Living Without Limits: Dynamic Syndicated Weekly Radio Show Dedicated to Disability Issues

Tari Susan Hartman
EIN SOF Communications

There are 54 million Americans with disabilities. If we are the largest minority, why do not we have our own weekly radio show? We do. It is called Living Without Limits and it is of particular interest to SDS members. Living Without Limits creator and host, Bob Enteen, Ph.D., is the author of the book, “Health Insurance, How to Get It, Keep It, or Improve What You’ve Got.” To date, Living Without Limits has broadcast over 150 programs that have featured over 700 of the nation’s leading experts on disability issues, including members of Congress and the Clinton Administration, renowned educators, scientists, researchers, entertainers, and dynamic grass roots organizers and activists. Living Without Limits’ list of interviewed guests reads like the “Who’s Who” of the disability community.

Living Without Limits is currently broadcast on select stations via the National Public Radio network, Community Radio Stations, high school and library stations and the Radio Reading Services, including the following University stations: KAMU (Texas A&M University); WSNC (Winston-Salem State University) and WHPC (Nassau County Community College). We are launching a dynamic and proactive national marketing and public relations in an effort to make Living Without Limits available and accessible to all those who desire cutting-edge disability information on education, state-of-the-art technology, trends in policy development, employment, entertainment and life style.

The best way to make issues known to policy makers and the general public is through the media. That is why we are contacting SDS leadership to learn which issues might be viable topics for future segments of Living Without Limits.

Living Without Limits is one of the fastest growing, and most comprehensive media strategies the disability community has to educate, raise awareness, affect public policy, and combat negative stereotypes that prevent people with disabilities from living in the community. Together, we can, and will make a difference. For further information on this exciting opportunity to bring Living Without Limits to your campus station and to your community, please write to Bill Rosen; National Multiple Sclerosis Society, 733 Third Avenue, New York, NY 10017-3288 or e-mail Rosen@NMSS.org for details, or call 212/476-0462.
The Hemlock Society has launched an all-out campaign to assure that legislation legalizing physician-assisted suicide is proposed in each of the 50 states. We recently defeated such proposed legislation in Maine (for this legislative session, at least). Since the Hemlock Society has targeted all 50 states, I encourage you to become educated on this issue, if you have not done so already. The Not Dead Yet coalition is an excellent source of information. They can be contacted at 7521 Madison Street, Forest Park, IL 60130; (voice) 708/209-1500; (TTY) 708/209-1826; (FAX) 708/209-1735; and on the World Wide Web at <http://www.acils.com/notdeadyet/>.

In addition, I want to share with you some of the arguments that I presented, as a social psychologist, in my discussions with individual legislators and in my statements at the public hearings held on this issue. These points are not specific to Maine, however, and they may be useful to others already engaged in or interested in becoming involved in this critical issue in other states. These arguments are based on my 20 years of experience as a researcher of public attitudes toward people with disabilities, as well as on the “real world” testing of similar legislation in the Netherlands.

It is important to note that any proposed legislation will almost certainly specify that the practice of physician-assisted suicide will be restricted to terminally-ill persons who have voluntarily consented to die. It is my belief that, even with such specific wording, this legislation would result in the involuntary deaths of many non-terminally ill disabled people and in the euthanizing of many nonconsenting terminally ill individuals. The fact of the matter is that, despite our combined efforts over the years, the majority of nondisabled people - and many newly-disabled people - still have serious misperceptions about individuals with severe disabilities. These misperceptions make it not only possible, but highly likely, that legislation legalizing physician-assisted suicide will lead to the nonconsensual euthanasia of disabled people.

Most people do not know the difference between severe disability and terminal illness. They assume that if a person has a serious, visible disability, the person is sick and he or she is in the process of dying (more so than we all are). I heard this sentiment expressed time and time again in 1994/1995 in relation to Corey Brown, a Lewiston, Maine, girl with cerebral palsy whose physician had convinced her mother to place a DNR (“do not resuscitate”) order on her and was trying to convince the Lewiston School Committee to do the same. Many people were shocked when I
emphasized at the School Committee meetings that Corey did not have a terminal illness. The Committee members, the press, and the public assumed that Corey must have been terminally ill because of the severity of her disabilities and/or the fact that her physician, who claimed to “know her best,” had placed a DNR order on her. Corey had cerebral palsy, which is not a terminal illness, yet a large number of people were willing to violate state and federal laws (not to mention Corey’s rights) to assure this child’s death. This misperception was perpetuated by the press, in fact, which reported that Corey (who died after a brief hospitalization for pneumonia and the hospital’s acknowledged “honoring” of a DNR order placed on her) had died “after a long illness” (Lewiston Sun Journal, December 8, 1995), an obvious reference to her cerebral palsy.

This confounding of disability and terminal illness is also readily apparent in the general public’s response (or, more accurately, in its lack of response) to the actions of Jack Kevorkian. Although three-quarters of Kevorkian’s victims were not terminally ill, I have yet to find a single person, other than those actively involved in the disability rights movement, who believes that even one of Kevorkian’s victims was not terminally ill!

If you look at a list of Kevorkian’s victims, you will also note that Kevorkian was more cautious at the outset; his earlier victims were much more likely than his later ones to have had terminal illnesses. It appears to me that Kevorkian grew bolder in his selection of “patients” as he became increasingly confident that his crimes would go unpunished - a vivid endorsement of the “slippery slope” argument raised by opponents of physician-assisted suicide legislation.

The second major misperception is that people with severe disabilities (or, for that matter, those with terminal illnesses) are suffering and, given the choice, would rather be dead than disabled. Although some disabled people do experience pain and/or inconvenience associated with their disabilities, they are as likely as nondisabled people to value their lives in good times and to devalue them in bad times. (For most disabled people, as well as for most nondisabled people, good times/bad times are more often predicated on social/financial/situational factors than on medical ones.) Often the greatest suffering experienced by disabled people is that inflicted on them by social obstacles - and not by the disability. People who are poor and/or homeless are certainly “suffering” by white, middle-class standards, yet I am quite sure that most people would be justifiably horrified by proposed legislation offering assisted suicide to people below a certain income level. Our goal should be to reduce human suffering by eliminating the conditions that cause suffering rather than by eliminating the people subjected to these conditions. Kevorkian (cited in Coleman & Gill, 1996, p. 4) advocated the exact opposite in a statement to a Michigan court in 1990: “The voluntary self-elimination of indi-
vidual and mortally diseased and crippled lives taken collectively can only enhance the preservation of public health and welfare.”

Two other related misperceptions also put disabled people in great jeopardy when physician-assisted suicide legislation is proposed: 1) that people with disabilities are dependent; and 2) that dependence is undignified and a fate worse than death. In the first place, the vast majority of people with disabilities, including those who have (legally-defined) terminal illnesses, are no more dependent than the so-called nondisabled population. Most others could be more self-sufficient if they were not denied access to the environment (e.g., through inaccessible architecture, poorly-constructed transportation systems, and single-modality media) and/or to services (e.g., through insufficient health care coverage and restricted access to community services, including education). Advocating that dependence is undignified and should be remedied by legalizing suicide is ridiculous, not to mention classist, ableist, and ageist. Yet Janet Good, founder of the Michigan Hemlock Society, recommends just such a solution: “Pain is not the main reason we want to die. It’s the indignity. It’s the inability to get out of bed or get onto the toilet, let alone drive a car or go shopping without another’s help” (Washington Post, August 11, 1996).

We are all dependent on one another, and to suggest that dependence poses a “burden” on others compounds the danger. It encourages people to feel guilty about needing assistance from others, including those (e.g., children, spouses) who had, at other times, needed their assistance; and it allows society to feel justified in euthanizing those who need support. According to Faye Girsh, Executive Director of the Hemlock Society, in a December 1997 press release, however: “Some provision should be made for a situation in which life is not being sustained by artificial means but, in the belief of the patient or his agent, is too burdensome to continue. It is pathetic that a son should have to shoot a suffering father. Death should come in a more humane and less violent way. A judicial determination should be made when it is necessary to hasten the death of an individual whether it be a demented parent, a suffering, severely disabled spouse or a child” (PRNewswire, December 3, 1997).

These misperceptions - that severe disability equals terminal illness, that people with disabilities are suffering, that disability creates dependence, and that dependence or interdependence is an unnatural human condition - will certainly lead to the euthanizing of thousands of people, far beyond the few extreme cases used by physician-assisted suicide proponents to justify such legalization. This is clearly demonstrated by the implementation of similar legislation in the Netherlands. Decriminalization of physician-assisted suicide in that country (as opposed to the more active legalization of this procedure
under legislation recently proposed in Maine and elsewhere) has resulted in the killing of many people, despite careful wording to “assure” that the practice not be abused. The Dutch government reported in 1990 that 5,941 individuals were given lethal injections without their consent, and, of these, 1,474 were deemed “fully competent” by their own physicians. Among the most frequently-given justifications for this euthanasia were that the victim was experiencing a “low quality of life,” that he or she showed “no prospect of improvement,” and that “the family could not take anymore” (McCuen, cited in Coleman & Gill, 1996).

It is critical to add that the decriminalization of physician-assisted death in the Netherlands has been accompanied by a significant decrease in alternative choices for living. The hospice movement in the Netherlands is now all but extinct, almost certainly the result of cost-efficiency measures (Coleman & Gill, 1996). This cost-saving is important to keep in mind in light of the recent emphasis in the U.S. on reducing medical expenditures by rationing health care.

It is also worth noting that the legislature in Maine, immediately after defeating the proposed physician-assisted suicide legislation, passed an emergency law to add hospice care to the list of services covered by Medicaid. Many legislators had been unaware that Maine was one of the states in which this coverage was not already available.

One other misunderstanding that we unexpectedly encountered in Maine was also significant in our lobbying efforts. A number of people (including legislators) with whom I spoke had confused the proposed physician-assisted suicide bill with already existing legislation (at least, in Maine) that allows a consenting adult to refuse medical treatment. One legislator suggested that the favorability with which some people view physician-assisted suicide may be the result of negative attitudes toward physicians who extend a person’s life by artificial means despite that individual’s wishes to the contrary. I explained that we already have legislation that allows an adult to complete a “living will” which will prevent the unwanted imposition of medical treatments or procedures. Refusal of medical treatment passively allows death to occur naturally. Physician-assisted suicide, on the other hand, actively terminates life unnaturally.

In the final analysis, the most compelling argument against the legalization of physician-assisted suicide is that, even if all legal safeguards were in place, the very real threat to thousands of people posed by such legislation would far outweigh any theoretical “benefit” to the few extreme cases used by physician-assisted suicide proponents to legitimize killing. People with disabilities have had to fight (and continue to fight) tooth-and-nail for the right to live - to have equal access to employment, housing, education, public services and facilities, etc. Why is the “right” to die being offered to us so readily?
Reference


Announcements

Get 'em while they're hot!
Get 'em before they're not (available)!


Society member and former president Corinne Kirchner received the George E. Keane Award, the most prestigious honor bestowed by the New York State Association for Education and Rehabilitation of the Blind and Visually Impaired, for over twenty years of outstanding national service to people who are visually impaired.

The Canadian Centre on Disability Studies announces The Royal Bank Research Chair in Disability Studies, a three year renewable term position. The person will be employed by the Centre and may also be appointed at the University of Manitoba. The salary range is $40,000.00 to $44,000.00 (commensurate with qualifications and experience). Applications are invited from individuals who hold a Ph.D. (or equivalent experience) in a field appropriate to disability studies. It would be an asset for the individual to have a personal connection to the disability community. Individuals should be committed to/have experience in the study of cross disability issues within an interdisciplinary framework. Suitable candidates will have the ability to present research findings to a broad audience including people with disabilities, non-academic community, academic community, government and industry. The successful candidate will have a demonstrated ability to obtain external research funding and to maintain a program of research leading to publication in refereed journals. The Centre is especially interested in candidates who have an understanding of/training to conduct both quantitative and qualitative research studies, and a commitment to consumer par-
participation in research. The ability to communicate in both English and French would also be an asset.

Applications, including a description of research and professional interests, accompanied by a curriculum vitae and the names of three referees, should be sent prior to the end of January, 1998 to: Dr. Michael Mahon, Chair, CCDS Research Committee, Canadian Centre on Disability Studies.

The United States Cerebral Palsy Athletic Association is offering the first year of a new membership free of charge to any eligible youth, 16 years or under. For more information contact Kim Kelly or Jerry McCole, USCPAA National Center, 200 Harrison Avenue, Newport, RI 02840; 401-848-2460; via email at uscpaa@mail.bbsnet.com on the Internet.

CORPOREALITIES: Discourses of Disability is a new book series from the University of Michigan Press. The series editors are David T. Mitchell and Sharon L. Snyder, Department of English, Northern Michigan University. The series focuses on a broad range of scholarly work analyzing the cultural and representational meanings of disability. Definitions of disability underpin fundamental concepts such as normalcy, health, bodily integrity, individuality, citizenship, and morality - all terms that define the very essence of what it means to be human. The series seeks work that will expand the interpretive options for theorizing disability in the humanities. Submissions are encouraged on any aspect of the social construction of disability: textual representations of people with disabilities in history; the relationship between narrative forms and bodily differences; disciplinary dependencies upon disabled people and definitions of aberrancy; linguistic studies of disability terminology; disability studies and methodologies; aesthetics and bodily variation; genre studies and disability "types"; theorizations of technology and disability; historical modes of institutionalization, segregation, and assimilation; the disruptive presence of disability in discourse; biological norms and the designation of deviance; bodily difference and theories of materiality; disability subjectivity and essentialism; disability and performance; disability in literature and medicine; the relationship of disability to philosophical systems of thought; "final" solutions and "cure" narratives.

Inquiries can be addressed to any of the following people: David T. Mitchell, Department of English, Northern Michigan University, Marquette, MI 49855; e-mail: dmitchel@nmu.edu. Sharon L. Snyder, Department of English, Northern Michigan University, Marquette, MI 49855; e-mail: shsnyder@nmu.edu. LeAnn Fields, University of Michigan Press, 839 Greene Street, PO Box 1104, Ann Arbor, MI 48106.
BEYOND AFFLICTION: The Disability History Project, a series of four one-hour programs distributed by NPR. Straight Ahead Pictures and National Public Radio are pleased to announce BEYOND AFFLICTION: The Disability History Project, the story of disability in the United States, told as it has never been told before: in a historical context. Laurie Block, series' creator, host and producer, takes us on an intriguing journey to uncover the common history shared by people with the full spectrum of disabilities and their families since the Civil War. NPR's Talk of the Nation will broadcast related coverage, part of which will be hosted by John Hockenberry.

As the name suggests, BEYOND AFFLICTION is designed to move the general public BEYOND the "affliction myth" and into a more authentic perception of disability community reality, past and present. BEYOND AFFLICTION: The Disability History Project was produced by Laurie Block and Jay Allison, and was broadcast in May 1998. Generous underwriting support for BEYOND AFFLICTION comes from the Corporation for Public Broadcasting, AT&T, the Massachusetts Foundation for the Humanities, and the California Council for the Humanities.

For information contact: Tari Susan Hartman, EIN SOF Communications 310/578-5955 (phone); 578-6065 (fax); EINSOFTSH@aol.com; or Marge Ostroushko 612/287-8686 (phone); 287-8757 (fax) or most@well.com.

ELA Foundation Fellowship, #17006; Deadline: July 6, 1998; Majors: Technology; Education Value: $2000, Number of Awards: 1. Description: Open to female graduate students with disabilities who are studying, researching and writing on disability policy in an accredited college or university. Must be a U.S. citizens with goals of careers in public policy or public information related to disabilities. An essay will be required. Additional Information: Contact the address listed for information or call (202) 376-6200. Contact: President's Committee on Employment of People with Disabilities, Scholarship Program, 1331 F Street, NW, Washington, DC 20004-1107
The Society for Disability Studies

The Society for Disability Studies is a nonprofit scientific and educational organization. It is a multidisciplinary and international organization composed of social scientists, scholars in the humanities, and disability rights advocates concerned with the problems of disabled people in society. The purpose of the Society is to bring together people from diverse backgrounds to share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The Society is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

Further information on membership and the annual meeting can be obtained by TTY or voice at 972-883-4122. The mailing address is: Society for Disability Studies, c/o Professor Richard Scotch, School of Social Sciences, University of Texas at Dallas, Box 830688, Mail Station GR3.1, Richardson, Texas 75083-0688. The email address is sdshq@utdallas.edu and the FAX number is 972-883-2735.

The Disability Studies Quarterly is published by the Society for Disability Studies. The Quarterly is a multidisciplinary and international journal of interest to social scientists, scholars in the humanities, disability rights advocates, and others concerned with the problems of people with disabilities. The purpose of the Quarterly is to provide a place where people from diverse backgrounds can share ideas and to engage in dialogues that cut across disciplinary backgrounds and substantive concerns. The Quarterly is committed to developing theoretical and practical knowledge about disability and to promoting the full and equal participation of persons with disabilities in society.

Subscription Information

Disability Studies Quarterly comes out four times a year. Each volume is the same as a calendar year. Although the Quarterly is a publication of the Society for Disability Studies, the subscription price for the Quarterly is not included in the dues for the Society. However, members of the Society are entitled to a reduced rate. The prices for a one year subscription are as follows:

- Individual $35.00
- SDS member $30.00
- Institution $45.00
- Student $20.00
- Low Income what you can afford

An additional payment of $15 will enable domestic subscribers receive
their copy by priority mail. Please specify "by priority mail" when subscribing. All subscribers outside of the USA and Canada add $15 because your copy is going by airmail. Subscriptions can be obtained by the exchange of newsletters and/or publications relating to disability. Please specify if you wish to receive the Quarterly by email or on diskette (IBM compatible ASCII, 3 1/2", high density). There is no additional cost for an alternative format. Checks for subscriptions should be made out to the Disability Studies Quarterly and sent to the Society for Disability Studies, School of Social Sciences, University of Texas at Dallas, Box 830688, Mail Station GR3.1, Richardson, Texas 75083-0688.

The Samuel Gridley Howe Library in Waltham, Massachusetts, is the repository for past issues of Disability Studies Quarterly. The papers and books of Irving Kenneth Zola as well as the books, papers, and manuscripts of Rosemary and Gunnar Dybwad are also deposited there. Bonnie Stecher is the librarian at the Howe Library. The Library is available for research into all aspects of disability.

Past issues of Disability Studies Quarterly are available for $7.00 each. Please specify the theme of the issue and the volume and issue number. Your request with a check made out to Friends of the Howe Library should be mailed to Howie Baker, MS #044, Brandeis University, P.O. Box 9110, Waltham, MA 02254-9110. The Winter issue of each volume is on general disability issues. The subject matter of available past issues can be found at the SDS web site: <http://www.wipd.com/sds>. Howie Baker <baker@binah.cc.brandeis.edu> can answer questions.

Instructions to Special Editors and Contributors are available from the Editor: David Pfeiffer, Disability Studies Quarterly, University of Hawaii at Manoa, 1776 University Ave UA 4-6, Honolulu, HI 96822.

Reviews, Indexing, and Advertisements

All books, films, and videos to be reviewed should be sent to Dr. Elaine Makas, 10 Sheffield Street, Lewiston, ME 04240. Persons wanting to volunteer to do reviews should contact her with your field of specialty. Disability Studies Quarterly is indexed in REHABDATA which is a data base maintained by the National Rehabilitation Information Center, Silver Spring, MD, 800/346-2742, ext. 15, http://www.naric.com/naric on the World Wide Web.

Appropriate advertisements are now being accepted. For further information please contact the editor.