

# Disability Issues

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## Opening the Doors to Outdoor Recreation

by Leslie Johnson

Cynthia Brown of Three Rivers, Massachusetts, is a very active person. She snowshoes in the winter, and she canoes, cycles and takes nature walks in the warmer seasons. Physical pain accompanies her. Psoriatic arthritis makes walking laborious, and osteoarthritis coupled with a damaged back from a car accident adds to the complications. Cynthia is 78 years old. A flustered friend once told her that at her age she should be sitting in a rocking chair on her porch. But Cynthia says she was always a physical person, even during the decades when the arthritis was creeping up on her. When asked why she does so many outdoor activities that cause her physical discomfort, she

said, "It's the trees and the grass and the sky, and the wind in your face.



Oh, and the pine needles! They have such a delicious smell!" She went on to rave about lady slippers. Birds. Flora. Fauna.

Cynthia takes full advantage of the accessible outdoor recreation activities that a program called All Out Adventures has to offer. The program runs events that are open to people of all abilities. Adaptive

equipment and extra human support are available for participants with disabilities. On some trips Cynthia has found herself to be the least disabled person; on others she's the most disabled. When it comes to hand-cycling on a local rail trail, she admits that the younger men with lower limb disabilities leave her in the dust.

Nonprofit and government organizations, as well as for profit organizations, have been individually and collaboratively opening the doors to outdoor recreation for people with disabilities. To make its facilities inviting the National Park Service offers individuals with disabilities a lifetime pass that

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## Aging with a Spinal Cord Injury

by Eileen McNamara

I had thought of subtitled this article "readjustment, part two" because for those of us with spinal cord injuries spanning decades, life has changed quite dramatically for the second time. Overuse and years of pushing ourselves, literally and figuratively, to excel in our chosen paths has taken an insidious toll on our joints and muscles.

But wait, isn't that what the rehab community advocated? Weren't we all told that the more active we were the healthier we would be? The "use-it-or-lose-it" approach to life became our mantra. And, speaking for myself, I took enormous pride in changing people's perceptions, in doing things to prove to the world, and perhaps myself, that I wasn't really disabled, simply "differently abled," although such a wonderfully PC term was not yet in existence in 1966 when I was injured. I competed in wheelchair sports, bringing home gold medals in swimming and field events. Popping wheelies was not only an effective tool to deal with an environment that had yet to create curb cuts, it also never failed to impress "walkies," an additional

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## Outdoor Recreation

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provides free access to parks. The pass is called the Golden Access Passport. More details are at this website: [www.nps.gov/fees\\_passes.htm](http://www.nps.gov/fees_passes.htm).

Effort is being made to blend some types of adapted activities with those typically participated in by non-disabled people—a reflection of the inclusion philosophy. As a result, boardwalks built for feet, canes, and wheels now wind through conservation lands. Educational information about nature is offered in various formats, including written, recorded and signed. Wheelchairs with specialized wheels that can traverse beach sand are available at some beaches. The list goes on.

Events scheduled specifically for people with disabilities are offered in addition to inclusive activities. Often, adapted equipment is used during these events. People with mobility impairments use adapted wheelchairs and extra help from personnel to traverse rugged hiking trails. Water sport events involve adapted boats. Specially designed skis make skiing possible, and unique ice sleds make a form of hockey possible.

Although hard and fast data about the growth of participation in accessible outdoor recreation is hard to find, Tom McCarthy, Director of the Massachusetts Department of Conservation and Recreation's Universal Access Program, says the program's accessible recreation events are much fuller in participation today than in the mid-1990s, when the program was new. Outdoor Explorations, a nonprofit outdoor recreation organization in eastern Massachusetts that runs events for people of all abilities, is now serving nearly 1,000 individuals a year, up from 100 individuals a year in the early 1990s, when it was relatively new. All Out Adventures, based in central Massachusetts, is the new kid on the block—all of four years old. Last year it served more than 1,400 individuals. About 50 percent of those participants had disabilities.

Program directors believe that targeted outreach, word of mouth, and information venues such as the Internet have contributed to increased participation. There is some belief that participation will significantly increase over time. Something seems to be catching on. Small communities in Massachusetts are approaching these organizations to ask for help with making their outdoor programs more accessible.

All the better for Cynthia Brown. She continues to plan for the upcoming seasons. The newest adventure on her horizon? "I was thinking about doing golfing."

Professionals in the field might want to attend a two-day conference on accessible outdoor recreation that will be held April 27-29 on Cape Cod, at the Chatham Bars Inn. The contact for more information is Bryce Fifield. His phone number is 413-527-8980.

Here is a list of just some of the accessible outdoor recreation programs in Massachusetts and Southern New Hampshire.

**Department of Conservation and Recreation  
Universal Access Program**  
PO Box 484  
Amherst, MA 01004  
Voice: (413) 545-5353 TTY: (413) 577-2200  
Website: [www.mass.gov/dcr/universal\\_access](http://www.mass.gov/dcr/universal_access)

**Outdoor Explorations**  
98 Winchester Street  
Medford, MA 02155  
Voice: (781) 395-4999 TTY: (781) 395-4184  
Email: [info@outdoorexpl.org](mailto:info@outdoorexpl.org)  
Website: [www.outdoorexplorations.org](http://www.outdoorexplorations.org)

**All Out Adventures**  
116 Pleasant Street, Suite 3103  
Easthampton, MA 01027  
Voice: (413) 527-8980  
Email: [elizabeth@alloutadventures.org](mailto:elizabeth@alloutadventures.org)  
Website: [www.alloutadventures.org](http://www.alloutadventures.org)

**Northeast Passage**  
University of New Hampshire, Hewitt Hall  
4 Library Way  
Durham, NH 03824  
Voice: (603) 862-0070  
TTY, NH Relay: (800) 735-2964  
TTY, ME Relay: (207) 955-3323  
Email: [northeast.passage@unh.edu](mailto:northeast.passage@unh.edu)  
Website: [www.nepassage.org](http://www.nepassage.org)

*Leslie Johnson works at Spaulding Rehabilitation Hospital's Patient/Family Resource Center. She serves the disability community and studies the use of assistive technology for communication and learning. She has enjoyed participating in wilderness adventures that include people of all abilities.*

## Information Briefs

### Deaf Art Exhibit at VSA arts



"Hands Sheltered"  
by Diane Squires

The 2nd Annual Deaf Art Exhibit will take place at the VSA arts of Massachusetts gallery during the month of April. This year's theme will be "From our Deaf Heritage: Visual Images, Symbols, and Meanings." The gallery is located at the China Trade Center, 2 Boylston Street,

Boston, MA 02116, and is wheelchair accessible and accessible by the T. Artwork from the exhibit will also be posted on-line at the VSA arts of Massachusetts website [www.vsamass.org](http://www.vsamass.org) in the Gallery section. For more information call 617-350-7713/Voice or 617-350-6836/TTY.

### ALDA Convention Scheduled for September in Salt Lake City

The Association for Late Deafened Adults (ALDA) has announced that the 17th annual International ALDAcon convention will be held in Salt Lake City, Utah, on September 7-11 at the Little America Hotel. The ALDAcon is a convention held by and for a diverse group of people who may be postlingually deafened, hard of hearing, or experiencing the onset of any degree of hearing loss. ALDAcon features a full schedule of workshop presentations on a variety of topics related to hearing loss, with keynote speakers at each meal. In addition, exhibits of technology and adaptive equipment are offered during the conference. For further information about the conference visit the ALDAcon website at: <http://www.aldasc.org/WEBALDACON/> or e-mail Carolyn Piper, Program Chair ALDAcon 2005, at [wicwas@wcv.com](mailto:wicwas@wcv.com).

### MRC Opens Assistive Technology Loan Program

The Massachusetts Rehabilitation Commission (MRC) has announced the opening of the Massachusetts Assistive Technology Loan Program (MATLP). This program provides a new opportunity for qualified individuals with disabilities to buy the assistive technology they want with low interest loans. It will be operated by Easter Seals Massachusetts in conjunction with Sovereign Bank.

Assistive technology is any device that enhances or expands a person's ability to live more independently. Many different items are considered assistive technology, including adapted computer equipment, walkers, hearing aids, scooters or wheelchairs, talking alarms, memory devices, vehicle modifications and augmentative communication devices.

The program offers assistance in applying for loans through 20 access sites across the state. For more information, call the program toll free at Easter Seals

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## Sailing Opportunities for People with Disabilities

by Susan Murray

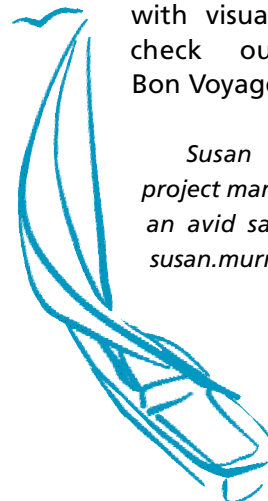
In the children's book *The Wind in the Willows*, Water Rat opines, "There is nothing — absolutely nothing — half so much worth doing as simply messing about in boats." Living in New England we are constantly reminded of our maritime heritage. From present day small boat sailing on the Charles River in Boston, to large clipper ships that sailed to ancient and exotic ports, sailing has been part of New England for hundreds of years.

Sailing is an opportunity to experience the exhilaration of converting the wind into movement as well as providing social opportunities and physical exercise. With summer coming, now is the perfect time to investigate this great sport. There are numerous sailing programs for people with disabilities around the world and in the New England area in particular.

The Duxbury Bay Maritime School on Duxbury Bay, MA has a sailing program, Accessail, for juniors and adults with physical disabilities. For more information go to their website: [www.duxbayms.com](http://www.duxbayms.com). The Courageous Sailing Center in Boston has a sailing program run with the Carroll Center for people who are visually impaired. For information on this program call 617-969-6200, ext. 221 or e-mail [peg@carroll.org](mailto:peg@carroll.org). In Rhode Island there is a sailing program for individuals with neurological disorders called Shakaleg. Information on this program can be obtained on their web site: [www.shakealeg.org](http://www.shakealeg.org).

For information about sailing programs in other parts of the country this web site is helpful: <http://www.footeprint.com/sailingweb/clubs.htm>

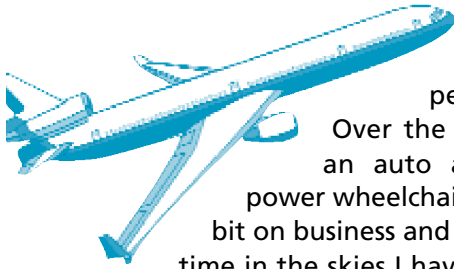
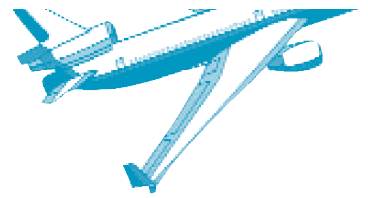
For information about sailing for people with visual impairments worldwide check out [www.blindsailing.org](http://www.blindsailing.org). Bon Voyage!



*Susan Murray is a consultant project manager to the MI-CEO grant and an avid sailor. She can be reached at [susan.murray@umassmed.edu](mailto:susan.murray@umassmed.edu).*

# Toward Friendlier Skies

by Ray Glazier



I am a social policy researcher who happens to be quadriplegic.

Over the last 30-odd years since an auto accident put me in a power wheelchair, I have traveled a good bit on business and for pleasure. During my time in the skies I have experienced air travel situations ranging from laughable to outrageous to life threatening. Temporarily able-bodied friends are amazed to hear how I get trussed into a tiny little airline chair, trundled down the narrow aisle of the plane, and bodily tossed into my seat. On occasion my handlers get sufficiently frustrated with the whole process that they stuff me into the first seat inside the door, which usually means I get first-class beverage and food service in place of pretzels and water.

Most planes, except for small commuter craft, have at least one aisle seat with a swing-up arm that makes it easier to get me into the seat. However: 1) this seat is usually halfway back in coach class, not the first seat in coach, which would be convenient; 2) I am never assigned that seat; 3) the flight crew has no idea which seat it is, nor do the boarding assistants or the counter personnel assigning seats; 4) other passengers and even flight crew find it inconvenient to have an immobile person in an aisle seat. On one flight the stewardess insisted that the boarding assistants move me to a window seat, so other passengers wouldn't have to "climb over him in an emergency." I wondered to myself when and where she thought we were likely to go down. Staff at the arriving end of my flight said, "Who put you in here, where we have to pry you out?"

In my book, the biggest problem with the boarding/deplaning process is the ignorance of most boarding assistance staff, who typically are not airline employees, but underpaid, illiterate, non-English-speaking baggage handlers or contractor employees. This is the same problem I have with persons responsible for stowing my power wheelchair in baggage. My chair is damaged on every second or third flight. If I'm lucky this only happens on the return trip. Airlines personnel, much less baggage handlers, have no concept that this is a \$12,000, highly customized piece of equipment that is very difficult and costly to get repaired and can't be replaced by a temporary loaner while parts are ordered and installed. The recurrent nightmare of wheelchair fliers is arriving somewhere with a non-functioning wheelchair, only to have the airline folks smile and say, "No problem, you can borrow one of ours." "Okay," I

feel like answering, "take that six-foot pole off it and put a jetpack on the back — with a joystick."

There is no reason that new planes cannot be designed with wider doors and readily removable first aisle seats and with tie-downs and seat belts that would accommodate the wheelchairs of passengers. Then we could remain in our chairs, just as we do on public buses. The pop-out regular seat could be carried in the baggage compartment and bolted back in place at the flight's destination. In this way, most planes of any size could accommodate 2-5 people in wheelchairs in the first row. But that would mean first-class perks for all of us, so it's not bloody likely. We're probably going to continue to be back-of-the-bus air travelers. Even that wouldn't be so bad, if only we had access to those noisy, obnoxious carts that zip around the airport corridors with prominent wheelchair access signs that make everyone think they're for us. In order to clamber aboard one of those vehicles, you would need to be able to pole vault — without the pole!

## Resources

The U.S. Department of Transportation provides information about the rights of consumers with disabilities under the Air Carrier Access Act and its nondiscrimination policy:  
[airconsumer.ost.dot.gov/publications/disabled.htm](http://airconsumer.ost.dot.gov/publications/disabled.htm)

DOT also offers an online and downloadable booklet "New Horizons: Information for the Air Traveler with a Disability" at <http://airconsumer.ost.dot.gov/publications/horizons.htm>

The U.S. Department of State also offers tips for travelers with disabilities:  
[travel.state.gov/travel/tips/brochures/brochures\\_1228.html](http://travel.state.gov/travel/tips/brochures/brochures_1228.html)

The U.S. General Services Administration has a useful publication called *Fly-Right — A Consumer Guide to Air Travel* with a section on disability available at:  
[http://www.pueblo.gsa.gov/cic\\_text/travel/flyrights/flyrights.htm](http://www.pueblo.gsa.gov/cic_text/travel/flyrights/flyrights.htm)

*Raymond E. Glazier, Ph.D., is Director of the Abt Associates Center for the Advancement of Rehabilitation and Disability Services in Cambridge, MA. He flies only when there is no other option. He can be reached at [Ray\\_Glazier@AbtAssoc.com](mailto:Ray_Glazier@AbtAssoc.com).*

# NGA Issues Data Book on State Aging Trends

To assist states in preparing for the challenges and opportunities they will face as baby-boomers age, the National Governors Association's Center issued a data book, "Measuring the Years: State Aging Trends & Indicators." A part of the NGA Center's Aging Initiative: State Policies for a Changing America, this publication is designed to identify current trends and future directions related to an aging America, and to assist state policy-makers in creating programs and policies that respond to unique needs of the people in their state.

Nearly all of the data is presented state-by-state, allowing for easy comparisons across states. According to the foreword, the book "provides information intended to assist state policy-makers involved in all aspects of governance including:

- Demographic shifts;
- Fiscal impacts of aging baby-boomers;
- Tools for promoting financial self-sufficiency;
- Chronic condition and disease prevention;
- Workforce shortages and caregivers trends;
- Seniors' housing and community choices;
- Transportation requirements;
- Educational needs; and
- Technology's impact on aging baby-boomers"

The data book was funded by the Robert Wood Johnson Foundation and prepared with the assistance of the Center on an Aging Society, Health Policy Institute at Georgetown University. The data book, in its entirety and by chapters, is at: <http://www.nga.org/center/databook04/>.

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## Information Briefs - cont. from page 3

Massachusetts: 800-244-2756/Voice and ask for Jason Luciano, Program Director at extension 431 or Kristina Koles, Program Coordinator at ext. 428. The program's e-mail address is [info@massatloan.org](mailto:info@massatloan.org). TTY users can call 800-564-9700.

### Olmstead Video Available

The Rights, Equality and Dignity of the Disabled group (REDD) has recently completed a video promoting the Supreme Court's Olmstead Decision. The production of this video titled "Promoting Olmstead: The Need to Improve Community Based Services" is one of the on-going advocacy projects of this Worcester based grassroots disability group.

REDD's main goal for this video is education about the Olmstead Decision and the benefits its implementation will have on elders and persons with disabilities who want to remain in their communities. The primary target audience is the Massachusetts Legislature, which controls the amount of money allocated for institutional and community based services.

REDD believes that senators and representatives will clearly learn from persons with disabilities that they prefer community living to institutionalization. In addition to

maintaining or improving one's quality of life, the substantial cost savings of living in the community as compared to existing in an institution emphasizes the need to shift the majority of funds allocated away from institutions and into community based services.

For more information or to purchase the video, contact the REDD group: by mail at REDD Group, PO Box 3028, Worcester, MA 01613 or by e-mail at [REDD-Group@yahoo.com](mailto:REDD-Group@yahoo.com).

### North Shore Music Theatre ASL Interpreted Season

The following shows of the North Shore Music Theatre have been selected to be ASL interpreted:

1. *Cinderella*: Saturday, July 30th at 2pm (\$35)
2. *Camelot*: Saturday, Oct 8th at 2pm (\$35)
3. *The Full Monty*: Saturday, November 19th at 2pm (\$35) (adult content)
4. *A Christmas Carol*: December 10th at 2 pm (\$25)

A special 4 show offer of \$100 brings a \$30 savings. For box office information contact Suzanne Kendall at [skendall@nsmt.org](mailto:skendall@nsmt.org). The North Shore Music Theatre is located at 62 Dunham Rd., Beverly, MA.

### Washington D.C. Internship Program for Undergraduates with Disabilities Accepting Applications

The Washington Center for Internships and Academic Seminars (TWC) offers undergraduate students with disabilities a comprehensive internship experience in Washington D.C that begins in the fall. More than just an internship, TWC's program includes lectures by well-known politicians and DC personalities, classes taught by professionals in the field and student/intern development. All interns are required to gain credit for the experience, making this program highly demanding, academic and worthwhile.

Scholarships are available for qualified undergraduate students with disabilities thanks to a US Department of Labor, Office of Disability Employment Policy (ODEP) grant. For more information go to: [www.twc.edu/diversityingovernment.htm](http://www.twc.edu/diversityingovernment.htm) or contact: JT Taransky, Internship Logistics Coordinator

Voice/TTY: (202) 457-0046  
or 1 (800) 840-8844  
E-Mail: [jennynt@twc.edu](mailto:jennynt@twc.edu)

### Senate Passes Genetic Nondiscrimination Legislation

In February the U.S. Senate unanimously passed the Genetic Information Nondiscrimination Act of 2005, which establishes protections against genetic discrimination in health insurance and employment. Introduced by Senator Olympia J. Snowe (R-Maine), the bill, S. 306, prohibits employers from using genetic information in employment decisions and insurance companies from denying coverage or basing premium rates on genetic information. The legislation also prohibits a group health plan from "requesting or requiring" an individual or family member to undergo a genetic test. In addition, S. 306 establishes privacy protections for genetic information held by employers, employment agencies, labor organizations, and others.

According to the Health Privacy Project (<http://www.healthprivacy.org>), "this legislation could mark a bold step in protecting patient privacy and encouraging full participation in health care. Advances in genetics could produce untold benefits for disease prevention, detection, and management, but without trust that their health information will remain confidential and will not be used against them, many patients will withhold participation from both individual testing and research initiatives."

However, "despite support from the Bush Administration, passage in the House of Representatives appears slim. Last year, a similar bill was passed in the Senate and died in the House."

### Senators Grassley and Kennedy Re-Introduce Family Opportunity Act

Sen. Chuck Grassley, Chairman of the Committee on Finance, and Sen. Edward Kennedy, ranking member of the Committee on Health, Education, Labor and Pensions, have re-introduced their bipartisan legislation to help children with disabilities and their families. The Family Opportunity Act allows states to create options for families with disabled children to buy into Medicaid while continuing to work. Parents would pay for Medicaid coverage on a sliding scale. Medicaid is critical to the well-being of children with multiple medical needs because it covers many services that these children need, including physical therapy and medical equipment, the senators said. Private health plans often are much more limited in what they cover. And many parents can't afford needed services or multiple co-payments out-of-pocket.

The senators won Senate approval of this measure last May, but negotiations with the House of Representatives to find a budgetary offset broke down, and the bill never received final approval.

"Medicaid works well for a lot of people," Grassley said. "The problem is some families fall through the cracks. Many parents of disabled children have to drop out

of the workforce or keep themselves in a low-paying job just to remain eligible for Medicaid. In effect, the government is forcing parents to choose between near-poverty and their children's health care. We need to fix that. We came close last year, but time ran out. I hope we'll succeed in this Congress."

Kennedy said, "The Family Opportunity Act may be the most important legislation we pass this Congress. It will close the health care gap for the nation's most vulnerable children, and enable families of disabled children to be equal partners in the American dream."

Grassley and Kennedy said the Family Opportunity Act is pro-work because it lets parents work without losing their children's health coverage, pro-family because it encourages parents to work and build a better life for their children, and pro-taxpayer because it means more parents continue to earn money, pay taxes and pay their own way for Medicaid coverage for their children.

### Sen. Harkin Introduces Bill to Support Community-Based Services

In February Senator Tom Harkin (D-IA) introduced the Medicaid Community-Based Attendant Services and Supports Act of 2005 (MiCASSA). The legislation, co-sponsored by Senator Arlen Specter (R-PA), would increase access to community-based services and supports to Americans with disabilities and older Americans.

"I strongly believe that it is important to level the playing field and give eligible individuals equal access to community-based services and supports," Harkin said. "This vital legislation will open the door to full participation by people with disabilities in our neighborhoods, workplaces, our economy, and our American Dream."

Specifically, MiCASSA gives individuals who are currently eligible for nursing home services and institutional facilities equal access to community-based attendant services and supports, and establishes a demonstration project to evaluate service coordination and cost sharing approaches for those eligible for both Medicaid and Medicare. The legislation also provides additional funding to states to help them reform their long term care systems and increase the provision of home and community based services.

"This legislation is needed to truly bring people with disabilities into the mainstream of society and provide equal opportunity for employment and community activities," Harkin said.

The following Senators co-sponsored the Harkin-Specter legislation: Edward Kennedy (D-MA), John Kerry (D-MA), Joseph Biden (D-DE), Mark Dayton (D-MN), Mary Landrieu (D-LA), Jon Corzine (D-NJ), Charles Schumer (D-NY), Frank Lautenberg (D-NJ), Joseph Lieberman (D-CT), and Christopher Dodd (D-CT).

*To thank your Senators if they are MiCASSA co-sponsors, or to ask your Senators to become co-sponsors go to [http://www.senate.gov/general/contact\\_information/senators\\_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm) to get their contact information.*

## Supreme Court Hears Cruise Ship Lawsuit

The Supreme Court recently heard oral arguments in *Spector v. Norwegian Cruise Line*, a case that will decide whether or not the Americans with Disabilities Act (ADA) applies to foreign cruise vessels sailing in U.S. waters. The plaintiffs in the case are people with disabilities and their companions who took cruises on Norwegian Cruise Line (NCL) ships sailing under the Bahamian flag. Afterwards, the plaintiffs sued NCL, asserting that they were discriminated against in violation of Title III of the ADA. They alleged that physical barriers on the ships denied them access to various equipment, programs, and facilities and sought injunctive relief, requiring NCL to remove certain barriers. The district court ruled that foreign-flagged cruise ships are subject to Title III of the ADA. But the Fifth Circuit Court of Appeals reversed that decision, saying that it found no indication that Congress specifically intended Title III to apply to foreign-flagged cruise ships. The Association of Retarded Citizens and United Cerebral Palsy both signed on to amicus briefs in support of the plaintiffs.

More about the background of the case, the legal issues it raises and their implications for people with disabilities can be found at the National Council on Disability website: [http://www.ncd.gov/newsroom/publications/2005/spector\\_norwegian.htm](http://www.ncd.gov/newsroom/publications/2005/spector_norwegian.htm).

## Aging with a Spinal Cord Injury

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benefit in a world that was more comfortable with the image projected by telethons than with active wheelchair users who wanted employment, respect, and equal opportunities.

To be fair, the rehab professionals were also dealing with the largely unknown, and doing the best they could in the relatively new territory of rehab medicine. We were among the first group of people with spinal cord injuries who could expect a normal life span, something virtually unknown only twenty years before. Pushing hard at our limits seemed intuitively logical. Only retrospectively is a path closer to moderation seeming to be the wiser approach, as active long term injured people lose function at a rate that is not related to their biological age as much as it is to their post injury years and activity level. In the case of people who had polio this phenomenon has been known for quite sometime and is labeled "post polio syndrome." But it seems apparent that the phrase "post disability syndrome" is closer to the mark.

I am finding this readjustment to be harder by far than my initial adjustment to injury. Call it false pride, call it a form of disability arrogance, call it whatever you choose, but my self image was tied up in breaking down barriers, of appearing athletic despite the chair, and of being incredibly adept at manual wheelchair use. When told at the age of seventeen that, if I was fortunate, I might be able to find employment in a secretarial pool, I refused to abandon my dream of working in medicine. I had won a full scholarship to nurse's training, but no one in 1966 could even imagine such a thing. So, I was forced to surrender my scholarship. Instead I went to school for medical technology and spent the next three decades plus working as a medical researcher and smashing two barriers simultaneously — being a woman in science and being a paraplegic working in any field outside the narrow range others considered possible. My motto

became "show me an obstacle and watch me get past it."

How ironic that now opening a supposedly "easy open" package feels like it is worthy of a gold medal and that getting my jacket on without becoming hopelessly ensnared in the sleeves is my daily accomplishment. Decades of overuse have caused carpal tunnel syndrome, shoulder tendonitis, cervical problems, and a grip strength that now measures only two pounds. I have given up eating off anything other than plastic ware, tired of cleaning up the shards of still another dish that I was unable to grip. No longer able to do wheelchair push-ups, I seem always on the verge of a skin breakdown. I have gone from willfully eschewing any and all adaptive devices to desperately trying to find the one more thing that might make life easier. I am grateful now for all the times that I smiled and was courteous when a well meaning able-bodied person insisted on giving me help that I did not need — even when someone once quickly put my chair back into the car for me, oblivious to the fact that I had just wrestled it out! I knew that somewhere there was another person who could use that level of help, and so I smiled and said my thank you, never dreaming that the day would come when the person in need of assistance would be me.

I agreed to write this article because I think it important for newly injured people and rehab professionals alike to understand that overuse leads to enormous problems down the line, that arm muscles alone are not, over the long haul, an acceptable substitute for leg mobility. Live well, play hard, work at something you love, but do it with an eye towards the future.

*Eileen McNamara became a paraplegic from a diving accident at the age of 17. She worked at Boston Medical Center for over thirty years, both in kidney research and pediatric HIV research. She is also the proud mother of two adorable felines.*

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# Disability Issues

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