

# rehabilitation gazette

## Independent Living: The Role of Gini Laurie

Joan L. Headley, Executive Director  
Gazette International Networking Institute, Saint Louis, Missouri

It has been written that there are two grandmothers of the independent living movement. One was Mary Switzer, the Director of the Office of Vocational Rehabilitation from the 1950s to the late 1970s. During her tenure and within a 15-year period, dollars for vocational rehabilitation increased 40-fold. An amendment in 1965 included tuition and attendant care for persons with severe disabilities. Mary Switzer demonstrated to Congress the financial rewards of turning adults with disabilities into "productive" citizens and "taxpayers."

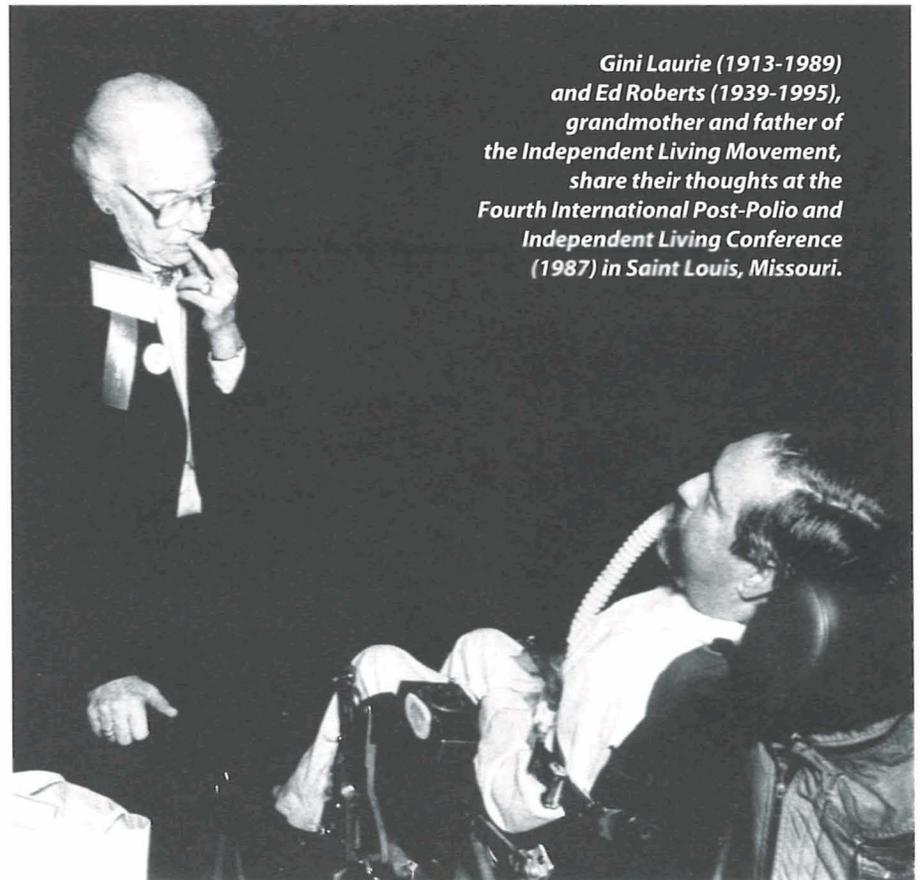
According to Gini Laurie, the other grandmother of the independent living movement, Mary Switzer's role was vital because vocational rehabilitation monies developed an educated leadership — which was essential to the independent living movement.

Why is Gini Laurie considered one of the grandmothers of the independent living movement? Who was she and why did she get involved with disability?

She revealed a very personal reason, October 1988, at the dedication of the new St. John's Rehabilitation Hospital in St. Louis.

"My father was a surgeon and on staff at the old Euclid Avenue St. John's [Hospital]. In 1912, the year before I was born, four siblings were struck by polio:

a 12-year-old sister was mildly disabled, a 6-year-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. John's chapel depicting them as angels.



**Gini Laurie (1913-1989)  
and Ed Roberts (1939-1995),  
grandmother and father of  
the Independent Living Movement,  
share their thoughts at the  
Fourth International Post-Polio and  
Independent Living Conference  
(1987) in Saint Louis, Missouri.**

"Sixteen years later, I watched my significantly disabled brother die of pneumonia and underventilation at St. John's. His funeral mass was in the chapel, underneath the mural of our sisters."

Because of her family experience, it was only natural for Gini Laurie to become a Red Cross volunteer

at one of the 15 polio respiratory centers operating in the late 1950s.

The centers, where individuals with severe polio in need of rocking beds and iron lungs were sent, provided superb medical and psychological rehabilitation but, until 1953, most of the permanent respirator users seemed doomed to remain in the hospital for the rest of their lives.

In order to save money by avoiding lifelong hospitalization at the high daily rate of \$37, Rancho Los Amigos Respiratory Center for Poliomyelitis in Downey, California, pioneered a system of home care that cost only \$10 per day and polio survivors were sent

PRESENTED AT THE  
1997 REGION V INDEPENDENT  
LIVING CONFERENCE,  
OAK BROOK, ILLINOIS, OCTOBER 1997

home with their iron lungs and chest cuirasses.

Meanwhile, Gini Laurie volunteered at the Toomey Pavilion Respiratory Center in Cleveland, Ohio, and kept up with her old polio pals who had gone home.

Reflecting in her later years, Gini commented that it was "apparent they [polio survivors] had two vital needs ... people and information. They wanted to keep [up] with each other ... and wanted to share information about their lives and equipment."

Gini and her husband, Joe, started to meet those needs by building a heated pool with a lift at their home, where they held annual reunions of the alumni of the respiratory center.

In 1958, the same year, they started publishing *Toomey j Gazette*, featuring news of how polio survivors managed at home.

By 1959, the vaccines had stopped polio, the public stopped giving to the March of Dimes, and the March of Dimes stopped paying for attendants and closed the respiratory centers.

The sudden loss of attendant payments caused panic. There was no Social Security Disability, no Medicare, no Medicaid, no vocational rehabilitation for people with severe disabilities. There was only welfare or help from churches or family. Fortunately, polio survivors who had gone home from the centers had worked with attendants for a few years, and had worked out some systems of community support. However, they also needed the psychological support of other survivors.

That is where the *Toomey j Gazette* (later to become the *Rehabilitation Gazette*) came in.

Gini led a letter-writing campaign in 1959, alerting survivors in every state to write to their congressmen urging national attendant care legislation. The national campaign was unsuccessful, but it called Washington's attention to the problems of people with severe disabilities.

However, the California campaign was successful due to the efforts of the respiratory polio survivors, and state legislation established attendant care (in her words) "that later cleared the path for the independent living movement — for attendant care is the linchpin of independence."

The 1959 campaign for national attendant care demonstrated and solidified Gini's belief in networking — the power of connecting people with people and the power of information.

"Networking links people who share common needs or common goals. Networking is a support system. It is a method of self-organizing. It is the structure of a social movement. Most of all, it is a method by which people get things done."

The following excerpts from the GINI archives demonstrate her persistence, her acceptance of people as they were, and her constant connecting.

Gini featured Ed Roberts in the Spring 1965 *Toomey j Gazette*, after receiving a clipping from *Parade Magazine* (April 5, 1964) with an article entitled "This Student Majors in Courage." The accompanying photo caption read, "Helped by brother Ron, polio victim Ed Roberts goes to classes."

Later she received this postcard from Ed Roberts. "Editor ... I am sorry you did not come to me to update the article. This article taken from *Parade Magazine* was not only inaccurate in many

instances but also poorly written. I am sorry to say that you have compounded the errors ..."

Gini responded August 3, 1965. "Dear Ed, Mea culpa, mea culpa, mea maxima culpa ..." and explained why she had not consulted him. "I shall be most grateful if you will tell the story of your teaching career, living at and attending university. It is vitally important, not only to the young would-be college students but to the vocational rehab departments who will be financing their studies ... Meanwhile, could you help with some information as to your present living arrangements at the Cowell Hospital? A very brilliant young respo in Germany is fighting to find a university in the U.S. which he can attend."

She sent Ed another note dated August 12, 1965. "Dear Ed ... My friend, Adolph of Germany, has sent the enclosed letter to me to forward to you. Do hope you are the magic button for him. I am so interested in helping him attain his pinnacles. Cheerio, Gini."

On September 9, 1970, Ed Roberts, in a postcard, made the following announcement. "I have begun [a] consultation business for anyone needing help with problems of cripples. Thus far I have consulted with Health, Education and Welfare in Washington, DC, about programs for cripples in higher education. Helped secure \$80,000 grant for University of California at Berkeley program run by cripples for the education of cripples. I brought John Hessler in as director. He is doing a magnificent job. Would you like to hear more? I believe no other consulting firm like this in country!"

He shared his philosophy with her in a 1970 letter. "I am tired of well-meaning non-cripples, with

their stereotypes of what I can and cannot do, directing my life and my future. I want cripples to direct their own programs and to be able to train other cripples to direct new programs. This is the start of something big ... CRIPPLE POWER."

Another clipping from the archives dated January 31, 1971 documents a shift in thinking. "Judy Heumann grew up being called crippled, but today calls herself 'disabled and discriminated-against.' She feels that the word 'crippled' suggests that a person is not physically whole. ... 'If militancy means asking for something that is yours, then we're militant,' said Judy, president of the group. 'We're just tired of remaining silent just because we're scared of losing the little we have.'"

In 1988, Gini Laurie, at the Center for Independent Living in Springfield, Illinois, reviewed the independent living movement. "Independent living did not just happen. Two quads in Berkeley in the early 1970s did not wave their mouthsticks and say, 'Let there be IL centers.'"

"The independent living movement was not isolated. It was very much a part of its time and a reflection of its time." She further mentioned some of the influences on its evolution.

"The movement was influenced by the awakening of the importance of the individual; of the worldwide awakening to the rights of individuals and minorities. The independent living movement paralleled and was patterned after the black and women movements.

"It was influenced by the fact that there were many more healthy and long-lived disabled and elderly because of medical advances, such as penicillin. There were many more healthy, long-lived,

and severely disabled veterans who survived Korea and Vietnam [wars] due to better evacuation and treatment learned during WWII. The movement was also influenced and preceded by other organizations: Canadian Paraplegic Association, Paralyzed Veterans Association, The National Paralysis Foundation, [and] American Coalition of Citizens with Disabilities (ACCD)."

"The ACCD was very important ... because, for the first time, people who were blind, deaf, and physically disabled worked together for their mutual benefit. It brought together people with disabilities from east, west, midwest, and south. I was a token non-disabled member of the coalition."

Gini continued to publish the *Rehabilitation Gazette* until her death in 1989. She had added *Polio Network News* for polio survivors who were experiencing what has come to be known as the late effects of polio, and *IVUN News* for ventilator users. She spent fifty years of her life supplying people with disabilities with information and knowledge and connecting people with people.

Gini many times ended her presentations with caveats.

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

"The [phone] calls usually start by asking for the name of a nursing home that will take people on ventilators. I react violently to the suggestion and remind them that they do not need nursing. They need a pair of hands that they can direct. They do not need to be buried alive in a nursing home. They need to continue to live their lives as they choose."

"Beware of bringing the hospital home; beware of making the cost of using a ventilator astronomical. Society will choose the more economical alternative — no ventilator."

"Beware of the edifice complex; people don't need buildings; they need improved systems."

"Beware of UBI, universal bureaucratic idiocy — be careful you don't become what you were originally created to fight against."

"Reach out to the aging population. ILCs should practice what they preach; hire [people over 70] as peer counselors; put older people on [their] boards."

"Respect each other; the elderly may feel same about young's lack of understanding that disabled feel about non-disabled's lack of understanding."

"We can't let divisiveness happen. We must all work together ... visual impairments, hearing impairments, physically disabled, mentally retarded, mentally ill, the elderly."

"We're a power if we work, think, and play together ... and only if we do."

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and Sheryl R. Prater

# An Accessible Lake Home



***It started as a dream*** of a rustic small shelter with the only real requirements that I be able to get in and out easily and that there be plumbing. I had bought the lot with 100 feet of shoreline some years before, and with retirement it seemed the right time to build. So, I found an accessible house plan that I liked.

I had heard that the state vocational/technical schools would build houses to order, to be moved to the customer's lot. In the fall of 1995, I contacted the school in Watertown, South Dakota, 20 miles from the lake, and asked about building. I talked to the man in charge, Dale Howlett, and set up a charge account at the UBC lumber yard.



*Jessie Easton, MD  
Sioux Falls, South Dakota*

David Gill at UBC looked at my plan and determined the house was too wide to go down the road.

He modified it to travel, as a two-bedroom, two-bath house with a large kitchen and living room and a laundry room that also served as the way out to the garage. He found subcontractors to do the concrete and electrical work, plumbing, and gutters, and for the foundation, garage, deck, and ramps, he recommended "Scooter" Jacobson, an independent contractor.

I was in charge of permits, carpet, and appliances, and had to choose lighting fixtures, wall surfaces, paint colors, as well as the kitchen and bathroom cupboards and plumbing fixtures.

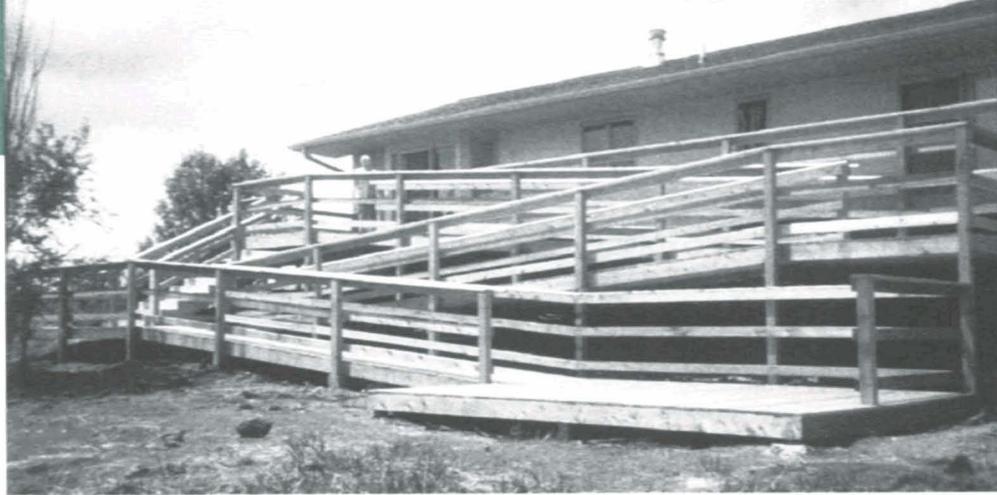
The house was built during the winter on a concrete pad at the school. A gas heater was installed as soon as the walls were up and the roof on. As the work progressed, I would get phone calls asking whether I wanted the walls textured or plain. I would ask what the students needed to learn and then would agree that "textured would be just fine." I missed seeing the painful times Dave told me about as the students struggled. I understood that sometimes I would be charged for extra wood or material when there was a difficult task to be learned. I understood it better when I had a chance to watch some of the finishing work being done, as one lad took four tries to get a piece of molding to fit over a door.

All the materials I chose were commercially available in our area. The house has a four-foot wide hall and three-foot wide doors. The doors have handles

instead of knobs. The carpet is a short-loop, firm, commercial type with a firm pad under it. The "big" bathroom, laundry room, and kitchen have non-slip vinyl floor covering.

In the bathrooms, the sinks have lower than usual counters (27-28") and are open underneath, with a medicine cabinet/light fixture combination set low enough for a seated person.

The guest bath has a tub with shower and grab bars as needed. The bigger bath has a shower that came with a low threshold, a seat,



In the kitchen, a bottom-freezer refrigerator has shelves that pull out. The upper part has a deep door for storing frequently used items, and shelves that are adjustable to accommodate different needs.



and a bar at the back. The students added grab bars at the sides. The grab bars at the toilets, which can have risers added, are standard height.

The closets have low bars (30") and adjustable shelves. One closet is a large walk-in to provide room for storage in a house without basement or attic. I chose the washer and dryer by going around the store checking which ones I could reach the bottom and back of easily. The dryer, which opens to the front, was installed on a raised platform to make it more accessible.

The cook-top has an open space beneath and is electric, with the switches along the right side. It is level with the counter (28") so I can slide heavy pots rather than lift them. The sink is also open underneath and lower (26") than the counter for sitting to wash the dishes. There is also a dishwasher beside the sink, at standard height, to hide the sink from the living room.

The wall oven, placed in the lower cupboards has a side-opening door for easier access. The counter is lower than standard (28") and there is a deeper kick

space (6") at the bottom. The cupboard doors have no knobs and open with a groove on the bottom or top. If pulls were to be put on, a plain round or oval knob would be easier to grip than some of the fancier small handles.

The garage is larger than usual (24' x 26'), with a ramp from the laundry room door to the floor. It has two doors, eight feet high. One is nine feet wide and the other is ten feet wide to accommodate a van.

There are electric openers for the doors, operated by switches at the back door and by a remote control in the car. (The one remote operates both doors at once, so it is necessary to have them both in the right position when leaving.)

On the lake side, there is a deck the length of the house, with a ramp to the shore level, and a flight of 6" steps for the impatient people. A second set of steps (5.5") leads off the other end of the deck so it is not necessary to go through the house. There is a smaller piece of deck at the bottom of the ramp, with a short ramp to the ground.

On the street side, a concrete ramp leads to the driveway. As the landscaping was considered, a graded ramp was put on the slope, to be seeded with grass and eventually graced with a rock garden. A set of steps beside the end of the wooden ramp, made of railway ties, allows quicker access to

CONTINUED ON PAGE 6

## Forty Years of GINI

In 1958, Gini Laurie became editor of *Toomeyville Jr. Gazette*, the mimeographed newsletter for Toomey Pavilion, Cleveland, Ohio, a respiratory center for poliomyelitis patients. Incorporated as the International Iron Lung Polio Assistance, Inc.

1964 Changed name to Iron Lung Polios and Multiplegics, Inc.

1959 Incorporated as the

International Iron Lung Polio Pavilion, Cleveland, Ohio, a respiratory center for poliomyelitis patients.

1970 Renamed Rehabilitation

Gazette, Inc.

1971 Moved from Chagrin Falls,

Ohio, to St. Louis, Missouri.

1979 Published letter by polio

survivor regarding new

problems.

1981 Coordinated first GINI

conference, Chicago, Illinois

— "Whatever Happened to

the Polio Patient?"; changed

name to Gazette International

Networking Institute, Inc.

a lady with multiple sclerosis for whom Habitat for Humanity built a home. I have had members of the polio support group for a Saturday picnic, and they got some ideas for their own places. The mover who brought the furniture walked around saying, "Oh, my!" and I learned later that he remodeled his house for a recently injured family member. Overall, it has been a great adventure. I have learned, and so have others, that commercially available items can be found to provide a house that works for people with and without disabilities at a fairly reasonable cost.

would have been easier to have a contractor to do the organizing and supervising at greater cost. I am particularly grateful to Scooter, who did the deck, ramp, and garage, and most of the picky little details at the end, putting up window shades and grab bars and shower curtains, making a wood box, and tidying up the yard. My rustic cabin turned out to be a second home. I look forward to using it and then turning it over for others to use when I no longer need it. It has taught a class of technical students about adapted housing, and has been shown to

the shore. My plan is to have most of the land in native-type grass and have it cut a few times a year. There is rural water and a septic tank and drain field. Some day there may be a proper sewer system. The furnace burns propane, and the water heater is electric. I use a cellular phone, however, regular telephone service is available. There are a few things I would do differently, now that it is done and has been lived in. The bathroom doors open in, as most do. If they opened out, the smaller bath would be more accessible and the larger would have space for a hamper or chair. The door on the oven and the dryer should open the other way. The cook-top switches should be in front. I would opt for three bedrooms to accommodate a greater assortment of guests. As it is, my next project is the addition of a screened sleeping porch on the north side of the house, with sliding glass to keep the wind out when needed and roll-down screens for privacy. That will come someday ... I acted, with David Gill's help, as my own general contractor. It



I am a 66-year-old semi-retired physician, who grew up in Alberta, Canada, where my parents bought a lake cabin (truly rustic, no plumbing) when I was about nine. I had polio at age seven, for which the doctor advised swimming. No pools were available, so I went swimming at the lake, and learned to use a saw and ax and make a fire and boat. After medical school and a career in physical medicine and rehabilitation, including a clinic for polio survivors and work with children with multiple handicaps, I am now ready to go swimming and row a boat again. The ax will not be used for a fun fire in my new fireplace.

1984 Published *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* edited by Laurie, Maynard, Fischer, and Raymond.

1985 Formed the International Polio Network.

1987 Organized the International Ventilator Users Network.

1989 Established The Gini Laurie Endowment.

1995 Created The GINI Research Fund.

## Attendant Services Debate MiCASA (H.R. 2020)

The House of Representatives will consider legislation (H.R. 2020) during the 1998 legislative session that was introduced by House Speaker Newt Gingrich (R-GA) June 24, 1997 at the counsel of Americans with Disabilities for Attendant Programs Today (ADAPT). Designed to amend Title XIX of the Social Security Act, the bill will redirect longterm funding, currently restricted to institutional use, to a consumer-controlled system. The bill is pending in the House Committee on Commerce and has bipartism support from 23 members of Congress.

Known as MiCASA, Gingrich introduced H.R. 2020 under the formal title, Medicaid Community Attendant Services Act. As its title suggests, this bill would create Qualified Community-Based Attendant Services, allowing only individuals eligible for Nursing Facility Services (NFC) or Intermediate Care Facility Services for the Mentally Retarded (ICF-MR) a choice of institutional services, community-based services, or attendant services.

Today, two million Americans who live in nursing homes may be eligible to take advantage of the MiCASA amendment to make the transition from nursing facilities into a home setting. The emphasis of the current system on institutional care and the resulting cost of such care are the main targets of this legislation. Currently, the United States spends 80% of Medicaid's long-term funding on nursing home care. The cost control measures proposed by H.R. 2020 would enable two people with disabilities to receive funding for adequate in-home or community-based care for every one person currently receiv-

ing the same care in a nursing home. The bill limits spending to what is currently spent on NFC or ICF-MR services.

The debate has several hurdles to overcome before the bill can be voted into law. The largest would be what Gingrich referred to as "significant cost implications." The Congressional Budget Office (CBO) released a letter to Gingrich that projects spending for this new service at \$10-20 billion and calls the spending cap "difficult to apply." At ADAPT's insistence, the CBO has agreed to reevaluate their findings using other medical models. The Office of Management and Budget (OMB) will also release its report on cost projections of H.R. 2020 to the President this session.

Other hurdles in the debate include similar bills before Congress. The Senate will be considering similar legislation (S. 879) introduced by Senator Russell Feingold (D-WI). Although there are significant differences between the language of the two bills, they hold similar goals: to allow people with disabilities to choose how services such as help with dressing, bathing, eating, toileting, and ventilator care are to be provided. Feingold is from Wisconsin, one of the few states which currently offers community-based and attendant services.

Concerning the upcoming debate over both bills, Mark Johnson, ADAPT, said, "We hope this won't become a contest [between S. 879 and H.R. 2020]. Let's get hearings, let's testify, let's draft language that makes both bills better ..."

H.R. 2020 is scheduled for hearings in the Commerce Committee's subcommittee on Health and Environment, headed by Representative Michael Bilirakis (R-FL), by the end of March 1998. To be involved in the debate, contact him at the House Committee

on Commerce, 2125 Rayburn House Office Building, Washington, DC 20515, Commerce@mail.house.gov, or 202/225-2927.

MiCASA is the first step towards future and expanded national attendant care legislation. Debate and discussion will continue in both the House and Senate in the upcoming year. To contact legislative leaders who will be involved in this debate, contact the Senate web site at [www.senate.gov/](http://www.senate.gov/), connect with the House of Representatives web site at [www.house.gov/](http://www.house.gov/), or call the Capitol switchboard at 202/224-3121. Written correspondence regarding MiCASA can also be sent by addressing letters to the Honorable (representative's name), US House of Representatives, Washington, DC 20515, or to the Honorable (senator's name), US Senate, Washington, DC 20510.

*If you have further questions, please contact Justine Craig, [gini\\_intl@msn.com](mailto:gini_intl@msn.com), 314/534-0475, 314/534-5070 fax.*

### *GINI expresses its appreciation for the contributions received in memory of friends and family ...*

Alan Brewington  
Hubert Edson  
Leland J. Longhofer  
Dorothy McGraw  
Art Madsen  
Susan Dorothy Pohland Mahan  
Thomas S. Marshall, Jr.

*GINI acknowledges a \$10,000 bequest from Robert J. Kinney to The GINI Research Fund.*

## New Publications

*The ABC-CLIO Companion to The Disability Rights Movement* by Fred Pelka; ABC-CLIO, P.O. Box 1911, Santa Barbara, California 93116-1911, 805/968-1911 or 800/368-6868, 805/685-9685 fax, sales@abc-clio.com; ISBN #0-87436-834-0; 1997; 422 pp.; \$60.00.

This encyclopedia is the latest work in ABC-CLIO Companions to Key Issues in American History & Life Series. It contains nearly 500 entries arranged alphabetically exploring prominent figures, historic events, programs, disability laws and issues, and key concepts. The book is cross-referenced, illustrated, indexed by subject, and contains a detailed chronology.

*1998-99 Accent Buyer's Guide*, 11th edition; *Accent on Living Magazine*, P.O. Box 700, Bloomington, Illinois 61702, 800/787-8444 or Acntlvlg@aol.com; January 1998; spiral bound; \$15.00 plus \$3.25 shipping.

*The Self-Help Sourcebook: Your Guide to Community and Online Support Groups*, 6th edition, compiled and edited by Barbara J. White and Edward J. Madara; American Self-Help Clearinghouse, Northwest Covenant Medical Center, 25 Pocono Road, Denville, New Jersey 07834-2995, 973/625-9565, 973/625-9053 TTY, 973/625-8848 fax, www.cmhc.com/selfhelp/; ISBN #0-9634322-7-3; 1998; 348 pp.; index; \$12.00 postpaid.

In addition to providing free help to anyone interested in starting a needed new mutual help support network, the American Self-Help Clearinghouse publishes this excellent resource. It has information on how to find or help form a group, develop an online support network, as well as the latest research studies. The resource lists over 800 national and model groups.

## New from GINI

*IVUN Resource Directory 1997/1998*, compiled by *IVUN News* editor Judith Raymond Fischer, is an excellent networking tool for health professionals and both longterm and new ventilator users. Sections are dedicated to health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. The cost is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only).

### Future GINI Publications

*Post-Polio Directory 1998* will be available March 1. Entries from 1997 are being confirmed. Other post-polio clinics, health professionals, or support groups committed to addressing post-polio issues should contact GINI to be included. The cost of *Post-Polio Directory 1998* (after March 1) is \$5 USA; \$6 Canada, Mexico, and overseas surface; \$7 overseas air (US funds only).

*The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* edited by Gini Laurie, Frederick M. Maynard, MD, D. Armin Fischer, MD, and Judy Raymond (1984) will be updated during 1998 thanks to a grant from the March of Dimes Birth Defects Foundation.

## Gazette International Networking Institute (GINI)

celebrating 40 years as ... a source of information ... a network of people

### GINI also publishes ...

**Polio Network News** — for survivors of polio, families, friends, and health professionals who treat them. After March 1, the subscription rates for this 12-page quarterly will be \$20 USA; \$25 Canada, Mexico, and overseas surface; \$30 overseas air (US funds only).

### Post-Polio Directory

**IVUN News** — for users of home mechanical ventilation, families, friends, and health professionals who treat them. After March 1, the subscription rates for the new 8-page quarterly will be \$17 USA; \$22 Canada, Mexico, and overseas surface; \$27 overseas air (US funds only).

### IVUN Resource Directory

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