formerly *Together*

Disability Issues

Vol. 19, No. 4

a publication of the *Information Center*

The Late Effects of Polio: They are Real & There is Help

by Joan L. Headley

"As everyone grows old it is natural that physical limitations increase. With polios, the limitations come much earlier and, in these days, it is necessary to cope to the best of our ability and without much assistance from the 'medical profession.'

"During the last few years, I find myself being able to do less and less and tire far too easily. I would, therefore, like to suggest that readers of **Rehabilitation Gazette***, which seems to be the last polio link, submit names of doctors they know in their home town who can easily relate medical problems to polio problems."*

Larry Schneider in *Rehabilitation Gazette* (Volume 22, 1979)

Gini Laurie, founder of Gazette International Networking Institute (GINI), responded to the polio survivor's plea and gathered together polio survivors, ventilator users, policymakers, physicians, and representatives from industry to explore the needs of aging polio survivors. This successful 1981 Chicago meeting was the catalyst for the expansion of the educational efforts of the nationwide and worldwide network now known as International Polio Network (IPN).

Poliomyelitis Today

Poliomyelitis (infantile paralysis) has been eradicated from nearly every country in the world since the approval for use of the Salk (1955) and Sabin (1962) vaccines. In 1997, 5,185 cases of polio were reported worldwide; in 1998, 5,867. The increase in the number of cases is due to improved surveillance and reporting techniques. The World Health Organization (WHO) estimates that there are five to six times as many paralytic cases as reports received. Nevertheless, WHO has targeted the year 2000 for the complete eradication of acute poliomyelitis.

WHO estimates there are 12 million people worldwide with some degree of disability caused by poliomyelitis. A 1994 National Center for Health Statistics survey reported a preliminary estimate of one million survivors in the United States. About 33,000 of them reported paralysis resulting in some form of impairment.

Survivors of Poliomyelitis May Experience Symptoms that Include:

-- Unaccustomed fatigue – either rapid muscle tiring or feeling of total body exhaustion.

-- New weakness in muscles, both those originally affected and those seemingly unaffected.

-- Pain in muscles and/or joints.
-- Sleeping problems.
-- Breathing difficulties.
-- Swallowing problems.
-- Decreased ability to tolerate cold temperatures.

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Help for the Homebound

by Raymond E. Glazier, Ph.D.

When we think "homebound," chances are we visualize a frail elderly person, or at least someone with severe physical limitations. Yet there are thousands of people in Massachusetts alone who are unable to venture out of the house due to agoraphobia (*an abnormal fear of having a severe panic attack in public or private areas*), post-traumatic stress disorder, panic disorders, or other equally limiting psychiatric impairments like depression. For these persons, their "house arrest" is as real as if the door were padlocked or they were chained inside.

Phobics United Foundation (PUF) is a statewide non-profit organization founded by Joyce Caggiano Hamilton in 1996 to serve the many needs of its otherwise largely unserved or underserved consumer base; there are more than 3,500 citizens of Massachusetts whose psychiatric or physical state restricts them to home. Despite its acronym, PUF is no cream puff, but a working organization that stocks a food bank, staffs a crisis phone line, and maintains an in-

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INSIDE ☞ ☞

Winter 1999/2000

From the Center

Lawrence Warnock

Information Center's Website Has Been Expanded [disability.net]

The Board of Directors established a goal recently to re-design the Information Center’s website. I’m pleased to report that we have accomplished that goal. The website is now fully functional and has been expanded to provide better service to individuals with disabilities, their families, and others working with people with disabilities.

The website now includes a message from the Center’s founder, a history of the Center, the current issue of ***Disability Issues***, the Center’s taxonomy and a volunteer page.

Our future goals include: creating an archive for issues of the newsletter, a complete set of fact sheets and information on each topic within the taxonomy, and an electronic version of the newsletter. We will also be inviting other disability organizations with websites, and disability information sources to link to our site. The Information Center will reciprocate with those sites.

We are hoping that many subscribers to ***Disability Issues*** will choose to receive the newsletter electronically. When a subscriber chooses to receive the newsletter electronically (delivered to the subscriber’s e-mail box), we will realize the cost savings for production, printing and postage. Those savings can then be invested in other activities of the Center.

To switch your snailmail version of ***Disability Issues*** to e-mail, simply go to our website. Click on the Volunteer Page, check off your choice, complete your information and send it in by clicking the “submit” button at the bottom of the form. The form also provides you an opportunity to volunteer, make suggestions, or offer a comment. We will be grateful if you can recommend to us sites you have found to be useful and describe what kinds of assistance they provide. Likewise, if you have found some site to be less that accurate or user-friendly, please let us know that as well.

The Information Center Website address is **http://www.disability.net.** We have recently moved our domain name, disability.net, to a different internet service provider. Both addresses will be merged as soon as the transfer occurs. This could take several weeks and may be accomplished by the time you receive this newsletter. If you don't find it there, however, the site may be accessed at: 209.58.147.12.

As always, your comments are welcomed. You can make your comments at the website.

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President: Nancy C. Schock   Editor: J. Archer O’Reilly III

Show Your Stuff

If you are an artist, you can enter the Sister Kenny Institute's 37th Annual Art Show displaying and selling fine art work by artists with disabilities slated for April 14 through May 11, 2000.

Any artist with a disability is eligible; crafts are not accepted; the work must be original and created within the last five years. Artwork is limited to two entries per artist and one of them must be for sale. You will be responsible for shipping your entries to Minneapolis which must be received by March 20, 2000.

A $500 cash award is given to the artist whose work is selected as "Best in Show." First, second, third and honorable mention ribbons will be awarded in all categories and winners will be given $100, $75, $50, and $25 respectively.

The six categories are: Graphic, Photography, Watercolor, Mixed Media, Oils and Acrylics, and Sculpture.

For more information contact the Sister Kenny Institute, Administration, First Floor, Abbott Northwestern Hospital, 800 East 28th Street, Minneapolis, MN 55407-3799 or call (612) 863-4463.

Work Incentives Improvement Act of 1999 Offers New Opportunities

by Raymond Glazier, PhD

For years now, 76% of those of us with disabilities who were surveyed have been telling Harris pollsters that we want to work, while the national unemployment rate in our community has approached 75%. Some people in government were puzzled that 9 million of us working-age adults with disabilities continued to live on inadequate Social Security benefit checks in this booming economy, with few people ever leaving the SSA disability roles to return to work. Disability activists have been trying to tell them, “It’s the health insurance, stupid!” Medicare eligibility for persons with disabilities has been tied to **not** working, and Medicaid tied to poverty status, which isn’t hard to qualify for when a Social Security check is your only income.

Finally, we’re beginning to be heard. House of Representatives 1180, the Ticket to Work and Work Incentives Improvement Act of 1999 (WIIA) was signed into law by President Clinton on December 17th. As Ted Kennedy noted in a statement about the bill he co-sponsored in the Senate, “The estimated cost of this new program would be recouped if only 70,000 people leave the disability benefit roles.” That is well below **one percent** of all current SSI/SSDI (Supplemental Security Income/ Social Security Disability Insurance) recipients.

A White House press release about the signing summarized succinctly the major provisions of the WIIA:

“Most significantly, H.R. 1180:

- Expands states’ ability to provide a Medicaid “buy-in” to individuals with disabilities who return to work. (See our comments on the Massachusetts CommonHealth program in the last issue, “Massachusetts is Ahead of the Game.”)
- Creates a new Medicaid demonstration to assess the effectiveness of providing Medicaid coverage to people whose condition has not yet deteriorated enough to prevent work, but who need health care to prevent or forestall that level of deterioration. This provision will allow states to help those individuals with diseases such as muscular dystrophy, Parkinson’s Disease, diabetes, and HIV.
- Lengthens from 4 years to 82 years the period for which Social Security disability beneficiaries who return to work can continue to receive reduced-cost Medicare coverage.
- Provides grants to states to design and administer infrastructures to provide services that support working individuals with disabilities.
- Provides Social Security disability beneficiaries a choice of providers for employment-related services.
- Authorizes the Social Security Administration to test new and innovative ways to enable individuals with disabilities to return to work and make economic independence a reality.
- Enables individuals with disabilities to reestablish eligibility for Social Security disability benefits on an expedited basis if their attempts to return to work prove to be unsuccessful. These individuals will be able to request reinstatement of benefits without having to file a new disability benefits application — thereby reducing the risk of returning to work.”

However, note that the WIIA does **not** require states to implement a Medicaid buy-in like CommonHealth, in which working persons with disabilities can purchase that broad Medicaid coverage by paying monthly premiums on a sliding scale. It simply makes it easier for the states to do that, if they choose. The WIIA provision for state grants to improve support services for working persons with disabilities (*worksite personal assistance services? job coaches for persons with chronic mental illness?*) also relies on the 50 states for innovative thinking and new programs. Obviously there will be great variation in the states’ approaches, levels of commitment to solutions, and the degrees of success their efforts experience.

The “Ticket to Work” part of the bill encourages private vocational rehabilitation service providers, including everyone from non-profit organizations like Morgan Memorial/Goodwill to for-profit job training firms to become more aggressively entrepreneurial. It offers these service providers a percentage of the disability benefit cost savings for each person with a disability placed in gainful employment as after-the-fact payment for the vocational rehabilitation services provided to make that person employable. On the face of it, this just sounds like “the American way in action.” But, in order for providers to provide services in anticipation of substantial future returns, they will want to be totally sure they can “rehabilitate” and place each consumer. This will probably encourage “creaming,” a gaming of the system in which only the least disabled persons with the greatest work potential, the easiest to “rehabilitate” (and the least needy), will receive services under “Ticket to Work.”

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Late Effects of Polio

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-- Decline in ability to conduct customary daily activities such as walking, bathing, etc.

These general symptoms are experienced in varying degrees, and their progression can be insidious. They should not be dismissed simply as signs of aging alone. Current research indicates that the length of time one has lived with the residuals of polio is as much a risk factor as chronological age. It also appears that individuals who experienced the most severe original paralysis with the greatest functional recovery are having more problems now than others with less severe original involvement.

The Diagnosis of Post-Polio Syndrome is One of Exclusion.

A definitive test is not yet available. Some of the confusion and doubt among polio survivors, health professionals, and family members is due to the lack of common understanding of terminology. It is helpful to think of post-polio problems in the following categories, remembering that the groupings are not distinct but parts of a continuum.

The largest and most inclusive category is called **Late Effects of Polio** or **Polio Sequelae** and is defined as specific new health problems which result from polio-caused chronic impairments, e.g., degenerative arthritis of overused joints, carpal tunnel syndrome and other repetitive motion problems, tendinitis, bursitis, failing joint fusions, overstressed joints due to compensatory body mechanics.

Post-Polio Syndrome, a subcategory of the late effects of polio, is defined as a neurologic disorder characterized by increased weakness and/or abnormal muscle fatiguability (decreased endurance). The cluster of symptoms includes new weakness, intense fatigue, and pain in muscles and joints resulting in decreased endurance and diminished function. Most clinicians use the following criteria to diagnose post-polio syndrome.

-- Confirmed history of acute paralytic polio. Some clinicians perform an electromyogram (EMG) to document changes compatible with prior polio.

-- Recovery followed by 15 years or more of stability preceding the gradual or abrupt onset of new weakness and/or abnormal muscle fatiguability, with or without generalized fatigue, muscle atrophy, and/or pain.

-- Other conditions that might cause the problems listed above must be excluded.

To distinguish new, slowly progressive muscle weakness that is neurologic in origin from that which is due to musculoskeletal and/or wear and tear problems, researchers coined the phrase **Progressive Post-Polio Muscular Atrophy** (PPMA), defined as progressive new weakness and atrophy in muscles with clinical or subclinical signs of chronic partial denervation/reinnervation compatible with previous acute poliomyelitis. The term is used less often today, giving way to post-polio syndrome.

Polio survivors may experience one or more of the problems described above and should not become unnecessarily concerned about the label for their symptoms. Polio survivors may, of course, experience the same health difficulties as everyone else, some with symptoms mimicking post-polio syndrome, some magnified due to neurologic damage from former acute polio.

As the First Step in Management

Polio survivors should undergo a complete, general medical evaluation by a primary care physician and a specialized neuromuscular evaluation by a knowledgeable and experienced polio specialist to establish a baseline from which to judge future changes and to develop an appropriate treatment plan.

Polio survivors should first and foremost take care of their health by seeking periodic, basic medical attention. Be nutrition-wise, avoid or reverse excessive weight gain, and stop smoking or over-indulging in alcohol.Polio survivors should listen to their bodies. Avoid activities that cause pain -- pain is a warning signal. Avoid unrestrained use of pain killers, especially narcotics. Do not overuse muscles but do continue activity that does not worsen the symptoms. In particular, do not over exercise or continue to exercise through pain. Avoid activity that causes fatigue lasting more than ten minutes.

Polio survivors experiencing symptoms should pace themselves in their daily activities, resting when tired. Stop for a 15- to 30-minute rest when needed, perhaps several times a day. Management may include the increased use of assistive devices. A change of equipment or new bracing may be recommended. Polio survivors should educate themselves, their families, and if need be, their health professionals.

The IPN will gather once again

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Late Effects of Polio

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in Saint Louis, June 8-10, 2000 for GINI's Eighth International Post-Polio and Independent Living Conference. For details, contact GINI, 4207 Lindell Blvd., #110, Saint Louis, Missouri, 63108, or telephone (314) 534-0475, (314) 534-5070 fax, e-mail gini_intl@msn.com, or the web site **www.post-polio.org.**

Resources

The following publications are available, as noted, from GINI at the above address:

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (ISBN 0-931301-04-1 pbk), revised in 1999, is a 120-page book in dictionary format containing 90 entries which are a compilation of the research and experience of more than 40 experts. Edited by Frederick M. Maynard, MD and Joan L. Headley, MS.

For 1-5 copies: $15 each, plus total s&h of $3.50 in USA; plus total s&h of $4.50 outside USA (Contact IPN for bulk order pricing.)

Polio Network News (ISSN 1066-5331), the quarterly newsletter of International Polio Network, contains current information about the late effects of polio, encourages research, and promotes networking among the post-polio community worldwide. Published quarterly in February, May, August, November. Edited by Joan L. Headley.

Subscriptions: USA $20; Canada/Mexico & Overseas surface $25; Overseas air $30. (Four most recent issues – USA $20, Overseas surface $250).

IVUN News (ISSN 1066-534X), the quarterly newsletter of International Ventilator Users Network, links ventilator users, their families, and peers with each other and with health professionals committed to home mechanical ventilation. Published quarterly in March, June, September, December. Edited by Judith Raymond Fischer.

Subscriptions: USA $17; Canada/Mexico & Overseas surface $22; Overseas air $27. (Four most recent issues – USA $17, Overseas surface $22).

Rehabilitation Gazette (ISSN 0361-4166), an update on disability issues, publications, resources, equipment, conferences, GINI activities, and other information useful in living independently. Published bi-annually in January and July. Edited by Joan L. Headley.

Subscriptions: USA $12; Canada/Mexico & Overseas surface $14; Overseas air $16.

Massachusetts Support Groups

Shirley Nisbet
The Cape Cod Support Group
North Falmouth, MA 02556
(508) 564-4957
(508) 564-4958 (fax)

Elaine Burns
Greater Boston Post-Polio Assn.
Wellesley, MA 02482
(781) 596-8245
meets Saturday, Quarterly

Carroll Dwyer, III
Post-Polio Information Connection
Springfield, MA 01108
(413) 732-4895

The following Direcctories are also available:

Post-Polio Directory lists self-identified clinics, health professionals, and support groups knowledgeable about the late effects of polio. The *Directory* contains over 500 entries including an international section. Published annually in March.

USA $5; Canada/Mexico/Overseas surface $6; Overseas air $7

IVUN Resource Directory is an excellent networking tool for health professionals and both long-term and new ventilator users. Sections include health professionals, ventilator users, equipment and mask manufacturers, service and repair, organizations, etc. Compiled by Judith Raymond Fischer. Published annually in October.

USA $5; Canada/Mexico/Overseas surface $6;Overseas air $7

Joan L. Headley is Executive Director of Gazette International Networking Institute (GINI) in St. Louis, MO.

The National Mobility Equipment Dealer's Association (NMEDA), the trade organization for vehicle conversion dealers, has recently released their new logo. They say it "represents a fresh, positive, image for our association and.....conveys a sense of freedom and independence." We thought you might like to see it.

For information on NMEDA, contact them at 909 E. Skagway Avenue, Tampa, FL 33604, or (800) 833-0427.

Book Shelf

The following are some of the books and publications which have come to the ***Information Center's*** *attention and which we feel may be useful and informative to the reader.*

Ahead of His Time

Selected speeches of Gunnar Dybwad, the outstanding trail blazer in the field of mental retardation and long-time friend of the Information Center, are available in a book published this year by the American Association of Mental Retardation.

These speeches give a view into the man and his creative philosophy which has enriched the lives of millions during his career of over six decades. The book reveals the dramatic changes that have occurred over time in the way our society has perceived and dealt with people with disabilities.

While *Ahead of His Time* concentrates on ental retardation, Gunnar Dybwad has always concerned himself with the rights and opportunities of all people living with disability and is one of the towering figures in the history of disability rights.

Any persons who consider themselves to be disability advocates should be interested in the insights and perspective contained in this book.

Ahead of His Time is available for $34.95 from the AAMR Publications Center, P.O. Box 25, Annapolis Junction, MD 20701, or you can order by phone at (301) 206-9789.

Access Expressed! Massachusetts: A Cultural Resource Directory

VSA arts of Massachusetts (previously known as Very Special Arts) has published a new edition of the *Access Expressed! Massachusetts, A Cultural Resource Directory*. The *Directory* contains extensive information about accessible arts venues, activities, and programs throughout Massachusetts drawn from exhaustive surveys conducted by this disability organization.

Categories include: Visual Arts Facilities and Museums; Performing Arts Centers and Theaters; Historical, Educational and Cultural Sites, Zoos; Sports, Entertainment Complexes and Parks; Hotels; Movie Theaters; Presenting Organizations; and Resources.

The *Directory* is very useful for the individual planning social activities, family outings, or for the organization wishing to assure that all members are able to participate and enjoy group activities.

We note with interest that VSA arts has changed it's name, this year, to reflect the advancement made by members of the disability community since the organization's inception. They say the letters VSA now stand for the **V**ision of an inclusive community, **S**trength is shared resources, and **A**rtistic expression that unites us all.

The *Directory* is available from VSA arts Massachusetts, China Trade Center, 2 Boylston Street, Boson, MA 02116. By phone at (617) 350-7713 (v), (617) 482-4298 (fax), or (617) 350-6836 (tty). Individual copies are available for $3.30 each (plus $1.70 postage and handling) while 10 or more copies can be ordered for $1.00 plus postage and handling.

That All May Worship

Now in its fifth printing, *That All May Worship, An Interfaith Welcome To People With Disabilities* is a publication of the National Organization on Disability addressing the removal of architectural, attitudinal, and communication difficulties that alienate people with disabilities from communities of worship in America.

It is directed to those without disability to help them understand the concerns of those with disability, identify barriers, and create a warm and welcoming environment. It is interfaith in scope and concerns people with all types of disabilities. While the book is intended for congregations, its message of understanding and inclusion can be instructive to businesses, clubs, schools, and many other organizations. It is well constructed by people who know what they are talking about and is an informative resource for anyone who cares about people with disability.

That All May Worship is available for $10.00 per copy from the National Organization on Disability, Religion and Disability Program, 910 16th Street, N. W. Suite 600, Washington, DC 20006. Telephone: (202) 293-5960 (v), (202) 293- 5968 (tty) or on the web at **noc.org**. Discounts are available for order of 10 or more copies.

Work Incentives Improvement Act

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This sort of creaming was a trend in the publicly funded vocational rehabilitation (VR) system until the Rehabilitation Act was rewritten to mandate that persons with severe disability be the first priority. Since most state VR systems have more consumers than they can serve with available dollars, many are operating under an "order of selection" process that gives preference to those persons the state defines as having severe disabilities. Those with lesser disabilities will now, at least in theory, have a shot at private services through "Ticket to Work," as the incentives are reversed for the private sector. If "Ticket to Work" works at all, it is a potential bonanza for the private providers who figure out how to play the game.

In the political tango that resulted in the ultimate passage of the WIIA, many tangentially related (or outrightly unrelated) provisions got written into the bill, in addition to the inclusion of "Ticket to Work." WIIA extends through 2001 tax incentive measures that:

❖ Encourage employers to pay for their workers' continuing education.
❖ Help disadvantaged people, including welfare recipients, find jobs.
❖ Encourage businesses to clean up polluted "brownfields."
❖ Stimulate low- and no-emission production of power.
❖ Assist first-time home buyers in purchasing a home in the District of Columbia.
Thus we in the disability community are not the only beneficiaries of the WIIA's passage.

However, we will certainly be held accountable for its success in fostering employment of persons with disabilities. If the prospect of losing Medicare and/or Medicaid health coverage has been holding you hostage, spruce up your resume and prepare to hunt for a job. Of course, it will take months to years before the detailed regulations get written to implement fully the WIIA's health care and other provisions. And we all know that "the devil is in the details." So, despite the rhetoric, be advised to bide your time and look before you leap.

To inform you better about workplace acceptance and accommodations, Cornell University's Program on Employment and Disability has recently published two reports based on telephone surveys of employers: *The ADA at Work: Implementation of the Employment Provisions of the Americans with Disabilities Act* (with the Society for Human Resources Management), which reports on what private employers say they are doing, and its government counterpart, *Disability Employment Policies and Practices in U.S. Federal Government Agencies.*

You can check out these, and many other ADA/employment titles for both employers and us folks, at their website: **http://www.ilr.cornell.edu/ped**

Ray Glazier is a founding Trustee of the Information Center, a wheelchair user, and a disability policy researcher at Abt Associates Inc. in Cambridge, Massachusetts.

Subscriptions to ***Disability Issues*** are available to all who find this publication useful and interesting. You may request a subscription for yourself, a friend, or a disability organization which may share it with others. There is no fee, however, contributions to help defray the cost ensure the future of our efforts. Your tax-deductible donation, in whatever amount you can manage, will be greatly appreciated, and put to good use.

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Homebound

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ventory of computer equipment to help consumers connect with the outside world. The foundation is registered with the Massachusetts Rehabilitation Commission (MRC) as a qualified community provider of a full range of vocational rehabilitation services, including: vocational evaluation, work adjustment training, skills training, job support services, and supplemental support services. Its staff have placed many people in telecommuting positions.

Joyce and the other volunteer staff of Phobics United Foundation are also consumers themselves, who know firsthand the full range of problems that being homebound entails: being unable to go out to work, to the store, to the pharmacy, to the doctor, to the dentist, to church or temple, to visit family and friends. They offer each consumer a range of resources, advocacy, and social contact with peers. The help might range from arranging home delivery of groceries and prescriptions to a therapy home visit to correspondence education to job support skills. In some cases the consumer can venture out if provided the company of a "safe person," a trusted companion in whom the consumer has sufficient confidence to overcome paralyzing fear; PUF volunteers often fit that bill perfectly.

Joyce likes to tell the story of 43-year-old Raymond (*not this author, but it might just as well have been*), who called for help in getting excused from jury duty. He had not been able to leave home to see a doctor in 14 years, so how to get the required medical certification for the court? PUF helped him with this and a host of other problems. Raymond now enjoys Social Security benefits, an apartment and furniture of his own, regular meals, and subsidized housing. He works at home as a day care provider for working mothers and is venturing out without safe person support for part-time employment as a landscape worker.

PUF also offers home visits by fully equipped and professionally staffed medical and dental vans, one-on-one cognitive-behavioral therapy, and in-vivo desensitization therapy. State-of-the-art virtual reality therapy is just now coming into play for persons with agoraphobia and related disorders. PUF legal advocacy for its individual consumers focuses on helping them obtain absentee ballots, qualify for Social Security benefits, and get released from jury duty. The Americans with Disabilities Act's protections are invoked to promote dignity and respect for persons with agoraphobia and related disorders.

Since the population served by Phobics United Foundation has a low profile, by the very nature of the problems of the homebound, PUF is advocating to the Massachusetts legislature for passage of the "Jake Bill," the ultimate intent of which is to establish parity for homebound consumers with persons with other disabilities in terms of rights to care, funding, and access to services. As a first step, the Jake Bill would establish a four-person commission to study the problem, review service programs, and issue a final report of recommendations.

To get involved in supporting the Jake Bill, or to seek help for yourself or for someone else you know who is homebound, contact: Joyce Caggiano Hamilton, Phobics United Foundation, 14 Crestway Road, East Boston, MA 02428, phone (617) 567-5062, FAX (617) 569-2222. Help send the term "homebound" the way of "wheelchair bound" -- onto the vocabulary scrap heap. PUF's consumers can become "home active" with the right support.