DIGEST OF ADA
January 2001
WORKING TOGETHER, WE DID IT!
NY State Building Unchanged – 100% Accessible; Complaint by a Majority of Units in New Buildings with Elevators
by Jim Dalton

Photo by Robert Jones

Recently we had a great victory as a result of being strong advocates. As most people are aware, there has been an effort orchestrated by real estate developers to have the Americans with Disabilities Act (ADA) and the Fair Housing Act (FHA) amended to exempt multi-family housing units without elevators from being required to be accessible and to be visitable.

"Digest of ADA" dreamed a meaning with a high-ranking policy advisor to Governor Pataki. During the meeting on Friday, February 9, 2001, there were some very strong and very good arguments made against the proposed amendments. The Governor's office was very impressed with the presentation and the strong arguments made against the proposed amendments.

The demonstration in New York City was supposed to be a meeting of members of ADAPT, DRI, and me to agree on the regional coordinator of the Systems Advocacy Network (SAN) and to discuss the upcoming demonstration in Washington, DC. Instead, it turned into a demonstration of the power of the disabled that certain developers, I am sure, will never forget.

The Systems Advocacy Network is intended to create an array of grassroots advocates that can quickly respond to various issues. Most of the independent living centers are members of the Systems Advocacy Network and are prepared to respond to any issue that may arise. The Systems Advocacy Network is also a very exciting concept, I'm getting more people involved than I ever thought possible.

It is exactly this type of coordinated effort that we must continue to grow and make our mission successful in the continuing battle for our civil rights.

Disabled in Action has been a leader in the fight against developers who have been building in violation of the ADA and the FHA. Disabled in Action has been successful in litigation against developers who have not provided accessible units. Disabled in Action has been very successful in the past, but we have been unable to get the attention we need to be successful in our efforts to get developers to comply with the ADA and the FHA.

For more information about continuing the systems advocacy at the local independent living center, call 800-4THEADA, or check out http://www.nyadpt.org.

Jim Dalton, 35, is a native of Long Island, New York, and a Walter Reuther Leadership Fellow. He is a former president of the Disabled in Action chapter in Long Island, New York.

Editor's Note: On December 19th, the Building Codes Council unanimously voted to remove accessible/adaptable to 100 percent of new building with elevators. This was a major victory for the disability community. Unfortunately, the Building Codes Council voted to remove the requirement for 20 percent of units in buildings without elevators to be accessible/adaptable. The Building Codes Council did not remove the requirement for 100 percent of the ground floor units and the requirement for the entrance to be accessible. The entrance must be accessible so that people with disabilities can visit their friends and family living in the building.

Photo by Robert Jones

Photo by Chris Pizzo

Who visited the Governor's New Rochelle Home? Around a meeting with Mark Kessinger (an undersecretary who resides on cards, namely Governor Jim Dalton, Jim Dalton's Dalton, Jim Dalton, Jim Dalton, Jim

1. an operating phone, cell-phone, and two-way radio so that emergency calls can be contacted;
2. a closing door;
3. supplies that enable individuals to block smoke from entering the room from under the door;
4. a window and something to write with (pencil, marker) or a "bagel" sign to alert rescuers that people are in this location;
5. and respirator masks.

Visit JAN's SOAR at http://www.jan.wvu.edu/soar/bearing/TTY.html for TTY vendors and http://www.jan.wvu.edu/soar/maps/index.html for respirator vendors. Also, Gillaine J. Isaac S. of JAN's Consultants' Corner summarizes information in "Fire Safety Radios as Accommodations." This is available at http://www.jan.wvu.edu/soar/soar/safft/safft3.htm

Escape ropes have properly constructed knots and are long enough to reach the ground? Note: Visit JAN's SOAR at http://www.jan.wvu.edu/soar/maps/respirator.html for information on flexible signage. Audible directional signage and pedestrian systems are also available.

- Are storage areas provided in several accessible areas for emergency supplies, which should include packs or backpacks that attach to walkers, wheelchairs, or scooters?
- Are employees trained and rehearsed for necessary evacuation aids? **Note:** Visit JAN's SOAR at http://www.jan.wvu.edu/soar/maps/emergency.html for information on emergency evacuation devices that are available to help remove individuals with mobility impairments from buildings. These devices typically help individuals quickly move people who are unable to walk down stairs or over to access rough terrain.
- Are heavy gloves, which are used to protect individuals' hands from debris when pushing their manual wheelchairs, a patch kit to repair flat tires, and extra batteries for those who use motorized wheelchairs or scooters, available in supply kits?
- Are fire extinguishers been distributed in Braille, large print, text file, and cassette tape formats?

TRAINING:

- Has disability etiquette been included in training? When training a workforce on emergency policies and procedures it is important that individuals become sensitive to disability issues and be generally appropriate when referring to people with disabilities. Visit JAN's SOAR at http://www.jan.wvu.edu/soar/bearing/bearingfeature.html#Etiquette for information on disability etiquette and http://www.jan.wvu.edu/media/etiquette.html for a publication titled "Disability Etiquette Tips for Speaking Engagements."
- Are employees trained on what procedures to use, particularly how to carry or assist individuals who use mobility aids, basic or specialized sign language, or effectively communicate with individuals who are deaf, and the instructions for those individuals who use assistance animals? **Note:** The traditional "fire fighter's carry" may be harmful to some individuals.

This publication was written by Beth Loy, Ph.D., and Linda C. Batiste, M.S., Human Factor Consultants with the Job Accommodation Network. 09/20/01

RESOURCES

Job Accommodation Network
A Service of U.S. DOE Office of Disability Employment Policy
West Virginia University
P.O. Box 6080
Morgantown, WV 26506-6080
800-526-7234 (Voice/TDD) 800-ADA-WORK (V/TTY)
304-293-7186 (Local Line, V/TTY)
http://www.jan.wvu.edu/

Equal Employment Opportunity Commission (EEOC)
1111 E Street NW
Washington, DC 20004-1007
202-376-6200 (Voice)
202-376-6205 (TTY)
http://www.eeoc.gov/index.html

Access Board
1331 F Street, NW, Suite 100
Washington, DC 20004-1111
800-872-2253 (Voice) 800-993-2822 (TTY)
http://www.access-board.gov/

Eastern Paralyzed Veterans Association (EPVA)
75-20 Astoria Boulevard
Jackson Heights, NY 11370-1177
718-803-3782
http://www.epva.org/

Federal Emergency Management Agency (FEMA)
500 C Street, SW
Washington, DC 20472
202-646-4600
http://www.fema.gov/

National Safety Council
1121 Spring Lake Drive
Itasca, IL 60143-3201
630-285-1121
http://www.nsc.org/

National Fire Protection Association (NFPA)
1 Batterymarch Park
Quincy, MA 02269-9101
800-344-3555 / 617-770-3000
http://www.nfpa.org/

License-to-Kill Hospitals Reserve the Right to Pull Your Plug

by Wesley J. Smith

San Francisco Chronicle - December 2, 2001 — "Imagine visiting your 84-year-old mother in the hospital after she has a debilitating stroke. You find out that, in order to survive, she requires a feeding tube and antibiotics to fight an infection. She once told you that no matter what happened, she wants to live."

But the doctor refuses further life-sustaining treatment. When you ask why, you are told, in effect, "The time has come for your mother to be euthanized against her wishes."

Sound far-fetched? It's not. It's already happening.

Just as doctors once heeded people up to madness against their will, many biomedicals advocate that doctors be permitted to refuse life-sustaining treatment that a patient wants because they deem "futile" or "inappropriate."

Alarmingly, hospitals in California and throughout the country have begun to implement these "futile-care" policies that state, in effect, "We reserve the right to refuse treatment."

Medical and bioethics journals for several years kept up a drumbeat advocating the implementation of medical futility policies that hospitals — for obvious reasons — don't want to publicize because they would be generally ignored by the public.

As a consequence, members of the public and their elected representatives remain in the dark as "finitilarians" become empowered to hand down unilateral death sentences.

Indeed, futile-care policies are implemented so quietly that no one knows their extent. No one has made a systematic study of how many patients' lives have been lost or whether futile-care decisions were reached according to hospital policies or the law.

Yet, the medical literature is clear: The patient wants life-sustaining treatment; the physician does not believe the quality of the patient's life justifies the costs to the health institution or the physical and emotional burdens of care; therefore, the doctor is entitled to refuse futher treatment (other than comfort care) as "futile" or "inappropriate."

Treatments withheld under this policy might include antibiotics to treat infection, medicines for fever reduction, tube feeding and hydration, kidney dialysis or ventilator support.

Of course, physicians have never been — nor should they be — required to provide medical interventions that provide no medical benefit.

For example, if a patient demands chemotherapy to treat an ulcer, the physician should refuse. Such a "treatment" would have no medical benefit.

But this kind of "physiological futility," as it is sometimes called, is not what modern futile-care theory is all about. Treatments are not refused because they don't provide many medical benefit, as in the case of chemotherapy to treat an ulcer.

Rather, they are refused because they actually sustain life — such as a feeding tube does for a persistently unconscious patient.

It isn't the treatment that is deemed futile but, in effect, the patient.

Early attempts to impose futile care upon unwilling patients and families were often ad hoc. For example, a few years ago I received an urgent phone call from a distraught woman who told me that her 92-year-old mother's doctor was refusing to give the woman antibiotics for an infection.

When I asked why, she said, "He told me my mother was going to die of an infection sooner or later, so it might as well be this one."

Although the woman got an attorney and threaten suit, the hospital did not budge. The doctor called her bluff and let her mother was being treated and was well on the way to recovery.

In 1988, the parents of a premature infant used to prevent the imposition of futile care upon their son, "Baby Ryan" Nguyen, after doctors told them they were ending his kidney dialysis.

The doctors and hospital did not take the Nguyens' defiance lying down. They filed an affidavit requesting the right to refuse to provide treatment, claiming that Ryan's condition was "futile" and that continuing life-sustaining treatment was inappropriate because it would be cruel.

Astonishingly, a hospital administrator even went so far as to request the Nguyen family to Child Protective Services for "physical abuse and physical neglect" of Ryan for their adamant opposition to the withdrawal of the injections to keep Ryan alive.

The case could have had a major legal impact on the entire futile care debate. But the trial judge never decided who had the ultimate right to determine Ryan's fate. The parties settled out of court. He remained in a Portlandville, disabled and deformed persons are no — patients who are too often dehumanized and callously viewed as parasites who gave high-fives and was the delight of his parents' hearts.