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INCITEMENT INCITEMENT

Vol. 6, No. 3

A Publication of Atlantis/ADAPT

November/December



Photo: Tom Olin

ATLANTA, A NEW BEGINNING ADAPT LAUNCHES NEW ISSUE: ATTENDANT SERVICES

Sitting beneath the statue of Dr. King which stands just outside the administration building at Morehouse College we could not help but be struck by each of the quotes from King which were carved in the base of the statue. It was clear the media and many on-lookers did not miss the parallel between these rights movements. The chants of the 150 of us outside, chants like "Free Our People Now", could be heard by our 60 people inside waiting on the negotiations with the President of Morehouse College. It was Monday at noon, October 1, 1990, and this was the start of ADAPT's fight for community based attendant services.

There were several reasons Morehouse had been chosen as the site to begin ADAPT's campaign. It is a college famous for its long civil rights history, and famous for being Dr. King's alma mater. It was also the alma mater of Health and Human Services

Continued, p.2

FREEDOM DAY!

ADAPT is calling for your support and involvement!

January 15th, Dr. King's birthday, is Freedom Day! We will call for a national attendant services program!

Across the United States ADAPT and other disability rights groups will be protesting the fact that people with disabilities are locked away in nursing homes and institutions, instead of getting the attendant services they need at home! We will be calling for the emancipation of our people by giving real options to live in their own communities!

Press conferences, picket lines, etc. will be held at symbolic places like: State Health Care Associations, Nursing homes, State Schools/State Home and Training Centers, Federal Buildings where the Health Care Financing Administration (HCFA) offices are located, State Capitols, etc.

If you want to be part of this national statement contact National ADAPT 303/936-1110. Get involved! Add your voice! Call for FREEDOM NOW!

For more info, see article on page 3



ADAPT visited the GA nursing home lobby group, but we were locked out. Photo: Gary Bosworth

ATLANTA *continued from p.1*

Secretary Dr. Louis Sullivan, who had also been a founder of their Medical School and its former President. In addition, although Dr. Sullivan had ignored ADAPT's request to meet with us and discuss the need for a redirection of priorities toward community based services, he had, just days earlier, found time to take part in an international conference on AIDS and minorities which was hosted by Morehouse.

But when the best the Morehouse President Leroy Keith's phone calls produced was a referral to the regional HHS Director (who would only commit to meeting with a handful of us, and only at his office the next morning,) the group dug in its heels. Those in the office committed to staying until Morehouse came up with a statement supporting ADAPT's position. Morehouse administrative personnel disappeared, and the wait began. Those willing to be arrested camped out for the night in the administrative offices, while the rest spent the day out front.

ADAPT has rarely had a group more primed and ready for the struggle than the group which came to Atlanta for the very successful kick off of the new issue of community based attendant services. Over 200 people came from 24 states and 35 cities to join in the call for a real redirection of our nation's priorities from institution based programs to community based programs, from a medical model to a consumer controlled model. Though there were many new faces in the crowd, everyone was primed for action, and wanting results.

Sunday's training and forum on the issue got everyone on the same wave length, but it was the movie that lit the fuse. Bernard Sofronski, the Executive Producer, of the Warner Brothers/AI TV movie *When You Remember Me* flew in from Hollywood for a pre-screening especially arranged for ADAPT, since the story had been so closely based on the story of the folks who started Atlantis. A ballroom full of over 300 activists was silent by the end of the film. And as we set off for Morehouse the next morning, everyone was downstairs and ready to go ahead of schedule (setting an ADAPT record).

At first many of the Morehouse students had been angered that we were tarnishing the reputation of their college, but as ADAPT members began debating the issues with them, many came to support our cause. By mid-day on Tuesday the issue was being discussed across campus and a group of students had come out in support of ADAPT. An agreement had been negotiated that the administration would hold a joint press conference with ADAPT, and the students stood with ADAPT members as first ADAPT's statement and then the statement of the Morehouse administration was read. The student's support and is deeply appreciated.

Those who had not spent the night at Morehouse left early Tuesday morning for the headquarters of the Georgia Health Care Association, GHCA (the state chapter of the nursing home lobby group). The media had learned of our destination the day before so it was all over the news that morning. Luckily ADAPT has learned not to count too heavily on the element of surprise. When we arrived the building

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Injustice anywhere is a threat to justice everywhere. We are caught in an inescapable network of mutuality tied in a single garment of destiny. Whatever affects one directly affects all indirectly.

*- Dr. Martin Luther King Jr.
as cited on his statue outside
Morehouse College.*

FREEDOM DAY ATTENDANT SERVICES NOT LIP SERVICE

January 15th is the birthday of Dr. Martin Luther King Jr and in 1991 ADAPT will observe this occasion with a nation-wide action: FREEDOM DAY.

ADAPT is calling on disability rights activists across the United States to join in our call for Freedom Now! On January 15th, Freedom Day protests will be held in cities across the nation to demand an end to our nation's institutionally biased funding, and to demand a national attendant services program which meets the needs of people with disabilities.

Our message will be that we can no longer sit idly by while our nation continues to lock up our brothers and sisters. We have rejected the wholesale lock up of other segments of our society; Japanese citizens are getting damages paid to them for the internments during World War II. Nursing homes and similar institutions are the plantations of our ne. The main difference is that people with disabilities are the crop, rather than the slave labor force. As it was in slavery, there is still a group which is profiting from the dehumanization of another, ie. people with disabilities.

Title XIX (19) of the Social Security Act is the section which deals with Medicaid, and Section 1905 of this Title requires that every state which gets Medicaid funds must have a nursing home program. Recently this section was further amended to mandate that every state have a hospice program as well. If they can require these kinds of programs, they can certainly also require a national attendant services program which meets the needs of people with disabilities.

Instead of mandating incarceration, our government should be mandating independence and freedom!

When ADAPT was in Atlanta and spoke with Dr. Sullivan on the National Public Radio health care talk show, he said our issues were beyond his control, that each state chooses the Medicaid programs it wants and it was up to the states to decide. (You don't have to believe in ESP or reincarnation to ask

yourself where have I heard this before? Local option!) Feigning neutrality, officials are once again supporting the status quo, which has a playing field that is about as level as the Grand Canyon.

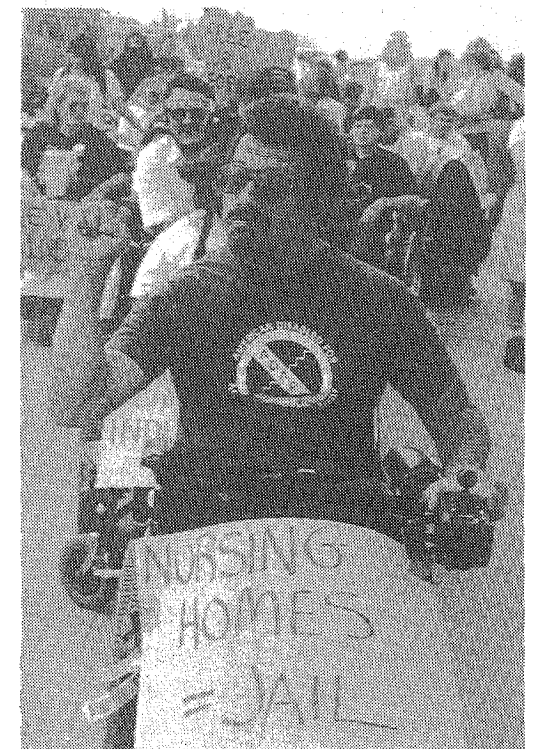
We have a national mandate for nursing homes, but no mandate for attendant services!

We must start trying new ways of serving people. Even people with very severe and involved disabilities, and older people with disabilities can be served in the community with well designed programs. Clustered living can allow these folks independence, while also allowing more intense service provision. We may even be looking to the eventual dismantling of the nursing home industry as we know it today.

If you want to be part of this national statement, Freedom Day, contact Mike/Wade at

National ADAPT: 303/936-1110.

(See also related articles pages 9-13, and 21)



WHAT'S INSIDE...

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Housing Actions Span the Nation

Nine simultaneous actions organized by Concrete Change were held at US Department of Housing and Urban Development, HUD, Regional Offices to show support for accessible housing. At noon August 28th, disability rights activists in Atlanta, Boston, Chattanooga, Chicago, Denver, Louisville, New York City, San Antonio and San Francisco sat-in at their regional HUD offices until officials contacted HUD Secretary Jack Kemp to call for HUD's speedy adoption of "Option One" of the proposed guidelines for the Fair Housing Amendments of 1986. In Boston 50 participated in the demonstration, and in Atlanta protesters were pushed out of the Richard B. Russell Federal Building (ADAPT's old stomping grounds) at the close of that business day. In San Antonio protesters arrived at the same time as the Federal office's fax warning of the action.

A few weeks earlier, Concrete Change folks had cornered Kemp at a Young Republicans fundraising dance. As Kemp began his speech, Concrete Change folks handed him a letter, began shouting and unfurled a six foot banner that said "OPTION ONE". Kemp was furious and yelled back "How dare you interrupt these kids' party? You didn't need to do this. I'm available to speak with people seven days a week." (A funny statement since he would not meet with Concrete Change in Washington, DC.) Concrete Change members yelled back "How about now?" and forced a meeting with him then and there.

HUD is currently considering three options for implementation guidelines for this housing law. Option One, developed by HUD, was considered too stringent by housing industry folks so the National Association of Homebuilders, NAHB, developed a second option (the least stringent of the three), and a third option, was also developed. Concrete Change and the vast majority of other disability groups believe both the second and third options allow so many exemptions to builders, they completely gut the law and make a mockery of its intent.

Eleanor Smith, one of Concrete Change's organizers said she felt the August 28th actions were quite effective, and helped to show the nation wide concern for accessible housing and support for Option One.

For more info: 404/378-7455 or 404/622-7292
1371 Metropolitan Ave SE Atlanta, GA 30316

Hi Tech Howdy, Ed. D.
Special Education Specialist



You got a problem? He's got a computer he can throw at it before you can say "ouch."
Inquiring Consumers can ask: "Where can I get me some of that there artificial intelligence like you got?"

This Brain has a MOUTH!

If your brain is tired of being an inspiration, if your soul longs to soar and be free, if your body itches to be out of the clutches of the "professionals", you will almost certainly enjoy a new disability rights publication: *This Brain has a MOUTH!*

Put out by someone called "Ed the Hothead", this National Magazine of People with Brains includes feature articles on topics like: Need A Hero?, Voodoo Rehab, My Life in a Coma, Daring Escapes from Forced Rehab, Hunting Vultures (the ones who pickpocket big bucks from brains), and My Son A Vegetable? Regular departments include: Mouth Off, Skull & Crossbones Award, Off the Top of My Head, and Laugh Your Head Off Cartoons.

To get your copy contact: This Brain Has A Mouth
Subscriptions

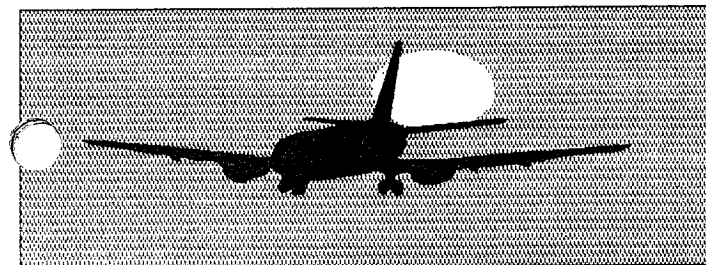
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716/473-67643

Some of the Mouth's cartoons are featured here, with permission from the Hothead of course.

Goody-Goody Meanswell,
M.A., Social Worker



Has meetings about you. Makes decisions for you. Calls you "we" when, last you looked, there was only one of you.
Inquiring Consumers can ask: "Have we had a good bowel movement lately?"



Passengers with Disabilities Celebrate Victories in Air Carriers Access Cases

August was a hot month at the National Disabilities Action Center, NDAC, based in Washington DC. NDAC won two major victories in the area of air carrier access for disabled persons.

ComAir Airlines has agreed to modify its national policy prohibiting the carriage of battery powered wheelchairs on any of its flights. Henceforth, ComAir will transport all passengers, regardless of whether they use battery-powered chairs.

Additionally, the US District Court in Tampa, FL awarded \$50,000 to Dennis Celorie in compensatory damages for ComAir's violation of his civil rights under the Air Carrier Access Act, for refusing to transport him due to the fact that he uses a

battery-operated wheelchair.

In a case concerning SkyWest Airlines, the US District Court in Salt Lake City Utah has rejected SkyWest's request that the case be dismissed. SkyWest has contended that Barbara Toomer, an ADAPT member and wheelchair user who was twice rejected for passage on SkyWest flights because she was not accompanied by an attendant, could not judicially enforce the Air Carrier Access Act and Section 504 of the Rehabilitation Act. The Court ruled that Ms. Toomer was entitled to have the case heard by a federal jury.

NDAC, which has successfully represented ADAPT on several occasions, is one of the few organizations devoted to protecting the civil rights of people with disabilities across the nation. Run by people with disabilities, NDAC's mounting victories demonstrate that they provide high quality legal representation to people with disabilities who too often face segregation and exclusionary practices. NDAC works to insure that persons with disabilities no longer are denied the benefits of accessible and integrated transportation, education, housing, public services, and employment. Access to air carriers, rail and bus facilities, education, employment, health care, buildings and community services are all areas of expertise to NDAC.

Justice. It's Yours for the Asking. So Ask.

Justice isn't a privilege. It's a right. But you have to ask for it—and work for it. It doesn't come easily, either. It takes effort, smarts, and support. We're NDAC, the National Disability Action Center, and for us the work of justice goes on every day. Whether it's negotiating a school placement for a child with autism, challenging the government to issue air carrier access rules, taking government officials to federal court for ignoring violations of disability rights laws (our specialty) or watchdogging the Americans with Disabilities Act for efforts to amend it to death, NDAC fights hard for your rights.

Justice doesn't come easily. But it *does* come.

Help us make it happen! Send your tax deductible contribution to NDAC today.

Name _____

Address _____

City _____

State _____

Zip _____

☐ \$100

☐ \$50

☐ \$25

☐ Other

Send to: The National Disability Action Center, 2021 L St., NW
Washington, DC 20036

NDAC

NDAC is looking both for donations to help support its work and to expand the number of people who can be served. If you have an access problem get in touch:

NDAC
202/467-5730
2021 L St NW #800
Washington, DC 20036

EDITORIAL: A Personal View Thoughts on the ADA

by Deborah Gately McKeen

I am forty one years old. I have had a physical disability for thirty six years. Today the Americans with Disabilities Act was signed, granting me my civil rights as a citizen of the United States of America.

I don't feel grateful. I will thank no one for giving me what I should have never been denied. I will thank the disability rights activists that placed their hearts, souls and bodies into the unceasing efforts to force the political hands to pick up their pens and respond to this despicable wrong. The reality of this is, however, that the work has only just begun. This is not a day for parades and parties. I believe it is an opportunity for deep reflection into the commitment we all must have to each other as people; people oppressed, pitied, feared, scorned and infantilized.

I feel angry that politicians and other groups who claim to serve the needs of disabled people will be showered with accolades for their insight and commitment. These will be completely undeserved. I cannot praise anyone who responds to pressure from a group and then is willing to accept a reward for their actions. Enlightenment is a deeply personal issue which merits no public fanfare. There are no medals for illumination. If any people have experienced this dimension of spiritual growth as a result of the disability rights movement, I would hope they could internalize that experience and be at peace, content in their self-discovery.

And so, today, I will sit quietly and reflect upon how I will spend the rest of my life as a full fledged U.S. citizen. I've always known I was a worthwhile person. I work hard to contribute to the world in which I live and struggle to improve my character. The successes I have achieved are as a result of my own efforts which have been stymied by access and attitudinal barriers through most of my years. As I said before, the work has just begun. This bill is thirty-six years too late for me. For others it may simply be too late.

DID YOU KNOW THE I.R.S. CODE, SECTION 190, ALLOWS UP TO \$35,000 PER YEAR IN TAX DEDUCTIONS FOR ACCESS MODIFICATIONS FOR PEOPLE WITH DISABILITIES? AND... THE NEW BUDGET ACT INCLUDES A TAX CREDIT FOR ACCESS IN SMALL BUSINESSES?

THE ADA REGULATIONS PROCEED A SOW'S EAR FROM A SILK PURSE? IT'S UP TO US

Since July 26th of this summer a steadier and steadier stream of Americans with Disabilities Act, ADA, summaries, time-lines, cheat sheets, and invitations to trainings has started flowing from more and more offices. While we are "learning all about it" a critical piece in the life of all legislation is taking place, a piece which could change the whole ADA picture, a piece we can not ignore: regulations.

The regulations are being written for four of the five Titles under the Act, and proposed versions will be published near the beginning of the new year. Regulations can and often do drastically change, ie limit, what it seems a law meant when it was passed. Once they are published, anyone can comment on them, either in favor or against, and you can be sure the folks who lobbied against the ADA will be commenting to limit the power of the ADA. So the more of us who comment for stronger enforcement the better.

Title I (Employment) regulations are being written by the Equal Opportunity Commission. Title II (Public Services) is being written in two parts: Public Transportation (city and intercity) is written by the Department of Transportation. Local and State Governments is being done by the Department of Justice, as is Title III (Public Accommodations). Title IV (Telecommunications) is being written by the Federal Communications Commission. In addition, the ATBCB, Architectural and Transportation Barriers Compliance Board (also known as the Access Board) is writing the specific access standards. For example: the Department of Justice will be saying which buildings must be accessible, and the Access Board/ATBCB will be writing how steep the slope of the ramp at the entrance will be. The ATBCB will be publishing regulations for the access standards near the beginning of the year also.

SUPERHERO SUPPORTS DISABILITY ACTIVISM!

ADAPT HAS FINALLY MADE THE BIG TIME! Better than a full page spread in the newspapers! Better than a lead story on the national TV news! Better than begrudging coverage on *Nightline* or *60 Minutes*! Marvel Comics' superhero Ironman, who was once a paraplegic until a biochip implant made him Ironman (hey ... this is the comics after all), has come out in support of disability rights activism. In a recent story entitled "Mobility" (*Ironman Annual*, Vol. 1, No. 11, 1990) a small dedicated group of disability activists take on the Silverhound Bus Lines, "one of the most stolid opponents of equal access", by protesting and chaining themselves to the bus. When one bus goes out of control Ironman intervenes, in full support of the activists. Evan Skolnick, the writer, created the story after seeing ADAPT in action! (Ironman reprinted with permission from Marvel Comics.)



For more information on the ADA,
or if you want to get a summary of the bill you can contact any or all of the following:

- * The Access Board/ATBCB 1111 18th ST NW Washington DC 20036 1-800-USA-ABLE (voice/TDD)
- * The US Department of Justice - Civil Rights Division PO Box 66118 Washington DC 20035-6118 Or call: 202/514-0301 (voice) or 202/514-0381 or 0383 (TDD).
- * The President's Committee on Employment of People with Disabilities 1111 20th St NW Washington DC 20036 -- 202/653- 5044 (voice) or 202/653-5050 (TDD).
- *The Disability Rights Education and Defense Fund, DREDF 2212 6th St Berkeley CA 94710 -- 415/644-2555 (voice) or 415/644-2629 (TDD).

"I have a very deep belief that transportation is a right up there with the fundamental rights that Americans demand and come to expect in their lives," says [Fred] Currey, who has agreed to buy Greyhound Lines Inc. from its parent, Greyhound Corp.. "I want to make us [Greyhound] the company people turn to to fulfill their national right of mobility," he said."

From the *Charleston Daily Mail*, March 3, 1987
Submitted by Norma Boone of West Virginia.

FAREWELL TO APTA AND HELLO TO MEMPHIS ADAPT!

by Jayne Embry and J.C.

The Wheels of Justice Rolled in Memphis. It all started on April 24, 1990 when Deborah Cunningham of the Memphis Center for Independent Living received a letter from the Memphis Area Transit Authority (MATA), inviting members of APTA to meet with MATA officials and members of the Memphis Police Department (MPD) to discuss ADAPT's plans for the upcoming APTA convention to be held in Memphis the next month. ADAPT's agreed upon list of demands for MATA included the following: MATA would provide paratransit or "Handilift" transportation to those individuals wishing to attend the first ADAPT march in Tennessee, (TN has NO lift equipped buses yet); MATA would proudly announce their plans for five new lift-equipped, mainline buses in press releases; and MATA would convey to APTA that ADAPT wanted 10 minutes to address the convention's general assembly and ADAPT be included in APTA's roundtable discussion on the ADA. MATA, acting very cooperatively, agreed to all the demands and agreed to fax ADAPT's written demands to APTA.

The next week, MATA backed out of their promise to provide Handilift services for the march, and there was no response from APTA. As a result, 10 ADAPT members went to the MATA offices to protest. MATA's general manager who stubbornly refused our demands or to telephone APTA and ask for their response to ADAPT's demands. So Memphis ADAPT staged its first sit-in then and there.

On Sunday, May 20th, ADAPT rolled in Memphis to celebrate the rights of people with disabilities and to announce the newly formed Memphis group. Despite threats of thunderstorms, nearly 100 people marched to APTA's convention site, the Peabody Hotel, for a rally. Jayne Embry, Sam Ware and Diane Coleman spoke on the civil rights of people with disabilities and APTA's long history of resistance to accessibility. The rally ended with Elaine Kolb's "We Are the People" and the enthusiastic crowd was invited to a meeting that evening to discuss the possibility of further action against APTA and to encourage involvement in ADAPT.

The action went off without a hitch. We split into two groups, each taking a main entrance. Entry into the hotel was no problem. We all met in the lobby and blocked off all four hotel elevators with ease, chanting in usual ADAPT style. Management was stunned by our actions, caught completely off guard. After re-grouping, the powers-that-be asked us to peacefully vacate the premises and the response in unison was a firm NO!

The police were called and requested that we unblock the elevators; our response was again NO. Eventually we were arrested and ironically three MATA Handilift buses were used to transport us to the Memphis jail. Males and females were initially separated and all belongings were searched; both of Bernard Baker's shoes and his socks were thoroughly searched for hidden "loot"! Eventually we were all directed to the jail's infirmary, (in the event we died or something,) then booked, photographed and fingerprinted many, many times. A judge came to the infirmary to announce that our arraignment would be postponed for ninety days; if we didn't get arrested in the meantime, our records would be expunged. Once released, we celebrated ADAPT's successful farewell to APTA!



Memphis ADAPT is born, kicking and yelling. Photo: Tom Olin

INFIRM, FEEBLE, INVALID, FRAIL, CRIPPLE, SUFFERER, PATIENT, SHUT-IN, CASE, VICTIM

The nursing homes argue that they are not locking disabled people up, that they are only allowed to serve people who are sick. But most people with disabilities could fit that description, legally at least. Do you take medications? Use a catheter or other urinary device? Need assistance with bowel care? We do not see ourselves as sick, but —lets face it — most of our society, including policy makers sees us that way, even after passage of the ADA.

The irony is that nursing homes avoid the people who need the most amount of care, those with the most medical needs. Many "homes" will not take these folks, or limit the numbers they will accept quite severely. Why? The margin of profit is not as high on someone who needs more assistance (higher labor costs), and more supplies, medications, etc. Even if they receive a higher reimbursement for these individuals, the expenses are higher; bottom-line, they bring in less money than those the industry affectionately calls "walkie-talkies" or "custodial care" clients.

Fighting the current nursing home/institutional bias of service delivery will also help to deliver some real body blows to the classic ways people with disabilities are seen. Attacking Medicaid's "medical model" and institutional bias cuts to the core of our government's subsidizing the industries which dehumanize us.

When we take the stand "the warehousing must stop" we will be looking dead into the eyes of the most deep seated and strongly held assumptions, beliefs so deep, their holders often do not even know they are there, and so wide spread we must watch that we ourselves do not buy into them.

*Nonviolence is a powerful and just weapon.
It is a weapon unique in history which cuts
without wounding and ennoble the man
who wields it. It is a sword that heals.*

— Dr Martin Luther King, Jr
on his statue in front
of Morehouse College

MARKETING ATTENDANT SERVICES

Just as the switch from paratransit to mainline is requiring marketing of mainline accessible transit, attendant services will also have to be marketed. No services and shoddy services have been all people have known for so long, a level of trust must be developed, and the services provided must show they can live up to that trust. Lack of back ups, no emergency services, severe limitations on availability and eligibility have conditioned many folks to think community based attendant services are more or less a pipe dream. This perception has got to change, and that will take marketing as well as plain old service improvements. In addition, we cannot trust that those who are incarcerated are getting the whole picture either. Many may not know if new options exist. If you had a nursing home with 25% of its beds empty (that's the bottom line way people who live in nursing homes are referred to: beds) and your livelihood, and the livelihood of your staff relied on the profits made from your "home" would you be trying to get more folks out?

When we use confrontational tactics, conflict arises. But we do not create the conflict; we are exposing the conflict which already was there.

— Shel Trapp, Organizer
National Training and Information Center

Incitement is looking for good pictures showing what attendant services are. People who don't know much about disability often have a hard time understanding what attendant services are all about, and as the saying goes ... "a picture is worth a thousand words." The pictures may be used for future issues of Incitement, posters, brochures, etc. Do you have any good pictures you could share? If so, please send them to:

ADAPT/Incitement
1208 Marshall Lane
Austin TX 78703.

MEDICAID - Why Do We Avoid It?

The Medicaid funding stream is enormous. Billions and billions of Medicaid dollars flow to the states to provide a really wide variety of services, some of which are attendant type services. (In 1989, the state of Texas alone got approximately \$2 BILLION dollars in Medicaid funding, while the total budget for Independent Living was approximately \$40 MILLION for the entire nation.) The problem is that the Medicaid funding stream is based on policies which strongly support the medical models of service provision and attitudes toward the people who use these services. In addition, but probably not surprisingly, these programs are very bureaucratic and can get pretty confusing. The challenge is to find ways to make it work for us.

ICF, SNF, Level of Care, Title XIX (19), OBRA, 1915 (c) waivers and ICF-MR are all terms that are used when discussing Medicaid. Pejorative words, like medical model and welfare, are also used by folks when describing the Medicaid system. What is Medicaid and why have we avoided it?

Medicaid is Title XIX of the Social Security Act of 1965, and provides federal grants to states for medical assistance to low-income persons who are aged 65 or over, blind, disabled, or members of families with dependent children. The program is administered by the states, and is jointly financed by state and federal dollars, since states must contribute some of their own funds (this is called match money) in order to get the federal funds.

When a state chooses to receive Title XIX, Medicaid dollars, it must provide ten required services which include: nursing facility and home health services, inpatient and outpatient hospital services, and physician services. Each state then can choose from 34 optional programs which allow them to provide services such as: prosthetic devices, Intermediate Care for the Mentally Retarded, ICF-MR (state institutions and group homes), rehabilitative services, and Personal Care services (attendant services.) Since a state must put up state dollars to receive the federal dollars, decisions on what optional services to choose are usually made on an economic, rather than needs, criteria. Each state which receives Medicaid funds must develop a Medicaid State Plan which tells how the state is using their Medicaid



ADAPT protesters in Atlanta. Photo: Tom Olin

dollars. This plan is public information, so you can ask for a copy, though it may be easier to talk with someone who is already familiar with your state's services.

Choosing the Personal Care option under the regular Medicaid program has been one way states have addressed the issue of providing attendant services with Medicaid dollars. Only 29 states have selected the Personal Care option, according to a report by the Commonwealth Fund. The difficulty for most disabled people in receiving attendant services from Medicaid is that they fall between the cracks of the myriad financial, medical and categorical requirements of the programs.

A recent method states are employing to use Medicaid funds, but eliminate some of the requirements that inhibit home and community based services, is use of Medicaid waivers, (under section 1915 (c) of the Social Security Act.) There are now 47 states operating a total of 142 waivers (National Governors' Association, 1990). Also called Home and Community-based Services waivers, the waivers are helpful, but, as you may have guessed, they have a few catches. The services these waivers allow are seen as alternatives to a nursing home placement, so the person receiving them must be at-risk of being institutionalized. Also, these waivers target specific categories and numbers of people such as: aged/disabled, mentally retarded, mentally ill, and disabled children. Traditionally the numbers

Continued, p. 11

MEDICAID, Continued from p. 10

targeted are very small compared to the needs of the people in the state.

There have been some efforts made recently to change some of the more restrictive requirements of the current Medicaid program. However since the groups promoting these efforts represent people with developmental disabilities and changing the whole system at once would be a bite too big for anyone to chew, these efforts are also limited, addressing only the Medicaid restrictions which primarily affect people with developmental disabilities.

The recently passed Omnibus Reconciliation Act of 1987, OBRA, (also called the Nursing Home Reform Act), prohibits the inappropriate placement in nursing facilities of persons with mental illness, mental retardation, and/or related conditions (in other words other developmental disabilities). It requires that a Preadmission Screening and Annual Resident Review (PASARR) assessment be completed for all Medicaid applicants with these disabilities. States are required to provide dollars for case management for alternate placement services, actual alternative placements and active treatment services for those who choose to remain in the nursing facility. The states have been given until April 1, 1994 to complete the process of getting people out of the nursing homes and into alternative placements.

The just passed 1991 Budget Reconciliation Bill added two new options to the Medicaid program. States will now be allowed to choose to provide Home and Community-based Care to functionally disabled individuals age 65 or over, who are eligible for Medicaid. Over the next five years a total of \$580 million has been allocated for this program. States can also choose to provide Community Supported Living Arrangements to individuals with mental retardation or a related condition, if they are eligible for Medicaid. Federal funding for this option will be capped at \$100 million, over five years, and will only be provided in two to eight states selected by Secretary of HHS, Louis Sullivan.

Last but not least, the Community and Family Living Arrangements, a bill which would mandate one piece of Medicaid reform by changing the in-

stitutional focus of the ICF-MR dollars to home and community-based services has died in Congress for the last four sessions, but will probably be reintroduced again. The general consumer movement has not spent much time on this bill because it has not been seen as a cross-disability bill. (Most of the ICF-MR dollars go to services for persons with mental retardation and other developmental disabilities.) The point is we need to get involved in the Medicaid fray to a much larger degree.

ADAPT protesters shut down the Russell Federal Building again this year, but attendant services was the new issue. Photo: Gary Bosworth



National
Headquarters

(303)936-1110
3005 West Gill Place
Denver Co. 80219



Photo by Tom Clon, Los Angeles, 1983
1478 Stayton Rd. Cumberland Furnace, TN 37051



QUOTATION #2

"Partial equality is no more acceptable in America than it is in South Africa... Like the Declaration of Independence, the Americans with Disabilities Act will pave the way for the emancipation of hundreds of millions throughout the world from the bondage of segregation, poverty and dependency."
Justin Dart, Jr.
Chair, President's Committee on Employment of People with Disabilities

"The Preamble to the Constitution does not say, 'We the able-bodied people.' It says, 'We the people.'... We will not let any barrier keep us from the equality that is rightfully ours."
Mike Auberger
Co-founder ADAPT

ADAPT CALENDAR ORDER FORM

PLEASE SEND ME:

A _____ (QUANTITY) CALENDAR(S) WITH QUOTATION # 1

B _____ (QUANTITY) CALENDAR(S) WITH QUOTATION # 2

AT A PRICE OF \$5.00 PER CALENDAR (ONE PHOTO, TEAR OFF EACH MONTH)

I HAVE ENCLOSED A CHECK IN THE AMOUNT OF \$ _____

NAME _____

ADDRESS _____

CITY, STATE, ZIP _____

PHONE _____

SEND ORDER TO: ADAPT OF TENNESSEE
1478 STAYTON ROAD
CUMBERLAND FURNACE, TN 37051
(615) 789-5236

QUOTATION #1

"We will not let any barrier keep us from the equality that is rightfully ours."
Mike Auberger
Co-founder, ADAPT

"People who advocate freedom, yet depreciate agitation, are people who want crops without plowing the ground... Power concedes nothing without a demand. It never did and it never will."
Frederick Douglass
1817 - 1896

CALENDAR

EDITORIAL: A Personal View DO AWAY WITH THE DEVELOPMENTAL DISABILITY DEFINITION !!

by Bob Kafka

Our system of services to persons with disabilities has evolved by using categorical rather than functional definitions for eligibility, especially our Medicaid system. This is nowhere more evident than in the governmental definition of developmental disabilities. Why do we have this definition? Does it make any sense in the delivery of services that persons with disabilities need? Does a "DD person" have some special need for housing, attendant services, protection of their rights different from people with other disabilities which are "non-DD"? No. The reason we have the DD definition is because of an imbalance of political power in the disability community, and because of the good lobbying done by the advocates for those with mental disabilities.

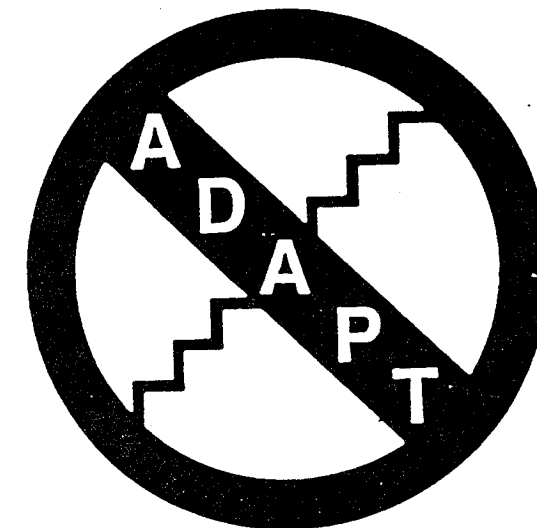
Most people erroneously equate DD with mental retardation. In reality it is suppose to mean any disability, physical and/or mental, that manifests itself before of the age 22 and limits three major life activities. Is a blind child classified as DD? A

person who had a head injury at age 21? A 19 year skydiver who has broken her neck in a bad fall? The answer depends on which state you reside in, how the disability services have evolved in that state, and how receptive the local DD community is to opening up the services provided. In most states the answer would be NO!

We have a unique opportunity to move from the current categorical system to a more functional service system. Both the Rehabilitation Act and the Developmental Disabilities Act are going to be reauthorized in 1991. Unless we make some major changes so that both these acts reflect our desire to have services delivered based on functional need rather than categorical definitions, we will continue to have a service system that pits groups against each other for scarce dollars.

The discussion on the validity of continuing the DD definition must begin. Cross-disability cooperation demands that our service system become more equitable and that both Medicaid and Vocational Rehabilitation dollars be available to all persons with disabilities. A National Attendant Services Policy can only occur if the services delivered are based on the functional needs of the individual rather than their medical or governmental designation.

ADAPT ATTENDANT SERVICES



FREE OUR PEOPLE

"I was in a nursing home for thirteen years. I had to fight to get out. It was the beginning of my life at 22."

- Claude Holcomb, ADAPT activist

"I'm going to do whatever it takes to make sure the disabled are included in the mainstream...."

- President George Bush

"Just try and honestly assess the situation and realize that I myself and others don't need to be in nursing homes."

- Larry McAfee, GA quadriplegic who legally won the right to kill himself, but has not yet won the right to live in his own home.

THE PROBLEM!

Today thousands of people with disabilities, old and young, are locked away in institutions and nursing homes or trapped at home because no effective community options exist.

For thousands of other people with disabilities, the fear of being placed in a nursing home or some other institution is an everyday reality.

It doesn't matter our age or disability, our race or sex, whether we are employed or not. Institutions are, for many, the only option.

More and more people are choosing to die rather than exist in institutions.

The medical community has too much influence over how our services are delivered.

We are being treated like commodities by a corporate nursing and large group home industry that is more concerned about profit than need.

Warehoused for "cost" and "efficiency" reasons, we are treated as part of the throw-away economy, dispensable and forgotten.

Without effective community options we lose our humanity.

THE REASON!

Services delivered to us are seen as medical services rather than simply the support we need to live in our own homes.

There is an institutional bias in most privately and publicly funded programs. The majority of funding is being spent for nursing homes and other institutions because of the influence of the American Health Care Association and other lobbying groups.

Our nation has invested in institutional models of services that lock us away, with little chance of getting out. We have few choices because the dollars flow to the institutions -- not to where we want to live.

The United States does not have a NATIONAL POLICY for a non-medical, user driven, community-based ATTENDANT SERVICES program that will allow us to live in our own homes.

SOME FACTS!

- * 7.7 million people in the United States require assistance from another person to accomplish every-day tasks, according to the World Institute on Disability, WID.
- * 3 million of these people are not getting the help they need. (WID)
 - 2 million non-institutionalized people
 - 1 million people are institutionalized, but could live in the community if support services were available.
- * A Lou Harris poll of non-institutionalized adults with disabilities showed 56% of those whose activities are limited, attribute the limitation to lack of attendant assistance.
- * Nursing home costs average more than \$30,000 per person per year. (Long Term Care Campaign)
- * Average cost to an individual for attendant services is roughly \$8,000 per year.
- * In 1987 \$41.6 billion dollars was spent on nursing homes!
 - \$17.89 billion paid by Medicaid and Medicare
 - \$21.20 billion paid by individuals and their families (Long Term Care Campaign)
 - \$ 3.6 billion paid by other sources
- * 28 states chose not to use a federal waiver program which allows children with disabilities to live at home and get assistance, so in these states children MUST be "placed" out of their own homes in order to receive services. (UCP)
- * Numerous studies confirm that people with disabilities, old and young, would rather have services delivered where they live rather than be forced to leave their homes.
- * Waiting lists for community based attendant services in all states are growing.
- * Less than 6% of 7.7 million individuals needing assistance have annual incomes over \$19,200 (34% of family incomes) while more than 43% have annual incomes under \$4,800 (13.3% of families' incomes). (WID and Rutgers Univ.)
- * 79% of people who need assistance can only rely on volunteer attendants, according to WID, while the Lou Harris poll showed 93%.

WHAT WE WANT!

People with disabilities have the civil and human right to dependable ATTENDANT SERVICES that meet our daily needs in the location and manner of our choice. Access to these services must include the following components:

1. Available based on functional needs, not medical diagnosis, or type of disability.
2. Available to people of all ages.
3. Allows maximum control of the service by people with disabilities.
4. Available 24 hours a day, 7 days a week, with provisions for back up and emergency services.
5. Allow people with disabilities options on employer/employee relationships.
6. Available to persons with disabilities on a cost sharing basis if appropriate. These services should not be a disincentive to employment.
7. The Federal Government must develop, in cooperation with ADAPT, national policies and funding to provide these ATTENDANT SERVICES to people with disabilities.

To accomplish this we are asking for no new funding. We are asking that 25% of the medicaid funding for nursing homes be redirected to fund these community based attendant services.



FREE OUR PEOPLE!

For more information contact:

National ADAPT
3005 West Gill Place
Denver, CO 80219
303/936-1110

AMERICAN DISABLED FOR ATTENDANT PROGRAMS TODAY

THE TEN WORST

Incitement /ADAPT is developing a 10 Worst Attendant Services list (similar to the transit systems list). We need your input though if we're to come up with the Terrible Ten. Why are the Attendant Services in your area great, why are they lousy? How many people can get service? How many people are being served? Do they only serve certain kinds of disabilities? Certain age groups? How many folks are on waiting lists? For how many years? How few hours, which days are the services available? What about back up and emergency assistance? How much medical red tape is involved? What about when you have a complaint, suggestion, concern? Is there something uniquely good, or uniquely bad about them? Let us know about the services you get, and/or the ones you know about, the ones you moved away from. Send your info to:
The Ten Worst c/o *Incitement*.

Please send us your comments, articles, photos, cartoons, etc. We want your input! Also your contributions are always WELCOME!



Stephanie
Send to: ADAPT/ Incitement
1208 Marshall Lane
Austin, TX 78703

PERSONAL ASSISTANCE FOR INDEPENDENT LIVING - P.A.I.L.

Under a contract from the National Council on Disability, the World Institute on Disability, W.I.D., has developed a draft bill called THE PERSONAL ASSISTANCE FOR INDEPENDENT LIVING ACT. The intent of this model bill is to look at the critical issues surrounding the delivery of what W.I.D. is calling 'Personal Assistance Services', and to get input from folks throughout the country on what the final draft should look like before it is introduced in Congress. To receive a copy of the draft bill write or call W.I.D. 510 16th Street * Oakland, California 94612 * (415) 763-4100.

OLD VERSUS YOUNG? WHY?

Community based attendant services do not need to become an issue which pits younger versus older users of such services against one another. It is an ageist assumption that older people need nursing homes, but younger people with disabilities do not. Many older people use attendant services (sometimes provided under another name, but the same basic services.) Many want to stay in their own homes as much as younger folks do, but many have lived their lives with the same assumptions we find in the general public, that nursing homes, etc, are the only option for those "who can no longer take care of themselves."

The reality is the need for attendant services is not based on age, it is based on disability. Bob Hope, Audrey Hepburn and Ronnie Reagan do not use or need attendant services, nor are they checking into the local nursing home. Yet they are all OLD. The people who are older and need services have limitations, disabilities, which often have been brought on by the aging process. Freedom should be everyone's choice, no matter their age!

AN INFORMED CHOICE

Does your state do all that it could to make sure people are not simply being warehoused in nursing homes and other institutions? Did you know that Medicaid requires that people who are to be placed in a nursing home must make an informed choice, and that they must be told about all other options which are available to them? We suspect this is a requirement which is often ignored. How is this done in your state? Or is it not done? Let us know what you find out!



Passages

Congratulations to George Roberts and Jeannet Klimach on their marriage July 9, 1990! Married by the Reverend Wade Blank, the newlyweds have not let the "institution of marriage" slow down their activism one bit.

Another union has been formed up among the CORD folks, when Kent and Carie Johnsen-Killam, also tied the knot! This one was in Las Vegas October 10th 1990, so perhaps the theme here is: "life's a gamble"? Keep your welcome mats out, since these two will be honeymooning on the highways and byways.

National Disability Action Center, NDAC, Director Tim Cook and Geraldine Heneghan joyfully announced the birth of their son Philip Emil Heneghan-Cook on July 19th, 1990. Sure to be an activist for disability rights, authorities have already put out an M.O. on the little fellow: 7 lbs 10 oz, blue eyes, and sandy peach-fuzz hair.

Sadly, Debbie Tracy, one of the original founders of Atlantis and ADAPT, was killed in a car accident this past summer. She is greatly missed.

We are also holding in our thoughts Jim Lundvill, another Atlantis and ADAPT founder, who is now in a coma, triggered when he was trapped in his home after an arsonist set fire to his ramp. Medical personnel were ready to give up on Jim some time ago, but Jim is hanging in there and has already given folks a few surprises.

We will also miss Mitch Snyder, one of the leaders of the Community for Creative Non-violence, who took his own life this summer. Shortly before his death Mitch had written to ADAPT expressing his support and congratulations on our recent transportation victory. Mitch and the Center for Creative Non-violence sent over blankets the night ADAPT camped out in front of the DOT building in 11 degree weather.

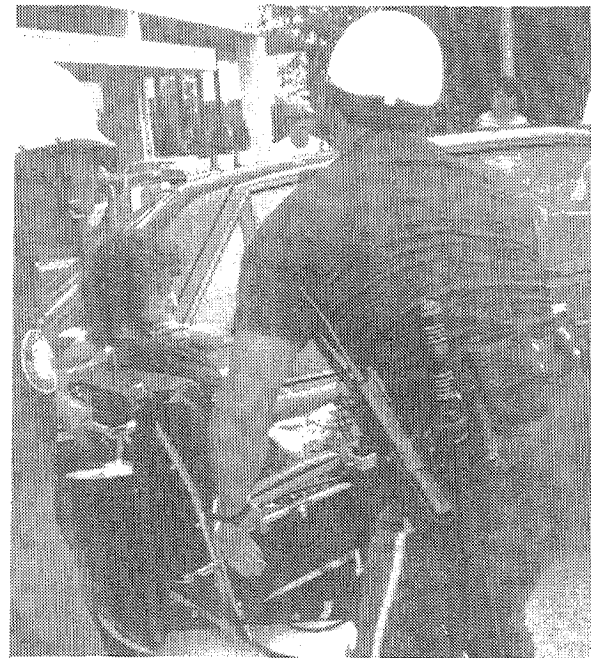
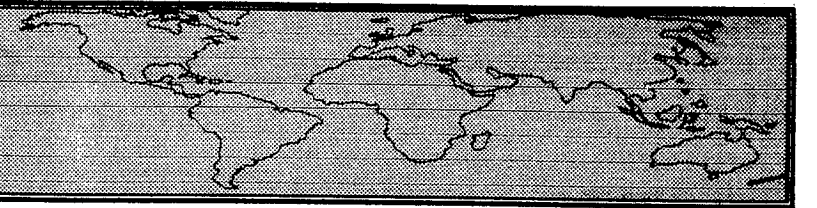


Photo: Gary Bosworth

BETTER DEAD THAN DISABLED?

Kenneth Bergstedt was killed by his father this fall so he would not have to go to a nursing home. Bergstedt, was a respirator user and a quad who lived with his father in Nevada. When Bergstedt and his father found out that the father had lung cancer, they began a legal petition for Bergstedt to die, rather than be placed in an institution, when his father could no longer do his attendant care. Far from offering suicide counseling, information on local attendant service programs, or the like, the professionals and legal system alike took up their arms and rushed to champion his "noble cause", to fight for his "right to die". With friends like that... "If Bergstedt were suicidal but not disabled, [his psychologist] would be compelled by law to recommend suicide prevention through counseling. Bergstedt would probably be involuntarily hospitalized, or even arrested to prevent the suicide. But Bergstedt's severe disability somehow sets him apart. Suddenly, his suicide feelings are 'reasonable,' 'competent,' and elevated to a right of self-determination" wrote Lillibeth Navarro, an ADAPT activist who tried to intervene with a counter point of view to the chorus of suicide supporters. But Navarro was never allowed to talk with Bergstedt. According to the *Disability Rag* article on Bergstedt, no one was. Navarro reports that a couple of weeks ago Bergstedt died and, within the week, his father, who had assisted him, died also. Yet the Nevada courts are determined to continue the case and set a legal precedent supporting this kind of "therapy".

AROUND THE WORLD



London, England – History was made on September 26th, 1990 when ADAPT's tactics and message went intercontinental; people in wheelchairs blocked buses in a demonstration for accessible public transit, in London. Tracy Booth told national ADAPT in Denver, CO that the protest was a huge success with 18 people arrested for demanding their equality. According to the report in the Daily Telegraph she sent, traffic was disrupted on Oxford St, and thirty people were taken into custody, but some were released. The Telegraph got the point too: "a protest against the lack of public transport facilities for the disabled" and noted the court in which the protesters appeared lacked accessible lavatories. It just goes to prove, the bus may be a double-decker, but the language of civil disobedience is universal.

Johannesburg, South Africa – Hundreds of people with disabilities protested on April 11th, 1990, against the political violence in the black townships or South Africa. Marching through the streets of the black township of Soweto, demonstrators sang and clapped. Many carried signs saying "I was shot..." and stating the year it happened. Protest organizers pointed out that in the past three years, over 10,000 people have been disabled in the southeastern province of Natal, one of the focal points for political violence, alone.

Jerusalem, Israel – "We are prepared to protest outside the prime minister's house and demonstrate in the streets of Jerusalem if we have to, until they give us what is our right as citizens," said Pinhas Newirth, chairman of Jerusalem Wheelchair-Access for Handicapped Committee. Currently the only accessible transit (except for a small work-trip-only program run by the National Insurance Institutes) is available through private sources and is too expensive for most people with disabilities, according to Newirth. "We will not be prisoners in our own homes.... Just because we are disabled doesn't mean that we have relinquished our right to use public transport. We want to live like normal people, to go shopping and visit friends when we want to" he added. The Committee has a long history of work-

ing within the system, but was hitting up against the same attitudinal barriers as we have faced here in the US. The plans supported by the Israeli government call for special buses which will run along the same routes as the regular buses. "The handicapped have every right to public transport. However, wheelchair access to regular transport is not feasible," according to Dr. Moshe Hirsh, National Transportation Inspector at the Transport Ministry. (From *In Jerusalem*, submitted by Barbara Waxman)



THANK YOU

ADAPT of Texas would like to thank both the Ben and Jerry Foundation and the Live Oak Fund for their contributions, grants, which went a long way to helping us be as active as we were in the final months of the push for passage of the ADA.

THANKS ALSO to Resist for their grant which helped us get out the Special Edition of Incitement announcing ADAPT's new issue, Attendant Services, and our campaign kick off in Atlanta!



RESIST One Summer St. Somerville, MA 02143
617/623-5110

National ADAPT would also like to thank Jean Stewart for her donation from the sales of her book *The Body's Memory*.

AROUND THE NATION

Denver, CO – It's not often you order a 60 cent taco and end up with \$20,000. But that's just what happened in Denver this year. Three of the group which were arrested for protesting at a taco stand down the street from the Atlantis office were recently awarded \$20,000 in damages for the false arrest and discriminatory treatment they received from the taco stand's owner. In addition the restaurant is installing a ramp.

Colorado Springs, CO – Active hardly begins to describe the ADAPT folks in the Springs. Everything from actions against a local TV station which refused to caption its new programs, included piling a bunch of dead TVs in their lobby (since they were useless to the deaf folks who left them), to liberating a guy who wanted out of a local nursing home which would not release him!

Hyannis, MA – CORD has been up to its usual watchdog activities, monitoring violations of the state accessibility codes. Their count was up to 212 (on Cape Cod and the islands of Martha's Vinyard and Nantucket) by July of this year. To demonstrate the problem they blocked the local Dunkin Doughnuts Shop, the site of two of the violations, for an hour. The owner put in a ramp the next day, while CORD was targeting a local hotel, also in violation of state code.

Boston, MA – CORD and other disability and human service groups in Massachusetts are hard pressed these days, as severe budget cuts are being adopted, and more are on the way. Vigils, rallies and other similar demonstrations are being held to call attention to the hundreds of millions of dollars worth of state services which hang in the balance. TDD Relay service, veterans benefits, talking books, and supported work are among the programs slated for massive cuts.

Chattanooga, TN – The local paratransit services run by Easter Seals were the target of Chattanooga ADAPT's first local action last June. In a statement to the press ADAPT blasted the transit providers for

what the called "grossly inadequate transportation services and unfair policy practices to the disabled citizens of Chattanooga by Easter Seals." About a dozen Tennesseans, including a few supporters from the Memphis ADAPT group were there for the kick off of the new group.

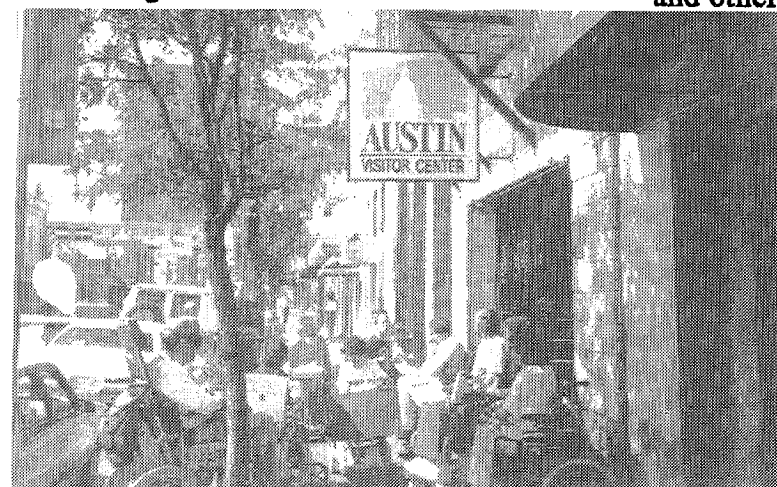
Nashville, TN – Nashville ADAPT also blasted their transit system this summer when it was learned that the Metropolitan Transit Authority of Nashville was planning to buy 16 new buses without lifts. Threatening a lawsuit ADAPT confronted the MTA pointing out the DOT's new policy, the intent of the then pending ADA, and even the ambiguity in interpretation of the 504 Regulations. The MTA even went as far as announcing the purchase on TV. However, ADAPT talked with an UMTA official, alerting them to MTAs plans and UMTA was true to their October 1989 agreement with ADAPT not to allow inaccessible purchases. Using the ever present red tape and bureaucratic fancy footwork, UMTA was able to convince MTA to submit a sole source bid for lifts for 13 buses. Not only did MTA agree to make this purchase accessible, they also wound up rehabing 19 old buses, so that one third of the fleet will soon be accessible!

Cumberland Furnace, TN – Diane Coleman and Tom Olin have recently moved operations to a converted school house/nursing home in Cumberland Furnace. They have received a grant to organize on disability rights issues in Appalachia and are looking for individuals and groups interested in getting involved. You can contact them at: 615/789-5136.

Galveston, TX – Pride Cruise Lines, which operates the Pride of the Mississippi out of Galveston, were caught red handed with their prejudices showing when Peggy Smith was denied entrance to the gambling ship because of her disability. Smith, who uses a wheelchair and is a member of Gulf Coast Coalition for Barrier Free Living (CBFL), was told staff would not help her on board and it was not safe for her companion to do. When she pointed out this was a discriminatory

AROUND THE NATION

practice she was told "Oh no! It's not just wheelchairs, we don't let any handicapped on board." When she enlisted CBFL's help to fight this policy, Pride Cruise Lines began using any excuse handy, such as inaccessible bathrooms or the possibility the elevator might go out. Pride changed their tune quickly enough however when CBFL, ADAPT and other disability rights advocates staged a demonstration on their dock a few days later. Pride spokesperson Sam Clark told reporters at the demonstration "We're going to change our policy... They have their rights too."



Welcome to Austin! Oops, we don't serve your kind here. Photo: Carolyn Long

El Paso, TX – Just when you thought it was safe to fly again... Maria Teresa Cano was barred from boarding a Servicios Aero flight bound for Chihuahua. The tired old cliches about lack of facilities and Cano's safety were, once again, used as justification. After a lengthy battle, Servicios staff dragged her step by step up the stairs to the plane, but the humiliating experience was not something Cano wanted to just forget. In a letter to the editor of the newspaper Diario de Chihuahua, Cano wrote "The word service should be removed from the company name because they don't understand its significance." Appeals to the US Federal Aviation Administration and other federal agencies turned out to be dead ends since Servicios Aero is not a US company. However the El Paso International Airport took the moral stance on the issue, saying they really did not care about the federal requirements. General Manager George Perry told the airline "As a tenant of this airport and in view of the city's strong

policies regarding handicapped access, Santos [manager of Servicios Aero] must find a way to carry disabled passengers..." or leave the airport.

Austin, TX – ADAPT of Austin has taken on a number of different issues in the past months. Texas' state human services budget has become a political football in the race for Lt. Governor, and advocates are calling foul play. Despite repeated statements supporting community based services, funding still flows six dollars to the nursing homes and other institutions for every one dollar that goes

to community based services. ADAPT has been there repeatedly fighting each stage of the battle. Meanwhile on the home front, ADAPT discovered the Austin Visitor's Center was located in an inaccessible building, a series of protests culminating in a ramp building ceremony by ADAPT – complete with painting the word discrimination on the offend-

ing entrance – has resulted in a commitment to move by the city, and the threat of a lawsuit against ADAPT by the building's owner. The local concert and events center, the Frank Erwin Center, has also been targeted for its policy denying access to floor seating for people who use wheelchairs. Major dents in the policy have already been made, but ADAPT will not be satisfied until the discrimination is completely done away with.

Philadelphia, PA – Disabilities Rights Advocacy Group had had enough of good intentions but no follow through, when they called for a demonstration September 29th. Their target was the Carousel House, built several years ago as a recreation center for people with disabilities, at a cost of over \$5 million dollars. Disability advocates have been trying to meet with the city and Fairmont Park Commission for over a year, but officials have refused to meet. Due to a lack of sidewalks and

AROUND THE NATION

curb cuts along Belmont Ave., the facility is not really accessible to the people with disabilities who live in the neighborhood. Ironically, part of the reason this site was chosen was because the neighborhood has several disability housing projects. About 25 to 30 people showed up at the rally, and since then a class action lawsuit has been filed against the city and the Fairmont Park Commission.

Integrated seating at the movies was the target of some ADAPT protests this summer. Photo: Tom Olin



Do you know someone who would enjoy getting Incitement? Just drop us a note with name, address and zip code and we will add them to our list.

Willimantic, CT -- One year ago June 17th, two disabled women thought they would escape the hassles of daily life in an inaccessible world only to find themselves not passing go, not collecting \$200, but going directly to jail!! Julie Reiskin and Linda Handscomb just want to sit together with their non-disabled friends while watching a movie, but United Artists (one of the major movie theater chain operators) has a policy similar to Birmingham's 1950's bus policy: your kind...stay in the back. So one year later ... they're back. Reenforced with other supporters from CT and a simultaneous protest in Tennessee, disability rights activists sent United Artists a strong message of their displeasure.

Memphis, TN -- After doing a protest in solidarity with the CT folks against United Artists, Memphis ADAPT was fired up! They did not have to think long before the next target was obvious. Malco Ridgeway Four got a surprise August 4th when about 25 to 30 Memphis ADAPT supporters arrived around 7:00pm and began picketing and handing out flyers calling for access to the movie theater. The theater, like too many others, only provided a few isolated spaces for wheelchair users at the back of the theater; ADAPT was calling for integrated seating locations through out the theater. At 7:30 the ADAPT protesters moved to block the doors of the theater, and within 15 minutes the district manager for Malco Theaters was meeting with the group and agreeing to set up a meeting with the president of the company. Despite a letter sent by ADAPT a month earlier, Malco officials claimed no prior knowledge of the problem, but stated "there's no problem that can't be resolved." A subsequent meeting and investigations have led to Malco removing several seats along the aisles and creating level spaces which allow for integrated seating. Memphis ADAPT members have been invited to come and inspect the results, and are planning to do so in the near future.

Atlanta, GA -- The first STREET HEAT "HUNGER & HOMELESSNESS" PUBLIC

HEARING was held October 13th Sweet Auburn Ave, under the bridge. Over 200 people took part, and local legislators came to listen, as people representing a number of disenfranchised groups, from spoke of their concerns ranging from homelessness to hunger, from exploitation of day laborers to lack of adequate human services. The groups cited Atlanta's theme of being the city which is "too busy to hate" and pointed out it might be more accurate to say Atlanta is the city which is "too busy to care." Johnnie Keith, President of DARE, spoke on behalf of people with disabilities saying how we pay taxes like everyone else yet we are treated as less than second class citizens.

Birmingham, AL -- On a short trip back to GA for medical examinations, Larry McAfee told the Atlanta Journal reporter Steve Goldberg, it felt "just fine" to be back in his home state. McAfee is currently living in a small group home in Birmingham which is run by United Cerebral Palsy, while GA officials try and put together a community care program for himself and others.

Tampa, FL -- A major civil rights lawsuit was filed in US District Court this past summer, by John Andrew Kirby, a Largo kindergarten student, and his parents. The National Disability Action Center, NDAC, has taken the case on behalf of John, who is five and has Cerebral Palsy. The Pinellas County Schools have barred John from attending his neighborhood school which his sister, neighbors and friends attend. Instead, they are only allowing him to attend a segregated "physically impaired" program, to and from which he must be bused for over an hour each day. NDAC Director Tim Cook points out the loss is not only John and his family's. The other students who attend John's neighborhood school "are the individuals who John will be interacting with in the community for the rest of his life, and who therefore most need to learn about his disability. Yet, all most of these students see and learn is that John, because of his disability, is barred from their school and forced to go to a different school on a different bus outside of their community. The school board's actions fortify all of the age-old stereotypes regarding John's disability."



Mr. Watson got a taste of other people controlling his life, just like people he helps lock away. Photo: Tom Olin

ATLANTA *continued from p.2* was locked as tight as a drum. The Executive Director, Mr. Watson, would only stick his head out the door, but refused to meet any of our demands, which included faxing a copy of a resolution to the national headquarters of the American Health Care Association, AHCA. It turned out later that Wilging, the Director of AHCA who had refused to meet with us when we wrote him several months earlier, was in Colorado at an all day strategy session with their state Health Care Association about how to respond to the reaction to the movie *When You Remember Me* which was to air on ABC later that week.

ADAPT surrounded the building and lined up along the boulevard which ran in front of the building. A banner made by the LA ADAPT folks, and which read "Institutions? Hell No We Won't Go!" was raised and hung across the GA Health Care Association's sign. Giant poster board was donated by a local furniture store and signs like "Nursing Homes are Nothing Like My Home" and "Attendant Services Now" were quickly made. Some people held signs which read "Honk if You Support Us" and soon the boulevard sounded like a traffic jam with all the cars honking their support.

The police arrived and started negotiations. Finally, Watson, the Executive Director was coaxed out of



Photo: Tom Olin

ATLANTA *continued from p.19*

the building, but when it was clear he had no intention of really negotiating, we blocked his reentry into the building.

Mid- afternoon the police pulled ADAPT members off the back doors and the GHCA staff ran for their cars. After a valiant struggle the staff drove away, but amazingly the Director parked his minivan a half a block down the boulevard and walked back to talk further with the police. ADAPT members swarmed the vehicle surrounding it, and after a brief but intense struggle Watson had to give up his van for the day and be driven home by the police. Having successfully pitched our first salvo at the industry which had held captive so many of our members and friends, ADAPT withdrew.

The final day of actions began with a march down Martin Luther King Dr. to the Richard B. Russell Federal Building we had successfully taken over less than a year earlier. Marching single file through downtown Atlanta our group stretched out over several blocks. To no ones surprise, building officials locked all the outside doors of the building as we arrived, so ADAPT in turn blocked all entrances and exits on the ground level.

It was National Health Care Day and we had timed our arrival to coincide with Dr. Louis Sullivan's speaking on a National Public Radio talk show on health care. One of our members was able to be one of the first to call in and confront Dr. Sullivan with the situation at the Russell Federal Building, Dr. Sullivan's refusal to meet with ADAPT, and demand

to know his stand on our issue of redirecting dollars to promote community based consumer controlled programs, versus institutional ones. Sullivan, irate that we had caught him so publicly, could only say weakly, that it was up to each state to design their own Medicaid programs and his hands were tied. Exposed in his "local option", "states' rights position", and exposed in his unwillingness to address the problem, Sullivan had shown his true "Jack Gilstrap" colors.

The best the Health and Human Services officials would offer in terms of negotiations was the typical bureaucratic response of a handful of us meeting with the Regional Director at his office, sometime later. It was clear this was simply their attempt to defuse us. We informed the authorities ADAPT did not do business like that. Later in the afternoon ADAPT members were told if they did not move away from the building they would be arrested. It was the first time ADAPT has faced arrest for a federal crime, but members stood firm. Those who wished to, moved away to the edges of the building but many did not budge. It took over three hours to arrest all 64 ADAPT members who held firm. They were taken, MARTA bus load by load, to a stadium near the hotel where we were staying. A judge came on the bus and did the arraignments right there, and then the protesters were dropped off at the hotel as the bus went back to the Federal Building for another load.

Everyone agreed the Atlanta actions had been a great success. We had established the issue of community based attendant services as a civil rights issue. We had sent notice to the lobbying arm of the industry that we were holding them responsible for the involuntary incarceration and lack of options for people with disabilities. Finally we had let the federal government know that this is an issue they are going to have to deal with, and if their promises and fancy talk are to be more than just hollow rhetoric, action will need to be taken, soon.

Anytime you're dealing with basic human rights, protests may inconvenience some people, but you have to understand that ultimately it's going to benefit all.

— Otis Moss, Morehouse philosophy and religion major.

ADAPT DEMANDS PASSAGE OF THE FOLLOWING RESOLUTION

WHEREAS ADAPT and most other major advocacy groups representing older and disabled Americans have recommended that the individuals and their families should have self-directed community based attendant service options and alternatives to institutional and nursing home services, and

WHEREAS the number of older and/or disabled Americans who want and need these self-directed, community-based, non-medical attendant services is growing every year, and

WHEREAS historical and current funding patterns of our society have put substantially more dollars into institutional and nursing home services than into self-directed, community based attendant service alternatives,

THEREFORE BE IT RESOLVED that the American Health Care Association adopt policies and programs that will promote the:

- 1) redirection of current \$5 Billion federal and state institutional and nursing home dollars to self-directed, community-based attendant service alternatives,
- 2) allocation of all new federal and state dollars in a way that significantly lowers the ration between institutional and nursing home program dollars and self-directed, community-based attendant services,
- 3) assign a full time lobbyist to lobby for the removal of all regulation, funding incentives and legislative initiatives that promote an environment that encourages institutional and nursing home programs over self-directed community-based attendant service alternatives.

BE IT FURTHER RESOLVED THAT the American Health Care Association work with ADAPT for the implementation of new federal policies that will change our long term care system from one that promotes the institutional and nursing home model to one that provides incentives for the development of self-directed, community-based attendant services.

BE IT FURTHER RESOLVED that the American Health Care Association set goals and specific time tables by which self-directed, community-based attendant services options will become the major focus of this country.

BE IT FURTHER RESOLVED that the American Health Care Association makes this position known to Dr. Louis Sullivan, Secretary of Health and Human Services, and to all the state Health Care associations throughout the country.

Compare the following to Sullivan's local option attitude about attendant services, when speaking with ADAPT during an NPR call-in talk show on health care in the US:

Days after President Bush announced the nation had reached its spending limit for AIDS, Health and Human Service Secretary Louis Sullivan advocated a spending increase for AIDS programs. Speaking to attendees of an international conference on AIDS in minorities held at Morehouse School of Medicine:

We must never allow funding for research, prevention and treatment of this disease to become the hostage of old prejudices [emphasis added]

