharing of information and experiences.
They are open to members of the general public who have experienced the common concern.

They meet face-to-face on a regular, ongoing basis. Groups are voluntary, and are open to new members.

There is no charge to participate in a self-help group, although a nominal donation to cover expenses is sometimes requested, but not required.

In most groups, there are three basic types of activity: emotional support, information exchange and coping strategies.

Most support groups are small, informal, financially insecure, and fluid. Members come and go as the group meets their needs. The usual pattern of their national organization is a loose network of autonomous groups. The most common is an association, supported by dues from the affiliated local branches or chapters that are authorized to use its name.

Support groups differ from professionally-run groups, which are more likely to resemble group therapy rather than self-help, and they can provide benefits that professional groups cannot. Self-help groups are not meant to replace
professional services but they supplement and may even prevent the need for them.

Professional human services agencies and mutual help groups may have a tense and competitive relationship. Historically, professionals have often tried to co-opt mutual help organizations, and they are frequently regarded as intruders. But they can all work together, as you have demonstrated so well at this conference.

The self-help movement has the endorsement of Surgeon General C. Everett Koop. To underscore his enthusiasm, he convened a Workshop on Self-Help and Public Health in 1987 in Los Angeles. (I was privileged to attend, representing the International Polio Network.)

I was very impressed that the Surgeon General opened and closed the Workshop. He promised to establish a mechanism for integrating self-help issues into public health policy. His first step will be a National 800 toll free number for Self-Help Telephone Referral.

The polio support groups are unique, because they are so strongly influenced by the survivors' early experiences of 30 or more years ago.
Until the 1950's epidemic, polio was "infantile" paralysis, and you, who as children, went to centers like Warm Springs, may have happy memories of friendship and pranks. But some of you spent years in children's hospitals - in and out of casts following repeated corrective surgery and you felt lonely and abandoned by your families. You glossed over these feelings for thirty or more years, and only now are you facing them and sharing your feelings in support groups.

In the epidemics of the 1950's, polio changed its target and adults with severe respiratory involvement were struck. To meet their needs, the National Foundation for Infantile Paralysis (March of Dimes) created and funded 16 respiratory polio centers around the country. They were in operation from 1951 to 1959.

By the mid-1950's, the majority of the respirator-dependent individuals were at home, trained to take responsibility for their equipment, attendants, and their lives. They lived full and productive lives - after a long, hard struggle.

The struggle began in 1959 when the March of Dimes had to close the centers and cease funding attendants, medical care, equipment, and research because the success of the vaccines had stopped donations from the public. You polio
survivors faced extraordinary adjustments. You were suddenly left on your own after being pampered, praised, and protected from all financial worries. Fortunately, you had had the protection and assistance when you needed it — during early rehabilitation — and you reacted with a fighting spirit of adaptation.

You, who were less severely disabled learned to "pass" as nondisabled. Others of you muddled on with your old braces or other equipment and worked out your own solutions. Many of you avoided medical care because of economy or early experiences. Those were lean years — before Medicaid, Medicare, SSI, Social Security disability benefits, independent living centers, or extended vocational rehabilitation services. You survivors had to rely on your own resources, your families, or welfare. But you also needed the mutual support of those who had shared your polio experience.

You survivors with respiratory involvement and you who were severely disabled had the most need for sharing. You had spent months and years together learning to live with iron lungs or portable respirators. You had evolved strong feelings of togetherness, and a need to keep in touch to share information and experiences.
To fulfill these universal needs for people and information, the "alumni" of some of the respiratory centers fostered social meetings and published mimeographed newsletters of at-home doings for a few years after the centers closed. For a few years, too, nonrespiratory survivors shared newsletters from Sister Kenny Institute and Warm Springs.

Eventually, they all faded away except two: the Los Angeles group was revived as the Polio Survivors Association, primarily for advocacy for ventilator users, and the Cleveland respiratory center group's newsletter became my life's work. While working as a volunteer there, I started a publication, Rehabilitation Gazette, to share experiences and provide information on do-it-yourself equipment. The publication has evolved into the Gazette International Networking Institute, the International Polio Network, and the International Ventilator Users Network.

I'd like to briefly share the history of the evolvement of the Rehabilitation Gazette into the International Polio Network because it is the history of the current awareness of the late effects of polio and of the evolvement of the support groups and clinics.

Starting in 1958, the Cleveland "alumni" had large annual picnics at our home and daily summer "support group"
gatherings of survivors and volunteers in and around our little heated swimming pool. Together the group wrote the 
Gazette and answered requests for information and networking with other survivors.

The Gazette became the only national advocacy organization of polio survivors, their only permanent network.

The Gazette expanded in the 1960's and the 1970's into an international journal devoted to independent living for people with all disabilities in 87 countries. Yet, it never ceased to maintain a living network of polio survivors. Consequently, in 1979, it was the first to notice and to publish the problems its readers were having with the late effects of polio and with their physicians whose education had not included polio. And in 1981, with the encouragement and help of Dr. Maynard, it was the first to organize an international polio conference.

That first conference drew 125 survivors and physicians. There began the unique partnership of lay and professional persons working together to solve an undocumented problem. There began the special spirit of mutual respect and sharing that characterizes all the Gazette's International polio conferences, the publications, and the support groups.
The conferences were the catalysts for the support groups. They brought survivors of all degrees of disability together and revived their former joy of being together and sharing problems and information. The first two conferences awakened the registrants to their vital psychological need for mutual support and they returned home to start support groups.

The conferences brought together medical clinicians and researchers and triggered Dr. Lauro Halstead and Dr. David Wiechers to organize the 1984 and 1986 international scientific conferences. The National Institutes of Health became involved in research as did the National Easter Seal Society and the March of Dimes Birth Defects Foundation.

In 1984, the Gazette reorganized and expanded to become the Gazette International Networking Institute to coordinate information and networking on the late effects and it publishes a summary of the knowledge in a clear, concise handbook for Physicians and Survivors. It is now in its fifth printing and has been translated into Swedish and Chinese and is being translated into Italian, Spanish, and Finnish.

The networking and flow of information on the late effects of polio from lay persons to health professionals has been unique - a reversal of the usual order.
Publications, support groups, and local and national publicity have gradually informed the general public and alerted health professionals. You've all seen articles in THE NEW YORK TIMES, the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, and TV shows, such as Kuralt's Sunday Morning Show and Nightline.

In 1985, more than 500 registrants came to our Third International Polio Conference in St. Louis. Highlights were the session chaired by Dr. William Masters and the conference banquet honoring Dr. Albert Sabin.

An important session brought together the leaders and members of the support groups to share plans and problems. The groups asked G.I.N.I. to coordinate and act as the official clearinghouse for the support groups in the United States and to maintain a directory of support groups, physicians, resource persons, and clinics. As a result, the Gazette's longtime international polio network was formalized into the International Polio Network (I.P.N.) and the quarterly newsletter, Polio Network News, and directory were initiated for members.

Since then, more than 250 support groups and 55 clinics have been started and many regional and local conferences held. Conferences, such as this, have been organized by support groups, often in cooperation with local independent
living centers, universities, hospitals, rehabilitation centers, Easter Seal, or March of Dimes.

In June 1986, International Polio Network organized a workshop for about 70 of the leaders of the support groups in St. Louis and there is another scheduled for June 3-6.

Meanwhile, two polio survivors and I.P.N. eased the way for approval of social security disability claims submitted by polio survivors unable to work due to the late effects of polio. Our combined efforts resulted in issuance and distribution of the Program Circular which documents the late effects of polio for the Social Security Administration.

The 1987 polio conference in St. Louis brought together 747 medical experts, health professionals, and polio survivors from all across the United States and 18 countries, including several from the Third World.

Of particular interest were the sessions on exercise, and bracing, and a workshop on face masks for nocturnal oral positive pressure developed by both users and prescribers.

At the conference, International Polio Network initiated National Polio Awareness Week through the concerted efforts of our Congressman Richard A. Gephardt of
Missouri and other congressmen around the country whom you support groups contacted to support his legislation.

Our International Polio Network’s services and programs have been expanded and improved since our new director, Joan Headley, joined us last August. A polio survivor, she was a high school biology teacher in Indiana before devoting her talents to I.P.N.

I.P.N. now not only coordinates the support groups in the United States, but works with a growing number across Canada and is spreading the support group spirit around the world through its international conferences and directories.

Last month, I spoke at the first European international conference on polio and underventilation in Munich. Attending were physicians and survivors from Germany, Austria, Switzerland, Spain, Italy, Denmark, Norway, England, and France. They asked me to open the conference with a 45-minute history of the late effects and support groups in the U. S. and to chair a two-hour workshop on how the American support groups could be adapted to Europe.

Throughout the conference, I became increasingly aware of the responsibility we all have as members of the International Polio Network and as local support groups to be sure that any information we present is accurate and does
not raise false fears and false hopes, and that we watch our words and guard the dignity of polio survivors as individuals with a disability, not as victims or cripples.

We have the responsibility to understand that polio survivor's health problems caused by the lack of funding for treatment, equipment, and home services are not just polio problems, but a national issue of justice for all who are disabled, of all ages, and they must be addressed in a national fashion - not piecemeal, disease by disease, or age group by age group.

After Munich, I went to speak at another conference in Salzburg and to meetings in London with physicians, polio survivors, and the British Polio Fellowship.

As always, it was an incredibly rewarding joy to meet old Gazette polio friends - close friends whom I had never met, but with whom I have corresponded for 30 years.

Everywhere, I felt that polio support group spirit - that same intangible, indescribable spirit of our international polio conferences that is a mixture of sharing friendship, laughter, empathy, and love.

...The same spirit that I feel here today...and I felt last night...
...and I hope that I shall see many of you at our next international polio conference in St. Louis - May 31 to June 4, 1989.

I thank you for the privilege of participating in your conference....
1988 - 14-16 May


Washington, D.C.
How Aging and IL Communities Can Strengthen Each Other

Identify common goals & needs & work together.

Long-term care - even if don't like "care"....
(remember NAACP.)

IL's

1. Practice what you preach... hire over-70 as peer counselors... put old on boards.

2. Work with local Gray Panthers, AARP, etc.

3. Respect each other... old may feel same about young's lack of understanding that disabled feel about nondisabled's lack of understanding.

4. Language - learn to translate. The old have adapted!
Stop to think about language that has been created in last 75 yrs (my lifetime): radio... TV... moon... computer... aviation... antibiotics... medical: CATSCAN, etc.... music (rock n roll)... fashion (mini)... auto (had to crank).... runningboards, roadster, rumbleseat, vans, motorhomes.... plywood, plastics.
AGE AND VITALITY

Commonsense Ways of Adding Life to Your Years

"Verdant old ages doesn't happen of itself; we need to work at it....need to develop a positive attitude to living."

"Have to work at the quality of life..."

"The aim is to enjoy our maturity, to extend our vitality, and thus to age well."

Challenges as a source of vitality.....
ETHICS OF LONG-TERM CARE CAVEATS

Florida professionals tried to pass law that would have made it illegal for anyone except registered respiratory therapists or technicians to provide incidental respiratory care to ventilator users.

Oregon: one of 5 states now limiting Medicaid financing of organ transplants. Other states considering changes.

Typically, states pay from 25% to 40% of transplant surgery, which range from $100,000 to $200,000; Federal Medicaid pays the rest.

But indigent patients not eligible for Federal money unless states pay for some of it.

No guidance from Federal govt on who should live and who should died.

Some move to Washington State or California; others beg for money over TV & in newspapers.

INCREASINGLY, LIFE AND DEATH ARE MONEY MATTERS.

Kidney dialysis experience of the 1970's soured. $3 bil yearly expected to be $6 bil in next 15 yrs.

Shift from clinical to financial control.

Doctors and hospitals under increasure pressure to controls costs.

Depersonalization of medicine.

Rationing has always existed. Old days, physicians made the decisions.

Fr. Brodeur, medical ethicist: Fed govt should provide equitable access throughout the country and, in some instances, subsidize it.

Providing adequate health care is a national issue of justice.

Medical economics is the major issue in med ethics today. How should health dollars be allocated. Whose responsibility?
What can we do about the old?

1. Banish stereotypes—same public image of old

2. "Practice what you preach"
   a. But do on staff—peer counselors
   b. "Join board"
   c. Recruit volunteers with our mailing parties—range 50-80

3. Encourage volunteers to use talents—tutors, engineers, etc.

4. Become members of Gray Panthers OWL AARP
   a. Get their info
   b. Attend Elderhostel to see what's going on

4. Become experts on equipment: use on arthritis
   a. Raised toilet seats
   b. Tap turners
   c. Canes instead of levers
   d. Elastic shoe laces

5. Gradual weariness or can't wait
   a. Ladies' urinals—men's urinals
   b. Prostate—ladies' privee

Ask: How many on staff
    PM 7:30-8:30?
Ethical Challenges of Chronic Illness
by Bruce Jennings, Daniel Callahan, Arthur L. Caplan

(3-yr project on Ethics and Chronic Illness. Supported by Luce Fdn.)

Medicine's historic response to acute, self-limiting diseases of short duration inadequate to understanding chronic illness and disability. Paternalistic attitude of medical model inadequate.

Chronic disability challenges
1. Ends of medicine
   Nature of physician-patient relationship
   Ethical principles of decisionmaking
2. Boundaries of caring
   Caregiving duties of family vs social welfare of state
3. Understanding of society's response to health care and social service needs.

Chronic disability - Definition
Organically based. Significant loss of function or disability. Generally slowly progressive debilitation.

Share many common characteristics: great personal hardships, heavy medical costs; cannot be cured; require some assistance with daily living and may, eventually, need custodial care in community or inst.

Most common in elderly: arthritis, hearing impairments, hypertension, heart disease, chronic sinusitis.

Lack of comprehensive chronic illness policy may be related to fact that advocacy groups have organized around specific diseases.
Instead of finding common cause in the generic needs, have competed for $.

More important to focus on common generic problems and shared needs. Common needs and interests more significant than differences

Chronic disability effects: transformation of personal and social life, family relationships, self-identity

Social policy must
1. Acknowledge distinctive needs, without treating like special class;
2. Provide needed health services.
3. Support families
4. Sense of public entitlements, within reasonable limits

Medical model - acute illness.
1. Aim is to cure, restore function.
2. Patient is passive & compliant

Chronic Care differs:
1. Component of person's overall state of being.
2. Aim is to mitigate limitations
3. Sustain meaning in life
4. Individual more knowledgeable than physician

Physicians and individuals must learn from and teach each other.

Families will continue to play a key but not exclusive role.

Need to provide families more professional and community support, and to integrate them into the network of care:
1. Publicly financed home care services, with appropriate quality assurance and licensure mechanisms.
2. Respite care programs.
3. Adult day care programs.
4. Counseling services
5. Educational programs.
6. Support groups.
PROPOSED LONG-TERM CARE LEGISLATION

Pepper - Medicare
Sen Mitchell - Medicare & combination

Senator Kennedy's "Lifecare" plan - nursing home and unlimited home care
Repr Waxman
Repr STark

MEDICAID


Introduced Sept 1987. By Sen Chaffee (R-RI) and
Sent Lowell Weicker (R-CT) and Re J. Florio (D-NJ)
(As of Jan 88: 26 Senat co-sponsors and 99 in House)

Eligibility: people with severe dis who meet SSI test and who were dis prior to age 22. Each fiscal yr age of onset for dis increased by 1 yr until reaches 50.

States may allow children under 18 living in homes, regardless of income of their families
Dear Friend:

One of the most important issues now facing Congress is that of easing the burden of rapidly increasing health care costs. For those people without adequate health insurance, a long term illness can mean financial ruin. This is an issue of particular concern to older Americans.

In 1981, about $80 billion was spent, publicly and privately, on health care for the elderly. It is estimated that by the year 2000, public expenditures alone will rise to well over $114 billion for elder care.

I have cosponsored legislation, H.R. 2470, to help ease the hardship imposed by long term health care costs. This bill makes important changes in Medicare coverage of long-term or nursing home care by reducing the cost to the retiree and increasing the days of covered care. H.R. 2470 has passed both Houses of Congress, and is now pending in conference committee.

Additionally, I am working to allow Medicare coverage of home care for the chronically ill. This could significantly reduce costs to both the chronically ill and their families.

Enclosed you will find an "Emerging Issues" newsletter on elder care. It describes the growing need for government and private industry support of a long-term health care policy in this country. It also outlines the trends associated with elder care, the implications of those trends and the policy options that must be addressed by decision makers.

There is no reason for anyone in our country to go without proper health care, or to be afraid to seek the care they need because of high costs. I am committed to working for legislation which ensures every American's right to adequate health care.

I hope you find my newsletter informative, and I welcome any thoughts you may have on this issue.

Sincerely,

MEL LEVINE
Member of Congress
1988 - September 22

Annual Dinner Meeting of Springfield Center for Independent Living. Speaker.

Springfield, Illinois
Introduction: Gini Laurie by Jack Genskow
SCIL Banquet 9-22-88

How does one introduce Gini Laurie? As a visionary, an international force for good, a breath of fresh air, a deeply spiritual person, an affirming friend, or the grandmother and chronicler of the independent living movement?

All would fit, but each would be too narrow.

Let me share what the awards committee wrote when Gini was given the St. Louis award in 1986.

Presented To
GINI LAURIE
Founder and Chairman

GAZETTE INTERNATIONAL NETWORKING INSTITUTE

For the national and international recognition she has brought to the city of St. Louis as an historian, researcher, and advocate for the right of persons with disabilities to live independently:

For her vision in creating a world-wide network of people and information with the power to dignify and motivate the lives of countless individuals:

For her brilliance and strength, her warmth and good cheer, and her tireless efforts to call forth the unique potential of every human being.

Gini has been the editor of what is now the Rehabilitation Gazette since 1958. Today this journal has 40,000 readers in 87 countries, lay people and professionals alike. Over the years the Gazette's chief contributors have been consumers who have shared their ideas on ways to live independently. Gini networked long before networking became popular.
Gini has hosted four international conferences on polio and independent living, but with Gini these have been gatherings of her friends - parties for the "whole world". In helping to plan the 1983 conference, I remember it was decided to introduce people only by their names, not their titles, since consumers and professionals were all considered experts and equals, and titles got in the way.

Gini has also been to Europe and China to study and speak on polio and independent living.

Here's a final quote from the St. Louis award:

"It's most important that you know Gini Laurie is not some grim crusader. She is simply a woman so filled with joy and vitality that she can't conceive of anyone not living life as Gini lives it--at full-tilt!!!"

So - with great esteem and affection, I am pleased to introduce my friend from St. Louis - and the world - Mrs. Joe - Gini - Laurie.
GINI LAURIE

SPRINGFIELD CIL DINNER MEETING - Sept 18, 1988

Thank you, Jack or Richard, I have lived the history of polio and independent living and I would like very much to share reminiscences of 1950s, and 1960s, and 1970s...of the people and the forces that influenced the movement.

And I'd like to underscore the contributions by your Illinois leaders...from Tim Nugent to Sue Suter.

I prefer to think of the movement as an interdependent living movement rather than an independent living movement.

IL DID NOT JUST HAPPEN. TWO QUADS IN BERKELEY IN THE EARLY 70'S DID NOT WAVE THEIR MOUTHSTICKS AND SAY "LET THERE BE IL CENTERS."

IL movement not isolated....Very much a part of its time.

1. Part of the awakening of the importance of the individual.
2. Of the worldwide awakening to the rights of individuals and minorities...paralleled and patterned after blacks and women movements.

3. Never before so many healthy and long-lived disabled and elderly because of medical advances, such as penicillin.

4. Never so many healthy, long-lived, and severely disabled veterans. Learned SCI treatment in WWII...Korean & Vietnam better evacuation and treatment saved more & more.

5. The movement was preceeded by other organizations of people with disabilities that had provided services: Following WWII in Canada, developed Canadian Paraplegic Association, run by disabled. Agency of the govt to distribute funds to other veterans who wished to live in the community. In USA, PVA, private agency, distribute information and lobby for veterans.

EXISTING LEGISLATION for attendants.
First IL center started in California. WHY THERE?
BACKTRACK TO THE 1950S to find out. Polio epidemic. The March of Dimes funded 16 respiratory centers. One in LA had most. 153 in iron lungs in 1953. To save money started a home care program, paying for attendants & equipment. .

Rest of country followed suit. March of Dimes paid about $300 a month for personal assistants or $10 a day instead of
the average per diem in hospital of $30. (Still same ratio: 1/4 to 1/10.)

Incidentally, I volunteered at one of the respiratory centers 10 years. (From 1949 to 1959). By 1958, vaccines had stopped polio and people were at home & wanted to keep in touch. I started a publication, TjG, which became the RG., (Still going - 30th year). First to our respiratory center in Cleveland, then all centers, then to people with all disabilities, all around the world.

So, when MofD suddenly stopped payments for personal assistants, California's two centers banded together and effected legislation to continue payments. And the Gazette organized the rest of the country to write to Congress for national legislation.

Obviously not successful. But it let people with disabilities know that they could work together and have influence.

The Gazette, then and now, has been an IL by mail. Peer models...peer counseling... A forum...A bond.

7. Back to the history of IL - It was started by university students. Significant because the movement needed educated leadership.
Illinois played an important part. Tim Nugent had pioneered an accessible campus at Champaign/Urbana. In the Rehab Act of 1967, Mary Switzer gave tremendous boost by paying attendants and all other expenses of a student with severe disabilities. Many present leaders of IL movement came from C/U...Dr. Fred Fay...Dr Jack Genskow...Love the sound of that PhD...! Love to read Sigma Signs! And the accomplishments of its alumni.

Tim Nugent made another significant contribution. One of the leaders to develop the NPF, civilian branch of PVA...the training ground for many present leaders of the IL movement. Headquartered in Chicago...held together by Jim Smittkamp & Ann Ford.

And another important contribution by Mary Switzer: the 1968 Rehab Act included homemaking as part of rehab...acknowledging that money-making at a job was not the only goal in life.

An important step in the evolution of IL was ACCD...started by an alumnus of C/U - Fred Fay...Dr. Fred Fay.

Other among the first ACCD board members: Eunice Fiorito (now at RSA)......Lex Frieden (then a graduate student at U of Houston)...Dave Williamson...Fred Fay...Fred Schreiber of Natl Assoc of the Deaf....Judy Heumann (then an aide to
Senator Harrison Williams...Diane Lattin, editor of Performance...Phyllis Rubenfeld...Lou Rigdon, attorney Justice Dept...Roger Peterson blind...and I - the only person without a disability - their "token nondisabled."...ACCD very IMPORTANT because, for first time, people who were blind, deaf, and physically disabled worked together for their mutual benefit......and because it brought together people with disabilities from East, West, Midwest, and South.

Finally...Back back to that first IL center in Berkeley. Early 1970s....with attendant/personal assistance legislation in place...and Mary Switzer's higher education program for people with severe disabilities...and a very determined and helpful physician at Berkeley....Ed Roberts with his iron lung and John Hessler, a high level quad, enrolled at Berkeley. They lived in the infirmary with their personal assistants.

By the time they graduated, there were 12 students with disabilities. Wanted to continue to live independently in the community. First thought of communal residence, a group home. FORTUNATELY, they said NO...or the IL would have died there - for a while - but it would have happened.

So, they decided instead to set up an office to arrange personal assistants and to locate and adapt apartments.
With the great help of Mrs. Roberts and Mrs. Hessler, who were their emergency assistants, etc. - and that's a large ETC

Worked to so well... nonstudents in Berkeley wanted to copy.

Then spread throughout California - largely because of that personal assistant legislation effected by the polio survivors in 1959.

1973 Rehab Act... demonstration of the power of working together ACCD....

Four years later, in 1977... really showed power in the sit-ins in DC and San Francisco.

Finally, VR funded first 10... Of course, Chicago was one of them.

NCIL next step.... still headquartered in Chicago....

National Council on the Handicapped... important cohesive force.... Lex Frieden.... Justin Dart important member of Natl Council, then RSA commissioner. Now most important in his role of covering the country, like Johnny Appleseed or an itinerant preacher, with his message of all disabilities working together for the Americans with Disabilities Act.
Before Judy talks about support groups, I'd like to add a few words about self-help support groups.

Since January I've been active on the Surgeon Generals's Planning Committee for a national workshop in September at UCLA on self-help groups and public health. I've learned a great deal about this exciting movement, which involves about 15 million persons in more than one-half million self-help groups. First, the definition which the Planning Committee adopted:

"A self-help support group is a collection of individuals who share a common concern, provide emotional support to each other, govern themselves, and charge members little or no fees for their involvement in the group."

"This definition allows the involvement of professionals (voluntary agencies, etc.) so long as the group is in control and the professionals serve at the wish of the group."

"In most groups there are three basic types of activity. These are emotional support, information exchange, and coping strategies. The degree of activity in each of these areas will vary dependent upon the particular needs of the members of the group."
One of the purposes of the Surgeon General workshop is to explore "the nature of the relationship between self-help and professionals."

In this context, I'd like to quote from THE SELF-HELP SOURCEBOOK published by the New Jersey Self-Help Clearinghouse. It is a very helpful book which I recommend highly.

"Observing the usefulness of mutual help groups, professional agencies have begun to sponsor groups of their own, choosing the participants and convening the meetings themselves. Since members do not control resources and direct policy, these are technically not mutual help groups and do not accomplish the same ends. The context in which help is offered may critically change its nature and effects. The more professionals are involved, the more likely it is to resemble group therapy or another professional service under a different name. This can be unintentionally deceptive."

"Professional human services agencies and mutual help groups sometimes have a tense and competitive relationship. Group members sometimes believe themselves to have been ill-served by professional helping systems, and members may be encouraged to only consult one another. Historically, professionals have sometimes tried to co-opt mutual help organizations, and they are often regarded as intruders. When groups turn to agencies for assistance, a struggle for control may result."
"But most mutual help organizations are not anti-professional and collaboration is possible if there is a mutual respect and understanding."

"In summary, mutual help groups are a powerful and constructive means for people to help themselves and each other. The basic dignity of each human being is expressed in his or her capacity to be involved in a reciprocal helping exchange. Out of this compassion comes cooperation. From this cooperation comes community."
Our living network is a positive power that has motivated countless thousands of persons with disabilities to work, play, travel, marry, raise families, and live independently and productively in their communities.

Most of them have been paralyzed by polio or other disabilities for more than 30 years. Many of them have been using iron lungs or other ventilators for those 30 plus years. Most of them have had successful careers and lived at home with the supporting services of their families or other attendants.

ALL OF THEM HAVE BEEN FAR MORE VICTIMIZED BY SOCIETY'S NEGATIVE ATTITUDES AND ENVIRONMENTAL BARRIERS THAN BY THEIR DISABILITIES.

Societal attitudes and societal barriers of inaccessible schools, churches, housing, workplaces, and transportation are Herculean and ubiquitous.
Though negative attitudes are still the most handicapping and the most pervasive, we feel optimistic when we look back — back to the times when President Franklin D. Roosevelt had to hide his disability, when photographs of FDR in a wheelchair were destroyed and he was propped up on platforms with concealed braces and supports.

Now, we see Itzhak Perlman, a polio survivor, proudly swinging across stage on his crutches. We see President Ronald Reagan casually wearing a hearing aid. We watched Senator Jacob Javits, who had Lou Gehrig's disease and used a ventilator, continue his distinguished career up into his 80s. We attend smash movies about people with impaired hearing and sight, such as "Children of a Lesser God" and "Butterflies are Free."

Many of these attitudinal changes have been accomplished indirectly through Sections 503 and 504 of the Rehabilitation Act of 1973... the bill of rights for people with disabilities.
Because of this legislation and changing attitudes, many cities have accessible transportation. Many states have home attendant care services. Many schools are accessible, and tomorrow's children, raised in totally integrated schools, will be both disability-blind and color-blind.

But, positive attitudes cannot be legislated. They are the personal responsibility of each one of us—whether disabled or nondisabled.

Each of us must strive to see, to feel, and to understand each other's humanity and to appreciate each other's value and uniqueness as a human being.

Our guests, who were freed from Russia—Simon, Tamara, and Mark—attest to the concern of many people for human rights and the power of working together to effect those rights.

In giving me this year's St. Louis Award, St. Louis recognizes the humanity and human rights of people with disabilities, and takes a commendable step toward removing societal barriers and achieving positive attitudes.

I thank you again, Dr. Danforth, and all of you who came to share this recognition with me today.