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## SPRING ACTION

Mark your calendar now for the next ADAPT national action! June 17 - 22nd Washington DC Be there or be square! MiCASSA will be cooking, Olmstead will be rolling along, the Presidential campaigns will be heating up, and who knows what other things will be popping!

Call Denver for rooms! 303/733-9324



Volume 15 No. 2

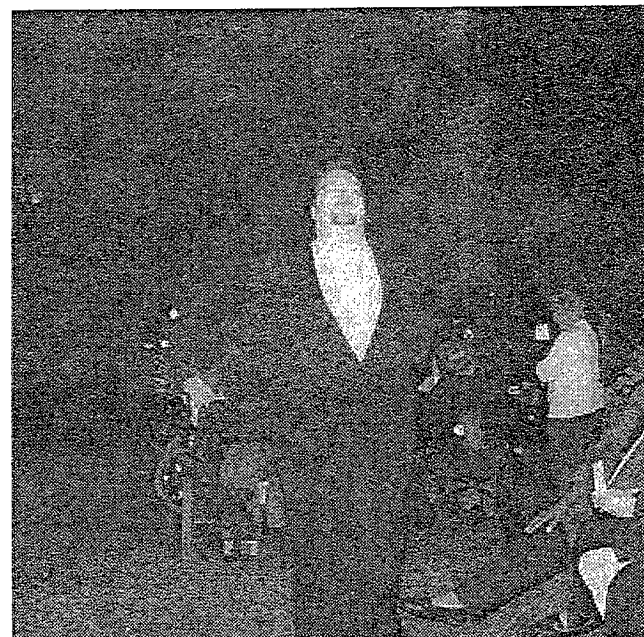
A Publication of ADAPT

Fall 1999

## Columbus Discovers ADAPT by Stephanie Thomas

### A REVEILLE FOR REAL CHOICE

As night gathered over Ohio on Saturday October 31, ADAPT members from across the nation gathered at the steps of the state Capitol for a Reveille for Real Choice. All Souls Night, otherwise known as Halloween, was the backdrop for the event, but the message



The ghost of Ohio's Governor Bob Taft's Great Grandfather President Taft visited ADAPT's All Souls' Reveille for Real Choice on Halloween night. photo: Erik von Schmetterling

was serious... The ghost of President Taft came out of the gloom and shared his thoughts with those gathered and promised to have a word with his great, great grandson Ohio Governor Bob Taft. ADAPT was in town because Ohio has such a marked preference for locking away people who need long term care, it had won the dubious distinction of being one of the ten worst states in the nation. Ohio spends 8 times more on nursing homes and other institutional services than it does on home and community services. Ohio ADAPT members had been chipping away, but the powers that be were not responding. The state's efforts to implement the Olmstead decision were basically nil, and a state version of MiCASSA, know as the Ohio Personal Attendant Services Act, OPASA, or HB 215,

was dying on the vine. It was wake-up time, reveille, for Ohio state leadership, the days of warehousing disabled people must end!

Around 4:00 on Friday afternoon, the Governor had sent a letter to our hotel welcoming ADAPT to the

**MiCASSA Updates!  
 Inside!!**

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state and claiming he wished to meet while we were in town. It seemed like a great start, but we would learn just how insincere Taft and his cohorts could be. A visit by his office that afternoon before 5:00 PM netted us a cool receptionist who allowed us to leave a note for the Governor's staffer whom we had been told to contact.

**A VISIT TO THE GOVERNOR  
AND SPEAKER**

When Monday morning arrived ADAPT's troops were ready for business, ready to get the ball rolling and turn around Ohio's trends toward stronger support for institutional services. Having still not heard back from the Governor's office regarding a time and date for the meeting, we marched up the street on a glorious Indian summer morning to the Riffe office building which houses the offices of the Governor and the entire state legislature. We figured we would set the meeting with the Governor and go to work on getting hearings for Ohio's OPASA bill. A delegation went up to the Governor's office, another to the office of the Speaker of the House JoAnn Davidson.

In the Governor's office instead of working to schedule the meeting the Governor had suggested, everyone was out of town and support staff tried to pretend they were unable to solve this dilemma. Could it be that in Ohio the Governor must be present to schedule his own meetings? It seemed unlikely, so ADAPT's delegation decided to wait until staff could figure out this tricky problem. Finally calls were made back and forth, but it seemed that over the weekend the Governor and his key staffers had lost the ability to commit to a real time and place for a meeting. "Maybe" was their best response. ADAPT folks thought

of the 100,000 people languishing in Ohio's nursing homes, waiting. They had been put in the horrible role of pawns in the game of profits for the nursing homes fueling campaign contributions for political campaigns. Maybe was just not going to be good enough. ADAPT waited for a concrete answer.

Meanwhile, another delegation had gone up to the Speaker's office. The most powerful person in Ohio's state legislation, Speaker Davidson, could schedule a real hearing for the OPASA HB 215. The first hearing had been a quickie, at which advocates were not allowed to testify and were discouraged from even attending. This was perhaps not so surprising since, reports were, the sponsor Representative Terwilliger had misrepresented the goals and contents of the bill. Advocates had tried to get a hearing at which those who were directly affected could participate, but were being given a major run around while



the clock ticked toward the end of the legislative session. If anyone could save the day Speaker Davidson was the one -- as she ultimately set the schedule for the House.

However, the response on the Speaker's office was remarkably like that of the Governor's office. So ADAPT's second delegation settled in to wait, and in the lobby on the first floor reinforcements were



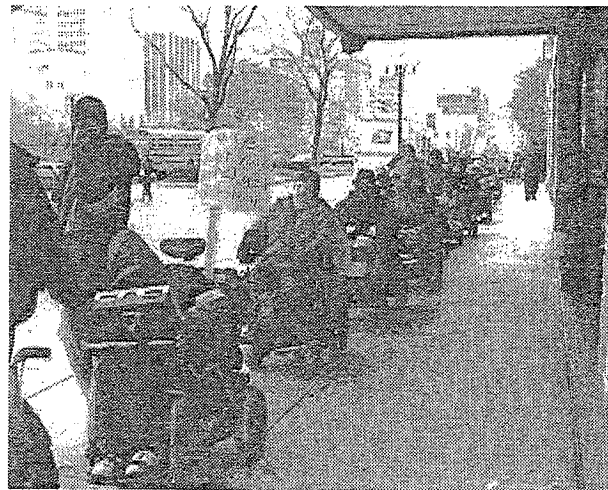
sent up to both offices while 200 more ADAPTERS settled in on the cold marble to await the results.

Like storm clouds, state troopers began to gather. Over 25 years after Kent State, Ohio's leadership had apparently learned little about dealing with dissent. The troopers response was to close off access to the rest rooms in both the Governor's and Speaker's offices. 100 people with disabilities, many with bowel and bladder issues, hard to picture what the troopers had in mind, except maybe they thought we would leave for the want of a bathroom -- Not likely!! Our brothers and sisters in nursing homes and institutions have to do without in this department often enough, we could handle several hours.

The media came at 5:00 PM, at 6:00 PM, at 10:00 PM and still we waited with no new negotiation developments. Around 11:00 PM the state troopers moved in and cleared the protesters, first from the lobby, then from the Governor's office, then the Speaker's office. Dumping some people from their chairs, giving others the bums rush, the mood changed from indifference to ferociousness. Close to 100 people were arrested and processed in the basement of the building.

**OHIO'S INHUMAN SERVICES**

Tuesday dawned as the reverse of Monday. Near freezing and raining weather greeted ADAPT's stalwart troops as we lined up for our second day of action, but we were ready to be tested. And tested we were! As we started our march around the Capitol square the rain turned to ice and SNOW! Wind whipped the freezing mess into our faces and then lifted our rain ponchos up over our heads. Heading into the storm we continued toward the state human services office tower, Rhodes Building, where the director of Medicaid Barbara Jenkins and her boss Jackie Sensky, Director of the Ohio Department Human Services, held



court.

As we forged on past the Riffe Center on our route we noticed that state troopers had surrounded the building, but we had another destination for our second day. The Rhodes Building was also swarming with Troopers, inside and out. One thing about traveling with 400 people with disabilities is that there is no sneaking up on a place. As we headed for the doors the troopers sealed them off and we were left out in the freezing rain. But it takes more than a snow storm to stop ADAPT! Folks covered the front of the building and then covered the doors on the back alley. Since Ohio was so fond of nursing homes, their bureaucrats

*Incitement*



could now get a taste of nursing home life, with no one leaving or entering without the go ahead from ADAPT. Tussles at the doors resulted in six arrests.

The icy wind whipped our chants along the stony plaza in front of the building as negotiations for a meeting with Sensky went on. It looked like there would be another stand off, as the minutes turned into hours. But for all the cold and wet ADAPT's troops maintained the chants and held strong on the doors; it was obvious we were not just going to melt, or go away. Finally Sensky sent word she would meet with a delegation from ADAPT! Just as the logistics of where and who were being worked out however, the State Trooper Commander declared there will be no meeting. Apparently in Ohio the state troopers outweigh cabinet level bureaucrats! So the arrests began. Troopers were



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apparently hoping we would scurry away but that was not to be. So slowly but surely they had to load up over 100 of us.

In sheltered workshop buses and accessible prison vans, we were taken to the Fair Grounds at the edge of town where we were processed one by one. No interpreters for the deaf were provided, despite several deaf arrestees requesting them. Then, oddly, the troopers, loaded us back on the workshop vans and drove us back to the hotel, and even guarded us through the hotel lobby door. Paternalism - mixed with a complete failure to grasp the issues - oozed from the entire process.

#### MESSAGES ARE SENT

Wednesday was not much better weather-wise. But the Director of Medicaid and some of her staff had agreed to meet with a delegation from ADAPT. Apparently some time on Monday or Tuesday the state had obtained a temporary restraining order against any more than five ADAPTs from entering a state building. Curiously, though they were able to send the initial letter from the Governor to us at the hotel, they were apparently unable to get us a copy of this order until we had returned home. Once again the state troopers were calling the shots as they said that no more than five ADAPT members could attend this meeting, since the restraining orders allegedly



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limited us in this way. Slavish obedience to authority, little desire to negotiate or consider other views, and an inability to think creatively seemed the hallmarks of Ohio state governance.

None the less, the goal of confrontational activism is to get to the negotiation table, so our delegation went to see if these people were educable. The meeting was in the Rhodes building, and as the five entered we were asked for picture ID and had to walk a gauntlet of state troopers to cross the lobby and get to the meeting room. Inside, as we met we were guarded by seven more state troopers. Barbara Jenkins and her troops were inflexible but they did listen, and in the end agreed to set up another larger meeting with herself, and a meeting with Ohio ADAPT and Jackie Sensky in the next few weeks.

Meanwhile, the ADAPT folks wanted to return the message to the Governor and State legislature. So the rest of the group returned to the Riffe building and held a closing ceremony outside. We lined up in front of the building. A coffin was delivered to the front of the building carried by a delegation of ADAPT pall bearers. Speeches were made. The names of those who had died in nursing homes waiting for bureaucrats to free them were ceremoniously dropped into the coffin. The state

troopers guarding the building looked on in shock and amazement. Finally the event ended with a delegation of five going up to the Governor's office to deliver an indictment of the state of Ohio for their piss poor excuse for a long term care system and their completely paternalistic view of persons with disabilities. ADAPT clearly sent the message that police force would not deter the battle to reform the institutional bias of the long term care system.

*Incitement*

## Medicaid Community Attendant Services And Supports Act of 1999 MiCASSA: A Summary

MiCASSA gives people real choice in long term services. Amending Title XIX of the Social Security Act (Medicaid), it creates an alternative service: Community Attendant Services and Supports. MiCASSA allows individuals eligible for Nursing Facility Services or Intermediate Care Facility Services for the Mentally Retarded (ICF-MR) the choice to use these dollars for Community Attendant Services and Supports. **THE MONEY FOLLOWS THE INDIVIDUAL!**

Specifically what does this bill do?

- 1) Provides community attendant services and supports ranging from assisting with activities of daily living (eating, toileting, grooming, dressing, bathing, transferring) instrumental activities of daily living (meal preparation, managing finances, shopping, household chores, phoning, community participation), and health-related functions.
- 2) Includes hands-on assistance, supervision and/or cueing, as well as help to learn, keep and enhance skills to do such activities.
- 3) Requires services be provided in THE MOST INTEGRATED SETTING appropriate to the needs of the individual.
- 4) Provides Community Attendant Services and Supports that are:
  - ◆ on an assessment of functional need;
  - ◆ provided in home or community settings like - school, work, recreation or religious facility;
  - ◆ selected, managed and controlled by the consumer of the services;
  - ◆ supplemented with backup and emergency attendant services;
  - ◆ furnished according to a service plan agreed to by the consumer;
  - ◆ and include voluntary training on selecting, managing and dismissing attendants.
- 5) Allows consumers to choose among various service delivery models including vouchers, direct cash payments, fiscal agents and agency providers, all of which we required to be consumer controlled.
- 6) For consumers who are not able to direct their own care independently, MiCASSA allows for

"individual's representative" to be authorized by the consumer to assist. This might be a friend, family member, guardian, or advocate.

7) Allows health-related functions to be assigned to, delegated to, or performed by unlicensed personal attendants, according to state law.

8) Covers individuals' transition costs from a nursing facility or ICF-MR to a home setting, for example: rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.

9) Serves individuals with incomes above the current institutional income limitation - if a state chooses to waive this limitation to enhance the potential for employment.

10) Provides for quality assurance programs which promote consumer control and satisfaction.

11) Allows states to limit the aggregate amount spent on long term care in a year to that amount the state would have spent on institutional services for such eligible individuals in the year.

12) Provides a maintenance of effort requirement so that states can not diminish more enriched programs already being provided.

### REAL CHOICE SYSTEMS CHANGE

- 1) MiCASSA provides grants for Real Choice Systems Change Initiatives to help the states transition from current institutionally dominated service systems to ones more focused on community services and supports.
- 2) Each state will create a Consumer Task Force to develop a plan for transitioning services into a more community oriented system. A majority of the members must be people with disabilities or their representatives.
- 3) The Secretary of Health and Human Services along with the National Council on Disabilities, will review regulations and report to Congress on how to reduce excessive use of medical services. The Secretary will also establish a task force to examine financing of long term services.

## Medicaid Community Attendant Services and Supports Act MiCASSA -- S. 1935 Introduced

### Senators Harkin and Specter Introduce Landmark Legislation S. 1935 Supports Real Choice in the New Millennium

WASHINGTON, D.C.-- S-1935, The Medicaid Community Attendant Services and Supports Act (MiCASSA) was introduced November 16 by Senator Tom Harkin (D-IA) and co-sponsored by Senator Arlen Specter (R-PA). MiCASSA will affect more than 2 million Americans who are segregated from society by outdated Medicaid law that forces them into nursing homes and other institutions. The legislation will reform Medicaid's entitlement to nursing homes and allow people the choice of receiving services in their own homes and communities.

In 1998, Medicaid spent \$44 billion tax dollars to warehouse people with disabilities of all ages in nursing homes and other institutions, reports the Health Care Financing Administration (HCFA), the Federal agency which oversees the Medicaid program. That same year, Medicaid spent only \$14 billion on home and community-based services, or just 25% of its total long-term care expenditures. According to data gathered by the University of California San Francisco's Disability Statistics Center, the average yearly Medicaid expenditure for a person using community-based services is \$7,276, compared to a taxpayer cost of \$23,225 for a person receiving Medicaid services in a nursing home.

MiCASSA is the result of years of work by ADAPT, a national grassroots disability rights group with many members

who have been locked away in nursing homes and other institutions. Last week, more than 200 ADAPT protesters were arrested in demonstrations in Columbus, Ohio, one state in which the track record on home and community based services falls considerably short of the national average.

ADAPT was successful in getting their Medicaid reform bill introduced by Rep. Newt Gingrich (R-GA) in the 105th Congress, where it enjoyed bi-partisan support of 77 co-sponsors, and was backed by over 400 organizations across the nation. Congressional hearings were held on the legislation in March 1998, but the session ended before the bill passed.

"ADAPT's goal is to reform the institutionally biased Medicaid long term care system by giving people with disabilities a real choice to live in the community. Nobody should be forced into a nursing home in the 21st century because of a lack of options," said ADAPT organizer Bob Kafka. "We are excited that Senators Harkin and Specter have shown the commitment of the 106th Congress by introducing MiCASSA." The bill, he said, kicks off ADAPT's "Real Choice in the New Millennium" campaign, which is about engaging Congress and the Presidential Campaign 2000 in the debate about community-based, Medicaid funded long term services and support as a real choice.

# "MiCASSA Supporter"

- Please list our organization as a MiCASSA Supporter.
- We would like to work on the state level to support MiCASSA.
- We can provide in-kind resources to support MiCASSA.
- We can provide financial support for MiCASSA.
- Please add us to the MiCASSA mailing list for updates.

Name of Organization: \_\_\_\_\_

Contact Person: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: (\_\_\_\_) \_\_\_\_\_ Fax: (\_\_\_\_) \_\_\_\_\_

TTY: (\_\_\_\_) \_\_\_\_\_ e-mail: \_\_\_\_\_

Our organization is a  national  state  local group.

Send to:

MiCASSA Supporter  
1339 Lamar SQ. DR., Suite 101  
Austin, TX 78704

512/442-0252  
512/442-0522 (fax)  
adapt@adapt.org

Date: \_\_\_\_\_



## Senator Tom Harkin's MiCASSA Introductory Statement - November 16, 1999

Mr. President. Today, along with Senator Arlen Specter, I am introducing the Medicaid Community Attendant Services and Supports Act. Our bill allows people to have a real choice about where they receive certain types of Medicaid long term services and supports. It also provides grants to the States to assist them as they redirect Medicaid resources into community-based services and supports.

We all know that given a real choice, most Americans who need long term services and supports would rather remain in their own homes and communities than go to a nursing home. Older people want to stay in their homes; parents want to keep their children with disabilities close by; and adults with disabilities want to live in the community.

And yet, even though many people prefer home and community services and supports, our current long term care program favors institutional programs. Under our current Medicaid system, a person has a right to the most expensive form of care, a nursing home bed, because nursing home care is an entitlement. But if that same person wants to live in the community, he or she is likely to encounter a lack of available services, because community services are optional under Medicaid. The deck is stacked against community living, and the purpose of our bill is to level the playing field and give people a real choice.

Our bill would allow any person entitled to medical assistance in a nursing facility or an intermedi-

ate care facility to use the money for community attendant services and supports. Those services and supports include help with eating, bathing, grooming, toileting, transferring in and out of a wheelchair, meal planning and preparation, shopping, household chores, using the telephone, participating in the community, and health-related functions like taking pills, bowel and bladder care, and tube feeding. In short, personal assistance services and supports help people do tasks that they would do themselves, if they did not have a disability.

Personal assistance services and supports are the lowest-cost and most consumer friendly services in the long-term care spectrum. They can be provided by a variety of people, including friends and neighbors of the recipient. In many instances, with supervision, the consumer can direct his or her own care and manage his or her own attendants. This cuts down on expensive administrative overhead and the current practice of relying on medical personnel such as nurses to coordinate a person's care. States can save money and redirect medically-oriented care to those who need it most.

Not only is home and community-based care what people want, it can also be far less expensive. There is a wide variation in the cost of supporting people with disabilities in the community because individuals have different levels of need. But, for the average person, the annual cost of home and community based services is less than one-half the average cost of institutional care. In 1997, Medicaid spent \$56 billion on long term care. Out of that \$56 billion, \$42.5 billion was spent on nursing home and institutional care. This paid for a little over 1 million people. In comparison,

only \$13.5 billion was spent on home and community-based care - but this money paid for almost 2 million people. Community services make sound, economic sense.

In fact, the States are out ahead of us here in Washington on this issue. Thirty States are now providing the personal care optional benefit through their Medicaid programs. Almost every State offers at least one home and community based Medicaid waiver program. Indeed, this is one of Senator Chafee's most important legacies. He was ahead of his time.

The States have realized that community based care is both popular and cost effective, and personal assistance services and supports are a key component of a successful program.

And yet there are several reasons why we have to do more.

Federal Medicaid policy should reflect the consensus that Americans with disabilities should have the equal opportunity to contribute to our communities and participate in our society as full citizens. Instead, our current federal Medicaid policy favors exclusion over integration, and dependence over self-determination. This legislation will bring Medicaid policy in line with our broader agreement that Americans with disabilities should have the chance to move toward independence. This bill allows people to receive certain types of services in the community so that they don't have to sacrifice their full participation in society simply because they require a catheter, assistance with medication, or some other basic service. Take the example of a friend of mine in Iowa. Dan Piper works at a hardware store. He has his own apartment and just bought a VCR. He also

has Down's syndrome and diabetes. For years Dan has received services through a community waiver program. But, he recently learned that he might not be able to receive some basic services under the waiver. The result of this decision? He may have to sacrifice his independence for services. Today, Dan works and contributes to the economy as both a wage earner and a consumer. But, tomorrow, he may be forced into a nursing home, far from his roommate, his job and his family.

In addition, our country is facing a long-term care crisis of epic proportions in the not-too distant future. We all talk about the coming Social Security shortfall and the Medicare shortfall, but we do not talk about the long-term care shortfall. The truth is that our current long-term care system will be inadequate to deal with the aging of the baby boom generation, the oldest of whom are now turning 60. Our bill helps to create the infrastructure we will need to create the high-quality, community based long term care system of the future. And it will give families the small amount of outside help they need to continue providing care to their loved ones at home.

And, finally, in a common sense decision last June, the Supreme Court found that, to the extent Medicaid dollars are used to pay for a person's long term care, that person has a right to receive those services in the most integrated setting. States must take practical steps to avoid unjustified institutionalization by offering individuals with disabilities the supports they need to live in the community. We in Congress have a responsibility to help States meet the financial costs associated with serving people with disabilities that want to leave institutions and live in the community, and the bill I am introducing will provide that help.

And so I call upon my colleagues for your support. Millions of Americans require some assistance to help them eat,

dress, go to the bathroom, clean house, move from bed to wheelchair, remember to take medication, and to perform other activities that make it possible for them to live at home. These Americans live in every State and every congressional district. Most of these people have depended on unpaid caregivers - usually family members - for their needs. But a number of factors have affected the ability of family members to help. A growing number of elderly people need assistance, and aging parents will no longer be able to care for their adult children with disabilities.

But they all have one thing in common with every American. We all deserve to live in our own homes, and be an integral part of our families, our neighborhoods, our communities. Community attendant services and supports allow people with disabilities to lead richer, fuller lives, perhaps have a job, and participate in the community. Some will become taxpayers, some will do volunteer work, some will get an education, some will participate in recreational and other community activities. All will experience a better quality of life, and a better chance to take part in the American dream. I urge my colleagues and their staff to study our proposal over the break. I hope there will be hearings and action on this bill next year. And, finally, I ask unanimous consent that the bill, along with letters in support of the bill, be printed in the Record following our statements.

*If you want to get on the MiCASSA update email list, send a message to that effect to [adapt@adapt.org](mailto:adapt@adapt.org)*

## ***WIIA Passed!***

Many disability rights groups including ADAPT, as well as tons of other advocates have been working for the final passage of the Work Incentives Improvement Act (WIIA). Thanks to a lot of hard work WIIA has passed! That means more people with disabilities will be closer to being able to work than ever before.

The Work Incentives Improvement Act will make employment a realistic choice for the first time for many people with disabilities. That is important to all of us.

WIIA alters and enhances the relationship between work and current federal support systems, by providing funds for State options, to be used for State run programs.

Passage of this bill will change the relationships between people with disabilities, Social Security, Medicaid, Medicare, and providers of rehabilitation or employment services by providing Consumer choice of employment services providers, such as VR, or any other provider within their community. This bill will also allow people to extend the time they can keep their health care benefits while working.

The shift is a significant first step to finally make these federal programs employment friendly, as well as ensuring that the funds go to only those providers that actually employ people with disabilities.

Though WIIA has some good options, they are just that, options. As usual it is going to be up to each state to make sure these options become reality. So start contacting your own state to implement this historic legislation.

# Guide for Greyhound Passengers:

## Accessible Bus Service Under the Greyhound Agreement

(from the U.S. Department of Justice)

Greyhound promised to improve its accessible bus service as part of a settlement agreement with the Department of Justice. The agreement resolves a series of complaints filed under the Americans with Disabilities Act.

This guide explains how you can get accessible bus service under the agreement between now and October 1, 2001. As of that date new Department of Transportation regulations will require Greyhound to provide accessible, lift-equipped service on demand with 48 hours' notice.

Greyhound is starting to put more accessible buses on the roads and train Greyhound's bus drivers and other workers to provide accessible bus service (for example, through the operation of lifts, other boarding devices, and disability awareness). Until all the buses are in service and all the drivers are trained, Greyhound will not be able to meet all requests for accessible bus service. By April 1, 2000, however, Greyhound will guarantee lift-equipped bus service to and from all of its destinations, except in a very limited set of circumstances.



For accessible bus services, please call the Greyhound ADA Hotline: 1-800-752-4841 or 1-800-345-3109 (TDD). Call at least 48 hours (two days) before you want to travel. Greyhound may need to call you back to make final arrangements.

### What to Expect Before April 1, 2000

If you call Greyhound's Hotline at least 48 hours in advance of your travel —

1. You may be able to travel on a lift-equipped bus with trained personnel, if:

- You are traveling along a route with regularly scheduled lift-equipped buses are. If so, then Greyhound must provide a lift-equipped bus, except in "excusable circumstances," as explained below.

- You are traveling along a route where lift-equipped buses are not regularly scheduled, but Greyhound is still able to provide a lift-equipped bus with reasonable effort. At first, Greyhound will not be able to meet all of these requests, but lift-equipped bus service will improve as April 1, 2000, approaches.

(You can get off the bus and get back on at each designated rest stop and meal stop if you wish.)

2. You may be able to travel with the assistance of station-based lifts or boarding devices if your travel plans include locations where these devices are, or can be made, available within 48 hours. If so, then Greyhound will provide such assistance, except in excusable circumstances.

3. You may have to be carried onto and off of a bus, if Greyhound is unable to provide a lift-equipped bus, station-based lift, or boarding device.

"Excusable circumstances" include, for example:

- A bus or lift suddenly breaks down,
- There is an unforeseen lack of trained personnel,
- There is an unusually high demand for services, or

- It would be very costly to provide service in a particular situation.

In these situations, Greyhound will not have to provide accessible service.

### What to Expect Between April 1, 2000 and October 1, 2001

Greyhound will be operating "Access Greyhound." With at least 48 hours' notice Greyhound will guarantee lift-equipped bus service from and to all of its locations, except in "excusable circumstances" (as explained above). Even in those excusable circumstances, Greyhound must still provide other boarding assistance. Also, as of October 2000, the new Department of Transportation regulations will require companies like Greyhound to ensure that all new buses that they purchase or lease will be lift-equipped. Ultimately, but not later than October 28, 2012, all over-the-road buses operated by companies like Greyhound will be lift-equipped.

### What to Expect After October 1, 2001

New Department of Transportation regulations require that as of October 1, 2001, companies like Greyhound must provide lift-equipped bus service on 48 hours' notice at every location that they serve. Ultimately, after all buses become lift-equipped, passengers will no longer have to provide 48 hours' notice to travel with Greyhound.

#### In All Situations

If you don't give 48 hours' notice, Greyhound still has to make a reasonable effort to provide an accessible bus, assistive devices, or other boarding assistance. This means that Greyhound can carry a passenger as a last resort.

### Complaints

You can file complaints about Greyhound's bus service with Greyhound, and Greyhound will investigate. You should file within 60 days of the incident.

You can also file a complaint with the Department of Justice.

If you file a complaint with either Greyhound or the Justice Department, please try to provide as much information as possible, including the bus number; driver's name; date, time, and location of the incident; and the name of other Greyhound personnel or other witnesses. The addresses for filing your complaint with either Greyhound or the Justice Department are:

Greyhound ADA Corporate Office  
P.O. Box 660362 Dallas, Texas 75266-0362  
U.S. Department of Justice Disability Rights  
Section Civil Rights Division  
P.O. Box 66738 Washington, DC 20035-6738

If you file a complaint with either Greyhound or the Justice Department, you won't waive your legal rights unless you accept compensation for the incident.

## Over the Road Buses- Court rules for DOT

On September 10, US District Judge Ricardo M. Urbina in the District of Columbia denied the American Bus Association's (ABA) suit against the US DOT Final Accessibility Rule for Over-the-Road-Buses, OTRBs.

Among the issues involved in the suit, the ABA claimed that US DOT's rule failed to adequately address safety issues related to transporting passengers with disabilities on intercity buses in their own wheelchairs or other mobility devices, and that the regulations providing denied boarding compensation went beyond US DOT's authority. However, the court found that the US DOT's safety considerations

and the rule establishing a denied boarding compensation penalty on operators that fail to comply with the rules and provide accessible service were within DOT's regulatory authority.

Between January and May 2000 the Federal Transit Administration, through Project ACTION, will conduct ten training workshops on motorcoach accessibility for bus and tour operators from across the US and Canada, educating them in the requirements of the US DOT OTRB accessibility regulation.

According to an ABA press release, it is considering an appeal of certain aspects of the decision but no action has been taken. Despite the possibility of appeal, this is an important victory for DOT's regulation requiring Greyhound and other fixed route OTRB companies to purchase only accessible buses after October 2000.

DREDF's Marilyn Golden says that sometime in the next few months DOT will publish a final regulation on Information Collection by private companies using OTRB's. Many disability advocates wrote in support of creating a strong docket which hopefully will result in DOT requiring these companies to provide adequate documentation, confirmation numbers, etc. to people with disabilities requesting accessible service.

Advocates should remember that, after October 2001 (for large companies, and October 2002 for small companies), if an individual with a disability who needs an accessible bus requests, but does not receive, accessible service, the company is required to pay financial compensation to the individual, between \$300 and \$700. This compensation is also available if the individual does not receive the service because accessibility equipment does not function or because operator personnel do not perform essential tasks (see details in the summary of the regulation at [www.dredf.org](http://www.dredf.org)).

Incitement

Around the World



### VISITABILITY IN ENGLAND

People with disabilities in England will be able to visit their neighbors' homes: get in, fit through the doors, and find a bathroom on the main floor!

Started in October 1999, a Building Regulation took effect in England and Wales mandating basic access in ALL new single-family homes. Parliament passed the "statutory instrument" mandating this access in March '98, and since that time the specific regulations for construction have been written and approved.

Among the requirements are an accessible approach to the dwelling, a zero-step entrance when topography permits, at least a half-bath on the main floor, wide halls and doorways, and accessible switches and electrical outlets.

Meanwhile in the USA, the National Association of Home Builders (NAHB) continues to swat down advocates' attempts to legislate access--unless the a law provides big bucks for them to do what's right--and at the same time refuses to implement effective voluntary reforms.

"Apparently, England realized the vast benefits of Visitability while America's NAHB actively opposes a great idea whose time has come!", says Zan Thornton member of the National Disability Rights Action Coalition for Housing (DRACH).

To see the copy of the British regulations, go to: <http://concretechange.home.mindspring.com>.

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## DOJ Settlement Forces Greyhound to Speed up Lifts

In response to a lawsuit filed by the Justice Department (DOJ), Greyhound Lines Inc. agreed Thursday September 30, 1999 to phase in lift-equipped buses for disabled riders two years before it is required to have them. DOJ had received numerous complaints that Greyhound drivers and employees had violated the Americans with Disabilities Act. Most involved refusal to assist with boarding, injuries that occurred when disabled riders were carried on or off buses or other mistreatment, the department told the Associated Press. DOJ had picked 14 individuals whose concerns represented those of numerous others; ironically, the Department of Justice failed to pick any ADAPT representatives despite ADAPT's extensive testing and advocacy on this issue.

Greyhound President Craig Lentzsch tried to down play their failure to serve, insinuating there were only 14 problems out the millions of passengers served.

"Carrying people with disabilities onto buses is often dangerous and humiliating," said Bill Lann Lee, acting assistant attorney general in charge of the Civil Rights Division. "This agreement is an important step towards eliminating carrying in intercity transportation."

The new Dept. of Transportation rules require that Greyhound and other large operators provide lift-equipped bus service on 48 hours notice, beginning Oct. 28, 2001.

But Greyhound agreed to take two steps before that deadline:

—Between now and March 31, 2000, passengers who call Greyhound's toll-free ADA hot line, 1-800-752-4841, 48 hours before they travel will start being provided lift-equipped buses or station-based boarding devices along major routes and Greyhound will try to make this assistance available on its other routes, as possible.

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Assistance, by carrying if necessary, to get on and off at all stops, includes rest and meal stops.

—April 1, 2000, Greyhound will guarantee accessible buses between any of the 2,600 locations it serves if it has 48 hours notice — except when there are sudden breakdowns in the bus or the lift, an unforeseen lack of trained personnel, an unusually high demand or the service at a particular site would be very costly. The company will assist with boarding even if a lift-equipped bus cannot be found.

Beginning Oct. 28, 2001, all newly purchased or leased buses will have lifts and Greyhound will provide lift-equipped buses between any locations on 48 hours' notice.

The company will also train all its employees in assisting disabled riders, set up an internal dispute resolution procedure to handle complaints from disabled riders within 90 days, inform passengers of their rights, set up a disability advisory committee and remove other barriers in Greyhound facilities.

In addition, Greyhound will pay more than \$17,500 in damages, including payments from \$500 to \$4,000 to 14 individuals who complained about its service.

It is important to note that since this is an agreement between the DOJ and Greyhound, these deadlines apply only to Greyhound trips. Other service providers, like Trailways, Peter Pan, Valley Transit, etc. are still held to the original dates in the Dept. of Transportation rules.

To get information about the ADA and your rights, call the Department of Justice's ADA Information Line, 800-514-0301 (voice), or 800-514-0383 (TDD), or visit our website, <http://www.usdoj.gov/crt/ada/greyfact.htm>. You may also obtain a copy of the settlement agreement from the website.

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# The Show Me State Provides Gateway To The Governors

"I have never seen so many police in one place in my entire ADAPT life" said Bob Kafka, "there are over 55 in my immediate sight as I stand here in front of the steps of Dred Scott court house across the street from the National Governors' Association, NGA, conference. "They have all the doors taped shut with orange police tape" added Michelle Steger of St. Louis ADAPT; "it's like an armed camp."

ADAPT was in St. Louis in August to remind the Governors at their national conference that over 2 million Americans continue to be locked away in nursing homes and other institutions because of the institutional bias in Medicaid and long term care, and because of choices these Governors have supported.

One would have to ask why our nation's Governors felt they needed to hide behind so many police. Could it be because they are feeling uncomfortable about their work to oppose integration for people with disabilities and to undermine the Americans with Disabilities Act? You just can't cover up something that big that stinks that bad, no matter how many police you cram on a block.

Over 150 ADAPT activists had gathered from around the nation to protest the NGA's anti-disability stand. The action started with a vigil outside the courthouse where the case of Dred Scott, a slave who unsuccessfully sued for his freedom, was heard. ADAPT's protesters erected a cross with a wheelchair hanging from it to symbolize people with disabilities being sacrificed to the long term care system. The cross was carried across the street and delivered to the Governors' hotel.

ADAPT challenged the NGA to:

\* Work with ADAPT to implement the most integrated setting requirement in

*Incitement*

the Americans with Disabilities Act, ADA so that people with disabilities, every child, young adult and older American has the choice of where they live and receive long term services and supports.

\* Create a "Most Integrated Setting" Task Force within the NGA, to include ADAPT, that will focus on technical assistance to states on ways to develop community long term services and supports.

\* Publicly state the NGA's support for the ADA's most integrated setting requirement.

\* Direct/encourage each member of the NGA to work with ADAPT and other members of the disability community to develop community options so that no individual is forced into a nursing home or other institution.

\* Support the introduction, funding and passage of the Medicaid Community Attendant Services and Support Act, MiCASSA which will give people with disabilities Real Choice in long term services and supports.

ADAPT protesters also rallied with bullhorns outside the Adam's Mark Hotel as President Bill Clinton's motorcade arrived Sunday at the National Governors' Association meeting.

Ten square blocks around the Governor's hotel had been cordoned off. Just when it looked like all was lost, the buses which the Governors were going to take to their social event that evening parked right to the foot of the driveway of the hotel at which ADAPT was staying. Folks rushed down the driveway and surrounded the buses while the police tried to pretend these were just some other buses. As long as our brothers and sisters remain locked away in nursing homes, ADAPT was not going to let these decision

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makers ignore the problem and party hearty! The chant "I'd rather go to jail than to die in a nursing home" echoed through downtown St. Louis as the NGA arrested 50 ADAPT that night for advocating for the right to choose where they live and receive attendant services.

"A nursing home and a jail are very similar," said ADAPT organizer Michelle Steger of St. Louis, "it's mainly that in jail your sentence has an end, while in a nursing home too often the only way out is a pine box. I've been in both jail and a nursing home was lucky I got out of there with my life! "Where do you want to spend your later years" Michelle added, "in your own home, or stuck in an institution?"

ADAPT concluded the protests by redelivering the set of demands on implementing the ADA "most integrated setting" requirement. Four individuals, demands in hand, got out of their wheelchairs and attempted to deliver a message to the security surrounded Governors, however they were stopped by the hundreds of police "guarding" the NGA conference location. One individual was arrested but later released. The NGA had created a "Governors Ghetto" by encircling their hotel, the Adams Mark, with hundreds of police officers and security personnel to protect themselves from people with disabilities. The Governors were invited to join ADAPT outside, but Gov. Jessie Ventura was the only one who came outside and spoke with ADAPT. Ventura said he would try to set up a meeting between ADAPT and the NGA.

The NGA has officially refused to meet with ADAPT, though they repeatedly tell the media they are setting up meetings. ADAPT is committed to meeting with the NGA and each individual Governor to assure that no individual with a disability will be forced into an nursing home or other institution.

The dispute is one of Civil Rights vs.

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States Rights, at stake the opportunity for freedom and self-determination of millions of Americans, perhaps - one day - even you.

*Around the Nation*



## AIR CARRIERS ACCESS ACT REGULATIONS IMPROVE AIR TRAVEL FOR PEOPLE WITH DISABILITIES

Good news for travelers with disabilities! Federal regulations published August 2, 1999 eliminate the previous cap on airline liability for damage to mobility equipment! In the past, the amount that airlines had to pay for damaged equipment was limited or capped at \$250, but now that cap is gone.

In addition, regulations published in March 1998 have changed the rules regarding requirements for airlines to accommodate the seating needs of people with disabilities. These final rules on this subject specify four priority conditions that require airlines to make accommodations, as well as stating that people with other disabilities who require seating accommodations shall be assigned to "any seat that has not already been assigned to another passenger, even if that seat is not otherwise available to the general passenger population at the time of the request." If you need special seating accommodations and request that accommodation more than 24 hours in advance, the airline cannot refuse to accommodate you on the basis that the only seats that meet your needs are reserved for frequent fliers or "full fare" passengers. If the seats are not yet assigned and would meet your needs, the airline must accommodate you!

To get the full text of these new sets of regulations for the Air Carriers Access Act (not the ADA) you can look on the

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Department of Transportation website www.dot.gov the website of the Access Board www.access-board.gov or call 800/872-2253 voice or 800/993-2833 tty. You can get this information in alternate formats too.

**ADA TITLE II RULED UNCONSTITUTIONAL IN 8TH CIRCUIT**

As elaborate plans are being developed to celebrate the 10th anniversary of the Americans with Disabilities Act, ADA, the very existence of this important law is in jeopardy. Our civil rights are threatened, as are our rights under Section 504 of the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act, IDEA. It seems, in some places in America, it is OK for us to have civil rights only so long as we don't ever try to use them.

On July 23, 1999 the US Court of Appeals for the 8th Circuit ruled in a case called "Christopher B. Alsbrook vs. City of Maumelle, Arkansas" No. 97-1825 LEXIS 16945 that "... extension of Title II of the ADA to the State exceeds Congress's authority under Section 5 of the Fourteenth Amendment." This same 8th Circuit has made similar rulings declaring Section 504 and IDEA unconstitutional as well.

They said: "In sum, it cannot be said in applying Title II of the ADA to the states, Congress has acted to enforce equal protection guarantees for the disabled as they have been defined by the Supreme Court. We find therefore, that the extension of Title II of the ADA to the states was not a proper exercise of Congress's power under Section 5 of the Fourteenth Amendment."

In real words they have said that in the 8th Circuit ( States included are: Arkansas, Iowa, Minnesota, Missouri, Nebraska, North Dakota and South Dakota) Title II of the ADA is unconstitutional!!!

YES- ADA TITLE II State and Local Governments UNCONSTITUTIONAL !!!

This ruling is in conflict with four other Circuit Courts which ruled Title II constitutional which means the Supreme Court will have to make the final determination.

What is clear is that ADA and other disability rights laws are under major attack not only in the 8th Circuit but all over the country. Some case testing the constitutionality of the ADA will almost certainly go before the Supreme Court next session. Get ready for the battles.

Even the Fair Housing Act Amendments, which extend housing discrimination protections to people with disabilities has been under attack, though in Congress rather than in the Courts.

**DON'T MOURN ..... ORGANIZE!  
DON'T TREAD ON THE ADA.**

**KANSAS SUPREME COURT**

On December 8, 1999 the Kansas Supreme Court heard arguments in LINK, Inc., Lou Ann Kibbee, & Brian Atwell vs. City of Hays, Kansas. Lou Ann Kibbee is the contact person for Western Kansas ADAPT and Brian Atwell is involved with ADAPT as well. The City of Hays appealed a ruling made by District Court Judge Will Madden that the City of Hays was failing to enforce Title III of the ADA in reference to issuing building permits and certificates of occupancy for new construction. The City of Hays contends that not only have they been assuring compliance of public accommodations, they have done as well as any other city. The plaintiffs, of course do not agree with this outlandish account of ADA enforcement. It is difficult to read which way the Kansas Supreme Court will rule, but there was a great ADAPT presence with well over half the spectators from Western Kansas ADAPT or Kansas ADAPT. The Kansas Supreme Court should be ruling on this by the end of January 2000.



**KANSANS END THE FREEZE ON ATTENDANT SERVICES**

This Spring the Department on Aging and SRS enacted a freeze on new clients eligible for attendant services through our Frail Elderly and Physical Disability waivers for Home and Community Based Services (HCBS).

We practically camped out at the statehouse while the Legislature argued over the Omnibus budget. We staged rallies and demonstrations to inform the public and pressure the government. Many of us contacted our legislators and the Governor via phone, fax, e-mail, letters, postcards and personal visits to express our concerns and our rights.

ADAPT covered the state doing town meetings in the home towns of several Legislators in an attempt to bring these issues to the public and discuss possible solutions with those Legislators. Advocates informed the public that the freeze was a violation of our civil and human rights. It is poor public policy, because on average the institutions cost at least \$8,000 a year more



Activists took followers to the State House and to the Department on Aging. There were approximately 700 flowerers, one for each life frozen on he waiting lists.

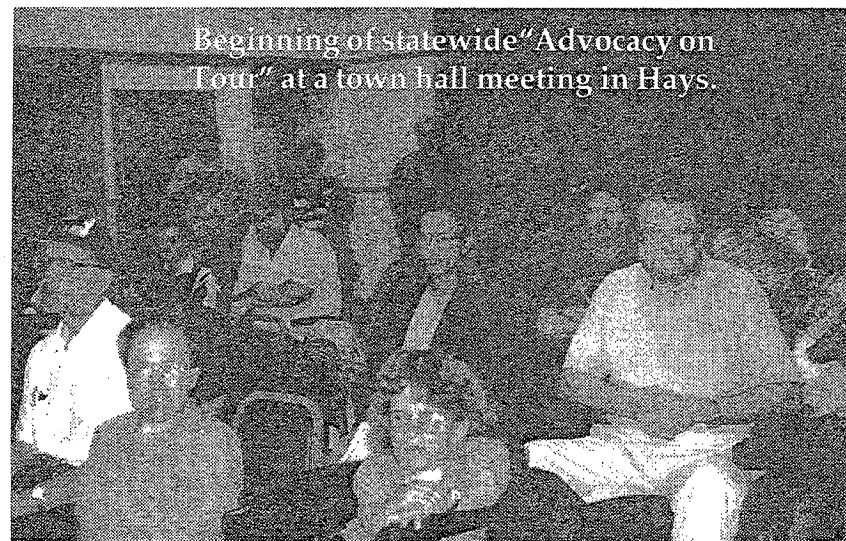
than home care services.

Advocates from TILRC, ADAPT, other Kansas CILs, and other dedicated people finally were able to convince the Governor and the legislative leadership to provide eligible Kansans in-home services rather than force them into much more expensive institutions, or to just go without.

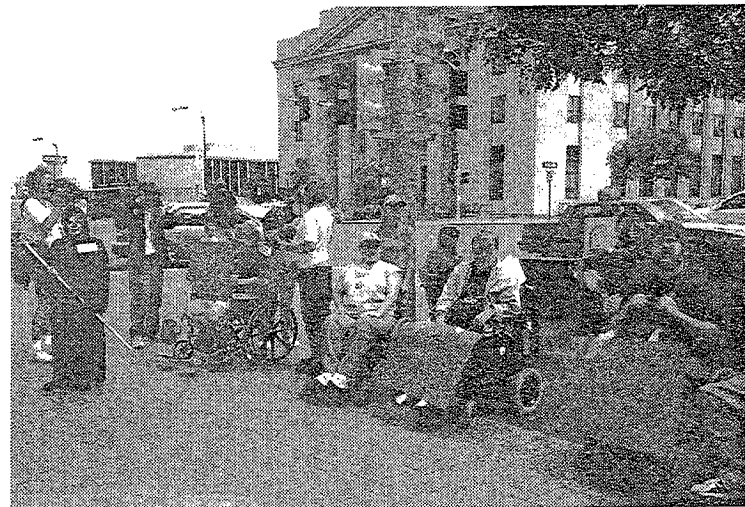
In October, the Governor and the legislative leadership succumbed to our political pressure and emotional appeals, and directed state agencies to start providing home-care services to elderly and disabled Kansans who need them to stay out of nursing homes.

At that time there were 351 people on the waiting list for the FE waiver and 334 on the PD waiver.

Maintaining the policy



Beginning of statewide "Advocacy on Tour" at a town hall meeting in Hays.



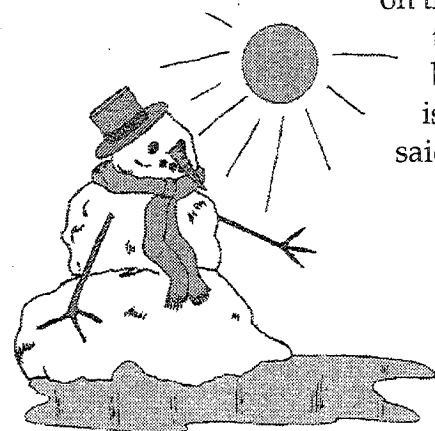
Death lingered among the protesters, representing what waiting too long could mean to someone who needs attendant services, of serving everyone who qualifies for services would cost an additional \$23.5 million in the fiscal year that starts next July.

Graves said while the agencies had sufficient funds to start the process of eliminating the waiting lists, the Legislature would need to add money to this year's budget when it returns in January.

"I don't think that there is any doubt that the Legislature will come through with the money," Graves said.

"It was the emotional aspect of having senior Kansans, and people with disabilities, (that caused) members of the Legislature and me to come to appreciate that this was just an issue we were better off to fund, and you might say make good

on the services that had been promised," Graves said.



### ASSISTANCE AT SELF-SERVE GAS STATIONS

U.S. Department of Justice  
Civil Rights Division  
Disability Rights Section  
June 1999

People with disabilities may find it difficult or impossible to use the controls, hose, or nozzle of a self-serve gas pump. As a result, at stations that offer both self and full service, people with disabilities might have no choice but to purchase the more expensive gas from a

full-serve pump. At locations with only self-serve pumps, they might be unable to purchase gas at all.

The Americans with Disabilities Act (ADA) requires self-serve gas stations to provide equal access to their customers with disabilities. If necessary to provide access, gas stations must:

- Provide refueling assistance upon the request of an individual with a disability. A service station or convenience store is not required to provide such service at any time that it is operating on a remote control basis with a single employee, but is encouraged to do so, if feasible.
- Let patrons know (e.g., through appropriate signs) that customers with disabilities can obtain refueling assistance by either honking or otherwise signaling an employee.
- Provide the refueling assistance without any charge beyond the self-serve price.

If you have additional questions concerning the ADA, you may call the Department of Justice's ADA Information Line at (800) 514-0301 (voice) or (800) 514-0383 (TDD) or access the ADA Home Page at: ([www.usdoj.gov/crt/ada/adahoml.htm](http://www.usdoj.gov/crt/ada/adahoml.htm)).



### ROADRUNNER COMPLIES WITH ADA

Topeka Independent Living Resource Center, Inc.'s legal department has entered into a settlement agreement on behalf of a consumer with Roadrunner Express, Inc., whereby Roadrunner agreed to come into compliance with the ADA.

Roadrunner Express, Inc., provides round trip or one way transportation to and from KCI (Kansas City International Airport). Roadrunner has no accessible vehicles and told consumers that they would have to be carried on to the vans or to contact A&A Transportation, which charges three times more. Roadrunner charges \$51.00 for a round trip from Topeka to KCI, and A&A charged \$250.00. Under the law, a private entity engaged in demand responsive service transportation, must provide accessible vehicles or comparable service with regards to fares and schedules. On September 9, 1999, Roadrunner entered into an agreement with A&A to provide equivalent service to disabled travelers at Roadrunner rates and Roadrunner will pay A&A the difference in transportation costs.

Please contact the TILRC Legal Department for details at (785) 233-4572.

### OLMSTEAD RESIGNS

Department of Human Resources Commissioner Tommy Olmstead resigned July 15, 1999. Audrey Horne becomes the new Commissioner.

### WISCONSIN PROTESTES CHUCK E. CHEESE

Wisconsin -- ADAPT folks in Wisconsin protested Chuck E. Cheese, a children's restaurant chain, when a local restaurant discriminated against an employee because of his disability.

### HCFA APPOINTS NEW DIRECTOR

In September the Health Care Financing Administration appointed Timothy Westmoreland, Director of the Center for Medicaid and State Operations (CMSO). He replaced Sally Richardson. For the past four years, Westmoreland was a senior policy fellow at the Georgetown University Law Center and a senior advisor to the Kaiser Family Foundation. He has also served as the Washington representative of the Elizabeth Glaser Pediatric AIDS Foundation. Prior to that, he served the House Subcommittee on Health and the Environment. He was principle advisor to the subcommittee on public health, prevention and education, AIDS issues, disability, privacy and health information systems.

### MARYLAND ADAPT DEMONSTRATES DESPITE HURRICANE FLOYD

Baltimore, MD -- September 15th, during the Mass Transit Administration's "Try a Ride" week Maryland ADAPT kicked off a long term campaign against them, starting with a raucous demonstration in front of their headquarters. Most of the core members came out for this testament to endurance, as this was the day before hurricane Floyd! But the troops braved the soaking for several hours as it got windier and wetter! They held out because MTA is still in the dark ages as far as compliance, and their condescending attitude needed to be addressed. After three hours we went inside the lobby to present our demand letter to MTA head Ronald Freeland.



### ADAPT PROTESTS NEW SYSTEM OF EVALUATING NEEDS.

Denver, CO -- ADAPTerS took on their state's Medical Services Board this fall to protest a new system of evaluating people's needs for assistance. The change would mean cuts in service, and force people into institutions activists asserted "the proposed [change] for bowel care is 10 minutes duration. How many people can do a bowel program in ten minutes?" asked Joe Ehman of ADAPT "and who will stand by with a stop watch?" The state's own Medicaid report states that in home services cost about \$11,189 per year per person, while nursing homes cost \$23,255; forcing folks into nursing homes will skyrocket costs by 200% the protesters pointed out.

### MAN ASSISTED WITH SUICIDE TO ESCAPE INSTITUTIONAL LIFE

Rochester NY -- ADAPT held a series of protests and legal actions this past summer to try and stop the assisted suicide of Bill White, who used a vent and had lived in a local hospital for over 30 years. He was fed up with living in an institutional setting of the hospital and felt his only way out was to end his life. The hospital apparently agreed as they were "supporting" him and his family and assisted with the suicide. Though Rochester ADAPT and Not Dead Yet's efforts did not save White, they were able to call attention to the issues.

### HUD FAILS TO SET UP A MEETING

Salt Lake City, UT -- Utah ADAPT was one of twenty groups which hit the Department of Housing and Urban Development after their failure to set up a meeting with Secretary Cuomo regarding concerns about HUD's support for institutional housing for people with disabilities over integrated accessible, affordable housing. The Department's incompetent scheduling staff is being used as an excuse for HUD's complete disregard of the concerns of ADAPT and other disability organizations.

### DESERT ADAPT REFORMS VISITING NURSE ASSOCIATION

El Paso, TX -- When a local home health agency began tightening up on the activities they were going to perform for their customers (activities like bowel programs and transfers) Desert ADAPT sprang into action and took over their offices. The activists demanded the agency, the Visiting Nurse Association, rescind their policies which would in effect force many people into nursing homes, since life cannot be lived for long without moving ones bowels and getting out of one's wheelchair or bed once in a while. The results were stellar, as VNA saw the error of their ways and has redone their policies and now is supporting several community based service efforts.

*MSNBC reports that 77 million baby boomers are heading into retirement age. When will the federal government wake and smell the coffee?*

# Passages

## Phyllis Burkhead

ADAPT experienced a major loss this fall. Just after the action in Ohio, Phyllis Burkhead of Louisville Kentucky passed away after having heart failure. According to those who knew her best, she had been having heart trouble for some time. Phyllis was a long time ADAPT activist, her involvement dating back to when ADAPT was pushing for lifts on buses. Her quietness belied her sharp wit and fiery personality, not to mention her love of the party. But with her infamous word board Phyllis soon cleared away any misconceptions about herself. She epitomized the saying "still waters run deep", as there are few -- if any -- who are more hard core believers in our cause. There is a well known picture of her lying on the ground under a car in Atlanta at the Federal Building during an action over access to the buses, giving an interview with a reporter. Less well known is that this was her first national action, and there she was under the car.

Phyllis spent four years in a nursing home in Kentucky, where she was sent to keep her mother company as she died. After witnessing another woman being abused by the staff she was finally able to leverage her way out and she swore she would never return. When she learned of ADAPT she moved quickly from the edge to one of the mainstays of the group. Phyllis' involvement including participation in all the national actions and numerous local ones, serving as a leader locally and nationally, supporting others in their efforts to liberate themselves from nursing homes and other

institutions. She even served as an attendant on occasion, making sure others doors were locked and that services were being properly provided.

She once told Sue Davis, "I do this for my mom." Sue said of Phyllis "I couldn't ask for anyone better to organize for and with. What she has given this group is something to celebrate!"

## Margaretta Newell

A 40-ish activist who never shied away from a battle, died of a stroke on Sunday, Dec. 12, in a hospital outside Tyler, Texas. She was the contact person for Houston ADAPT from '97 until recently. Although her MS kept Margaretta away from most national actions, her leadership in Houston was dynamic, and she will not be replaced any time soon.

Margaretta understood ableism. In an interview, she once said, "Those people who say they love you the most, when they see you going through a crisis, you can see the wheels turning as to what they feel is best for you. We may have a disability like MS, but we want to be the ones to know our own limitations and to plan for our own future. Don't expect us to give up our own lives to ease your conscience..."

She liked obnoxious women. Takes one to know one.

Margaretta is succeeded by her service friend, Forest, and the scores of Houstonians whose lives she enhanced. I worked for her in her home for a year, where she sculpted and sang. I rejoice in knowing her, and I will miss her dreadfully.  
--Crosby King, Maryland ADAPT