DIA ACTIVIST
May 2009

Making a Commitment to Activism

By Jim Ellis

As you all know, DIA means one a month. This year, DIA will meet every month. It seems to us a great deal that more members do not make a commitment to the organization and to activism. We want to see more of you. We want to see more participation in our activities. We want to see more people who are willing to take on more responsibility.

For too long, the same one group of activists have been working on many issues because no one else is willing to take up. I know not everyone is healthy. Many people have other commitments. But there are many who are able to do more than they do now. We want to see more of you. We want to see more people who are willing to take on a little more responsibility. We want to see more people who are willing to take on a little more responsibility and who are willing to be trained strongly in what's our working model. We, efforts paid off in a big way.

The objective of activism is not to make someone else's life better. The objective of activism is to make sure that we are able to live the long, hard, easy, changes in our society that will make our lives better. We want to see more people who are willing to make a commitment to activism and who are willing to make a commitment to be trained in the transitions from fear of absence to participation. You can do it but it is a commitment to other members and to the overall philosophy, putting the work being done.

I urge you to consider making a commitment to activism. It is a commitment that needs to be done. I recommend highly to people current. You can make a difference. We want to see more people who are willing to make a commitment to activism. Please, please, please. Contact us at http://www.disabilitiesarts.org/contact.html

Let us a 1-718-202-2537 if you want to join a committee or help out.

Letters to the Editor

Note from the editors: This issue marks a new section, Letters to the Editor. We encourage your comments and ideas about what you want to be SUPPORTED or other disability issues. Please send your letters to the editors at DIA, 1 Pennsylvania Plaza, Suite 1100, New York, NY 10119. We reserve the right to edit letters for length and clarity. Letters may be edited for grammar and spelling.

Proposal for a Working Group on Repressive Practices

Dear Disability Independence Group, I would like to propose the formation of a working group to discuss and develop strategies for the elimination of repressive practices against disabled people and other discrimination. DIG anticipated a lot, but only half-measure. Disabled people are still treated like children.

I am a disabled person and I live in a nursing home against my will. I am 21 years old. I have been in this place for two years. My life is spent in a 2 bed ward, sharing with a stranger who is mentally ill. I am not allowed to leave. I am saying that I am a prisoner. I am not allowed to go out when I want to go out. I am treated like a child. I am distressed by this.

The objectives of this working group would be to: Raise awareness of the issue of repressive practices against disabled people. Develop a strategy for the 1996 Civil Rights Bill. Develop a strategy for the 1996 Civil Rights Bill. Develop a strategy for the 1996 Civil Rights Bill

"A little faster, the right shrapnel, and I probably wouldn't be here today to address these issues,"" said Perner

Penner and six others from the Rochester area were traveling to Albany to meet with state lawmakers regarding disability issues

""If they are going to provide amenities to people with disabilities, it has to be more than a decal on the side of a car. Someone should be thinking about chairs, people and equipment,"" he said.

Sherry Lampert 1947-2001

Some of you may remember Sherry Lampert's insightful and humorous articles in THE ACTIVIST through the years. Sherry lost her valiant fight against breast cancer on March 23, 2001. Her friends and colleagues remembered her with a memorial service on April 3rd. Below is a piece she wrote that gives the reader Sherry's spirit and the ways we knew her.

For Sherry

by Philip Bennett

I don't remember the first day I met Sherry Lampert. It was probably at one of my first DIA meetings, many years ago. My first words to her were probably, ""Do you need any help?"" And I'm sure, if she did need help, she told me politely and in no uncertain terms that she didn't need help and that I understood every word she said. That's the way she was.

Some who barely knew Sherry, who only saw the chair and twisted hands and face, who struggled to make out her garbled speech, and who assumed that she could not possibly have a life worth living, will be surprised to hear that Sherry was one of our greatest and toughest fighters and most loving friend. She may never have had a job or a family of her own (outside of us), she may never have mounted a podium to make a speech or physically helped with a mailing, but her commitment to the Cause was no less grueling than any of ours.

Her favorite activity was demonstrations. And she attended just about everyone we had, even if it meant getting up at 3 in the morning, staying from dawn to dusk in Washington D.C. and then heading home to Rochester. I remember she was there when we shut down a state office building and even arrested, just a few days after learning she had cancer.

She had opinions and was not shy about expressing them. And we all knew where she was coming from when she spoke; even when we disagreed with her. We had to make damn sure we knew what we were talking about when we responded to her comments. Anyone who spent any time with her knew this woman was no metal lightweight.

After her mastectomy she was determined to get past it and move on, and even used the experience to highlight the attitudinal shortcomings of some medical professionals. And, of course, she was back at the demonstrations, and Washington, and Albany. She was ""real hot,"" as she would say, ""real in vivo,"" and the radiation was ""a blast.""

And when she was told several months later that the cancer had spread and death became a real possibility, she refused to let that get her down either, insisting that, at her service we had to tell her jokes and she wanted to be buried in her ""Not Dead Yet"" tee-shirt. Too soon the cancer ate through her body and the morphine took much of her spirit. She spent the last two days of her life in a hospital bed dreaming the dying of the light. My deepest regret is that we did not have her hear her valiant heart finally came to rest, but I'm grateful that I was able to hug her one last time and say goodbye the day before the end came. Regretably, she did not get her wish. I don't know what she wore when she was buried. All I know is that this beautiful woman, though born into the Jewish faith and rejecting organized religion, died with a huge wooden cross and figure of Christ mounted on her chest. I'm sure she died, that she had no service at all and, at her bowel, had to suffer the final indignity of a Rabbi proclaiming to one and all that Sherry's life was empty and filled with pain and sadness.

I'd like to think that Sherry is with us right here and now, and that she's as pissed off as ever. Yes, Sherry, we will never ever forget you as we struggle to fill the cavernous hole your passing has left in our Cause. We will attempt to be worthy of your memory and your pursuit of justice as a united people and, as individuals, to live at least half as full a life as yours. Much like Dr. King believe you, you didn't leave a huge estate behind, or a lot of money or titles greater than DIA Board member behind, but you left a magnificent life behind. And those of us who still walk and talk and use our hands in a so-called ""normal"" way must spend the remainder of our lives trying to be as rehabilitated as you.

Goodbye, sister. And keep givin' 'em hell.

Rae Unzicker

In March, the international company of people committed to the empowerment, dignity, freedom, independence, rights, capacity and humanity of people considered to have a psychiatric disability lost one of our greatest leaders. Rae Unzicker was the founder of the National Association for Rights Protection Advocacy (NARPA) and, most recently, founder of the organization, Voices for pioneering change on the behalf of people with psychiatric disabilities.

More important, she was mother, inspiror and model for thousands of advocates all across the nation working to promote the rights and needs of people with psychiatric disabilities.

""To Be A Mental Patient""

To be a mental patient is to be stigmatized, ostracized, socialized, patronized, psychiatrized.

To be a mental patient is to have everyone controlling your life but you. You're watched by your shrink, your social worker, your friends, your family. And then you're diagnosed as paranoid.

To be a mental patient is to live with the constant threat and possibility of being locked up at any time, for almost any reason.

To be a mental patient is to live on $82 a month in food stamps, which won't let you buy Kleenex to dry your tears. And to watch your shrink come back to his office from a weekend in Montreal.

To be a mental patient is to take drugs that dull your mind, deaden your senses, make you jitter and drool and then you take more drugs to lessen the ""side effects.""

To be a mental patient is to apply for jobs and lie about the last few months or years, because you've been in the hospital, and then you don't get the job anyway because you're a mental patient. To be a mental patient is not to matter.

To be a mental patient is never to be taken seriously.

To be a mental patient is to be a resident of a ghetto, surrounded by other mental patients who are as scared and hungry and bored and broke as you are.

To be a mental patient is to watch TV and see how violent and dangerous and dumb and incompetent and crazy you are.

To be a mental patient is to a statistic.

To be a mental patient is to wear a label, and that label never goes away, a label that says little about what you are and even less about who you are.

To be a mental patient is to never to say what you mean, but to sound like you mean what you say.

To be a mental patient is to tell your psychiatrist he's helping you, even if he is not.

To be a mental patient is to act glad when you're sad and calm when you're mad, and to always be ""appropriate.""

To be a mental patient is to participate in stupid groups that call themselves therapy. Music isn't music, its therapy; volleyball isn't sport, it's therapy; sewing is therapy; smoking dishes is therapy. Even the air you breathe is therapy and that's called ""the milieu.""

To be a mental patient is not to die, even if you want to -- and not cry, and not hurt, and not be scared, and not be angry, and not be vulnerable, and not to laugh to loud -- because, if you do, you only prove that you are a mental patient even if you are not.

To be a mental patient is to be nothing, in a no-world, and you are not.

Rae Unzicker © 1984

Victory in Federal Paratransit Case

A dispatch by Steve Gold from Philadelphia, January 8, 2001

'MAY NOT RELY ON ITS OWN INADEQUACIES'

Transportation authorities throughout the country have known that they were supposed to comply with the DOT's ""next day"" requirement, but have blatantly violated it.

Now, a United States District Court has issued the first decision in the country under the ADA and Section 504 on the ""next day"" issue. The court upheld the U.S. Department of Transportation's regulation that a public transportation entity ""shall schedule and provide paratransit service to any ADA paratransit-eligible person at any requested time on a particular day in response to a request for service made the previous day.""

The Court stated that DOT expected public transportation ""to attempt to provide prompt requested rides to all ADA-eligible riders, without exception.'' That means 100 percent of people with disabilities are entitled to paratransit service ""to the same degree that people without disabilities are provided service.

In rejecting the transportation authority's defense, the court said that ""the focus is not on the percentage of paratransit rides provided to the disabled but rather the number of rides that the transportation authority fails to provide these patrons and the reasons for that failure.'" Further, ""while the transit authority provides rides for many patrons it cannot rely on the fact that it is able to provide rides to some passengers to justify its noncompliance for all.''

One of the two plaintiffs, Liberty Resources (the CIL of Philadelphia) had standing in the suits, the Court held, because it was injured by the authority's nonperformance. Liberty spent employee time meeting with the transportation authority, participating in protests, and staffers were also unable to schedule rides to visit clients. Volunteers to the center had also been unable to schedule rides. The Court found that Liberty Resources provided ""an undisputed record that shows a concrete and particularized injury, specifically, expending time and resources to counteract the effects of wrongful conduct.

[Moath Magazine Note: Gold was attorney in the case. He adds that ""The decision and the requirement for next-day service is a great organizing handle.'" He also salted the U.S. Department of Justice for filing an extremely helpful and persuasive amicus brief. The decision is on the Internet at http://www.paed.uscourts.gov.]

Post March/April 2001 Moath Magazine, page 8

ACTIVIST editor's note: Access-A-Ride in NYC should also focus on its mistakes to try to rectify them instead of saying how many rides they provide. Our people are still being stranded by AAR and not getting rides for the next day. Steve Gold was also one of the attorneys on the lawsuit against Access-A-Ride in which DIA participated.

BREAKING NEWS: On April 20, 2001, Paratransit in Philadelphia struck back by saying that it will try to eliminate ten percent of the 6,000 people who take paratransit by requiring people who want to be found to be able to agree to travel at from a bus stop, not a wheelchair lift, and have to schedule and transfer from one route to another. They will look at individual's pattern of travel. But Gold said that transit agencies are not allowed to restrict people with disabilities to certain transit routes. By allowing fewer people to take the paratransit, the agency is hoping it will save money. Hopefully this unfair idea will be stopped in its tracks.

Florida Adopts ADA Notification Flyer for Businesses

On February 12, 2001, Florida Secretary of State, Katherine Harris, held a press conference to launch the Florida's ADA Notification Flyer. She collaborated with disability advocates to create this document which is now being mailed with every application for a Florida occupational business license and to all license renewals. It is also included in all incorporation document applications. The object of the initiative is to provide notice to businesses that they may have an obligation to remove obstacles to accessibility if they deal with the public and qualify under Title III, public accommodation provisions of the Americans With Disabilities Act (ADA).

Harris is promoting this initiative to all secretaries of state in the other forty-nine states. Advocates are urging people to contact the secretaries of state in their state. Disability advocates also hope to convince Representative Mark Foley (R-FL) that there would be no need for his Americans With Disabilities Notification Act if every state followed Florida's example.

ACTIVIST editor's note: It would be great if we could do something like this in our state, hopefully we would have more accessible places and less work to do in forcing businesses to become accessible.

From Disability News Service, November, 2000.
Posted about it at http://www.adaacademy.org/
See a copy of the Notification Flyer at: http://www.disabilitynews.com/flada.htm

Finally!!
The Nation's Largest Nonprofit H.M.O.Agrees to Become Accessible

The nation's largest nonprofit H.M.O.agreed in April 2001 to revamp all its California health centers and policies to ensure that people with disabilities, nursing homes and back rooms. People with disabilities are still the poorest of the poor.

The agreement will settle a class-action lawsuit, the first of its kind in the nation, that was filed last year against the health maintenance organization, Kaiser Permanente, on behalf of all in California unable to walk, see, hear or speak. The lawsuit argued that Kaiser discriminated against disabled persons by giving them inferior medical care.

Part of the problem, the lawsuit said, is inaccessible medical equipment, like examination tables that do not lower and scales and mammography machines that cannot be used by people in wheelchairs.

""My first reaction was, 'Oh, my God, we have a lawsuit,'"" said Richard Pettingill, president of Kaiser's California division, ""but it only took about five minutes before it was apparent to me that we needed to step up and provide some leadership.''

The settlement Kaiser agreed to is far-reaching, covering not only the installation of accessible medical equipment and the removal of architectural barriers, but also a broad commitment to develop training programs, handbooks and a complaint system to meet the needs of the disabled. Kaiser also agreed to consider developing specialized clinical programs in disabilities and to review all its policies, to ensure that they are fair to people with vision, hearing, cognitive, speech and mobility disabilities.

""We believe this will be revolutionary in terms of its impact on health care for people with disabilities,"" said Sid Wolinsky, litigation director of Disability Rights Advocates, the Oakland group that brought the lawsuit. ""The agreement with Kaiser provides a comprehensive blueprint that could be used by any health provider anywhere in the country. We intend to use this as a template to present to other major health-care providers, to urge that they, too, adopt this approach.''

Editor's Note: We need accessible medical care in New York City, too. Let's work towards getting it.

Justin Dart on Bush Tax Cut

Today, March 1st, 2001, People For the American Way and a coalition of more than 500 organizations held a Washington Press Conference to protest the tax cut proposed by President Bush.

Justin Dart spoke representing the disability community. Andy Imparato, president of AAPD (American Association of People with Disabilities), was also present. Dart's remarks follow.

""I know that the great majority of 54 million Americans with disabilities join me in congratulating President Bush on his pledge to build 'a single nation of compassion and opportunity' and his New Freedom Initiative for the disability community.''

But conscience demands that most of us oppose the President's tax cut proposal that would benefit principally the well-to-do at the expense of programs like Medicaid, Medicare and Social Security and the elimination of deficits and debt.

In the midst of world record prosperity, millions of Americans still lack adequate food, housing, education and health care. Millions face old age with no guarantee of security.

Millions of people with disabilities are still unemployed. Millions are segregated from the mainstream in institutions, nursing homes and back rooms. People with disabilities are still the poorest of the poor.

Americans, let us transcend partisan arguments, and unite in what will add age - reverence for individual human life. Instead of cutting taxes for the fortunate few, let us invest in the empowerment of all to live their God given potential. Rich and poor will profit, economically, and in quality of life.

Mr. President, lead us indeed to a nation of justice and opportunity for all.''

During the question and answer period, one reporter asked the panel members if they would refuse to accept the Bush tax cut on their personal tax returns -- returning the money to the government. Justin Dart answered,""I would receive a substantial tax cut under the Bush plan. I would not return the money to a government that is attempting to repeal Abraham Lincoln democracy. I would donate all of it to the People for the American Way, the Leadership Conference on Civil Rights and the American Association of People with Disabilities.

That is a promise.""

(from the *Justice For All* website: http://www.jfaonline.org/)

The FDR Memorial: Who Speaks From the Wheelchair?

by Rosemarie Garland-Thomson

As public spaces transformed into collective stories, memorials are inherently controversial. Didactic narratives about who we are and what we believe, they span generations and vast differences in human perceptions, bringing to light all sorts of divisions in the national ""we.""

One of those divides has occurred between a group of scholars in disability studies and the designers of the Franklin Delano Roosevelt Memorial in Washington. The five-year struggle over the collective story told by the F.D.R. memorial could only begin with this premise: Disability, not President Clinton dedicated an addition to the memorial. The controversy -- and, unfortunately, its not entirely satisfactory conclusion -- tells us much about disability in American culture, about disability studies, and about ourselves.

Even before its dedication, on May 2, 1997, the memorial had splintered the national ""we."" The original monument consisted of four granite-walled outdoor ""rooms,"" which narrated F.D.R.'s presidency with inscriptions of his own words and with nine bronze bas-reliefs and statues, representing scenes of his presidency, all intermingled with pools, waterfalls, and greenery.

The segment of the American ""we"" representing disability-rights activists and scholars in disability studies had wanted to avoid repeating the persistent stereotypes of disability -- the sick man in the wheelchair, the helpless invalid, the pitiable victim -- that relegated to the private realm of charity and medicine, but inappropriate in the public sphere.

We had wanted the memorial to tell the story of a man who was both disabled by polio and president of the United States for 12 years; to claim F.D.R. as a disabled public figure who represented not just the 15 percent of the U.S. population who have disabilities, but everyone, since we will all become disabled if we live long enough. The centennial's powerful and beautiful image of a disabled president would contest if people were transformed by civil-rights movements that included the disability-rights movement, and by legislation like the Americans With Disabilities Act, the landmark law that mandates full integration of people with disabilities into mainstream society.

But the only statue that even remotely referred to F.D.R.'s disability showed him seated, covered by a cape, on a chair with small wheels barely peeking out. The threat of protests by disability activists at the memorial's dedication convinced President Clinton to seek an addition, and the designers agreed -- the first time that an existing national memorial was altered. The new addition, Mary Lou Zeallos's stunning bronze statue, depicts President Roosevelt with empty-sleeved figures of soldiers, but those traditionally heroic statues only flank, rather than fundamentally change, the somber black-granite slab and the space of meditation and mourning it creates.

The bold mandate to reimagine F.D.R. as at once heroic and disabled has now been realized. A new ""room"" at the entrance to the present memorial contains a simple, life-size bronze statue depicting Roosevelt seated in his wheelchair, wearing his trademark rumpled suit, pince-nez, and fedora. It differs from the regal, robed, larger-than-life statue of President Roosevelt that stands in the adjacent room and dominates the rest of the disability. The new statue witnesses and celebrates the simple humanity of the great leader and registers it as the universality of disability. It also marks today's historical moment, when disability defined as a civil-rights issue is superseding disability as a medical or charitable issue.

Yet the controversy continues, because the story that the new ""room"" of the F.D.R. memorial tells is still fraught with contradiction. At issue is the phrasing of the words inscribed on the granite wall behind the new statue of F.D.R. A group of us from the field of disability studies had been invited to recommend potential quotations, from which Roosevelt would choose a few for inscription. As historians and the public critics who traffic in words, we refished the chance to influence the way that people present and future would understand disability. The memorial's other inscriptions are illustrious words that enrich the story told by the spaces and the statues. F.D.R.'s eloquent verbal commitments to equality are built in once, shaping the story of his presidency and of the nation itself. One powerful quotation reads, ""We must scrupulously guard the civil rights and civil liberties of all citizens, whatever their background. We must remember that any oppression, any injustice, any hatred, is a wedge designed to attack our civilization.'' Was it the hubris of wanting to continue the theme of equal rights for all that kept the Kaiser disability-rights movement and the F.D.R. memorial

We had a story about disability that we wanted the new room to tell. We sought to offer a quotation as crisp, powerful, and unambiguous as the bold ""I hate war"" chisled into the wall above the tumbled stones that suggest the blasted buildings of World War II while creating a majestic waterfall that implies transcendence.

F.D.R.'s strategy in the Depression had been to alter the environment to meet the needs of the people. That was parallel, we reasoned, to the idea that people with disabilities need a minority model of disability to change the environment to respond with sympathy, admiration, and charity rather than with support for equal access and integration. A more effective way to humanize F.D.R. would be to suggest that his impairment reinforced his commitment to the universal rights of ""people with disabilities.'' Such a quotation would contradict the stereotypes.

The designers also mistakenly justified the choice of their text on aesthetic grounds. The story of ""Franklin's illness"" as well as of his ""strength,"" ""courage,"" ""patience,"" and ""persistence"" would create an aesthetically differentiated and inspirational space, they argued in commenting on our recommendation. The new room was to be a ""prologue."" In reality, that suggests the personal story of disability from the political context of the memorial's other rooms. The quotation clings to the stubborn stereotypes of disability that still feel comfortable to many Americans, simply because those ideas are so easily recognizable. A wheelchair-using F.D.R., spoken for by others, is segregated within his own memorial. That denies the political work of disability-rights activists and scholars, who have sought to eliminate precisely such segregation.

Many of us in disability studies wish to register our dissent from the choice of the inscription for the new room of the F.D.R. memorial. Pleased as we are with the statue itself, we worry that this memorial to our first markedly disabled president ultimately replicates the segregation and privatization of disability. The inscription undermines the work of disability-rights advocates who worked so hard to make the new room a reality. It tells the story that disability is separate from politics -- a personal problem rather than a public political struggle.

In the year 2001, we are on the cultural cusp of a new way to understand disability. The memorial's figures, spaces, and, particularly, its words implicitly instruct visitors to think about disability. The controversy over the F.D.R. memorial's inscription of disability from the political context of the memorial's other rooms. The quotation clings to the stubborn stereotypes of disability that still feel comfortable to many Americans, simply because those ideas are so easily recognizable. A wheelchair-using F.D.R., spoken for by others, is segregated within his own memorial. That denies the political work of disability-rights activists and scholars, who have sought to eliminate precisely such segregation.

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Rosemarie Garland-Thomson is a professor at Howard University. This article, which was in the Chronicle of Higher Education, is reprinted here with her permission.