DIA ACTIVIST

January 2001

New Blood, New Ideas

by Anthony Trocchia

As the new President of Disabled In Action of Metropolitan New York, I am determined to breathe life into what was once an exciting and formidable organization. I truly believe that there exists no other organization for people with disabilities like DIA. This is as grassroots as you can get.

DIA is made up of people with disabilities who want to bring about changes. As disabled folks, I don't think we should ever be content with the existing situations. Our abilities and status are always being undermined (perhaps not intentionally, but it happens regardless). I have grown weary of good intentions. I am tired of being patient, and I'm fed up with having to be so understanding until non-disabled America gets it right. I firmly believe that anger, if used constructively, can be quite powerful. Let us discard with the “"thank-you's"” and feelings of gratitude. No, I am not suggesting that we all become mean and bitter individuals. I am simply saying that in the year 2000 (heading into 2001), people with disabilities must learn to fend for themselves.

I want the One Step Campaign to be pursued with vigor. Everyday, establishments scoff at the ADA, the New York City Human Rights Law, and Local Law 58. When a business opens with a step at the entrance it is tantamount to hanging a sign in the window of that store which states “"Disabled people not welcome!"”

As you all know, the New York City subway system is not accessible despite claims made by New York City Transit (NYCT). What good are elevators and ramps if a wheelchair user cannot get onto the damn subway car? For too long, NYCT has ignored the problem. Well, it's time to wake them up.

The problems with the buses which operate (supposedly) under the auspices of NYC Department of Transportation continue to provide shoddy service to the disabled. What's wrong with blocking the bus when you've waited and three buses in a row either have a broken lift or no lift? Why do you think NYCT buses are so reliable? Yes, it's partly because Mayor Giuliani has no hand in the operation of NYCT, but it's also because disabled folks protested and blocked buses until NYCT finally got it right.

Speaking of protest, there will be more of them. Besides increasing visibility, demonstrations are a great way to show that disabled people aren't passive spectators of life. We know what we want and shouldn't stop fighting until we get it.

If you're the type of disabled person who is easily satisfied with getting a pittance of the American Dream, then you're not a good candidate for joining DIA. However, if you're fed up, disgusted, tired of complaining to blank walls, and know that changes only come about via activism, then please join us.

DIA wants/needs dedicated men and women.

From the Editor

I'm the new editor of the DIA ACTIVIST, and as such, I will try, along with the newspaper team, to bring you timely articles on issues which affect us. It will be hard to follow Nancy Rolnick's wonderful example of hard work, organization, quality writing, and fairness. Thank you, Nancy, for having faith in me to continue the ACTIVIST after you resurrected it from the dead and made it into a vital newspaper again.

But neither I nor the rest of the newspaper committee can have a vital paper without contributions from you, the members of DIA. Send us your hearing testimonies and your activist news and views. We'll be happy to print them as long as they are about a page long (typed or hand-written) and your name, address and phone number are attached (we won't print your personal information).

This is a great organization. It's good to be here working with all of you.

Jean Ryan

Testimony of Daniel Robert

At Voter Assistance Commission Public Hearing

December 15, 2000

I want to thank the Voter Assistance Commission for giving New Yorkers the opportunity to speak our minds about the state of the voting system as we have experienced it and as we would like it to be.

For the first 23 years of my voting life, I was an Upright, an able-bodied citizen. I took the great privilege, the grand, inalienable right to vote for granted. Not so much the ideal of one person one vote. About that, I've always been passionate. But the mere physical act of moving the levers and pulling the big final handle. I never thought that I wouldn't be able to do that.

I always voted. I voted for school boards, for appropriations for sewer systems and highways and environmental cleanups. I voted for aldermen, judges, City Councilmembers, Assemblymembers and State Senators; Congressmen, US Senators and Presidents. I voted in every election for 23 years.

When I was 43, in 1990, as a result of Multiple Sclerosis, I started using a wheelchair. Imagine, if you can, my dismay the first time I went to my designated polling place in a wheelchair. It was in

November of 1990. Bush, Sr. was in his second year, and the Gulf War was heating up. I honestly can't remember who or what was on the ballot. But I do remember signing the book and rolling up to the booth. I stared up at the levers with my mouth open. I couldn't reach them. I was devastated. I felt like I was in the Twilight Zone. I just sat there.

After a while, a poll worker came over. “"Can I help you?"” he asked. I just sat there. Finally, I said “"I guess you'll have to help me. I can't reach the levers. I want to vote for so and so and so and so, the straight Democratic ticket and 'Yes' and 'No' on the propositions."”

I guess I've voted at least 25 times since then. Sometimes, I get a poll worker to flick the levers, and sometimes I bring my own PCA (personal care attendant) along to do it.

On Election Day, November 1996, my PCA at the time did what I told him to do and flicked the Clinton-Gore lever; and then, before I could stop him, in the blink of an eye, he pulled the big handle and that was that. End of story. I had been, to all intents and purposes, disenfranchised by my own employee. Now, I am more careful.

New York City's current voting machines are inaccessible to tens of thousands of New Yorkers - many of us wheelchair users, others who are blind or visually impaired and still others with cognitive disabilities. *This is a massive, chronic, flagrant violation of the Americans with Disabilities Act.* And it manifests society's entrenched prejudice against us. It is one of the countless instances of bigotry directed at people with disabilities.

The current Presidential Debacle has a two-pronged up-side. Bright spotlights are focused on the needs for electoral reform and for across-the-board uniform upgrading of the machinery of enfranchisement. It's the voting machines, stupid.

Many states have already made the quantum leap to either Optical Scanning or Direct Response Electronic (DRE) voting machines, both of which are a lot more accessible than what we have here. The national percentages are: 34% Punch (the dreaded chad maker), 23% Optical Scanner, 19% Lever, 9% DRE, and 25% Other, according to a recently published Federal report.

I know there are Board of Elections people here as well as assorted legislators or their representatives. Ladies and gentlemen, the window of opportunity is wide open for the first time in Heaven knows how long. You know what to do. Just do it!

Access-A-Ride Survey Volunteers Wanted

We need your help. Access-A-Ride users in New York City are being asked to participate in a study that will run two months. Volunteers will fill out a simple form for every ride you request and every ride you take. The purpose is to ascertain whether or not the terms of the lawsuit settlement are being met with regard to denial rate, length of time on hold for a reservation, pick-up time, length of ride, and whether or not you were late to your appointment. Unfortunately, it is up to the riders ourselves to get this information on top of our exhaustion and frustration with service breakdowns and poor scheduling.

In September, there was a rushed study that fell apart and disillusioned many participants and people who tried to participate but weren't sent the forms. This study will be different! We are looking into hiring someone to tabulate the results and we will make sure that all volunteers are called and receive the forms in time.

If you or anyone you know use Access-A-Ride, please contact us and leave your name, address, and phone number. We will call you and send you the forms before the survey starts. We need hundreds of people in this survey.

Thank you!

Moving Right Along

For months, but without success, we have been trying to get an appointment with the new NYC DOT Director of Sidewalk Management and Pedestrian Ramps (curb cuts), Irvin Lowenstein. We will next be attempting to meet with his boss, the newly appointed DOT Commissioner, Iris Weinshall (who is Senator Schumer's wife). We want to discuss what DIA members can do to get specific pedestrian ramps put in and what to do about old ones (or new ones, for that matter) which are sub-standard or in need of repair.

The ongoing lawsuit between EPVA and New York City is still in the process of being settled although it is closer than it was several months ago. According to James Weisman, Esq. of EPVA, the lawsuit is in mediation over setting sanctions for not installing most of the pedestrian ramps by 2006, the date that the City agreed to do them by. Right now, the Office of Management and Budget is stalling by not agreeing to sanctions if they don't do the ramps on time. The statute requires a timetable by location, but if there are no teeth in the requirement, why would the City want to follow a timetable? By 2006, all but one percent of the City's curbs, about 1700 curbs, would be done, and these would be difficult-to-do ones such as ones with a fire hydrant or pipe in them. There would also be a contingency fund to repair ramps that need it. The type of construction plan that is anticipated for the pedestrian ramps is going to be “"blitz"” construction, where a contractor does one area very intensively before moving on to another area. It is likely that there will be at least one contractor for each borough. Hopefully, by the next issue of the DIA ACTIVIST, we will have a settlement to announce.

The annual Margaret Mead Film Festival in early November at the American Museum of Natural History (in NYC) exhibited documentaries about disability culture and life in a series called Reframing Disability. Cheryl Marie Wade was featured in a lively and informative film by Jerry Smith called *Disability Culture Rap*, a combination of in-your-face dialogue about ongoing disability issues and a history of the struggle for disability civil rights. Another film, *Stairway to Heaven*, by Erol Morris, featured Temple Grandin, an inventor with autism. It was remarkable both in its showcasing Ms. Grandin's accomplishments in humane slaughterhouse design (is there really such a thing?) and also in its candid interviews with Ms. Grandin about her disability and how she uses her unique point-of-view in her work. Afterward, a photographer friend of Ms. Grandin showed slides and answered questions from the audience. One of the most interesting elements of the film and slide show was the “"squeeze machine"” that Ms. Grandin invented to reduce her anxiety. Another outstanding entry in the Festival was *Liebe Perla*, a moving Israeli film by Shahar Rozen about an actress, Perla, who is the only surviving member of a family of performing dwarfs who were imprisoned in a Nazi concentration camp and studied by Dr. Josef Mengele. If it wouldn't have been for their dwarfism, the family would certainly have been put to death. The film does justice to the complexities of the human spirit as we glimpse conversations between Perla and her new German friend, Hannelore. The audience was able to participate in a post-screening discussion with the director, Hannelore, and several disability rights activists and scholars.

The Festival was interesting but there was room for improvement in the way tickets were sold to mobility-disabled viewers who came with wheels. Some of us were mistakenly told it was not necessary to buy tickets in advance, and then when we got there, we were told they were sold out, even though we brought our own seats. That fact was lost on some of the staff, and it was only through determination and luck that some of us managed to get in to the series about disability!

It's about time! This was the first year that the New York City Marathon had an official wheelchair division. Although prize money will not be awarded until the 2001 race (why the wait?), the reason for the change after 31 years of unofficial status was a 1999 lawsuit against New York Roadrunners Club, the official sponsor of the race. The official wheelchair winner of the twenty-six mile November 5, 2000, race was Kamel Ayari in 1 hour, fifty-three minutes, and 50 seconds. Way to go!

Listen-up disabled teens! Here's a website for a web'zine for you called @ctive Teen, and it is at http://www.disabilitycentral.com/. The 'zine is written by teens with disabilities for teens with disabilities with a grant from the US. Dept. of Education. There are plans for articles, forums and chatrooms. Check it out.

The FDR Memorial in Washington, D.C. is going to have a new statue! On January 9, 10, or 11, 2001, there will be a dedication of a statue of FDR in a wheelchair. This beautiful, peaceful memorial by the Potamac River will be enhanced by the new statue as a testimony to what people with disabilities can do.

Keys to Managed Care: A Guide for People with Physical Disabilities, has been published by the Paralyzed Veterans Association (PVA). You can get it by calling **1-888-860-7244** or by going online at http://www.pva.org/pubsandproducts/pvapubs/Keys.htm

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Sound familiar? In November three civil rights groups sued Los Angeles County's transit agency in federal court for allegedly failing to meet the transportation needs of tens of thousands of disabled riders. They claim that the L.A. Metropolitan Transportation Authority and the company it contracts to provide almost all of paratransit service for the disabled is violating the Americans with Disabilities Act because paratransit service is not comparable to regular public transportation.

According to the Associated Press release, “"lawyers for the plaintiffs say that means disabled people should not be required to wait any longer, should not have to book further in advance and should be able to take public transportation to any place serving the general public. The suit was filed by the American Civil Liberties Union, Western Law Center, and Protection and Advocacy Inc.."”

Why should we in DIA demonstrate when it is hot/cold, rainy/snowy, boring, tiring, and time-consuming? So we can exercise our first amendment rights when we disagree with something an agency or the government is doing or saying. Who knows if it will be successful? No one knows that in advance, but like the saying says, “"Nothing ventured, nothing gained."” In 2001, we hope to see more DIA members out in force for our demonstrations. We need you. You count! Come and be heard. Anyone who is interested in being on a list to donate their time for a demonstration should please call Olga Hill at **1-718-261-3737**.

Happy Birthday, ADA!

by Nadina LaSpina

Speech given in City Council Chambers
July 26, 2000

Happy Birthday, ADA! Ten years old! And it seems like only yesterday! It seems like only yesterday when the ADA was just a dream: “"If only we could have a law - stronger and more definitive than 504 - a law that said we're equal citizens ...A law that said: the way we're treated is discrimination and it's wrong! If only we could have our own civil rights act, our own emancipation proclamation!"”

Most people think the ADA came about because of good old American good-heartedness - that's if they even know there is an ADA. Most people have no idea of the struggle - the work, the activism, and yes the dreaming that went into it. They don't know that the ADA was the achievement of a social movement: our movement, the disability rights movement. Nothing would have been accomplished without the disability rights perspective of our people as a minority group that has been subject to discrimination and unfair treatment, and without our willingness to take to the streets and risk arrest to bring public attention to our issues.

Of course, there were key players that made the ADA happen. Robert Burgdorf, Justin Dart and the other members of the then National Council on the Handicapped who drafted the bill. Pat Wright who came from California to lobby for it. There were the politicians who helped push the bill along, like Senator Tom Harkin, Ted Kennedy, then Congressman Tony Coehlo, and New York's own Major Owens who appointed a special congressional task force on ADA.

But what really made the ADA happen was us: the disability community. It was to fight for the ADA that for the first time we really ALL came together: people with all different types of disabilities, people from all walks of life. We all did it in different ways: letter writing, lobbying, demonstrating and even crawling up the steps of the Capitol. Do you remember the D.C. rally in March of '90 when the ADAPT activists crawled up the 83 marble steps of the Capitol building? We all wanted this law so badly! For so many of us such a law had been our own private dream. Now we saw the possibility of the dream becoming a reality, of our dream becoming the law of the land.

And then the ADA was the law of the land. “"Let the shameful wall of exclusion finally come tumbling down."” With those words George Bush signed the ADA while three thousand people with all kinds of disabilities gathered on the White House Lawn to watch and rejoice.

Well, I'll be honest, the joy was bittersweet for many of us. There was disappointment because the original version of the ADA had been watered down quite a bit, extending compliance dates way into the future, granting business the “"undue hardship"” excuse. There was worry that the ADA was really a law with no teeth - no strong enforcement mechanism, and largely non funded. Many of us were uncomfortable with the political climate in which the ADA was produced. We were worried that, since now they were supposedly opening the doors of opportunity for us, we'd see even more cuts in social services and entitlement programs. But in spite of all of that, in spite of the law's limitations, the ADA did something incredible: it validated our struggle. Here it was carrying the congressional stamp of approval: “"Historically, society has tended to isolate and segregate individuals with disabilities... discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation..."”(*Findings of Congress, Sec.2*).

In spite of the disappointment and the worry, we could all identify with Justin Dart when he said: “"The ADA is the world's first comprehensive civil rights law for people with disabilities, a landmark in the history of human development! After thousands of years of rejection every waking hour of every day, we are declared to be equal members of the human race! By the United States of America! My spirit soars! I am a certified American! Alleluia! I'm a human being!"”

Now it's been ten years. The ADA remains what Justin Dart called it then: the most comprehensive, far-reaching civil rights law for people with disabilities in the world. All over the world disabled people look to us, and the ADA has become a symbol of the promise of civil and human rights.

Now it's been ten years. President Clinton issued a proclamation declaring July 2000 “"Spirit of ADA"” month. In it he says: “"America is now a dramatically different - and better - country because of the ADA."”

There has been change, no question about it. We all know that. We all remember the way it used to be.

As a wheelchair user, of course, I'm thrilled every time I see a new ramp, maybe going into some fancy restaurant.... BUT as I go up the ramp I have to think what good is this ramp here to my brothers and sisters who are trying to survive on $599 a month of SSI? Or to those who are locked up in nursing homes, mental hospitals and other institutions?

The ADA's goals - equality of opportunity, full participation, independent living, and economic self sufficiency - have not been achieved. We're not even close. Two thirds of our people are still unemployed. Disability discrimination in employment is as rampant as ever but it's really hard to prove. We lose in court in 92% of employment cases. That's after 87% of cases filed with the EEOC are thrown out and never even get to court. Since the burden of proof is on the person discriminated against, an employer would have to discriminate openly to lose a suit and they're smarter than that.

What about “"independent living"”? Last year our community united to support two women with labels of mental retardation and mental illness who were fighting the state of Georgia for freedom from a mental institution, and whose case went to the Supreme Court (*Olmstead v. L.C.*). The Supreme Court heard us and ruled that unnecessary institutionalization is segregation and is a violation of the ADA integration mandate. It was a big victory for disability rights. But implementation of the Olmstead decision by the states is very slow, and our people remain locked up in institutions.

We need to get MiCASSA (Medicaid Community Attendant Services and Supports Act) passed. MiCASSA would establish a national program of assistant services and supports.

What about “"economic self sufficiency?"” Our people are among the poorest. Many are at below poverty level, they lack adequate housing, some are homeless. We're kept poor by discrimination and by outdated policies. Indeed, we are expected to be poor. We're even *required* to be poor in order to receive services that are vital to our survival and independence (we can only get personal assistance services if we are poor enough to qualify for Medicaid).

Now it's been 10 years. The ADA, is still the most comprehensive civil rights law but it is also the most disregarded, the most violated of laws. Nobody just complies with it because it's the law. We have to file complaints and lawsuits. That's a very slow process. I'm not just talking about businesses not being in compliance, but state and city governments. Let me ask you, what do you think? Do you think New York City is in full compliance? Do you think this administration has done much to bring it into compliance?

Because the ADA is largely non-funded, state and city governments can cry “"unfunded mandate"” and delay compliance forever. And business, of course, can claim “"undue hardship."” In other words, they're really telling us that we can have our rights but only if it doesn't cost them too much.

The National Council on Disability (NCD) just put out a report “"Promises to Keep: A Decade of Federal Enforcement of the American with Disabilities Act."”[*] That report says that the federal agencies charged with enforcement of the ADA - like the Department of Justice and the Equal Employment Opportunity Commission - are not doing a good enough job of enforcing the ADA. The NCD makes some strong recommendations to those agencies. But they have to hear from us too. Let's let them know we're angry. It's our civil rights they've been screwing around with!

The ADA is not only the most disregarded and the most violated but also the most openly attacked of all laws. It's attacked in the media, attacked in the courts, attacked in congress. Attempts to weaken the ADA are constant. The latest, at the legislative level, is the ADA Notification Act, HR3590, which says we have to give businesses ninety days' notice before we file a complaint. As if it wasn't bad enough that we can have our rights only if our rights don't cost too much, now they want to make it so we can have our rights only if we ask pretty please! If you haven't done it yet, please call your representative and say that we oppose HR3590!

The most serious attack lately has come from states' rights. This fall the Supreme Court will hear arguments on a states' rights case: *Garrett v. University of Alabama.*[**] At issue in that case is whether Congress had the constitutional authority under the fourteenth amendment to enact the ADA. If the court rules against us on this one, it could be a major step on the road to gutting the ADA. We have to let the justices know we won't allow that. So, on October 3, when the Court session opens, we'll be in D.C., thousands and thousands of us. Mark your calendar - you all have to be there!

The ADA is also the most ridiculed of laws - they don't make fun of other laws like they make fun of the ADA. They figure we're fair game, and so is our law. And the ADA is the most misunderstood of laws. After ten years people still don't get it that it's a civil rights law. Even the Supreme Court sometimes forgets.

Last year, ruling on three Title I cases, the Supreme Court got stuck on trying to decide if the individuals claiming discrimination were really disabled, disabled enough to use the ADA. As if the ADA was a benefit law, as if the protection of the law was a privilege, as if it was compensation for an unfortunate plight.

Many who insist they support the ADA, put the ADA at the same level as the Jerry Lewis telethon. How long will it be before people understand that we're not asking for favors, and we're not asking for privileges, and we're not asking for pity? We're asking for civil rights!

It's been 10 years! But we cannot rest. Don't you relax even for a minute, just because now there's a ramp going into your favorite restaurant, and they let you in with your guide dog, and you can use relay to call your friends. We must not rest. We have to keep fighting. Not only do we have to fight to make sure we don't lose what we worked so hard to achieve, and to make sure the ADA is not weakened in any way, we must also fight with all our strength to make the ADA stronger.

The only way we can have that much strength is if we all unite, like we did when we got this law passed. We must all unite -- all of us with all kinds of disabilities, visible and invisible, as well as those with illnesses and those who don't even call themselves disabled (like our sisters and brothers who are Deaf and proud, and our sisters and brothers who have had their civil rights stripped away by a psychiatric diagnosis). We must all unite because we're all discriminated against in the same way and all we've got is the ADA! We must fight with the strength that only comes from unity so that the ADA can have the power to deliver on its beautiful, revolutionary promise of equality for all! Our dream has not come true yet! Lets make the promise of the ADA a reality, let's make the dream come true!

[*] To get a copy of the extensive NCD report “"Promises to Keep: A Decade of Federal Enforcement of The American with Disabilities Act,"” go to http://www.ncd.gov/newsroom/publications/promises_1.html

[**] The Garrett Case will be decided by the Supreme Court during the first half of 2001.

DIA Demonstrations

DIA members took part in two demonstrations since the last DIA ACTIVIST was published. The first one, in September, 2000, took place at Gracie Mansion in a pouring rainstorm during a reception that the Mayor's Office for People with Disabilities (MOPD) had to celebrate the Tenth Anniversary of the ADA. Because Mayor Giuliani and this administration's MOPD have been particularly inhospitable to people with disabilities, we felt this occasion was the perfect time for a demonstration. We have since gotten feedback that our presence was irksome to and very much noticed by MOPD and some people from agencies the City funds. Mayor Giuliani stopped by our demonstration, but he was as obtuse as ever in his lack of understanding of the issues.

On October 3, 2000, people from DIA went by Amtrak to Washington to march on the Supreme Court to protest the attempted erosion of the ADA that the Garrett case could result in. Varying estimates of 2,000 to 4,000 people were at the demonstration and march. It was a hot, thrilling, anxious time. One never knows if a demonstration makes a certain difference, and the press coverage of the demonstration was not very widespread, but the demonstration was noticed by the disability community, that's for sure, and we hope that the members of the Supreme Court paid heed. When the ADA is threatened, it is imperative that disabled people do as much as possible to counteract the threat.

Fact Sheet on Telephone Access for People with Speech Disabilities

If you have a speech disability and live in one of the sixteen states listed below you can now use a new, free telephone assistance service 24 hours a day. This service, called Speech-to-Speech (STS), provides communications assistants (CAs) for people with difficulty being understood by the public on the telephone.

The FCC recently ruled that STS must be available nationwide in March 2001. STS will be provided through the TTY relay in each state.

Unlike TTY, STS enables people with speech disabilities to communicate by voice through a CA as many people with speech disabilities have difficulty typing.

People with speech disabilities can dial toll free to reach a patient, trained CA who is familiar with many speech patterns and has excellent language recognition skills. This CA makes telephone calls for them and repeats their words exactly in a 3-way calling environment.

Every month users make about 6,000 calls nationally. STS is the only way for many people to telephone others not accustomed to their speech. Many STS users have Parkinson's disease, cerebral palsy, multiple sclerosis, or Muscular Dystrophy. Other users stutter or have had a laryngectomy or ALS. STS also helps some speech synthesizer users.

Dr. Bob Segalman has cerebral palsy and developed the concept of STS. Now it makes telephone use much easier for him. To try out STS, report problems or get more information: Call **1-800-854-7784** and ask for Dr. Bob Segalman (direct **#916-263-8689**). Or e-mail him at: bob.segalman@att.net. Ask Bob to add your name to the STS List Serve. See also the STS web site: http://stsnews.com/

Here are the U.S. Speech-to-Speech access numbers:

ARIZONA **1-800-842-6520**
MINNESOTA **1-877-627-3848**
UTAH **1-888-346-5822**
NEVADA **1-888-326-5658**
MARYLAND **1-800-785-5630**
WASHINGTON **1-877-833-6341**
GEORGIA **1-800-229-5746**
WISCONSIN **1-800-833-7637**
CS* **1-800-682-8706** CS* **1-800-283-9877**
CALIFORNIA **1-800-854-7784**
ILLINOIS **1-877-526-6690**
CS* **1-800-735-0373**
KENTUCKY **1-888-244-6111**
SOUTH CAROLINA **1-877-735-7277**
NORTH CAROLINA **1-877-735-8261**
SOUTH DAKOTA **1-877-981-9744**
TEXAS **1-877-826-6607**
STS/VCO **1-877-826-6608**
NEW MEXICO **1-888-659-3952**

*CS = Customer Service

Visitability

by Frieda Zames

Eleanor Smith organized Concrete Change about ten years ago in Atlanta, Georgia where the concept of Visitability was devised. It includes two major ideas: 1) all homes must have at least one accessible entrance and 2) all homes must have wide interior doors (32 inches). Broadly, the idea is defined as “"To get in and pee."”

The purpose of the concept of Visitability is to broaden accessibility in housing--required by the Fair Housing Amendments Act of 1988 for houses with four or more units--to include one, two, or three family houses so that people with disabilities would not be so isolated and could visit friends and relatives. Although most people in New York City live in apartment houses with at least four units, some in the City and many in New York State live in smaller houses.

To truly achieve accessibility, the seven requirements of the Fair Housing Amendment Act are necessary. These include:

1. Accessible building entrance on an accessible route
2. Accessible and usable public and common use areas
3. Usable doors
4. Accessible route into and through the covered dwelling unit
5. Light switches, electrical outlets, thermostats and other environmental controls in accessible locations

6. Reinforced walls for grab bars
7. Usable kitchens and bathrooms

We plan to fight in the New York State legislature next year for Visitability, the Senior Citizen Rent Increase Exemption (SCRIE) for people with disabilities under 62, as well as more affordable and accessible housing.

Surviving My Oncologist

by Sherry Lampert

People think surviving cancer is hard. I think it's a piece of cake compared to surviving my oncologist. Let me explain exactly what I mean. I am a fifty-three year old woman with cerebral palsy. As someone capable of thinking for myself, I have been trying to prove that I am reasonably intelligent for a long time. I would appreciate that people speak directly to me instead of directly at me.

Recently, I went to my oncologist who asked my nondisabled friend questions about me. When I tried to answer these questions, my oncologist looked at me like I was crazy. It was clear that this “"charming person"” did not want to bother understanding me, so I deliberately answered all her questions. She still ignored me.

I would have expected such an attitude from an older person but she is a little younger than I am. Now you think I would be used to people like her but I'm not. Somehow, I never get used to people like her.

I had a dream that I woke up after my surgery and realized that this person was the only one in the room. I thought I died and went to Hell. So I thought to myself that I better get rid of her before I really die.

I always wondered what my purpose was for being alive. I think I just found out. It is to teach people like her that just because I'm in a wheelchair and partially brain damaged the thinking part of my brain is not damaged.

She may not understand me but I do understand her. She doesn't seem to know where the brain is situated. She thinks disabled people sit on their brain. Well, this is one disabled person who intends to teach her an anatomy lesson.

In my opinion her attitude is much more difficult to overcome than breast cancer.

A True Fairy Tale

by Frieda Zames

Frank Montalbo realized that it was getting more and more difficult, as his multiple sclerosis (MS) progressed, for him to walk down the six steps from his Sunnyside apartment to his scooter parked in a garage a block away. In July 1998, realizing that his disability was not likely to improve, Montalbo asked the Phipps Housing Complex to find him a wheelchair accessible apartment in the Complex to which he could bring his scooter.

Finally he called his City Councilmember, Walter McCaffrey, who sent Montalbo to Randolph Wills, the Deputy Commissioner of Law Enforcement for the New York City Commission on Human Rights. Dick Connette, “"ramp man"” of Law Enforcement, investigated and noted that although the different houses in the Complex had a varied number of steps, only one had a single step at the entrance.

Because no empty apartment existed on the first and second floor of the house with one step, Connette suggested that Montalbo appeal to each of the residents of those two floors to request that they trade their apartment with his. Luckily, Traci recognized that it would be to her and her family's advantage to swap apartments.

Montalbo explained to me: “"The single step at the entrance was ramped. And now I can think of my future. I can no longer perform my previous job as a New York City bus driver, so I will embark on a new career in computers."”

Feng Shui: Not Just About Room Arrangement

by Theo Semel

As Emerson observed, “"First we shape our environment; then our environment shapes us."” While architecture and interior design are based on structure and spatial impact, Feng Shui [pronounced <fung sh'way>] delves much deeper into actual energy re-balancing as well as the conscious and unconscious associations within the space and the objects found therein.

There's a huge misconception that Feng Shui is just about the rearrangement of furniture or objects. Feng Shui consultations correct one's environment, thus allowing for a clearing to balance the Vital Energy Force, or Ch'i within the space and within the person.

Feng Shui encompasses both the concepts of Bau-Biologie as well as Feng Shui Integrated Matrix Energy Healing (FSIMH)® that I have developed. FSIMH® is a holistic approach of healing utilizing similar applications that are found in Acupuncture and other holistic modalities such as the application of Zone Therapy in Reflexology.

I specialize in ADA Ecology-Green design solutions to fit the needs of people living with physical disabilities and to help identify products and materials that are free of Volatile Out gassing Compounds (VOC's) normally found in carpeting, material finishes, paints, etc.. We are finding a direct correlation between illness and building products that are unsafe. We help people who feel that their residential/commercial indoor environments are associated with their particular health problems and help eliminate environmental sources which may trigger or sustain health problems.

Many people are environmentally sensitive and yet are not aware that a large amount of their illnesses are EMF or VOC based. What exactly is EMF? EMF stands for Electro-Magnetic Fields which are found not only in cell phones but also the thousands of cell antennas which are being installed at a rapid pace worldwide. Besides antennas, medical equipment like MRI's and other equipment such as computers are also contributing to immune compromised illness.

More than ever, persons living with disabilities need safeguards that will boost their immune system and will eliminate additional complications, but most people who have been accustomed to their lifestyle with their particular disabilities are often very reticent to make life changes. Change can be effective. For example, a natural supplement like Stevia can be used to substitute for aspartame, a chemical sweetener found in diet sodas and artificial sugar packets. As a person living with diabetes and with fibromyalgia, an EMF illness, I completely changed my life in terms of the quality of food that I consume: all organic and not supermarket-radiated foods, plus I changed to an energy-balanced lifestyle. I am amazed how much better I feel and how much more well I have become.

I use a combination approach of Black Sect Feng Shui for spatial balance and Feng Shui Integrated Matrix Healing® to allow energy blocks to be released and to free the individual to realize true energetic and creative potential.

The goal of Feng Shui is to accelerate prosperity and healing, to create balance and harmony, and to enhance relationships. We might have challenges and disabilities, but we can still enjoy a healthier way to live our lives. My commitment as a DIA member is to assist my brothers and sisters to reach a better quality of life.

Regarding the X-Men and Other Minstrel Shows

by Philip Bennett

Not very long ago the United States celebrated a form of entertainment known as the Minstrel Show. This usually involved Caucasian entertainers smearing their faces with black make-up, painting their mouths with white lip stick and covering their heads with so-called Afro-wigs. These men would then perform on stage acting out some of the worst stereotypes racist Caucasians held of African Americans, much to the delight of Caucasian audiences throughout the nation, and the chagrin of powerless African Americans.

For African Americans, times have changed. Today even the idea of Caucasian performers putting on “"black-face"” is, at best, controversial if not utterly unacceptable.

But, for people with disabilities, the minstrel show vigorously lives on. The recent release of *The X-Men* provides ample proof. Here we have the courageous Professor Charles Xavier, a wheelchair user and spiritual leader to a band of mutant misfits, fighting for acceptance of those who are in any way different from the “"normal"” hoards of humanity. He is, of course, brilliant and asexual, as befits the stereotype. And his role is performed by a non-disabled actor.

Again, the story in the film, and the comic book on which it's based, is about inclusion of all types of people in all walks of everyday life. And so it is bitterly ironic that the producers of this film, by excluding disabled actors from the role of a disabled character, have miserably failed to practice what the story preaches.

The entertainment industry has a long tradition of excluding disabled performers going back to the silent era in such films as *Orphans In the Storm*, where Ruth Gish played a child-like blind woman, and an equally long history of rewarding nondisabled actors with Tonys, Oscars and general acclaim (Jane Wyman in *Johnny Belinda*, Dustin Hoffman in *Rain Man*, Al Pacino in *Scent of a Woman* ...the list goes on). It remains a truism that playing a disabled character in a major film or play is a giant step to stardom.

Only once in a great while has a disabled actor been welcomed in any principle film or stage role. Most often a disabled person is hired to teach the nondisabled person how to act, then must watch from a distance while the minstrel puts on “"crip-face"” and enjoys the money, glory and career.

Sadly, other than the disabled performers themselves, few people seem very upset by all this, just as few people were upset when the minstrel shows were about race not so long ago.

Arguments made for excluding the disabled are many. “"We need an established star for the film to make money."” “"There are no disabled performers with the stamina or ability for that kind of work."” “"We might write in a scene where the character is not disabled."” “"Our insurance won't cover a disabled actor."” “"Worrying about making the sets accessible is too much of a hassle."” “"We already had a particular performer in mind when we first thought up the project, so we're not excluding anyone!"”

All of these arguments have been made as reasons to bar disabled people from other jobs, as well as from housing, transportation, the enjoyment of public places and every other area where we continue to seek inclusion, and we have rejected every one. So why are these alibis for bigotry totally acceptable in the entertainment industry?

Some in the Disability community, such as the Jesuit Brother Rick Curry of the National Theatre Workshop for the Handicapped, have tried to make a place for disabled performers to learn their craft, then go forth and compete with the nondisabled. But, just as not so long ago there were few places for women and non-Caucasians to study law and medicine, but no law firms or hospitals who would hire them regardless of how brilliant they were, so it is with disabled people. Bro. Curry, for all his hard work, provides little better than a treadmill to nowhere other than an occasional bit part for disabled performers who come out of his program.

What are the alternatives to the minstrel show? What was the solution when it demeaned African Americans? Nothing changed as long as the public tolerated and encouraged it. Today African Americans have come a long way. Though very few, compared with Caucasians, have won the major acting awards, principal roles are becoming more plentiful and diverse, not because the entertainment industry has grown benevolent, but because the public demands it.

Why should anyone outside the entertainment industry care about this ongoing minstrel show? For that matter, why not go back to excluding African American performers and just have Caucasians in black-face? This was perfectly acceptable for Ava Gardner in *Show Boat*. Or why not exclude women from most roles, as was done in Elizabethan times, and just use them as body doubles when the role calls for a nude scene?

We must also ask ourselves, do we really place value in our lives as disabled people when we show such little interest in allowing our artists to express themselves? We must consider the waste of some of humanity's greatest artists when they are given no place to display their genius.

Consider the price humanity pays for this minstrel show when you buy a ticket for *The X-Men*, or when you rent videos such as *Scent of a Woman*, *My Left Foot* or *Passion Fish*.

Note from the editor: Two other movies with non-disabled actors are *The Men* and *Coming Home*.

The Offensive NIKE Ad: Perpetuating Stereotypes

by Jean Ryan

Recently NIKE put an offensive ad in quite a few outdoorsy and men's magazines with a total circulation of millions. The text of the ad perpetuated some of the worst stereotypes of disabled people and mocked us. In print! In 2000! For those of you who have not seen the ad (you can go to www.ragged-edge-mag.com to view it), it showed a photo of a shoe with the NIKE stripe on it and it said:

Fortunately, the Air Dri-Goat features a patented goat-like outer sole for increased traction, so you can taunt mortal injury without actually experiencing it. Right about now you're probably asking yourself, “"How can a trail running shoe with an outer sole designed like a goat's hoof help me avoid compressing my spinal cord into a Slinky® on the side of some unsuspecting conifer, thereby rendering me a drooling, misshapen non-extreme-trail running husk of my former self, forced to roam the earth in a motorized wheelchair with my name, embossed on one of those cute little license plates you get at carnivals or state fairs, fastened to the back?"” To that answer, hey, have you ever seen a mountain goat (even an extreme mountain goat) careen out of control into the side of a tree? Didn't think so. (At the bottom of the ad is an image of a NIKE stripe in a triangle that says ACG.)

What on Earth is happening at NIKE and the ad agency they use? Many people must have considered that ad and approved it. It could not have been the act of just one misguided, ignorant, intolerant and ill-informed person. It is what some people really think about wheelchair users and it is not funny. It perpetuates myths about people who use wheelchairs. Wheelchair users are not “"drooling, misshapen ...husk[s] of [their] former [selves]!"” We are productive, intelligent, thoughtful, life-loving people. Anyone who has had an accident that damaged his or her spinal cord is not roaming the earth with the implication that the person is useless or scary. For Pete's sake!

According to an article in Ragged Edge Magazine Online, “"NIKE's first attempt at a formal apology still didn't get it, and irritated disabled people even more. The company clearly realizes it made a mistake with its ad ....and issued a statement Oct. 24; but phrases like 'people with different abilities' and 'suffered a spinal cord injury and is confined to a wheelchair' signaled that the company didn't really understand crip culture."”

Finally, NIKE issued a better apology. Part of it said:

> “"Purely and simply, we made a mistake.

> That ad should never have been approved, much less written, and we are examining our internal approval system to make sure such a mistake does not happen again. We offer a sincere apology to anyone who was offended by that ad and we have immediately pulled it from all publications that have not already gone to print.
>
> We also are submitting apologetic letters to the editor to these same magazines. We are discussing both internally and with external advocacy groups some possible additional measures we can take to attempt to right this wrong."
>
> ”

Ironically and sadly, NIKE's own statement about their company says the following:

> “"NIKE. A sports and fitness company. Built by thousands of professionals. Professionals who are players, not spectators. Professionals who elevate ....The word itself means **to improve morally**. To lift up intellectually or culturally. Exhilarated in mood and feeling. At NIKE, we're thinking about the big idea behind diversity. How it's based on teamwork and what we can do together instead of apart. We're moving beyond how most people view diversity **by not focusing on what makes us different. But on what makes us better**."”

To e-mail NIKE please send your e-mail to Lee Weinstein, Director U.S.A. Communications, NIKE, Inc. The e-mail address is lee.weinstein@NIKE.com. Lee Weinstein's telephone number is **1-503-671-3080**. You can also call the office of the C.E.O. of NIKE, Philip Knight, at **1-503-671-6453**. Their mailing address is: Department at NIKE World Headquarters, One Bowerman Drive, Beaverton, Oregon 97005-6453.

Let NIKE know now how you feel about their ad! Efforts are underway to convince/force NIKE to run favorable ads featuring disabled people in wheelchairs in magazines with the same circulation as the magazines that the offensive ad ran in. Fred Shotz, an ADA consultant, proposes that the ad agency “"present a pro disability posture and a pro-ADA posture"” for free. He also suggests that NIKE pay for putting the ads in magazines. I think if it is not too late that a few Super Bowl ads showing disabled people at work and with their families and playing sports would be very effective and would reach a huge audience. Many people watch Super Bowl ads because they are so good. Marcie Roth of the National Council on Independent Living suggests that NIKE should contribute a sizeable sum such as $250,000 to the Spinal Cord Injury Network.

Ok, so many of us might not be able to climb up steep mountains (although some disabled people do climb mountains). We can do so many other things. Nondisabled people must learn that we can accomplish many feats. One of the first feats we have to do soon is to convince/force NIKE to comply with our demands, so please write to them or e-mail them or call them with your opinion of their ad, their apologies, and what remedies you propose.