

# DIA ACTIVIST

[www.disabledinaction.org](http://www.disabledinaction.org)

## DUANE READE CASE SETTLED!

*Access is Good for Business*

by Jean Ryan

After almost five years of litigation, *Disabled In Action's* access lawsuit against the Duane Reade drugstore chain has been settled, and it affirms our civil right to shop by being able to do such things as pass through store aisles, reach counters and credit card swipe machines, and communicate privately with pharmacists. We are looking forward to the improvements that Duane Reade has promised to make.



*Carr Massi, DIA President, speaking*

*Photo by Marianne Lado*

Magistrate Debra Freeman, of the U.S. District Court, Southern District of New York, signed the consent decree on January 24, 2006, to end the lawsuit that Disabled In Action and 10 named plaintiffs initiated with New York Lawyers for the Public Interest, Inc. and Fish and Neave, LLP (now Ropes and Gray, with one of our principal attorneys now at Wilmer, Cutler, Pickering, Hale, and Dorr, LLP). Judge Freeman's order came more than a year after the

## *Duane Reade, continued*

parties agreed to avoid trial and settle on many issues. The two issues the parties could not agree on, and which Judge Freeman ruled on, were standards for stock in the aisles and whether or not the terms of the consent decree would be confidential. In a victory for Disabled In Action's long held view that civil rights cases have to be public knowledge, Judge Freeman ruled that the settlement and her decision would



*Activists Anne and Fusun with signs*

*Photo by Marianne Lado*

be open to the public, not confidential, but that the parties must try to collaborate on press about the case. We held a joint press conference in front of a Duane Reade store in midtown on April 19, 2006.

It is *Disabled In Action's* view that through publicizing information about civil rights cases, other people with disabilities can be inspired and

encouraged to fight for their civil rights, and hopefully other businesses will realize their responsibilities and provide access without expensive, time-consuming litigation.

While several recent articles in the popular media have characterized Duane Reade stores as cluttered, too often, people with mobility and sensory disabilities have experienced their stores as inaccessible. We have been unable to get into some stores because of steps, locked doors(!), blocked entryways, or double sets of doors that don't allow enough clearance between them for a wheelchair. Thanks to the lawsuit settlement, most of these problems will be surveyed and corrected within two years.

Once in a store, we often could not get through the aisles because of displays on the floor or stock in the aisles or because of the way shelves (gondolas) are placed. Duane Reade has agreed to provide 36" of clear aisle space (typically the width of 3 floor tiles) with the exception of infrequent, very small sections of 32" width where the larger width is impossible to achieve.

Hooray! Not being able to get to merchandise has been frustrating, but literally being blocked by heavy boxes of merchandise or by empty boxes in a narrow aisle or in an elevator, unable to

## *Duane Reade, continued*

get out, and yelling for help, are experiences we are happy to put behind us.

After Judge Freeman participated in discussions with each side, Duane Reade offered to pack out (put away) new merchandise in 2, 4, or 6 hours (depending on the store) after the delivery truck leaves, and Judge Freeman incorporated this into her order. "That will be a great improvement over having merchandise on the floor blocking the aisles," said Marty Sesmer, a plaintiff.

Duane Reade officials also agreed to lower high counters to 37" and in new stores have them be 36", and to have a private telephone to the pharmacist in bi-level stores without an elevator. No longer will a clerk be an intermediary when we have to communicate with the pharmacist about medication.

*Disabled In Action* would like to thank New York Lawyers for the Public Interest, Inc., especially Marianne Lado, Dennis Boyd, and Gavin Kearney, as well as Ropes and Gray, LLP (formerly Fish and Neave, LLP) attorneys, especially William McCabe, Stanley Liang, Tom Vetter, Paul Keller (who is now at Wilmer, Cutler, Pickering, and Hale, LLP), Nina Horan, Shazi Malik, and Spencer Yee for their tireless, dedicated, and excellent work on this case. They attended countless meetings,



*Three of our Lawyers – Marianne Lado and Gavin Kearney from NYLPI and William McCabe from Ropes and Gray*

*Photo by Jean Ryan*

calls, wrote depositions, e-mails, letters, and briefs, and researched the issues, surveyed stores, watched security tapes, and gave their time to come to DIA meetings to explain and discuss the issues.

DIA plaintiffs and officers put in a great deal of work, too, in this case. Sometimes suing seems easy because a disability rights group may think that the lawyers will do all the work and we'll get everything we want, everything that is necessary for access. The real world does not work that way.

We talked with our lawyers from the very beginning, telling them about access problems. We surveyed stores. We had conference calls and meetings at their offices and at DIA meetings. We had to provide documents, receipts,

*Duane Reade, continued*



*Jean Ryan with attorneys Wm. McCabe and Gavin Kearney*

*Photo by Marianne Lado*

letters, e-mails, even our wheelchair and scooter manuals(!).

A number of plaintiffs and DIA officers were singly deposed (asked questions) in a room by Duane Reade lawyers for several days in 2004. It was grueling for all of us. I am very sensitive to cold and drafts, and, even though the weather was 95 degrees outside, I actually brought winter clothes and wore a blanket on the second day to cope with the cold inside. We were asked all kinds of questions about DIA and about store access, like when we could not get down an aisle, what did the outside of the boxes say?

Frieda Zames, bless her heart, was deposed on behalf of DIA. She was asked about her Duane Reade shopping experiences by the attorney for Duane Reade. If you knew Frieda, who died

last year before the conclusion of this case, you knew she was not a shopper. Her partner, Michael, did all the shopping. As Frieda reported it, the deposition went something like this:

DR Lawyer - "What have been your experiences shopping in Duane Reade stores?"

Frieda - "I don't shop. I have not shopped in a Duane Reade store, but I want them all to be accessible."

DR Lawyer - "What? You don't shop?"

Frieda - "No, I don't."

DR Lawyer - "Then what are you doing here?"

Frieda - "I am here to represent DIA and answer questions about it."

Several of us went to court for long days. The first few days we were there, we actually had to go to the security office and be escorted to the hidden,



*More access equals more business*

*Photo by Marianne Lado*

## *Duane Reade, continued*

locked accessible restroom. After complaining mightily that this was like kindergarten and is not what other people have to go through, we progressed to being able to independently get into the rest room, but it was still hidden and unmarked.

We also prepared for a trial that was to be held in mid-December, 2004. We found people to attend court every day, even in holiday season, but both sides were able to agree to settle on the eve of the trial so we did not have to go to trial. The two issues that the sides could not agree on, stock in the aisles and whether or not the case would be confidential, were decided in January 2006 by Judge Freeman.

Any lawsuit is hard work and is a gamble; you never know what the judge will order or what the two sides will be able to agree on. Also, the ADA does not mandate total access. While we sought only access for the plaintiffs and not money, Duane Reade agreed to donate \$50,000 to *Disabled In Action* so we can continue our work.

Our lawyers repeatedly told us that

in a settlement agreement, it is a good agreement if neither side is totally happy because you each have to compromise to agree. An example of something we wanted but could not get is the total elimination of displays in the aisles. As long as Duane Reade keeps 36" clearance in the aisles, they can have displays because we can still get through, and if merchandise is blocked by the displays, it is blocked for everyone, not just for people with disabilities.

Another thing we wanted was access to every pharmacy, even those currently on an inaccessible level, but the ADA does not require an elevator in every store, nor is there necessarily room for an elevator in every bi-level store.

The third thing we wanted and could not get, that the Kmart plaintiffs got (see <http://www.foxrob.com/pleadings/Kmart/Settlement%20Agreement%20-%20no%20exhibits.pdf>, section 14.7) was for Duane Reade to agree to tie accessibility to the managers' evaluation, promotions, and pay because accessibility is not just structural - it is often a matter of practice, of people's behavior to keep



*Every press conference needs a cop*

*Photo by Marianne Lado*

## *Duane Reade, continued*

the aisles clear. Hopefully, Duane Reade will realize as a company that this is a good way to assure access.



*Ramon Santos of CIDNY speaking on need for accessibility*

*Photo by Marianne Lado*

Follow-up is necessary for any settlement agreement and order. Duane Reade will have two years to make changes to all its stores which need it, but the 20 exemplar (sample) stores specifically noted in the agreement have to be modified within 6 months of Judge Freeman's signing the consent decree. Employees have to be retrained and pack-out policies that maximize accessibility have to be followed immediately. If problems come up, we need to report them. Duane Reade is required to post a customer service number in all of its stores, and it will have boxes for written complaints in some. It is important that anyone with an accessibility problem in a Duane Reade store report it directly to Duane Reade—they are only responsible for fixing problems of which they have

notice. It is also important that we be informed of any accessibility problems so that we can ensure that they are properly reported and addressed by Duane Reade. The complaint forms will be available on DIA's website ([www.disabledinaction.org](http://www.disabledinaction.org)) and a dedicated, toll-free telephone number is available through New York Lawyers For The Public Interest for reporting such problems. It is 1-888-DIA-DIA-8 (1-888-342-3428). If the parties cannot agree that something needs fixing, the settlement calls for a "neutral person", who is an accessibility expert, to settle that specific issue.

After all, access is good for business. We are customers. We buy, too, and where we can go, people with baby strollers and shopping carts follow. What store wouldn't want more customers?

**Editor's note:** Judge Freeman's order and the DIA vs. DR consent decree are available on DIA's website at [www.disabledinaction.org](http://www.disabledinaction.org). The Kmart settlement is available at <http://www.foxrob.com/pleadings/Kmart/Settlement%20Agreement%20-%20no%20exhibits.pdf>. More Duane Reade press conference photos on our website at [www.disabledinaction.org](http://www.disabledinaction.org).

Gavin Kearney contributed to this article.

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# SETTLEMENT TO PROVIDE COMPREHENSIVE WHEELCHAIR ACCESS TO ALL KMART STORES

*March 13, 2006 - Denver* - Fox & Robertson, a firm of Denver civil rights attorneys, announced today it has settled a nationwide class action lawsuit filed to resolve disability access issues at Kmart stores.

Under the terms of the settlement, Kmart will survey and bring all of its stores nationwide into compliance with Department of Justice Standards over a seven and a half year period following court approval, and will institute policies to ensure access to merchandise, counters, restrooms, fitting rooms and parking. Kmart has also agreed to pay \$13 million in damages.

The lawsuit was filed in 1999 but was delayed during Kmart's bankruptcy proceedings. During those proceedings Kmart's top management team was replaced, and the settlement was reached with Kmart's new management. The case has been pending in federal district court in Denver, before Judge John Kane, with whom the settlement papers were filed today.

"This settlement ensures that people with disabilities can shop at Kmart just like anyone else," said Carrie Ann Lucas, one of three people who originally brought the complaint. "It also shows

that Kmart values all of its customers and wants to do what it takes to make sure we can shop at their stores."

Ms. Lucas and the other plaintiffs filed suit under the Americans With Disabilities Act.

"Kmart did the right thing for its customers," said Amy Robertson of Denver-based Fox & Robertson and co-lead counsel for the plaintiffs. "The company's management chose to make the changes necessary so all their customers have access to the wide range of products in these stores."

"Kmart's comprehensive commitment to provide access for individuals with disabilities in all of its stores is a landmark in the implementation of our national civil rights laws," said Bill Lann Lee, of the San Francisco law firm of Lief Cabraser Heimann & Bernstein. Mr. Lee, former head of the United States Department of Justice Civil Rights Division, joined the case as co-lead counsel for the class after it was certified last July.

The settlement contains several innovative features, including a Kmart-initiated plan to provide customers with disabilities with two-way communication devices that permit them to

## ***Kmart Settlement, continued***

request assistance retrieving merchandise and a website through which Kmart and the plaintiffs will seek feedback on the implementation of the settlement.

In addition to wide-ranging architectural and policy improvements, the settlement requires Kmart to pay \$13 million in damages to members of the settlement class in California, Colorado, Hawai'i, Massachusetts, New York, Oregon and Texas, states which impose statutory minimum damages for failure to comply with disability access laws. This is the largest recovery in a lawsuit filed over access for individuals with disabilities.

In addition to the damages, Kmart will pay the plaintiffs' attorneys' fees and costs.

"We have been very pleased with Kmart's approach to the resolution of this case. We hope that all companies will act as responsibly as Kmart has in addressing these issues," Robertson said. In the papers filed today, the parties request that Judge Kane give preliminary approval to the settlement. If he does so, notice will go out to potential class members and they will have an opportunity to review and comment on the settlement.

The settlement agreement is available on Fox & Robertson's website: [www.foxrob.com](http://www.foxrob.com).

## **More Information on Boarding Buses**

If you need the lift, even if you are not in a wheelchair, you are entitled to use it. If the driver refuses, tell him he has to board you on the lift. If he still refuses, get the time, location, and bus number and route, and report the driver to Bus Customer Relations at (888) 692-8287 or the Transit Authority General Complaint Number 718-330-3322. You are also entitled to have the driver kneel the bus and move the bus to a curb if he or she cannot get to the curb at the bus stop. If you need help boarding or disembarking from the bus, the bus driver has to help you if you ask. Some people in manual wheelchairs cannot get up the steep lifts on the front loading buses, especially when the bus driver does not pull over to the curb. Then he or she has to get out and push you up the ramp if you need it.

# ELECTION REFORM MUST INCLUDE STATE'S DISABLED

by Brad Williams

*January 15, 2006 - Albany Times Union* - Governor Pataki's recent State of the State address discussed a wide range of topics, but the issue of election reform was conspicuously absent. This is because New York has been in violation of the full implementation deadline of the federal Help America Vote Act since Jan. 1.

New Yorkers with disabilities have the most to lose because of this. They still are being denied full access to voting machines, the ballot and polling places after more than 200 years in the history of our state and country.

At issue is HAVA's mandatory requirement to remove barriers and increase access so that citizens can vote "privately and independently," as further supported by Title II of the federal Americans with Disability Act of 1990 and the 14th Amendment to the U.S. Constitution.

Modest estimates project that the state won't be able to meet this requirement until 2008. This is both unacceptable and another dismal example of how dysfunctional New York state government has become.

Other groups have expressed additional concerns about HAVA-related issues, including the types of voting machines that the state Board of Elections will certify for use, and the requirement for a paper trail for each voter. These issues must still be resolved.

Since our state government has yet to uphold its moral and legal obligations to fully implement HAVA, I suggest that the state should demonstrate an interim act of good faith by immediately establishing a new program for New Yorkers with disabilities.

The "Fundamental Right" state income tax break would give qualified enrollees a two-fifths break on their state income tax. Only a person enrolled in the program could take advantage of the tax break.

To qualify for the tax break, a person would have to:

- \* Be a resident of and registered voter in New York state.
- \* Have a disability, as defined under the federal Americans with Disabilities Act.

## *Election Reform, continued*

- \* Sign a sworn statement to verify that he or she cannot vote privately or independently at his or her designated polling site.

In return, participants in the program would agree not to file and pursue legal action related to their voting rights against New York State during the time that they are enrolled and take the tax break.

The tax break would end the year after the U.S. Department of Justice verifies that New Yorkers with disabilities can vote privately and independently, as specified under HAVA.

It must be understood that this program is an interim measure, not meant to replace or prolong providing New Yorkers with disabilities their fundamental rights to vote privately and independently as American citizens. The money the state saves from avoiding extensive litigation costs, fines, and awards would more than pay for the program.

In his State of the State address, the governor called for several new breaks, while stating, "We've led the nation in cutting taxes -- 81 cuts to 19 different state taxes."

He capped his speech by talking about how the new Freedom Tower in Manhattan will "transcend great challenges," similar to the way the dreams and aspirations of our forefathers led to "limitless hope, opportunity and freedom."

New Yorkers with disabilities have been waiting over two centuries to gain full access to their voting rights, which directly impacts their hopes, opportunities and freedoms. Time will tell if the governor extends his penchant for tax cuts to New Yorkers with disabilities, consistent with our forefathers' belief in "no taxation without representation."

# DOT Offers Training Program to Help Airlines Better Serve Passengers with Disabilities

The U.S. Department of Transportation today offered airlines a training program that will make it easier for them to comply with laws protecting the rights of disabled air travelers.

The new model training program highlights practices found by airlines to work best in meeting the needs of individuals with disabilities. The training program is designed to help airlines comply with the Air Carrier Access Act (ACAA), which prohibits discriminatory treatment of persons with disabilities in air transportation. While airlines are not required to implement the model training program, the Department encourages carriers to use it to complement their existing disabled access training programs.

"Everyone has a right to be treated equally when they travel by air," said U.S. Transportation Secretary Norman Y. Mineta. "This new model training program is part of our effort to help the airlines provide disabled travelers with the service to which they are entitled."

The training program provides guidance for employees and contractors of air carriers that serve passengers with disabilities. The program suggests practices and procedures for airline personnel to follow to help disabled

travelers with boarding, deplaning and making connections, as well as information on the airlines' responsibilities in such areas as service animals and assistive devices. The program consists of three components: a manual for participants, an outline for trainers, and a PowerPoint presentation, which carriers may use separately or together depending upon their individual needs.

The model training program builds on a technical assistance manual, completed in July 2005, on air carriers' responsibilities under the ACAA. DOT's outreach efforts to the carriers also have included regular forums, beginning in May 2001, on how to improve air travel for passenger with disabilities.

Details on the model training program, as well as the text of the technical assistance manual, are available on the Internet at <http://airconsumer.ost.dot.gov/training/index.htm>.

**Source:** <http://www.dot.gov/affairs/dot18505.htm>

DOT 185-05 Thursday, December 22, 2005

Contact: Bill Mosley Tel.: (202) 366-4570

# PEOPLE WITH DISABILITIES EARN A SEAT AT THE TABLE

*NYSILC Press Release* - On Thursday December 15, 2005, one day before a court mandated hearing before State Supreme Court Justice Thomas McNamara, the New York State Board of Elections formally appointed Dennis Boyd as the New York State Independent Living Council (NYSILC) representative to the new Citizen Election Modernization Advisory Committee.

"I am happy to be a formally approved member of the Advisory Committee and hope that NYSILC's role will ensure accessible voting machine systems for people with disabilities throughout the state," said Dennis Boyd of NYSILC and the New York Lawyers for the Public Interest (NYLPI).

This appointment came two months after NYSILC filed an Article 78 action with the New York Supreme Court demanding that the New York State Board of Elections comply with Section 1A of the Election Reform and Modernization Act of 2005 under New York State Election Law. This law mandates the inclusion of a NYSILC representative on the Citizen's Election Modernization Advisory Committee.

"It was inevitable that NYSILC would prevail in its lawsuit against the Board of Elections because the New York State Election Law is clearly on NYSILC's side," remarked Martin Coleman, the lead attorney for this lawsuit.

In addition to this matter, New York State has the dubious distinction of being the last state to implement HAVA by the mandatory deadline of January 1, 2006, which is only two weeks away.

"This lawsuit is evidence that the disability community refuses to back down regarding access to our voting rights," stated Susan Cohen, who provided an affidavit in the lawsuit. "This could be just the beginning in terms of litigation."

It is the vision of the New York State Independent Living Council, Inc. (NYSILC) to achieve a world where people with disabilities realize equal rights and opportunities in all aspects of society.

# Aid for Blind & Deaf at Movies in New York

*December 5, 2005 - Albany - AP* - Did you catch the new movie that everyone's talking about at school and at work? If you're visually or hearing impaired, there's a good chance you couldn't. But that's slowly changing.

Nationwide, more than 150 movie theaters have added special systems to help the deaf, hard of hearing, blind or visually impaired, according to the nonprofit National Center for Accessible Media.

Most of those theaters are in major cities that made the move voluntarily, but states are now putting pressure on theater chains to spread the technology much further or risk discrimination lawsuits.

A deal being announced in New York today involves eight national theater chains. The chains agreed to implement technology to help the visually and hearing impaired enjoy movies in 140 theaters across New York State - up from about a dozen now.

"Movies are an important part of popular culture," said New York Attorney General Eliot Spitzer.

New York theaters will add rear window captioning, in which hearing disabled customers can use an acrylic panel to read captioning projected from the back of the theater.

Thirty-eight of the New York theaters will provide on-screen captioning of some movies and headsets that offer descriptive narration of films under the deal.

## Simi Linton's My Body Politic

While hitchhiking from Boston to Washington, D.C., in 1971 to protest the war in Vietnam, Simi Linton was involved in a car accident that paralyzed her legs and took the lives of her young husband and her best friend. Her memoir begins with her struggle to regain physical and emotional strength and to resume her life in the world. Then Linton takes us on the road she traveled (with stops in Berkeley, Paris, Havana) and back to her home in Manhattan, as she learns what it means to be a disabled person in America.

Read this book!

# NYC PARKS AGREES TO IMPROVE ACCESSIBILITY FOR PERSONS WITH DISABILITIES

## New Construction, Renovations Do Not Meet ADA Requirements; Parks Department Will Make Suggested Improvements

**Editor's Note:** Margie Rubin of DIA has been working very hard to get the NYC Parks Department to make their parks accessible to people with disabilities, especially when Parks renovates or re-designs a park. Instead of really dealing with the issues and improving accessibility, some Parks people and some politicians have tried to make Margie the issue. This is typical when we fight for our rights. It isn't easy to keep on pushing for change through so much resistance. This report validates what Margie and others have been saying all along. Great work, Margie! Let's hope the Parks Department can redeem themselves and now make our parks truly accessible to people with disabilities. They could start with Washington Square Park! We will be following Parks accessibility closely.

*December 28, 2005* - The New York City Department of Parks and Recreation will make improvements in accessibility for people with disabilities recommended by a State Comptroller's audit, Comptroller Alan G. Hevesi and Parks Commissioner Adrian Benepe announced today. While many sites operated by Parks have been upgraded in recent years to improve accessibility for persons with disabilities, other Parks facilities are not accessible even after renovations, and a lack of on-site signage and other information regarding accessible sites increases difficulties for persons with disabilities, the audit found.

Auditors found that the department has not fully met the legal requirements of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Act (ADA) and U.S. Department of Justice Rule 28 CFR Part 35. Parks does not provide adequate information to the public regarding how to find facilities that do meet ADA accessibility requirements and also does not have a required formal process to investigate complaints about accessibility issues.

"New York City's parks should be open to all. I am pleased that Commissioner Benepe has committed to doing a better job following both the letter and the spirit of laws and regulations that

## *NYC Parks, continued*

make New York City's parks accessible to people with disabilities," Hevesi said.

"Parks & Recreation is committed to meeting or exceeding ADA recommendations in our parks. For the last four years we have reached out to the disabled community in many areas, and have invited groups, including the United Spinal Association, to advise us on the building and reconstruction of parks and park facilities," said Commissioner Benepe. "We look forward to working with the State Comptroller and our non-profit partners to implement these suggestions as part of our commitment to work on behalf of all our visitors, regardless of their abilities."

U.S. Department of Justice Rule 28 CFR Part 35 requires identification of accessibility barriers in existing facilities, needed modifications and a timetable for making the changes. Auditors determined that Parks did not meet these requirements and that the agency's policy was that accessibility standards would be met only in new construction and major alteration projects, although the department has not defined what constitutes a "major alternation."

Auditors reviewed a sample of 50 new Parks construction projects to see whether ADA accessibility requirements had been included in the department's scope of work document, which

provides a general description of the project and helps to guide the actual design process. Twenty-nine of the projects included no specific plans to address ADA-accessibility requirements and some of the projects did not have accessibility elements.

At the Queens County Farmhouse, for example, the scope document failed to note needed work on an access ramp. Moreover, the ramp was not accessible for wheelchair users because it could only be reached by crossing a grassy area. At the Gorman Playground in Queens, a \$654,000 playground renovation project did not include converting restrooms for ADA accessibility. However, auditors did find that ADA-accessibility elements were included in some projects even though they were not noted on the scope documents.

While there is no requirement that all Parks facilities be ADA-accessible, the department is required to help the public locate those that are accessible. In visits to 50 Parks facilities, auditors found no signage indicating accessibility or directing users to ADA-accessible entrances. Ideally, signage should also direct persons with disabilities away from potentially hazardous conditions. At Riverside Park, for example, auditors found that there was no posted information regarding excessive slopes, steps and stairways.

## *NYC Parks, continued*

Auditors recommended that Parks enhance information on its website regarding accessibility, because information on the site was not always complete.

The department agreed with all of the recommendations in the audit, and said that it would take steps to implement them. The complete response is included in the audit.

The New York City Department of Parks & Recreation has some 4,000 facilities including playgrounds, athletic

fields, tennis courts, swimming pools, recreation centers and beaches, and encompassing 28,700 acres. Its facilities include Central Park in Manhattan, Prospect Park in Brooklyn and the Bronx Zoo. The department's capital budget was about \$406 million in fiscal year 2003 and \$465 million in 2004.

The audit covered the period from January 1, 2000 through January 19, 2005.



*For a copy of the audit, visit [www.osc.state.ny.us](http://www.osc.state.ny.us).*

For more information on ADA Guidelines:

US Access Board - <http://www.access-board.gov>

"Play Area Guidelines" - <http://www.access-board.gov/play/finalrule.htm>  
(800) 872-2253; (800) 993-2822 (TTY)

National Center on Physical Activity and Disability -  
Fact sheet on "Designing Accessible Play Areas" -  
Information about specific sports - <http://ncpad.cc.uic.edu/>  
(800) 900-8086 (voice and TTY)

For help with planning a safe and accessible playground:

The National Program for Playground Safety - <http://www.uni.edu/playground> -  
1-800-554-PLAY

Boundless Playgrounds - <http://www.boundlessplaygrounds.org/>

## *NYC Parks, continued*

ADA guidelines require that:

- Children in wheelchairs can move around on the playground surface or path to the play area.
- There are transfer ramps with wheel stops and guardrails for children to get on to higher equipment.
- There is separate equipment for all developmental levels.
- The playground equipment and surface are maintained.
- There is space for adults to help children play on the equipment.
- All openings on elevated play platforms are limited in width.
- There are hands-on areas for children sitting in wheelchairs.

## Side-by-Side Comparison of Old and New ADAAG, IBC Available

The Access Board has issued a comparison between the new ADA Accessibility Guidelines (ADAAG), the original ADA standards, and the International Building Code. This side-by-side comparison is arranged and ordered according to the format and sequence of the new ADAAG, which the Board published in July 2004. Provisions in the ADA Standards maintained by the Department of Justice, which currently are based on the original ADAAG (1991), are provided alongside corresponding sections of the new ADAAG. The Department of Justice is in the process of updating its ADA standards according to the new ADAAG. The comparison is available in a variety of formats on the Board's website at [www.access-board.gov/ada-aba/comparison/index.htm](http://www.access-board.gov/ada-aba/comparison/index.htm).

In updating ADAAG, the Board sought to reconcile differences from model building codes, including the International Building Code (IBC). Used by a growing number of states and local jurisdictions, the IBC contains scoping provisions for accessibility and references the technical criteria of the ANSI A117.1 standard, a voluntary consensus standard issued by American National Standards Institute. The comparison includes accessibility provisions of the IBC, including those referenced in the ANSI standard. For further information on the IBC, visit the International Code Council's website at [www.iccsafe.org](http://www.iccsafe.org).

# **IN AND OUT THE MEDICARE PART D DONUT HOLE & DONUT HOLES TO COME**

by E.M. Prentiss

I fell into the dreaded Donut Hole on February 3rd, when my pharmacy's computer printed out a receipt with a \$61 co-payment instead of \$28. The next day, my insurance provider said something was wrong and I should call back in four days. When I did, they still didn't know why I'd been charged \$61. I asked, "Could I be in the donut hole?" "Oh no, it's too early," was the response. After checking another computer she said, "Oh yes, you are. Have a nice day."

You don't know you're in the Donut Hole because it is based on the plan's payments. By mid March when the insurance company sent EOB's (Explanation of Benefits), I was rapidly exiting the Donut Hole for catastrophic coverage. I was out of the Donut Hole on March 27th.

Since you must be 65 to be eligible for EPIC (New York State's Elderly Pharmacy Assistance Coverage), I will be facing eleven Donut Holes before I am 65. EPIC participants are protected from paying into the Donut Hole. I was thankful my father's estate had finally been settled. I was thankful my father's

estate had finally been settled so I can pay the Donut Holes. In today's money we calculated it was over \$40,000!

Did the President and Congress really think beneficiaries would have \$3,600 or more available to fill the annual Donut Hole and move over to the other side of the Donut for catastrophic coverage? It seems as if there are article daily about seniors, often cancer patients, who had received their medication on Pharmaceutical Assistance Programs but now being forced into Part D and dreading the Donut Hole. In New York State, financially eligible seniors are protected by EPIC, but people who are on Medicare but who are not seniors are not eligible for EPIC.

In 2007, Part D's costs are all increasing: The initial deductible from \$250 to 265; Out of pocket expense from \$3,600 to \$3,850. Co-payments are increasing: those who qualify for Extra Help (Low Income Subsidy): full benefit from \$1/3. \$1/3.10 to \$2/5; partial subsidy from \$2/5 to \$2.15/5.35; catastrophic coverage (beyond the Donut Hole) from \$2 to \$2.15 (generics) and from \$5 to \$5.35

## *Donut Hole, continued*

(brands). These may seem like small and inconsequential increases but they add up, particularly for those who take numerous medications.

So, recalculating, I can look forward to probably over \$50,000. But many Medicare beneficiaries do not have the means to pay even one Donut Hole much less eleven. Unfortunately, there are no estates pending as I slog through future Donut Holes to EPIC when I finally reach 65.

The cost to expand EPIC to younger Medicare beneficiaries would be \$15 million dollars in the first year. In this

year's proposed \$110 billion state budget,, the legislature and governor are fighting over a much greater amount for member items. The Manhattan Institute's Empire Center for New York State Policy has calculated that over the past three years member items have cost just over \$479 million.

This year, could the Mets and Yankees get only \$135 instead of 150 million in member items, so younger Medicare beneficiaries can have EPIC and be protected from the financial ravages of the Donut Hole?

## **Accessible Taxis in NYC? Still Only a Few**

There are 12,787 yellow taxis in NYC and only 25 of them are wheelchair-accessible. Your chances of finding one that is where you are and available are miniscule. That's why Taxis for ALL Campaign is working to change the situation. Taxis for ALL Campaign is a coalition of disability rights groups and groups interested in disability rights: Disabled In Action (DIA), Disability Network of New York City (DNNYC), United Spinal Association (USA), Center for Independence of the Disabled in New York (CIDNY), the MS Society, the Anti-Discrimination Law Center of Metro New York, New York Lawyers for the Public Interest (NYLPI), and 504 Democratic Club. Many other groups support our work. We are working for accessible yellow cabs as well as accessible liveries, black cars, and limousines in NYC. We WILL ride!

# THE TENUOUSNESS OF FREEDOM

by T.K. Small

This past January I received an urgent telephone message, from a friend who was trying to find a lawyer to help release someone from the clutches of the King's County Psychiatric Hospital. In responding to this request, I spoke with Connie Lesold, who is one of the coordinators of the Brooklyn Mental Hygiene Court monitoring project. In Brooklyn, as in many other jurisdictions, a special court has been established to address mental health issues. Connie, and the other monitors, attend these proceedings to keep track of how folks are being treated.

Despite my lack of direct experience with mental health issues, Connie suggested that simply another person, particularly an attorney with a disability, could perhaps be helpful. Since Mental Hygiene Legal Services (MHLS) had already become involved in this case, I headed to court to simply support a fellow member of the disability community that I didn't even know. What I saw that day in the Brooklyn Mental Hygiene Court has caused me to reflect on the tenuous grasp that we all have on our freedom.

As we waited for the hearing to begin, I started to see some disturbing trends in almost all of the cases that were

presented. Apart from the almost complete lack of wheelchair accessibility to the courtroom, there appeared a remarkably fast rush to invoke judicial intervention in considering whether mental health services should be officially imposed.

From my limited perspective it seemed that the testimony of family members, psychiatrists and social service entities, were given more credibility. It also appeared that there was a heavy-handed, authoritarian dynamic present between those who were supposedly there to help and the people "alleged" to be mentally impaired. From a number of the court monitors I learned that in too many instances the result of these proceedings is forced treatment and medication in a psychiatric facility, and occasionally, the sanctioning of electro-conclusive therapy. It seems that once a person has some sort of "psychiatric label" the rules change dramatically.

The person in question, as mentioned earlier, ended up getting legal representation from MHLS and they did an excellent job. I am happy to report that the person is back in the community, doing just fine. But what happens to the people that are not as

## *Tenuousness, continued*

fortunate to get adequate legal representation?

When I first became involved in the disability rights movement in the early '90s, a large part of a national conference I attended was dedicated to the importance of our movement truly being represented in a cross-disability perspective. There are 54 million people

with disabilities in America and our strength is only magnified when we work together. There are all sorts of clichés about "weak links in a chain" and "hands washing each other" but I especially like what Benjamin Franklin said: "We must all hang together, or assuredly we shall all hang separately."

## Accurate FDR Statue for the First Time Ever

Next April, in 2006, sculptor Martin Dawe is going to make an accurate statue of FDR, Franklin Delano Roosevelt, for the 62nd anniversary of FDR's death. The statue will be placed in F.D. Roosevelt Park in Georgia, near a town called Warm Springs, which is also the name of a rehabilitation facility that FDR founded and loved to relax in. When he was at Warm Springs, FDR, who was disabled from polio as an adult and could not walk, used a wheelchair in public, wore his braces on the outside of his trousers, and did not hide his disability.

Before and during his four-term presidency, Roosevelt, who was president during almost all of World War II, hid his disability, kept his braces out of sight, and was not photographed using a wheelchair. When he had to appear in public, he had a strong man on each side and they helped propel him forward using his arms. In order to appear strong and in control (and probably to keep power), FDR did not want people to know he was disabled. An excellent book about FDR and his disability is *FDR's Splendid Deception*, by Hugh Gregory Gallagher.

This new statue of FDR will be the first one of him showing him wearing his leg braces. He will be depicted sitting on a car seat because that is what he used to do sometimes when he was relaxing in Alabama. Secret service agents would remove the car seat from his car and put it on a rock so he could sit on the seat and look out at the view and think.

# **THE SORRY STATE OF NEW YORK NURSING HOMES**

by Marvin Wasserman

1/10/2006 - State Attorney General Eliot Spitzer has just offered a report on staffing levels in nursing homes. You can access the report with the following link: <http://www.oag.state.ny.us/press/2006/jan/final.pdf>

According to the report , "Numerous studies have shown a strong relationship between the hours of care a resident receives and the quality of care..."

The report further states that "about 98% of New York's nursing homes fall into the range at which, in the comprehensive federal study, quality of care for long-stay residents was shown to suffer. Staffing levels in about 70% of our homes do not meet the standards set in Florida; about 38% do not meet the standard in California; about 26% do not meet Vermont standards; about 25% do not meet Ohio's standard for registered nurses and about 3% don't meet the standards in Illinois.....

"The consequences of understaffing can sometimes be tragic."

The staffing levels are based upon information provided by the nursing homes themselves, and even this paints a sorry picture. Unfortunately, New

York State, unlike Florida, California, Vermont, Ohio and Illinois, has adopted no minimum standard, and a large number of nursing homes in New York City reported staffing levels below the minimum standards in all but one of these states, and several reported staffing levels below the minimum standard in all of them!

As you may know, many of us believe that nursing homes are similar to prisons, where senior citizens and persons with disabilities are warehoused. There is a governmental bias in favor of nursing homes, perhaps because of the money that nursing home owners funnel to political campaigns. The Olmstead Supreme Court decision is supposed to guarantee the right of individuals with disabilities to living in the community, but this decision has been difficult to implement because, among other things, the difficulty in locating low income accessible housing and the seeming lack of will of both the State and City governments.

Studies have shown that many are happier and live longer when living in his or her own home, and nursing home

## *Nursing Homes, continued*

placement often shortens the lives of individuals.

While the Attorney General's Report focuses on staffing levels, which have a great deal to do with the health and well being of nursing home residents, I believe that this is not the entire story.

My mother-in-law was placed in a nursing home in my community several years ago. This nursing home comes off rather well in the AG's report, which does not jive with what I observed while visiting her there. There was always a foul odor in the hallways (which experts often cite as reason to avoid a particular nursing home). Moreover, I was appalled by what I called the "Alzheimer Room," in which residents who weren't lucid were herded into. In this room a television set, which virtually no one paid attention to, was turned "on." Many were lost in their own selves or talking to no one in particular. At the door, there was a burly aide standing guard to make sure that no one left the room. I was relieved that, for the first month or so, I never found my mother-in-law in that room. However, not long afterward, that was her permanent station for the day, and she died shortly after that.

According to this report, the top nursing homes in New York City were the William D. Beneson Rehabilitation Pavilion in Flushing and the Elizabeth Seaton Pediatric Center in Manhattan. These are the only two in the City who meet the Centers for Medicare and Medicaid Services (CMS) standard for staffing levels.

The worst were the following nursing homes: Brooklyn/Queens Nursing Home, East Haven Nursing and Rehabilitation (Brooklyn), Haven Manor Health Care Center (Far Rockaway), Lilly Pond (Staten Island), Terrace Health Care Center (Bronx), Throggs Neck Extended Care (Bronx). **CLOSE THEM DOWN!**

According to my figures, there are about 21 others who meet the minimum staffing standard of only one state cited in the rankings. Noticeably, this includes Coler-Goldwater Hospital on Roosevelt Island, where over 2,000 members of our community are warehoused, the largest facility of its kind in the country. **CLOSE IT DOWN!**

# EMERGENCY PREPAREDNESS FOR PEOPLE WITH DISABILITIES

by Edith M. Prentiss

Despite the terrorism attacks on the World Trade Center, Madrid, and London, I'm more concerned with power outages, natural disasters and emergencies.

Emergency planning must be more than how much water you need and certainly more than what goes in a GO BAG. We need to focus on telephones that do not require electricity and networking in our buildings. Telling us not to use elevators and to plan on meeting on a specific corner is problematic. If you're home how do you get out and if you're out how do you get home? If you end up in a shelter, will it have the equipment and supplies you need?

In November 2004, the National Organization on Disability commissioned Harris Interactive to determine the degree to which jurisdictions included the needs of people with disabilities and also if people with disabilities were included in the emergency preparedness planning process. Harris found 69% said they had incorporated the needs and 22% reported a plan was in development. But only 42% included an informational campaign and only 16% were available in accessible formats.

The instructions posted by elevators simply say not to use them in case of fire and sometimes directs you to wait for further instructions. If you're able to use the stairs finding them from the map can be confusing. And if you can't climb stairs, do you just wait to be found?

Recently, a settlement was announced in a suit against Marshalls department store requiring they adopt evacuation procedures for shoppers with disabilities. They became the first national retailer to agree to address the emergency evacuation needs of people with disabilities. The suit was brought by a shopper who exited into a basement level of a mall from which there was no accessible egress.

When the MTA tested the single operator L train, on the train were 100 MTA employees, three of whom were designated as people with disabilities. The 97 able bodied employee passengers were successfully evacuated, leaving behind the 3 individuals with special needs and the test was considered a success!

Several months ago, I was on a Long Island Railroad train that struck and killed a pedestrian. Other passengers

## *Emergency Preparedness, continued*

were walked through the train, and put on buses to their destination while I waited. What if it had been a major blackout, would the conductor and I have sat on the train for a day or more?

A passenger with auditory and visual impairments was on a D train that was evacuated due to a fire. It was another passenger who noticed her sitting as the police evacuated them from the train. In that circumstance, what would a wheelchair using passenger do? I

guess, the Fire Department would carry us out, but getting me out is only the first step, would they get us to the street and leave us there?

The first step is for emergency planners to include individuals with special needs in the dialogue, and that includes making sure the dialogue is accessible. Having a special need does not preclude your capacity to engage in the planning process and the process itself.

## **Policy On Boarding A Bus In A Wheelchair in NYC**

Both MTA Bus and New York City Transit (NYCT) Bus Department's rules say that wheelchair users can board the lift going forward or backward, whichever way the wheelchair user is most comfortable doing. It is NOT up to the driver to decide. It is up to the passenger to decide which way he or she boards the lift and the bus. If there is a dispute, you ask the driver to "call console" and the driver will be told by the Command Center to let you board.

Recently, a NYCT bus driver refused to let me board going forward. He took the bus out of service for about 30 minutes until 2 supervisors came and ordered him to let me board forward and drive me to my destination. In the meantime, the passengers blamed me for making them late to work. They got out of the bus, came close to me, and hurled insults at me in voices full of hate. "You selfish b----!" "Take a taxi!" "People like YOU shouldn't take the bus, you should take Access-a-Ride!"

It shows that discrimination and prejudice against people with disabilities is alive and well in New York City.

— Jean Ryan

# DISABILITY ADVOCATE CHECKS UP ON NYC TRANSIT

by Beth Fertig

*New York City - December 02, 2005*  
- WNYC Radio [Transcript of report]— In 1984, New York City Transit agreed to make its buses and subways more accessible for people with wheelchairs. The move followed a landmark lawsuit by disability advocates. Now, a 21-year-old college student is fighting to make sure that agreement is enforced throughout the transit system. WNYC's Beth Fertig has more.

REPORTER: Almost everyone at Manhattanville College seems to know Michael Harris.

STUDENTS ON LINE: Michael, Michael Harris!

REPORTER: As he waits in line for sushi in the college cafeteria, Harris is greeted by friends and acquaintances. He's easy to recognize. He whizzes by on a 350 pound motorized wheelchair. And he doesn't dress like your typical college student. He's almost always wearing a suit.

MAN: Hey, how are you?

HARRIS: California please.

REPORTER: But Harris will be the first to admit his visibility is also by choice.

He's the kind of student who gets involved in almost everything, from the debate club to campus politics.

HARRIS: When I ran for freshman class president, I did not run a very discrete campaign. I spent several hundred dollars on my campaign for freshman class president and won with a very large margin. But, I mean I've chosen to stand out by getting actively involved in on campus activities, in student organizations, by going to on campus events.

REPORTER: Lately, Harris has been spending a lot more time organizing events OFF campus. As the founder and campaign coordinator of the Disabled Riders Coalition, Harris has been coming to every MTA monthly board meeting for almost a year. He speaks out about all kinds of issues affecting the disabled.

HARRIS: The MTA has been violating its own rule. As I have documented for the past 2 years the MTA consistently places masking tape covering the auto gates installed for the purposes of allowing disabled riders to enter and exit photo stations. As you can see by this photograph...

## *Michael Harris, continued*

REPORTER: MTA Board member Barry Feinstein says some of his complaints aren't true.

Michael Harris grew up in Brooklyn and he's been using a wheelchair since he was a child. He suffers from generalized dystonia – a neurological disorder that causes constant, painful muscle spasms. He's able to control the spasms with medications, two titanium rods in his spine and two pacemakers connected to his brain. And he gets around campus easily with his wheelchair.

The Disabled Riders Coalition started off as an independent study project. A professor suggested that Harris write about his frustration with the public buses near Manhattanville's Westchester Campus. He then attended an MTA hearing last fall about the impending fare increase and a plan to close token booths.

HARRIS: And it was just bothering me. That you had all of these elected officials talking about the disability issues. And there was nobody from the community saying anything and I felt that had to be done. And so I sort of sought out to try to figure out what I could do to give a voice to disabled riders.

REPORTER: Harris now has a website and an email list with almost 2000 names. He's constantly taking phone calls on his earpiece and he uses a blackberry to send out press releases to the media. But despite his professional demeanor, Harris is an infamous slob. He calls his dorm room an ecological hazard. And it is. The floor is littered with trash, clothing and books.

HARRIS: I have my fax machine just sitting there in the middle of the floor.

FERTIG: How can you find anything the floor is covered with papers?

HARRIS: Yes it is but I keep the important papers in a file drawer. Those are the unimportant papers!

REPORTER: His important photographs are prominently displayed. There's Harris posing with John Kerry, Al Sharpton, and Ben Affleck. As the only child of two city teachers, Harris grew up in a political family. He's extremely active with the Democratic Party. His college buddy Jonathan Reed Fallon says Harris is relentless. He recalls when Harris had brain surgery during their sophomore year — just as he was campaigning for Democrat Howard Dean.

***Michael Harris, continued***

FALLON: No lie. I kid you not. The surgery I think took place on a Thursday, I got the call on a Wednesday. Friday I see Michael in the wheelchair.

MICHAEL: Working.

FALLON: Yeah, in a suit in the wheelchair, and I said you've got to be kidding me. You just had brain surgery. I said what are you doing on campus right now? And he says to me, well, I have to campaign tomorrow for Howard Dean.

HARRIS: I just don't believe in letting things get in my way. And so yeah, I had brain surgery one day. But the next day is a new day. And so my philosophy is it's a new day, I'll start fresh and so I went to work - so I went to work the next day.

REPORTER: Harris still isn't slowing down. He recently sued the Transit Authority over broken elevators. He appears to have had more success with Metro North. The railroad has been working with him to make sure conductors always look for disabled passengers on the platforms, so they can bring out ramps when necessary. On a train bound for New York City, Harris says he's no longer left behind because conductors always notice him now on the platform.

HARRIS: I got the guy who saw me on the platform, came over, took out a bridgeplate put it on eliminated the gap, I got on, he came over, took my ticket, I paid my fare and I'm good to go.

REPORTER: The disabilities movement has come a long way. The Americans with Disabilities Act was signed in 1990 to provide more access in public spaces. New York City got a jump start when the MTA signed a consent decree in 1984 agreeing to install wheelchair lifts in buses, and elevators in dozens of key subway stations. Jim Weissman won that lawsuit as an attorney with the United Spinal Association of New York. He sees Michael Harris - who was born that same year - as part of the next generation of advocacy.

WEISSMAN: He's the constituency, he's the guy we did it for, he's the guy who's taking public transit to school and work which just didn't exist before and people didn't think it would.

REPORTER: Harris never saw himself as an advocate. When he started college three years ago, he says, he wanted to be a lawyer or a politician. He never thought he would be an advocate for the disabled.

*Michael Harris, continued*

HARRIS: Mostly I saw this as being selfish and advocating for myself. I never really thought that I would do this as advocating for a larger community. But it ended up happening that way and I'm in a sense glad that it did.

REPORTER: Harris is already working on another project. He's making a

student documentary comparing the accessibility of Metro North trains with New York City subway cars. For WNYC I'm Beth Fertig.

**Editor's Note:** Michael Harris' website is [www.disabledriders.org](http://www.disabledriders.org). You can contact him at [mharris@disabledriders.org](mailto:mharris@disabledriders.org)

## **DISABLED IN ACTION CALENDAR 2006**

All DIA meetings are open and wheelchair accessible. DIA meetings are held in a smoke-free, fragrance-free, and beeper-free space at 135 W. 23rd Street between 6th & 7th Avenues. An assistive listening device is available. For DIA information or sign language interpreter, call Olga Hill at 718/261-3737. For TTY, Call 711. To add items to the agenda, e-mail Anthony Trocchia at [<atrocchia@aol.com>](mailto:atrocchia@aol.com) or call 917/865-3339. Disabled In Action's website address is [<www.DisabledInAction.org>](http://www.DisabledInAction.org).

<b>May 21</b>	<b>Sun</b>	<b>1:30-4pm</b>	
<b>June 11</b>	<b>Sun</b>	<b>1:30-4pm</b>	<b>DIA Officer and Board Nominations</b>
<b>July 16</b>	<b>Sun</b>	<b>1:30-4pm</b>	
<b>Aug 20</b>	<b>Sun</b>	<b>1:30-4pm</b>	
<b>Sept 17</b>	<b>Sun</b>	<b>1:30-4pm</b>	<b>DIA Election for Board Members and Officers</b>
<b>Oct 29</b>	<b>Sun</b>	<b>1:30-4pm</b>	
<b>Nov 12</b>	<b>Sun</b>	<b>1:30-4pm</b>	<b>DIA Election Results Announced</b>
<b>Dec 10</b>	<b>Sun</b>	<b>1:30-4pm</b>	<b>Holiday Party:</b> Contribution of \$10 per person or an entrée or dessert for 10 people to share. Call Marty Sesmer at 212/684-6287 to confirm your attendance.

*2006 Meeting Schedule is on DIA website: [www.disabledinaction.org](http://www.disabledinaction.org)*

# **T IN BOSTON AGREES TO SPEND \$310 MILLION ON ACCESSIBILITY**

by Mac Daniel

## **Suit Settlement Calls for Upgrades**

*April 4, 2006 - Boston Globe* - The Massachusetts Bay Transportation Authority would spend more than \$310 million over the next five years to make the transit system one of the most accessible in country to disabled riders, under a settlement announced yesterday by T officials and groups representing people with disabilities.

The agreement calls for upgrading elevators and escalators, speeding the purchase of low-floor buses, replacing unreliable mobile wheelchair lifts on subway and trolley platforms, accelerating a new \$23 million public address system, training MBTA employees with the help of disabled riders, and creating an assistant general manager for accessibility who will answer directly to the T's general manager.

"Certainly for 20 to 30 percent of our customers at the MBTA, we are an essential component in their ability to live their life, enjoy their lives, go to work, go to a movie, and to get there in a reliable fashion," said MBTA General Manager Daniel A. Grabauskas. "Therefore, it merits a substantial investment."

Plaintiffs and their supporters planned to celebrate the settlement by wearing T-shirts today reading, "To boldly go where everyone's gone already."

The settlement still needs the approval of the federal judge overseeing a four-year-old class-action lawsuit against the T under the Americans with Disabilities Act. If it is approved, a court-appointed monitor would oversee progress, which would include using undercover passengers. After the five years covered by the pact, the monitor would have to give passing grades on three quarterly reports before the settlement officially ends.

Daniel S. Manning, lead counsel for the 11 plaintiffs and the Boston Center for Independent Living, said 100 depositions and other information gathered for the lawsuit detailed extensive impediments facing the disabled throughout the T system.

For example, when many elevators and escalators were not working last year, some of the plaintiffs in the lawsuit told of having to take both outbound and inbound trains simply to

## *T in Boston, continued*

reach a working elevator or to change tracks.

"One of our goals is to really try and bring riders back" through this settlement, said William Henning, executive director of the Boston Center for Independent Living. "We know a number of folks who have had problems and haven't used the system in two, three, four years, and it's time we get them back in as part of the mainstream community."

Both Manning and Henning said the settlement talks over the last nine months were the most productive they ever had with the T. They credited the agency with being open to change. "I know my clients are very excited both to have a seat at the table and to be partners going forward in this," Manning said.

The settlement calls for no monetary damages to be paid to the plaintiffs, though the T will incur all or a portion of the plaintiffs' legal costs. That figure was not disclosed yesterday.

The list of settlement terms includes:

- Spending \$122 million over the next five years to add, replace, or upgrade elevators and escalators and to ensure continued, uninterrupted service. Park Street, Downtown Crossing, Harvard Square, and Porter Square stations would get additional elevators.

- Involving disabled passengers in rider-assistance training for MBTA employees. In past training, T employees either viewed videos or practiced maneuvering wheelchairs with fellow T employees who were not disabled.
- Continuing to buy accessible low-floor buses, which are easier for disabled people to board. The T has about 610 of those buses now and plans to get 400 more so that they would be on almost all T routes by 2007.
- Closing platform gaps on subway cars and repairing and replacing the tactile yellow warning strips at the edge of some subway platforms.
- Whenever possible, assigning one low-floor car to each streetcar train on the Green Line.

T officials and the plaintiffs declined to release a copy of the settlement, which includes the deadlines, until US District Judge Morris E. Lasker signs off on it.

Grabauskas made accessibility his top priority when he took over the agency about a year ago. The settlement now makes those pledges binding, with little or no room for the T to delay accessibility projects.

Much of the funding for these changes was already part of the MBTA's capital budget. T officials could not say yesterday how much more they are

## *T in Boston, continued*

spending to reach the settlement's terms.

"Every investment that we're going to make that's essential for a subset of our customers in the disability community is going to be a huge plus for every one of our customers," Grabauskas said.

For instance, getting rid of the cumbersome wheelchair lifts, mostly on the Green Line, should speed service for all riders.

Many passengers also complain about not being able to understand public address announcements, which Grabauskas compared to Charlie Brown's mumbling teacher.

The lawsuit, which was filed in 2002, accused the T of failing to keep elevators and escalators in good repair, preventing the disabled from riding buses and trains 10 percent to 20 percent of the time.

According to the lawsuit, the groups said the T had 1,900 elevator failures in 2004.

The number of broken or out-of-service escalators and elevators at T stations hit a five-year high at the start of 2005, prompting the Federal Transit Administration to begin monitoring the problem.

On some days in the late winter and early spring of last year, more than 20 percent of the MBTA's 167 escalators and more than 15 percent of the 143 elevators were not working, T documents indicate.

Those numbers have vastly improved: 98 percent of the system's elevators have been in full operation in the last two months, official say.

*Mac Daniel can be reached at [mdaniel@globe.com](mailto:mdaniel@globe.com).*

# COMPLAINTS CITE AIRLINE WHEELCHAIR SERVICE

by Barbara De Lollis

*November 27, 2005 - USA Today -* Bad service for passengers using wheelchairs drew more attention than any other problem on the government's first tally of disability-related complaints to airlines. In all, according to the recent report from the U.S. Department of Transportation, passengers filed 10,193 complaints with U.S. airlines in 2004, and about two-thirds involved wheelchairs.

In addition to inadequate assistance, passengers also complained of damaged chairs, poor seating arrangements, inaccessible aircraft and excessive waits for stored chairs upon landing. About 17 million disabled passengers fly each year, according to the government's most recent estimate.

The complaints about poor assistance don't surprise Bob Herman, senior attorney with Paralyzed Veterans of America. "That's where they fail the most often," he says of airlines.

Wheelchair users might wait an hour for help, and the person who arrives might not know proper lifting techniques or speak English, he says.

Congress ordered the report to draw attention to special travel challenges of the disabled.

The government will use the data to identify trends and bolster enforcement of laws meant to protect the disabled, says DOT lawyer Sam Podberesky.

Advocacy group officials say airlines have grown more responsive to their needs in recent years, but they hope the new information prompts even more action.

"The DOT is watching, so (the airlines) have to be a little more careful," says Kleo King, program counsel for the United Spinal Association, an advocate for people living with a spinal cord disability.

Partly due to the complaints from disabled passengers, Tempe,-Ariz.-based America West in the last year has changed its wheelchair-service vendor, doubled the number of wheelchairs at its Phoenix and Las Vegas hubs and added employees to oversee the operation, spokesman Carlo Bertolini says. The airline — now part of US Airways — has seen complaints fall 19% compared with the same time last year, he says.

Delta, too, upgraded its program. In August, it increased training for employees and vendors likely to deal with disabled passengers. Delta also

## ***Airline Complaints, continued***

has had customers with disabilities address front-line employees to give them their perspective on travel. Complaints are down from a year ago, Delta spokeswoman Chris Kelly says.

Four big carriers — American, Delta, United and Northwest — accounted for nearly 60% of the complaints in 2004.

Contributing: Barbara Hansen.

## **11 BUS FIRMS ACCUSED OF DISABILITY ACT VIOLATIONS**

by Bill Brubaker

*March 2, 2006 - Washington Post -*

In a recent sweep of 14 bus companies that operate in the busy Washington-New York-Boston corridor, investigators found that 11 carriers had violated the federal law that guarantees interstate service to disabled passengers, according to government officials.

The purported violations are being investigated by the Justice Department, which enforces the Americans with Disabilities Act, officials said.

The act requires, for example, that large carriers, those with an annual revenue of \$7.2 million or more, must outfit at least some of their buses with wheelchair lifts. Disabled passengers must give smaller bus lines 48 hours' notice, but the carriers must accommodate them.

"There have been some pretty horrendous stories" about disabled passengers being denied bus service, said Annette Sandberg, who heads the Federal Motor Carrier Safety Administration, which regulates the interstate bus and trucking industries.

Sandberg is scheduled to be at a congressional hearing today on low-fare bus carriers, which offer rates as low as \$35 round trip between Washington and New York.

The December sweep was part of a crackdown by the Federal Motor Carrier Safety Administration on interstate bus companies, low-fare lines, and charter carriers among others that flout federal safety regulations. Sandberg and other federal officials declined to discuss the alleged Americans with Disabilities Act

## ***Bus Firms, continued***

violations or name the 11 companies under investigation.

All told, the December compliance reviews found 176 alleged violations, most for safety-related infractions such as failing to conduct random drug and alcohol tests on drivers, officials said. These reviews followed surprise inspections of 403 buses in October that turned up more than 500 alleged violations, including speeding, faulty brakes, and falsifying records on how long a driver has been on the road.

Sandberg, who is leaving her Federal Motor Carrier Safety Administration post tomorrow, plans to detail the agency's new level of oversight at

today's hearing before a House Transportation subcommittee.

Previewing her testimony, Sandberg said new bus companies are being targeted for inspections after nine, instead of 18, months, and the Federal Motor Carrier Safety Administration plans to make its annual grants to states contingent on state agencies demonstrating that they have effective bus safety programs.

Asked what prompted these measures, Chuck Horan, the administration enforcement and compliance director, said: "We have recently seen a spike in the death toll in the bus industry. . . . And it also seems like a lot of these of buses are catching fire."

## **Did You Know This About Broken Elevators?**

If your apartment elevator is broken for a substantial amount of time or if it is going to be replaced and you will be trapped in or out of your apartment for a substantial amount of time, the landlord OR coop board are responsible for paying for you to live in alternate, accessible living quarters. One DIA member, a wheelchair user, recently lived in a motel for several months while her building got a new elevator installed. Other people, whose elevator has been in disrepair for months, have been able to be moved to a temporary and accessible apartment. The NYC Human Rights Commission at 212) 306-7330 can help you.

# FIVE FIRST STEPS AT THE CITY COUNCIL

by Doug Israel

*February 2, 2006 - Gotham Gazette*

- Less than a month after her selection by her colleagues as City Council Speaker, Christine Quinn convinced them to pass five small but significant reforms meant to make the legislative body more democratic. (see the Stated Meeting Report Of February 1). Some skeptics might find it ironic that the reforms passed with little discussion -- and that the vote was unanimous.

The relentlessly lopsided votes in the New York City Council are one of the things that make so many New Yorkers so skeptical about the council.

Some are more than skeptical; they are outraged. Preservationists certainly were outraged late last year, when the council voted 43 to 6 to overturn the decision by the Landmarks Preservation Commission to designate the 1913 Austin, Nichols warehouse (built by architect Cass Gilbert) as a landmark. Members of the council have since admitted that they did not know anything about the building before the meeting and were not prepared to weigh in; Councilmember Albert Vann, for example, recalls that he "did not come prepared for any deep thinking" on any issues that day. The council members subsequently overturned the

mayor's veto of their decision, saying they now understood the issue and did not think the building deserved landmark status. But this hasn't made the skeptics any less skeptical.

Advocates for the disabled are outraged that a bill to make New York City's taxi fleet accessible to those who use wheelchairs -- currently, less than one percent of the taxis are -- has not even made it to the floor for a vote.

Civic organizations and neighborhood groups that rely on the City Council to champion their causes, on everything from ensuring cleaner air in the Bronx to addressing patterns of housing segregation, long have been asking for a more open legislative process, so that they not only know the status of the bills that concern them, but can feel that their views are being taken into account.

Openness, transparency, accountability, greater participation, timeliness - these are some of the principles that reformers believe need beefing up in the day-to-day procedures of the City Council, as laid out in a report (in pdf format) issued last month by Citizens Union that I co-authored.

## ***Five First Steps, continued***

And this is what new City Council Speaker Christine Quinn is promising to do. "We in the City Council have a responsibility to make our government responsive to our constituents' needs," Quinn declared at the news conference announcing her package of reforms. "By allowing for more transparency and by instituting these progressive changes we are making the City Council a stronger, better and more effective institution."

### **The Power Of The Speaker**

To realize the significance of the reforms, it helps to understand how much of the council's power has been concentrated in the hands of the Speaker. She has the ability to control the flow of legislation and even the level of debate in many different ways. The speaker not only has the power to set the agenda for full council meetings, she exercises control over the agenda of the committees as well, including making decisions on what bills they will vote on. As a further show of power, the Speaker (rather than the committee chairmen) hires and pays for the counsels to the committees, and the Speaker's staff is often given the responsibility to draft a bill, translating it from an idea into the necessary legal language. While these counsel are often conflicted between allegiance to the committee and the Speaker, the Speaker

ultimately pays their bills. All of this presents a hurdle to individual council members -- and their constituents -- from having more of an impact.

With the new rule changes, Christine Quinn is signaling that she is willing to do things at least a little differently.

### **The Five Rule Changes**

The new reforms are meant to be the first steps in addressing the problems for which the council has been criticized:

1. **Timeliness:** The Speaker's staff often delays drafting into legal language the bills that are proposed by individual members of the Council (as opposed to the Speaker herself). The new reforms include a requirement that the staff must write such draft legislation within 60 days after a request.
2. **Transparency:** The public and even most members of the City Council can only easily get ahold of the first version of a bill when it is introduced for consideration. It is much more difficult to learn of the various changes that the bill undergoes in committee, so that they can follow the progress of the bill and be more informed when it comes to a vote. The new reform calls for the most current version at any given time to

## *Five First Steps, continued*

be posted on the City Council Web site.

Active Participation: Two of the rules just passed are meant to encourage council members to play a more active role in the political process by making it easier for them to use two rarely-employed procedures to go around the power of the Speaker.

3. Many bills, after being considered in the appropriate council committee, never make it to the full council (called the floor) for a vote, because they lack support by the Speaker. Theoretically, if enough city council members feel strongly enough about a bill, they can insist that it be brought to the floor. But this almost never happens. The new rule, which says that a bill must have the support of only seven council members (reduced from the previous nine) to bring it to the floor over the objection of the Speaker, is meant to signal this Speaker's willingness to have this procedure used on occasion.
4. Similarly, the fourth new rule encourages members of the City Council to offer amendments to a bill after it already has been passed. Offering amendments is commonly practiced around the country.

5. Openness. Committees are now required to post notice of their hearings -- and, perhaps more importantly, their proposed agendas -- 72 hours in advance of committee meetings, online, to the news media and in a public place at City Hall.

### **What From Here?**

Will the new rules be effective?

Reformers on the council itself are optimistic. Reformers outside the council, such as Craig Gurian, executive director of the Anti-Discrimination Center of Metro New York, are hopeful. "A useful early test," Gurian says, "will be to see if the council is able to enact some of the long-overdue legislation that has been sitting for years without getting to the floor for a vote."

In addition to the rule changes, the Speaker has pledged to create a "working group" on reform to review and evaluate other proposals.

Councilmember Gale Brewer, chair of the technology committee, sees no great conspiracy to keep council members in the dark but believes the council has not done an adequate job informing council members of the issues that are being worked on. "Because the budget is so large and because many of the issues that come before us and that affect New York are

## ***Five First Steps, continued***

so complex, it's a challenge to get everyone up to speed," Brewer said. What will help, she believes, will be "more council and staff briefings as part of the council process and better use of list serves and the Web."

Proposals need not come just from the council – or at least not just from the New York City Council.

The Web site of the Columbus, Ohio City Council is available in eleven different languages, including Spanish, Chinese and Korean, all languages that are widely spoken in New York City.

The City Council of Los Angeles must post on its Web site a list of expenditures neighborhood by neighborhood.

In Detroit the City Clerk's office is required to post introductions of laws not only at City Hall but in a daily

newspaper, so that the public knows what's going on as well. And any public hearing cannot be held sooner than five days after the publication of the notice.

Support has been growing for a number of other measures. One common peeve is the way that funds are distributed to council districts and "stipends" to council leadership. The amount of money added to their \$90,000 annual salary -- for what is officially (but only rarely in actual practice) a part-time job -- ranges as high as an extra \$28,500. That is for the Speaker herself, of course, but even those rewarded less handsomely have one person to thank -- the Speaker.

**Doug Israel** is policy director at *Citizens Union Foundation*, which publishes *Gotham Gazette*

# CHANGE NEEDED IN ATTITUDE TOWARD PEOPLE WITH DISABILITIES

by J. Elizabeth Strohm

*February 9, 2006 - University of Pennsylvania News - Judith Heumann used to be classified as a fire hazard.*

"I learned that discrimination was unfortunately a natural part of life in the United States and, as I would learn later, in the world," Heumann said.

Heumann, who has been disabled since she contracted polio in 1949, visited Pitt yesterday as the 2006 keynote speaker for the Thornburgh family lecture series on disability law and policy. Her speech attracted an audience of more than 150 people, a disproportionate number of them with disabilities, to the Barco Law Building's Teplitz Courtroom.

Heumann, who serves as the World Bank's first adviser on disability and development, discussed her own history battling barriers faced by disabled people, as well as the development of disability laws in the United States and the future of disability issues in the nation and the world.

There are 54 million people with disabilities in the United States and half a billion in the world, according to Chancellor Mark Nordenberg, who

joined former Pennsylvania Governor and U.S. Attorney General Dick Thornburgh in introducing the topic and speaker.

"Eliminating obstacles ought to be a national and international priority," Nordenberg said.

Pity, fear and lack of knowledge create barriers for people with disabilities, Heumann said.

"The physical barriers may be coming down, but attitudes change very slowly," she said, explaining that attitudes and acts of discrimination are the biggest problems facing people with disabilities.

Heumann said that no amount of money could remove the obstacles created by biases.

Early experiences provided Heumann with powerful lessons about many people's attitudes toward disabilities. She was denied admission to school because she could not climb the building's steps, even though her mother offered to assist her each day.

Public facilities were not accessible for people with disabilities when

## *Change Needed, continued*

Heumann was young, and although many organizations sponsored research toward cures for disabling diseases, few fought to remove barriers — and few thought to include people with disabilities in waging the fight, she said.

One group that did manage to find a voice early on was composed of disabled World War II veterans. Their efforts brought about the first state legislation to make new buildings and sidewalks accessible to people with disabilities.

Heumann began taking major steps toward rights for people with disabilities in college; she organized rallies and protests with other students with disabilities. When Heumann got out of school and was denied her New York teaching license because the board did not believe she could get herself or her students out of the building in case of a fire, she took the case to court.

After the judge suggested that New York City's Board of Education rethink its decision, Heumann became the first person in a wheelchair to teach in New York City.

On her first trip out of the United States, Heumann attended the Paralympic Games as a spectator in Heidelberg, Germany. Meeting people with disabilities from other countries for the first time, Heumann said she

realized that people in every country had to deal with many of the same challenges.

"It was very exciting to see how our visions were the same," she said, adding that people from wealthier nations had better technology and opportunities but that "we all faced the same barriers."

At her current position, Heumann works to introduce disability issues into the World Bank's many international programs.

"Disability has to be part of every development discussion," Heumann said.

For example, less than 10 percent of disabled children around the world attend school, Heumann said.

"Too many people in the United States remain uninformed about the problems and challenges faced by the more than 400 million people with disabilities living in developing countries," she added.

Heumann emphasized the importance of applying a "disability lens" to every situation, so that everyone might better understand the challenges faced by people with disabilities.

"We're integrating disabled people into the fabric of everything that's happening," Heumann said.

## *Change Needed, continued*

Heumann described disabilities as a factor to incorporate into decisions, and not as a problem to solve.

"Many of the institutions really think about disabilities as something that will someday no longer exist," Heumann said

"We don't see disability as a tragedy," she said, describing it instead as simply "something that will always exist, at least in our lifetime."



Judith E. Heumann was appointed as the World Bank's first Adviser on Disability and Development in June 2002. She is an internationally recognized expert on disability and diversity issues who has traveled widely among the countries of the world. Heumann leads the Bank's disability work that integrates the needs of people with disabilities in the Bank's discussions with client countries, its country-based analytical work and its support for policies, programs and projects to improve economic and social life around the globe. Heumann, a life-time human rights advocate, has been the recipient of many awards including two honorary doctorates and the first Henry B. Betts award. She was also the founder of Disabled In Action in 1970.

# **GAP WIDENS BETWEEN WORKING-AGE PEOPLE WITH AND WITHOUT DISABILITIES IN THE WORKFORCE, REPORT SHOWS**

by Linda Myers

*October 5, 2005 - Washington, D.C. - Cornell News Service -* Between 2003 and 2004 the employment gap widened between the number of working-age Americans with disabilities who are employed and those workers without disabilities, a new report released today (Oct. 5) on Capitol Hill shows.

The finding, which coincides with the start of National Disability Employment Awareness Month, was part of a series of reports released by Cornell University in collaboration with the American Association of People with Disabilities (AAPD).

The researchers found that in 2004 the "employment gap" between those with disabilities in the workforce and those workers without disabilities was 40.3 percent. That represents a .6 percentage point increase from 2003, when the gap was 39.7 percent.

The growth in the gap means that there are fewer people with disabilities in the workforce relative to the total number of Americans employed. "The rise in the employment gap suggests that people with disabilities are

not participating in the recovery from the 2001 recession," said Andrew Houtenville, director of the Cornell's Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC).

The first Annual Disability Status Reports from Cornell, which contain a range of statistics about people with disabilities, including statistics by state, are available online at <http://www.DisabilityStatistics.org>.

The reports, which will be issued yearly at the beginning of October by Cornell, "fill a pressing need for timely and relevant statistics about people with disabilities," said Houtenville. "We hope they will become an annual event that policy-makers, advocates, the media and people with disabilities across the United States will anticipate and depend on," he said.

Another key finding in the reports: The poverty rate rose more between 2004 and 2003 for people with disabilities than for those without. For people with disabilities, it increased .8 percentage points, to 24.1 percent of working-age Americans in 2004, from

## *Gap Widens, continued*

23.3 percent in 2003. For people without disabilities it increased .2 percentage points, to 9.1 percent, from 8.9 percent.

Robert Weathers, senior research associate at Cornell's Employment and Disability Institute, said, "The findings about the overall rise in poverty are consistent with the recent Census Bureau announcement that the poverty rate increased in the United States between 2003 and 2004." The Disability Status Reports use the American Community Survey -- the public-use version of the raw data that the Census Bureau uses in its report, Weathers said.

Some Cornell researchers are investigating whether the employment gap may be due, in part, to what they call the "poverty trap." Under current federal rules, people with disabilities must be essentially unemployed to receive government benefits, but the support they receive isn't enough to keep them out of poverty, they point out.

"Those with the lowest incomes lose 50 cents for every dollar they earn. That's a higher tax rate than Bill Gates pays," said David Stapleton, director of

the Cornell Institute for Policy Research. Stapleton and others recommend that federal policy be revisited to reward, rather than punish, people with disabilities who earn income through employment.

The Cornell reports also showed that the employment rate of working-age people without disabilities was 77.6 percent in 2003, compared with 37.9 percent for working-age people with disabilities that year. In 2004, the employment rate for people without disabilities rose .2 percentage points, to 77.8 percent, while the employment rate of people with disabilities declined .4 percentage points, to 37.5 percent.

The StatsRRTC is the statistics arm of three Cornell units: the Employment and Disability Institute in the School of Industrial and Labor Relations, the Institute for Policy Research located in Washington, D.C., and the Department of Policy Analysis and Management in the College of Human Ecology. It is funded by the National Institute on Disability and Rehabilitation Research.

<http://www.news.cornell.edu/stories/Oct05/Disab.work.rpt.html>

# Daniel Porro Wins an Award for Community Advocate for the Disabled

On April 25th, 2006, Daniel Porro won an Award for Community Advocate for the Disabled given out by the Commission on the Public's Health System in New York City. Congratulations, Daniel! Our next issue will have an article about some of Daniel's experiences fighting for his rights and the rights of others to get care in public hospitals.

As written in the awards program, Daniel ". . . has lived in the Bronx almost all of his life. He went to Stevenson High School in the Bronx, where he was in Special Education classes because of his dyslexia and reading problems. After graduating with a vocational certificate, Daniel worked as a jeweler for ten years and then went to work for the NYC Housing Authority. Daniel met Rev. Sharpton and has been active in the National Action Network for the last seven years, particularly focusing on people with disabilities. He is also very active in the Bronx Mental Health Council and its subcommittees, and monitors how services are provided to residents of the Bronx. He is a representative of the Bronx Council on the Mental Hygiene Executive Federation, which is citywide.

Daniel has learned how to speak out on issues of importance to the disabled community and he does! Daniel is getting tutoring on a scholarship from the Fisher-Landau Center, a special institute for learning disabilities, and is an intern in the Mayor's Office for People with Disabilities. He is a member of Disabled In Action, and has recently joined their singing group. Daniel does not allow his disability to interfere with his role as an important contributor to the advocacy world in the city. His . . . serious approach to issues makes him an important contributor to CPHS and other organizations."

# **NATIONAL COUNCIL ON DISABILITY CALLS FOR IMMEDIATE CHANGES TO GET PEOPLE WITH DISABILITIES WHO RECEIVE FEDERAL BENEFITS BACK TO WORK**

*December 7, 2005 - Washington -* The National Council on Disability (NCD) today released its report *The Social Security Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems* ([www.ncd.gov/newsroom/publications/2005/ssa-promote-employment.htm](http://www.ncd.gov/newsroom/publications/2005/ssa-promote-employment.htm)) calling on Congress and the Social Security Administration to make immediate changes that will get more people with disabilities who receive Social Security benefits back to gainful employment.

According to NCD chairperson Lex Frieden, "Our nation's current disability benefit programs are based on a policy principle that assumes that the presence of a significant disability and lack of substantial earnings equate with a complete inability to work. Americans with disabilities remain underemployed, despite the fact that many are willing and able to work. This scenario is alarming. Although the Social Security Administration (SSA) has instituted a number of incentives to reduce the numerous obstacles to employment faced by its Supplemental Security Income (SSI) and Social Security

Disability Insurance (DI) beneficiaries, such efforts have had little impact because few beneficiaries are aware of these incentives and how they affect benefits and access to health care."

In recent times there has not been a comprehensive, research-based examination of the practices that are most likely to support the employment of SSI and DI beneficiaries. NCD undertook this study to address that absence and found that the complex obstacles to employment faced by SSA beneficiaries require a comprehensive set of solutions. New approaches must be identified that emphasize beneficiary control of career planning and the ability to access self-selected services and supports.

Public and private health care providers must develop new collaborations and new approaches to combining coverage from multiple sources to improve program efficiencies. SSA must continue to work with the Rehabilitation Services Administration and the Department of Labor to improve implementation of the Ticket to Work program and identify new approaches that will overcome the traditional

## *NCD, continued*

inability of SSA beneficiaries to benefit from services provided by the nation's employment and training programs. Secondary and postsecondary educational institutions must emphasize benefits counseling and financial management training as the foundation for beneficiary self-direction and economic self-sufficiency. Federal agencies and the business community must realize that collaborative approaches to incorporating beneficiaries into the workforce are needed as a way to reduce dependence on federal benefits while simultaneously enhancing the productivity and competitiveness of large and small business," Frieden concluded.

The recommendations discussed in this report need to be addressed in policy and procedural modifications by both Congress and the Social Security Administration to significantly address the continuing number of SSA beneficiaries who never leave the SSI and DI rolls, and to increase the number of beneficiaries who enter, or reenter, the U.S. workforce.

For more information, contact Mark Quigley of NCD at 202-272-2004 or 202-272-2074 TTY.

## **NY State Access to Home Program**

On Wednesday, December 7, 2005, Governor George E. Pataki today announced State funding awards worth over \$10.2 million to help New York seniors and those with disabilities to remain in their homes and out of nursing homes. These awards mark the first round of funding under the State's new "Access to Home" program launched by the Governor earlier this year in his State of the State address.

The following is the link to the complete press release: <http://www.ny.gov/governor/press/05/1207053.htm>

# WHEELCHAIR UNBOUND

by Harriet McBryde Johnson

*April 23, 2006, NY Times Magazine* - I'm at the United States Holocaust Memorial Museum in Washington, touring an exhibition: "Deadly Medicine: Creating the Master Race." Tomorrow evening I will be interviewed onstage by a museum official. In a sense, that will make me a temporary display, an object of interpretation, a body in a wheelchair, a body so pared down and twisted up by a genetic neuromuscular disability that it doesn't need a nearby Nazi to get a reaction. In another sense, I will be an interpreter, talking from experience as a disability rights lawyer and activist

The exhibit tells of a eugenics movement that sought to apply principles from Darwin and animal husbandry to humans. In Germany, it proceeded step by step from voluntary "healthy baby" campaigns to forced sterilization and the murder of some 200,000 disabled children and adults.

Looking at the photos of doomed children, I see my old crowd. They could be us. In "special" schools and camps for children with physical and mental disabilities, we grew up knowing we were a category of person that the world did not want. Most of us had a story of some doctor advising our parents to put

us away or to let us die. We owed our survival to parents who had irrationally bonded with us, who held old-fashioned notions of right and wrong. We knew we were lucky and hoped our luck would hold. To increase the odds, we tended to be charming. We developed thick skins.

My skin is thick enough now to let me wind through the exhibit without weeping, almost without trembling. I roll onto the tile floor meant to resemble those in the gas chambers that the Nazis designed for the "humane" killing of disabled patients. I see a photo of a girl who was once held dear by someone who put a bow in her hair but could not protect her.

Then I see the wheelchair. It's similar to other prewar wheelchairs I've seen, but there's something unusual about the frame. Is this a tilting mechanism? A fancy suspension system? Looks like fine German engineering. I like vintage wheelchairs. An obsolete Everest & Jennings drive belt hangs in my office as a bit of nostalgia, like an old wagon wheel in a barbecue shack. I have an urge to jostle the chair, to see what that frame does. The sign mentions a German institution. So, no single owner. But even in institutions, people manage

## *Wheelchair Unbound, continued*

to bond with chairs. A state-owned chair may be occupied by the same person every day, parked beside that person's bed at night. Maybe the chair was used by someone with cerebral palsy until he died, then someone with a stroke until he died, and on down the line, until . . . until they all died?

The people who used this wood-and-metal survivor probably loved it, liked to move about even as they were sucked into the nightmare. The nightmare began when the state removed them from their families, concentrated them in institutions. The same state provided them with beautifully engineered chairs and then killed them for eating up the resources of the "fit."

I pull myself away and try to absorb the rest of the exhibit. It tells how the eugenics dragnet widened, of the way concentration strategies, gas-chamber technology and sterilization techniques first designed for disabled people were applied against whole populations defined as genetically undesirable.

By the time I roll onto the stage the next night, I've thought a lot about there and here, then and now. When the first question comes, I tell them about my fascination with the wheelchair, and somehow it sounds funny, and laughter fills the room. We shuttle between the tragedy of Germany then to the comedy of here now, from the horror of

bureaucratic killing to a funny confession that I, too, tend to stare at disabled people on the street. Before I know it, I'm giving them a real show.

What has come over me? Part of it is surely the tendency to compartmentalize. But there's more. In this room, people with disabilities in thrilling variety make me feel at home. It's like the disability ghetto of my childhood, but so much better. That was a community of exclusion, created by nondisabled people who considered us unfit. This is a community of inclusion. Here people, disabled and not, are gathered by choice.

I haven't forgotten that two million people remain in U.S. disability institutions, that some disabled children still cannot attend mainstream schools, that too many of us live in poverty. But I can't hold onto anger and sorrow in this room. It is too full of life. Behind the laughs I keep getting, I feel a shared sense of possibility, a drive for a world that will embrace both the fit and the unfit and hold them so dear that the categories die.

**Harriet McBryde Johnson** is the author of the memoir "Too Late to Die Young" and the young-adult novel "Accidents of Nature," to be published by Henry Holt next month.

# **RICHARD PRYOR: GONE TOO SOON**

**by Philip Bennett**

Some of you reading this may have a problem with the above title. Possibly because we remember the late Mr. Pryor before the Multiple Sclerosis, back when he was one of the most physical of performers. Some of you may actually equate the value of his life with that physicality.

Greg Tate, in an article published in the December 14, 2005, issue of the Village Voice did just that. As he opined: "Richard Pryor really was ready to die. When I interviewed him a few years ago, he told me what bothered him the most about his MS was not being able to jump around like he used to, reminding us that this most verbal of men was also as physically comedic as Chaplin. For those reasons Pryor's demise was a sweet release, a right fitting and proper breaking on through to that other side."

Sadly, the Voice published only one letter in the next issue referring to this "he's-better-off-dead" junk. And that was to agree with Mr. Tate, that "Pryor has been waiting to rest." [12/20/05]

It would have been useful to Mr. Tate and Ms. Scott, the letter-writer, if they had

visited Mr. Pryor's website ([www.richardpryor.com](http://www.richardpryor.com)). A year's worth of Mr. Pryor's final postings are still up, and there is not the slightest dram of ready-to-die in anything he wrote. He remained passionate about animal rights, the war and nurturing the next generation of comedians.

Obviously Mr. Tate never visited that site (I found it after a simple Google-search). Nor did he interview Mr. Pryor's family. Was it because of deadline pressures? Or maybe the truth can often be too inconvenient to one's preconceived notions?

Daryl "Chill" Mitchell, a veteran actor and rap artist who recently became a wheelchair-user, understands these notions. As he told the New York Post not long ago, he'd been fighting his entire professional life to be accepted as a black actor. Now he must also struggle the same struggle as a disabled actor.

For those of you who believe Mr. Pryor was indeed ready to die, or even that he should have died sooner, you're the reason the fight must continue.

The **DIA ACTIVIST** is published by Disabled In Action of Metropolitan New York, Post Office Box 30954, Port Authority Station, New York, NY 10011-0109, (718) 261-3737, <www.DisabledInAction.org>. DIA is a civil rights, non-profit, tax-exempt organization.

Call Jean Ryan at 718/745-6705 to receive **taped** issues of the **DIA ACTIVIST**.

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