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## Community Choice Act National Kickoff Draws Thousands

**Reprinted from ADAWatch.org, March 24, 2009**

ADAPT's National Kickoff for the Community Choice Act concluded in Washington, DC with a rally call to "Pass CCA Now!"

With thousands of advocates in DC and at more than 120 conference call-in sites across the country, Community Choice Act (CCA) cosponsors Senator Tom Harkin, Senator Arlen Specter and Congressman Danny Davis made crystal clear their commitment to passing the Community Choice Act in the 111th Congress. The event was an upbeat event at times filled with thunderous applause and the chanting of "Pass CCA Now!"

Sen. Tom Harkin led off this important event on Capitol Hill and declared that CCA will pass in this Congress and be on the President's desk either as a part of the healthcare reform bill or on its own. He noted that it has been 10 years since the Supreme Court's *Olmstead* decision which affirmed the Constitutional rights of people with disabilities to live in the least restrictive environment and he told the critics who say CCA will cost too much that by allowing individuals with disabilities to live and work in their own homes and

communities rather than institutions, the costs will be offset by new taxpayers. Harkin declared: "We can't afford not to do this!"

ADA Watch and the National Coalition for Disability Rights (NCDR) are longtime supporters of CCA, formally known as MiCASSA, the legislation that gives people real choice in long term care options. This legislation ends the institutional bias in the Medicaid program by giving individuals who are eligible for nursing facility services or other institutional "care" equal access to community-based services and supports, like attendant services.

The event was moderated by Kansas ADAPT member, Mike Oxford and the other speakers included Dawn Russell, ADAPT, Andy Imperato, American Association of Persons with Disabilities (AAPD), Marty Ford, Coalition of Citizens with Disabilities (CCD), John Lancaster, National Council on Independent Living (NCIL), Victor Robinson, Self Advocates Becoming Empowered (SABE), and Mitch LaPlante, University of California, San Francisco.

Congressman Danny Davis received huge applause when, after promising to do everything in his power in the House this session, he quoted the lyrics to a Sam Cooke song:

*I was born by the river in a little tent  
And just like that river I've been running ever since  
It's been a long time coming  
But I know a change is gonna come, oh yes it will*

With a progressive president in the White House, powerful co-sponsors in a more receptive Congress and more than 700 disability organizations signed-on in support of the Community Choice Act, the chant of "Pass CCA Now!" at the conclusion of this rally had an empowered and celebratory tone rather than a pleading one. All of the speakers, however, acknowledged that there is hard work ahead for all as the community works to attract Congressional sponsors to the bill, educate the media and mobilize public support for CCA.

Today, everybody seemed ready to take on that hard work.



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# ADAPT Hits DC on A Mission to Pass CCA!



*ADAPT members arrive to begin week of advocacy. Photo by Tim Wheat.*

ADAPT rolled into Washington, DC on April 25, 2009 intent on doing all they could to make real choice in long-term care a reality by getting the Community Choice Act (S 683 and HR 1670) passed by the 111th Congress! The Community Choice Act when passed will give Medicaid-eligible people the choice to get the long-term services and supports they need in their own homes and communities, instead of being forced into nursing facilities or other institutions. As usual ADAPT members from all across the United States arrived at the Capitol Holiday Inn throughout the day and began to get settled in for four days of grassroots advocacy. By the end of the day over 500 activists had arrived, anxious to get started on their mission to end the institutional bias in our nation's system of long-term care.

Sunday morning, April 26th began with meetings to orient folks who were attending their first national ADAPT action and to organize the activities for the coming week. By mid-day ADAPT members began massing outside the hotel preparing to head up Capitol Hill to participate in the ADAPT FUN\*RUN.

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## **ADAPT's 2009 FUN\*RUN for Disability Rights Celebrates the 10th Anniversary of the Olmstead Decision!**



*The FUN\*RUN begins. Photo by Kevin Siek*

A seemingly endless line of members of the ADAPT Community came streaming up Capitol Hill into Upper Senate Park in Washington, DC at midday on Sunday, April 26th to participate in the 2009 FUN\*RUN for Disability Rights. ADAPT holds the FUN\*RUN each Spring as their main fundraising event to support their grassroots disability rights advocacy activities. Since ADAPT doesn't rely on donations from corporations or other groups it's up to our members to come up with the funds necessary to carry on our mission. The FUN\*RUN is an opportunity for people to raise money for the national organization and their state chapters.



*Fun\*runners enjoyed the beautiful spring weather.  
Photo by Kevin Siek.*

This year's event celebrated the 10th anniversary of the landmark US Supreme Court's [Olmstead decision](#), which occurred on April 22, 1999. In the case of *Olmstead v. L.C. and E.W* the Supreme Court ruled that keeping people with disabilities locked up in institutions when they could be getting the care they need in the community is discrimination. The Court declared that "unnecessary institutionalization amounts to segregation and is a violation of individual civil rights under the Americans with Disabilities Act." The decision made it possible for hundreds of thousands of people with disabilities and older Americans to get out of nursing homes and other institutions and receive their long-term services and supports in the "most integrated setting". The 2009 FUN\*RUN was a celebration of Olmstead's 10th anniversary and of our commitment to the principle of "most integrated setting", a principle at the foundation of The ADAPT Community's advocacy.

This year's National Celebrity Fun Runner was Lois Curtis, who was the "L.C." in *Olmstead v. L.C. and E.W.* Ms. Curtis still lives in Atlanta, Georgia, but now as an artist living in the community instead of as an unwilling inmate in an institution. She will be joining ADAPT again for the Fall Action in Atlanta, October 4-8, 2009.





*"Master of Ceremonies" Bob Kafka.  
Photo by Kevin Siek.*

ADAPT advocates enjoyed the sunny spring afternoon as they walked, rolled and ran laps around Upper Senate Park, just across the street from our nation's capitol. The exercise was a good way for the folks to get limbered up for the coming days of serious advocacy activities, but this afternoon's mood was light-hearted as people completed their laps or relaxed in the shade as they were entertained by the musical background provided by DJ Johnny Crescendo and the witty (or some might argue, corny) banter of "Master of Ceremonies" Bob Kafka.

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*National Celebrity Fun\*Runner Lois Curtis.*

## **Obama Breaks a Promise, but ADAPT Fights On!**

On Monday morning, April 26, 2009, ADAPT headed to the Whitehouse for a meeting with senior officials in the Obama administration to discuss the inclusion of the Community Choice Act (CCA) in the healthcare reform legislation that the President and Congress are working on passing during this session. The President and Vice-President were co-sponsors of CCA in the Senate and had promised their support for CCA on the campaign trail. As recently at March 2009, Henry Claypool, who is Obama's Director of the Office of Disability in Health and Human Services, in testimony on healthcare reform before the US Senate Special Committee on Aging said, "To strengthen our country's financing for LTSS and increase the availability and accessibility of community living services, I recommend that Congress work with President Obama to enact comprehensive LTSS reforms such as those envisioned in the Community Choice Act and the CLASS Act." We felt that we had a commitment from the administration to help us get CCA passed as part of the broader healthcare reform legislation.



*ADAPT arrives for their meeting at the Whitehouse.  
Photo by Kevin Siek*



*ADAPT lined up outside the Whitehouse.  
Photo by Kevin Siek*

As ten representatives of the ADAPT Community met with the administration officials, who included Nancy-Ann De Parle, Counselor to the President and Director of the White House Office of Health Reform, aka the President's Health Care Czar; Jeff Crowley, Director of Office of National AIDS Policy and an advisor on the administration's development of disability policies; Henry Claypool, Director of the Office of Disability in Health and Human Services (HHS); and Mike Hash, coordinator of the HHS-White House reform efforts, the rest of us rallied along Pennsylvania Avenue singing and chanting our support for CCA.

After meeting with President Obama's people for over an hour the ADAPT representatives emerged from the White house with the bad news – the President had backed out of his commitment to help us pass CCA in this Congress! The administration officials made it clear that they did not intend on including long-term services and supports in healthcare reform and people who are trapped in nursing facilities and other institutions would just have to wait until the healthcare reform legislation was passed before the Obama administration would consider working on CCA.

Dawn Russell, one of the many ADAPT members who had campaigned for candidate Obama and was present at the meeting, was incensed. "All they wanted to talk about was them implementing Money Follows the Person and all of those things - that was the last administration, what is this administration going to do?" Russell said' "Our message in there, to the president, was this is a civil rights issue and we want you to FREE OUR PEOPLE and they're response was NO!"

Bruce Darling who also attended the meeting said, "We told them that saying no to us was a slap in the





*ADAPT Demonstrators outside the Whitehouse.  
Photo by Tom Olin.*



*Angry demonstrators chain themselves to the Whitehouse fence. Photo by Kevin Siek.*

face, that we had dogged McCain [during the presidential campaign], we made it clear that there was a difference. This candidate [McCain] opposed CCA, this candidate [Obama] was a co-sponsor [in the Senate] and he put it in his four point plan about what he was going to do around people with disabilities. We don't see a thing, we've had word none from this administration since the campaign!" Darling went on to say, "When Obama was inaugurated he took the oath on Lincoln's bible. For our community that was a message the lightening was going to strike twice, the wave was going to come around and this man was going to free our people! It's disturbing and it's a betrayal of our community!"

Upon hearing of the abrupt about-face by the Obama administration the ADAPT Community expressed their outrage at the betrayal with chants of "Obama is a liar!" and "people are dying, shame on you!" as people began handcuffing themselves to the Whitehouse fence, which lead to the arrest of over 90 demonstrators.

As the arrestees were being processed by the police the rest of the demonstrators waited across the street in Lafayette Park. They cheered on their brothers and sisters handcuffed to the Whitehouse fence until all were processed and released. Then everyone marched back to the hotel, certain that the administration had heard our message loud and clear – we will not take no for an answer when it comes to ending the institutional bias in long-term care and freeing our people from forced incarceration in institutions.

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## ADAPT Demands Leadership from Congress on CCA



*Capitol police prepare to clear the street of ADAPT demonstrators in front of the Russell Senate Office Building. Photo by Kevin Siek.*

Following the previous day's meeting with representatives of the Obama administration it was clear there was only one other place left to look for leadership in including CCA in healthcare reform – Congress. With that aim in mind, on the morning of April 28, 2009, ADAPT headed back up to Capitol Hill to tell congressional leaders that CCA and reform of our nation's system of long-term services and supports must be included in healthcare reform legislation. As the group of activists approached the foot of the hill they split into two separate groups. One group went on up Independence Avenue and the other group split off and headed up Constitution Avenue where they promptly blocked both streets on either side of the Capitol. ADAPT wanted to speak to leadership from both chambers of Congress about including the language in CCA in the healthcare reform legislation, but before that could happen the police began arrests as the demonstrators chanted, "I'd rather go to jail, than die in a nursing home!" In all 100 protesters were arrested!

Once the police had cleared the streets and finished with arrests the remaining 400 demonstrators marched to the Capitol. In remembrance of how far people with disabilities have traveled on the road to freedom and as a symbol of how far we have yet to travel many of the group reenacted the famous "Capitol Steps Crawl" from nearly 19 years ago when members of ADAPT climbed the Capitol steps to illustrate the need for passage of the Americans with Disabilities Act (ADA).

It was a moving experience for veterans of the struggle to pass the ADA as well as for newer ADAPT members who felt privileged to be able to relive such a historic moment. British ex-patriot Johnny Crescendo said, "Way back I saw on English TV, ADAPT climbing up those steps for the ADA and today for me to be able to climb up them steps was an f-ing privilege. It made my day!"





*The famous "Capitol Steps Crawl" from 1990. Photo by Tom Olin.*

The police took their sweet time processing our brothers and sister who had been arrested earlier in the day, holding them in the bowels of the congressional office buildings until nearly midnight. Once all the arrestees had been released they made their way back down Capitol Hill to the hotel where they were greeted by an enthusiastic throng, some of whom had been waiting up all night for their return to make

sure they knew how much their dedication and sacrifice was appreciated.

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*ADAPT demonstrators fill the street at Independence Avenue near the US Capitol. Photo by David Wittie.*



*ADAPT on the Capitol steps 2009. Photo by Tom Olin*

## **A personal account of the Action at Constitution Avenue, by Jeremiah O'Dell**

Sometimes standing up for the right thing can get you arrested. On April 28th I was one of hundreds of ADAPT activists who took our message that the Community Choice Act should be included in any health care reform bill and was proudly arrested.

We started out the day marching and chanting up Capital hill, we were getting close to the Russell Senate building, none of us but the leaders knowing where we are going. We got close to Constitution Avenue in front of the Russell Senate building, and all of a sudden the leaders told us to block Constitution Avenue.

Somewhere around 100-150 activist flooded into the intersection in front of Russell Senate Building. We quickly had chants going and signs up, and bullhorns going.

Within what seemed like seconds I noticed the police were beginning to deploy. I was handed a bullhorn and kept on chanting "CCA we won't go away".

After about an hour or so of non-stop chanting I noticed the duffle bags full of zip-cuffs come out.

Shortly after seeing the bags of cuffs the police got on their bullhorn and told us that this was our first warning to disperse the area or face being arrested. Knowing that we still had two more warnings we just chanted louder and made more noise.

Shortly after the first warning came the second warning and the police put their gloves on. This is usually when the people who cannot or choose not to be arrested move outside of the "arrest zone".

This time though it seemed like no one left; it was amazing to see. The only people that I saw leave were ones that had to because we could not have all of our leaders in jail.

The police then started individually coming to people asking if they wanted to leave or go to jail. They were



*Jeremiah and the Man. Photo by Kevin Siek.*

trying to scare us away by telling us if we didn't leave we were going to prison. Knowing our rights we laughed it off and took our chances.

When they got to me they asked if I wanted to leave or be arrested. I told the officer, "I'd rather go to jail then die in a nursing home!" I was promptly cuffed behind my back and carried to the sidewalk.

After we were cuffed and carried to the side we were then paraded around the block for some reason, and back to the front of Russell Senate Building. We then were taken into one of the front doors and marched through the Senate building to a committee hearing room that was used as a detainment room.

Once everyone had been brought in I realized the scope of the protest, it was very moving to see all the dedication in that room! We had 60-70 people gladly arrested for standing up for our rights. We were then told we were under arrest for incommoding, and unlawful assembly. We got our property inventoried, and the number for our place in line for our mug shots. Then we waited and waited.

After about an hour a Captain came in and tried to scare us again telling us that the people who were arrested the previous day protesting the Whitehouse might possibly have to go to the county jail for at least over night. I happened to be one of those people. We were willing to take whatever happened.

About two hours later we were told no one would be taken to county, and the officers were waiting for our paperwork to return from downtown. They said that the paperwork should be here "shortly". So we patiently waited while we all talked and met new friends, after about two more hours some of us needed to take meds including myself. I needed to have a full meal to take my meds; I was told that I was not allowed to get food from the property officer out of my bag, because "I was in Jail".

After about 5 minutes of informing the officers that we knew our rights, they finally gave in and we got our meds. We spent a total of around 11 ½ hours in "jail". The 11 or so hours is a very small price to pay to keep our rights. Being a disabled youth it gives me great pride to be part of such a great cause. I never thought I would say this but I am proud that I was arrested.

Free Our People.  
Jeremiah O'Dell

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# Harkin's Speech Inspires Advocates to Carry-on the Fight for CCA



*ADAPT and SEIU brave the cold, rainy weather to Rally for CCA.  
Photo by Tom Olin.*

On Wednesday morning, April 29, 2009, the brisk, rainy weather did nothing to dampen the enthusiasm of ADAPT as they set out for a rally in Upper Senate Park and a day of hill visits with members of Congress in their quest for passage of the Community Choice Act. They were joined at the rally by members of Service Employees Union International (SEIU) who also accompanied ADAPT on the hill visits. SEIU is one of the biggest unions in the country and represents many personal care workers in the home health industry and nursing facilities.

There was music and various speakers, including ADAPT organizers Cassie James and Mike Oxford, while the crowd waited for the arrival of CAA champion, Senator Tom Harkin. Symbolically, the rain ended and the clouds began to break just in time for Senator Harkin's arrival.

In his speech Senator Harkin pledged do everything he could to get CCA passed. "I am going to fight. I am going to take my case to the President who was, by the way, when he was a Senator a supporter of the Community Choice Bill that I sponsored. And now we got to get him to push the bureaucracy to get them onboard. So I'm going to be down there talking to the President, I'm going to be talking to Senator Baucus and Senator Grassley of the finance committee and others to let them know that this is a major civil rights struggle in American history."

Harkin exhorted the crowd to take our message to Congress, saying, "Go over there and hit those offices and let them know that we are not going to be left behind. We are not going to be left behind out of health care reform. That this is a Civil Rights measure, it was promised by the ADA, it was confirmed by the Supreme Court in the Olmstead decision.

And now this Congress and this President have to make good on those cases. They got to make good on ADA and they got to make good on Olmstead by making sure that people with disabilities can live in their

own homes and in their own neighborhoods and not be forced into nursing homes.”



*Senator Harkin at the CCA Rally. Photo by Kevin Siek*

Advocates spent the rest of the day visiting every member of Congress. They left information about the bill and met with congressional staff when they were available to tell them we need to pass CCA now to give people a choice to get long-term services and supports in their own homes and communities, instead of costly, isolating institutions!

That evening ADAPT held their traditional wrap-up party to celebrate a week of grassroots advocacy and to share one last evening of camaraderie before heading back home the next day.

View Senator Harkin’s speech (with open captioning) at: <http://www.duhcity.org/flash/harkin/harkin.swf>

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*CCA advocates visit Congressional offices. Photo by Tom Olin.*

## **ADAPT Heads Home to Work Locally on CCA**

On Thursday, April 30, 2009 the members of the ADAPT Community packed up and headed home. Many had already made plans to visit the local offices of their members of Congress when they returned to thank those who had sign-on in support of CCA and to work to convince the rest of them to sign on as co-sponsors. Plans were already in the works to expand our efforts to persuade the Obama administration that long-term services and supports must be included in healthcare reform and to target Congressional leadership working on healthcare reform legislation to get them to include CCA.

Since returning home there have been lots of activities to work on getting CCA included in the healthcare reform legislation including visits to local congressional offices by state chapters, numerous call-in campaigns to key members of Congress and an online petition to the President.

You can sign the on-line petition by the American Association of People with Disabilities at:  
<http://petition.aapd.com/healthcarereform/>.

You can find contact information for members of Congress at:  
<http://www.congress.org/congressorg/dbq/officials/>

## **Join ADAPT this October in the Land of Olmstead!**

**October 10 -15, 2009 in Atlanta GA**

**For more information contact: [adapt@adapt.org](mailto:adapt@adapt.org)**



# ADAPT Youth Summit 2009

by Mike Matthews

From June 12th to June 15th, 2009 I attended the youth summit. This was a intense weekend and despite the stress I feel like I'm a better ADAPTer for attending the summit. Being away from my local chapter was hard because we work so well together, but the trainers pushed me to see what kind of leader I can be no matter the team or circumstances.

On Monday, June 15th, members of the summit conducted an action at the Region Five Office for Civil Rights (OCR) located in Chicago. OCR has dropped the ball in following up with Olmstead complaints, leaving many of our brothers and sisters left to die in nursing homes. Valerie Morgan-Alston is the regional manager and we went there to get a meeting with her on why after moving to Region 5 she stopped meeting quarterly with ADAPT.



*Mike & Zorytza at the Youth Summit.  
Photo by Amber Smock.*

The team did great getting her to agree in writing to resume meeting with us on a quarterly basis, meeting with us on June 26th, willing to have a open dialog with ADAPT on how Olmstead complaints are going, OCR being trained by ADAPT about the experience of people with disabilities in nursing homes, and that she'll help us set up quarterly meetings in all the regions with other regional managers.

I was one of the negotiators and it gave me confidence that I could work with other ADAPTERS to get our message done. I didn't have my partner in crime with me, Donya Smith of SWPA ADAPT who is usually a negotiator with me, but to know that I have in me the ability to lead outside my comfort zone and do a good job without a safety net really encouraged me as a member of ADAPT.

This weekend caused me to take a deeper look at why I'm with ADAPT and the trainers helped me do that. At times they ticked me off, but they were seeing what I was made out of. I would encourage people to attend the summit next year because it will empower you to be great ADAPTERS. Free Our People!

Mike Matthews

(Mike is a Civil Rights Specialist at Tri-County Patriots for Independent Living in Waynesburg, PA)

PS- We are asking that local ADAPT chapters contact their regional OCR and get quarterly meetings with them about Olmstead.



*The 2009 ADAPT Youth Summit Participants. Photo by Amber Smock.*

## **ADAPT Follows DC Action with Nationwide Demonstrations in July**

Tuesday, July 21, 2009 began a four day vigil by forty members of ADAPT at the Democratic National Committee (DNC) Headquarters in Washington D.C. The demonstrators entered the DNC Headquarters at 1:00 pm, while simultaneously in 24 other cities around the country local ADAPT groups began demonstrations at their state Democratic Party Headquarters and the offices of other influential state Democrats.

ADAPT wanted to meet with DNC Chair Tim Kaine. The protesters demanded that the DNC apologize for creating Medicaid's institutional bias which has forced millions people needlessly into nursing facilities and other institutions, issue a public statement calling for elimination of the institutional bias in 2009 either as part of healthcare reform or as a separate CCA bill and facilitate a meeting between ADAPT and Democratic leaders to develop a plan to pass CCA.

Kaine flatly refused to meet with ADAPT and at closing time the activists were physically carried from the building by police. Thus began the first night ADAPT's vigil camping out in front of the DNC.



*Inside the DNC. Photo by Nancy Salandra*

Meanwhile in other cities across American local ADAPT groups had been talking to Democratic Party officials in their states. Local party officials in eleven cities agreed to fax letters to the DNC in support of ADAPT's efforts to end the institutional bias in Medicaid long-term care policy and include provisions of CCA in healthcare reform.

Colorado ADAPT, in addition to getting the Colorado Democratic Party to fax a support letter to the DNC, was able to get Representative Diana DeGette, who is the Vice Chair of the House Committee on Energy and Commerce (one of the key committees working on healthcare reform) to commit to working on "including the core provisions of the Community Choice Act" in healthcare reform. Chicago ADAPT got Mayor Daley's staff to fax a letter urging the DNC to support the Community Choice Act in any health care reform purposed by the Obama administration. His staff also agreed to call Valerie Jarrett, the Senior Advisor and Assistant to the President for Intergovernmental Affairs and Public Liaison, to urge her to help develop a plan to pass the Community Choice Act and to set up a meeting with Chicago ADAPT and the Mayor to discuss an implementation plan for the Community Choice Act in Illinois.

intrepid ADAPT activists wrapped snug in their sleeping bags on lawn chairs, in tents and under a lean-to constructed from PVC pipe and plastic tarps in front of the DNC. Several large banners showed the group's support for the Community Choice Act. It was clear that ADAPT had no intentions of leaving when an accessible portable toilet was delivered to the site of the DC demonstration.

In Topeka, staff for the Kansas Democratic Party arrived for work and encountered members of Kansas ADAPT, outside their office, back for another day of picketing. They told the demonstrators that their executive director was out of town, but would be back the next morning and really wanted to meet with them and Kansas ADAPT agreed to

The sunrise on Wednesday, July 22, 2009 illuminated the sidewalk camp of



*Sleep conditions were less than ideal at the DNC camp.*



meet with him the next day. In Denver, Colorado ADAPT members met again with their state Democratic Party to talk about how they could work together on ending the institutional bias and in Austin Texas they began the second day of an all night vigil they had kept in solidarity with the folks in DC.

Through out the day the ADAPT demonstrators outside the DNC chanted and passed out flyers. Several members of Congress stopped by to chat with the demonstrators and express their support for CCA, some asked about becoming co-sponsors of the bill.

On day three of ADAPT's vigil, Thursday, July 23, 2009, the ADAPT activists in DC were awakened early by a thunderstorm. Storms came and went throughout the day, at times completely flooding the streets, and police took away their portable toilet, but the tenacious ADAPT demonstrators persevered.



*ADAPT members dry out after a rainstorm. Photo by DRC.*

In Chicago ADAPT demonstrators braved the rain to picket a presidential fundraising event attended by President Obama at the home of a Chicago billionaire. Kansas ADAPT met with the executive director of their state Democratic Party who sent a support letter to the DNC, Senator Baucus, Representative Waxman and HHS Secretary Sebelius.

At intervals throughout the day the DC demonstrators chanted and shouted through a megaphone calling for DNC Chairman Kaine to come out and meet with them. The only response they got was when one ADAPT member with a megaphone got what was apparently uncomfortably close for denizens of the DNC and police were called to the scene. Police were called a second time when

ADAPT's mascot Gremmie was placed on the stairs leading to the front door of the DNC headquarters. ADAPT kept their vigil even after DNC staff had their accessible portable toilet removed.

Friday, July 24, 2009, ADAPT ending the four day vigil at the DNC when they marched to the Whitehouse to attend the President's press conference to announce his plans to sign the United Nations Convention on the Rights of Persons with Disabilities. The bedraggled, but determined ADAPT patriots were chagrined at the irony of the situation. "We are pleased that the President has decided to do this, said Bob Kafka, an ADAPT organizer from Texas, "but ending the institutional bias in U.S. public policies would be a true test of the Obama Administration's commitment to people with disabilities and to the principles in the UN Convention.

Article 19 of the CRPD specifically recognizes 'the equal right of all persons with disabilities to live in the community.'"

Although the lack of response from the DNC was disappointing ADAPT was gratified by the positive response they received from state Democratic Party officials, the renewed pledges of support they received for Congressional Democrats, like Representative DeGette, and the 14 new CCA co-sponsors who signed on during or directly following the week of coordinated actions.

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*ADAPT's camp outside the DNC. Photo by DRC.*

*Around the Nation*



## **President's Day CCA Outreach, 02/09**

To celebrate President's Day in February state chapters around the nation did some local outreach to drum up support of the Community Choice Act. Here's a sample of what folks did to promote passage of CCA:

Members of Southwestern Pennsylvania ADAPT visited the offices of U.S. Representative Tim Murphy and Senator Bob Casey. (Following the meetings both Rep. Murphy and Sen. Casey signed on as CCA co-sponsors!)

ADAPT DELAWARE met with their new Governor and new Secretary of Health and Social Services and the State Medicaid Director

Members of Atlantis/ADAPT attend President Obama's signing of the economic stimulus bill in Denver. They all wore their orange CCA t-shirts and passed out packets of information about The Community Choice Act to their entire Congressional Delegation and to Senator Max Baucus from Montana who was also there. They all got the informational packets and a five minute spiel about how important their signing on to CCA as original co-sponsors is.

Southeast Kansas ADAPT visited the offices of Representative Lynn Jenkins and Senator Sam Brownback in Pittsburg KS. In Topeka, Kansas ADAPT members visit the local offices of all their Congressional Delegates dressed in stovepipe hats and fake beards in honor of Lincoln's birthday with the message that CCA means "emancipation" for people with disabilities. (As of this writing all the Kansas Reps and Senator Pat Roberts have all signed on as CCA co-sponsors leaving Se. Brownback as the lone member yet to sign on.)



*Kansas ADAPT members visit the office of Rep. Lynn Jenkins.  
Photo by Kevin Siek.*

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## **Virginia newest ADAPT member protests alone and wins, By Zan Thornton, 03/09**

Here is the power of ADAPT ...

My twin sister (yes there are 2 of us in the world-Sandy Thornton) was advocating for her husband who recently had a stroke. The hospital was going to kick him out on day # 30 and place him in a horrible nursing home with no additional supports (he was declared needs 24-7 services)

My sister placed her truck with a valid disability hanger in the front disability spot in front of the hospital and off the back of her truck she had the following:



Here is our new home (canvas laid out like a tent off her truck) here is our new toilet (a 5 gallon bucket) Why? The hospital claims he has to go to a nursing home. We say HELL NO WE WON'T GO!

Then another poster said:

ADAPT is a national disability rights group. They will be in DC on April 25-30, 2009. Maybe they would go thru here or come back thru here.

Within 5 minutes her husband was found a non-institutional setting with full rehab services, an electric wheelchair and supports for in home care for at least the next 6 months plus an accessible trailer for him to move into soon.

My sister asked them what made them change their minds... ADAPT! The power of ADAPT!

BTW she did call several CILS and NO ONE ever returned her call. She lives in Roanoke Virginia.

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## **HUD action in Philly!, by Cassie Holdsworth, 03/09**

About 27 Philly ADAPT folks gathered together to give the Acting Director of our Housing and Urban Development (HUD) Department region the message that we need to meet with HUD Secretary Donovan and let him know that disabled people need affordable accessible integrated housing! When we got there German and I took the first elevator, but German went back down to let the people know what floor to go to. When he did two rent-a-cop's locked him in the elevator. Cassie and DJ got charged with anger over that and the fact that they had shut all the elevators down and would not let anyone in wheelchairs use them. At first I had requested the HUD Director, but when I saw how they had blocked access I shot through security and took over the elevator to HUD along with DJ. Minutes later DJ got off the elevator to let everyone know what was going on downstairs. Zach was leading the chanting and had everyone downstairs block the elevator and stairs.

Meanwhile many of our walking warriors had taken the stairs up to the lobby where the HUD elevators were. Fran and Mark took the elevator next to me and refused to get off so they shut her in. Then the acting director came down and said she would talk to me if I would move out of the elevator. I said, "No you need to talk to everyone. Get everyone up to this lobby and we can talk." Then a cop came and threaten to remove Mark and me. I said, "You won't need to remove us if you get 10 people up to HUD.

Then we can do what we came for.” It took them about 20 minutes to get the elevators back on and a little more time to get people up to HUD. We refused to leave the hallway and go in the board room until everyone was up.

Once we finally got down to asking them to fax Sec. Donovan our demand to meet with us to discuss our policy paper things went well, they faxed it and had it hand delivered to the Secretary at HUD. Our victory happened because everyone did what they had to do when the building people went nuts on us. Everyone stood their ground and if you had heard our chants you would have thought we had a 100 people with us and if you saw all the cops and civil affairs people who came out just because they over-reacted you would have thought we were dangerous. I believe they know what they have done wrong and they know we are right in demanding affordable, accessible, integrated housing!

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## **Disability Groups Tell Quinn to Stop Wasting Tax Dollars on Poor Care, *March 31, 2009***

Springfield, Illinois – Individuals with disabilities representing disability groups from across the State marched to the Governor’s Mansion this evening to bring their message to Governor Pat Quinn: Stop paying millions of taxpayer dollars for grossly substandard service to people with disabilities.

The group spoke out against to the conditions at Howe Developmental Center in Tinley Park. The state operated institution houses about 300 individuals with developmental disabilities. It has an annual budget of about \$60 million.

“Howe has been cited for serious and prolonged violations of health and safety standards, including failing to initiate CPR, failing to adequately respond to pain, failing to monitor vital signs, using restraints when not safe to do so, failing to provide enough food and drink, and falsifying physician documentation,” said Zena Naiditch President and CEO of Equip for Equality, the federally mandated Protection and Advocacy system for Illinois. “Investigations into the deaths of 31 residents at Howe since 2005 revealed many instances of poor care. In one case, an individual was left unattended, died, and was not discovered for many hours after rigor mortis had set in,” Naiditch continued.

Naiditch also said, “On February 25, 2009, a sister of a Howe resident who choked to death last year, filed a wrongful death suit against the State. The most recent death at Howe occurred about four weeks ago on March 2, 2009 when yet another resident also choked to death.”



*Advocates tell Gov. Quinn to FREE OUR PEOPLE!  
Photo by Tom Wilson.*

"Two years ago, inspectors from the Illinois Department of Public Health notified Howe that conditions at the facility were so unsafe that it was no longer eligible for Medicaid funds, said Lester Pritchard of the Campaign for Real Choice in Illinois. "Medicaid usually reimburses the State for 50% of the cost of the care of people with disabilities in these types of facilities. Over the past two years Illinois taxpayers have lost \$60 million in federal funding. Considering the State's fiscal crisis and the prospect of tax hikes, common sense dictates that Howe be closed and residents moved to a safer living environment. The State could then regain millions of dollars in federal funding" he added.

"Last September, State officials announced plans to close Howe and offer individuals a choice of either moving to a community-based program or another state facility," said Mark Karner of the Community for All Coalition. "Governor Quinn has been silent on the conditions at Howe. We need him to speak out, that's why we're here," Karner continued.

Organizations that participated in the event included the Springfield Area Disability Activists, Campaign for Real Choice in Illinois, **Chicago ADAPT**, Equip for Equality, the Coalition of Citizens with Disabilities in Illinois, the Illinois Network of Centers for Independent Living, the Springfield Center for Independent Living, the Statewide Independent Living Council, Access Living of Metropolitan Chicago, Illinois Voices, Progress Center for Independent Living, People First of Illinois and the Institute on Public Policy.

*(UPDATE from Tom Wilson: Closure is still somewhat up in the air although ADAPT has met with the Governor's staff since the action. After that the Governor appointed an "objective" observer from Illinois to examine the situation. The report has not come in yet. But the Governor also had a Taskforce look at the state Budget which is in crisis this year and among their recommendations is one to close Howe. We think the pressure is continuing to mount for closure but the final decision to close Howe still eludes us.)*

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**Austin's CCA week, by David Wittie, 03/09**





*ADAPT of TX display their giant banners outside the State Capitol. Photo by David Wittie.*

ADAPT of Texas members in Austin participated in a week long nationwide effort to "get the word out" about the CCA. It was HOT and WINDY just days after the Texas Legislative session ended when twenty sweaty and tired folks decided they had not yet had enough and decided to spread TWO forty feet long banners in front of the Lone Star State's Capitol building during afternoon rush hour. Proclaiming "Our Homes Not Nursing Homes" and "Community Choice Act", the tandem banners stretched wider than Congress Avenue, the busiest thoroughfare in the downtown business district.

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## **Philly ADAPT takes over SEPTA Buses, by German Parodi, 04/09**

Philly ADAPT was out in the rain at 7am on April 14, 2009 taking over SEPTA (Philadelphia/surround counties public transportation company) buses at the corner of Cheltenham Ave & Oakland St. In a matter of minutes as negotiations were happening we had stopped and taken over 5 buses. Throughout the entire time of rush hour we kept them at a standstill while SEPTA and city cops were trying to get us to move.

About 10:45am still blocking buses Action news came and interviewed us. A little after 11am we were loud and strong chanting, "How do you spell power? A-D-A-P-T!" Then we marched to the Frankford Terminal where a couple of SEPTA officials met with us and are supposed to schedule a meeting with the general manager of SEPTA, Joe Casey.

We will fight against the discriminating attitude SEPTA has against people with disabilities until they let every single one of us ride!

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*Philly ADAPT tells SEPTA, "We Will Ride!"*

## **Texas Capitol Protest of Legislature's failure to address LTC for Texans with disabilities, 05/09**

Desert ADAPT, ADAPT of TX and our fellow activists with Community Now! (which focuses on the State institutions) and PACT (Personal Attendant Coalition of Texas) held a press conference/action at the state Capitol, Tuesday, May 13, 2009.

It was great! We unfurled the 3 banners from the balcony on the 2nd floor of the Rotunda (shower curtains - thanks National ADAPT theater folks for the great idea), and the press conference began on the main level below.

There were at least 30 people there from El Paso, Ft Worth, San Antonio and Austin, ready for whatever! ADAPT's David Wittie, then Cathy Cranston, then Kika Grajeda (a PACT member from El Paso who spoke in Spanish) then Jeff Tate of Community Now and ADAPT spoke. They were all great, hitting all the highlights. Lots of tourists, and a couple of school groups came through and were listening to the speeches. Eventually State Troopers took away our banners, but they had been seen and photographed by then. We chanted, and there were 4 reporters (AP, Dallas, Lubbock and the AP photographer) who asked questions of several people. This was better media than we've had in a while!

Then we split into 3 groups and delivered the report cards to the House, the Senate and the Governor's office. The Senate folks were invited into the Senate Health and Human Services meeting. The Governor's group dropped it off and joined the other 2 groups. The House folks made a gauntlet and gave a copy to the Speakers Health and Human Services staffer as well as any Representatives going into session.

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## **Kansas ADAPT joins state employees and other advocates to tell Kansas Legislature enough with the cuts already!, by Kevin Siek, 05/09**

On May 6, 2009 members of Kansas ADAPT and SE Kansas ADAPT joined a group of approximately 100 people, representing seniors, Kansans with disabilities and state employees in a rally on the lawn outside the Kansas Statehouse. We were there to tell the state legislature that they needed to look at some type of revenue enhancements to the budget before they considered any further cuts to programs and compensation for state employees.



*Cecil Walker leads the demonstrators into the Capitol to deliver the People's Ballots to the Legislature. Photo by Kevin Siek.*

The day before and earlier that morning members of Kansas ADAPT had stationed themselves around the capitol complex and outside the Social and Rehabilitation Services and Dept on Aging office buildings to pass out leaflets and encourage people to sign ballots voting for the "People's Budget" in support of a state budget that used revenue enhancements instead of additional service cuts to balance the state's budget.

At one point the Secretary of Aging came out of the Department on Aging office building to sign a ballot and took a bunch of the ballots back in for Department on Aging employees to sign!

By the time of the rally the group had collected over 600 ballots, which they delivered to the President of the Senate and Speaker of the House.

Although the legislature did make additional cuts, they were less than what were originally planned and they dropped plans for pay cuts and furloughs for state employees. We'll have to wait and see how the across the board cuts to agencies will effect our HCBS waivers and other programs that help people get the services they need to stay in their homes, but the Secretaries of Social and Rehabilitation Services and Aging and the new Governor have said they will work to lessen the impact on these programs to the extent possible.

It's bound to be a tough year ahead, but not as bad as it might have been if the legislature hadn't heard from us as they wrapped up this

year's legislative session!

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## **Speaker Madigan is unresponsive to ADAPT demand to stop the cuts, by Tom Wilson, 06/09**

Chicago ADAPT organized June 10th to fight severe cuts proposed to the state's Human Services budget and especially to Home and Community Services. The Legislature only appropriated 50% of the Governor's



proposed budget after the House of Representatives voted down the Governor's proposal for raising taxes and funding services at a sparse but workable level. The Senate passed this budget but it failed to pass in the IL House.

Speaker Michael Madigan, who controls the House, did not show his leadership power, he did not show concern for people with disabilities. He did not express support or concern for people who use Home Care Services or for the workers to be laid off. He did not do the right thing and he allowed the tax increase to be voted down with 27 Democrats voting no or present on the Governor's proposal. Speaker Madigan has been Speaker for many years, he raises enormous sums of campaign dollars for his party, and he is the most powerful person in Springfield. He let this fiasco happen.

ADAPT organized 28 people to go to the office in an attempt to meet with the Speaker and describe the suffering a 50% budget cut would create. We arrived at his office with flyers, banners and signs. Unfortunately the elevator to his second floor office did not work so we occupied the building lobby and had a member take the stairs to ask a staff person to come down and hear our complaints. It took some time but eventually the office manager did come down and listened to a few stories but did not stay long and rejected the demand for a meeting with Madigan. We have met with him only one time in many years and then only after occupying his office. The police then tried to get us out with phony threats and intimidation but we stayed strong chanting and calling upstairs for a meeting.

Eventually a Chicago police Commander showed up who was interested in resolving the situation by getting a meeting arranged but he was unable to get the staff in Springfield, where the Speaker happened to be, to agree on a date for a meeting on the cuts. Madigan's office staff and his Springfield staff were not responsive to our needs. After another hour of chanting and calling their office phones we decided to leave with the messages, "We will be back!" and "Don't mess with Home Services!"

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**Desert ADAPT Erects CCA Billboard, *June 20, 2009***



To celebrate the 10th Anniversary of the [Olmstead Decision](#), Desert ADAPT erected this billboard promoting the Community Choice Act!

## **Montanans to Sen. Baucus: Include Long-term Care in Health Care Reform- It's Key!, June 30, 2009**

**Missoula, MT---** Montanans with disabilities and those who are aging are angry that current federal health care reform efforts exclude the very services and supports that allow them to live in their own homes with the assistance they need. On July 2, they took that anger to the streets, with rallies and marches in seven of Montana's larger cities that delivered the message that "Long-Term Care is KEY."

"It's especially important that Sen. Baucus hears this message," said Travis Hoffman, Advocacy Coordinator at Summit Independent Living. "Not only is he a "key" figure in health care reform, he represents our interests in Washington, and we want to be sure he knows not to compromise our freedom. We want him to

end the bias in Medicaid that currently pays for us to be forced into nursing homes and institutions, but won't pay less for us to get assistance in our own homes."

Title II of the 1990 Americans with Disabilities Act assures older and disabled Americans the right to receive services in "the most integrated setting." This "civil right" was affirmed by the June 22, 1999 U.S. Supreme Court's decision in *Olmstead v. L.C. & E.W.* when the court stated that "Unjustified isolation, we hold, is properly regarded as discrimination based on disability," and is, thus, illegal. Despite the law and the court decision, the Bazelon Center in Washington reported, on June 24, 2009 that NO state in the nation has adequately fulfilled the mandate contained in the ADA and in *Olmstead*.

"Sen. Baucus has been adamantly opposed to including long-term care in health care reform," said Bob Liston, Board President at Summit Independent Living Center, and Montana organizer for ADAPT. "This is simply unacceptable because we are talking about people's lives here. Not only do people die waiting to get out of nursing homes, but when people are forced into nursing homes because of how Medicaid funding is now structured, they lose control over their lives, they lose their privacy, their freedom, they often lose their connections with family and friends, and their health deteriorates, which then costs more."

More than 80 national aging and disability groups called for Sen. Baucus and Congress to include the Community Choice Act (CCA) in the health care reform effort. The CCA would remove the institutional bias from Medicaid, allowing people to choose where they want to receive assistance, whether in their own homes, or a nursing home. While some states, Montana included, provide some home and community-based services under a state-run program and/or by getting federal permission to "waive" the Medicaid rules, these services are considered "optional" and are among the first things cut when states tighten their belts. These services are not guaranteed in the same way that nursing home services are, and do not serve all the people who need them. Advocates are stating the CCA is "Key" to health care reform.

"We can look to health care reform now to insure millions more people, which is clearly a good thing. But if we don't include long-term services and supports in reform, all these people will still potentially get forced into nursing homes and other institutions as they age or have disabilities," added Liston. "We need to be included in health reform NOW, not wait for another 40 years."

Rallies and marches occurred across Montana in Missoula, Bozeman, Butte, Helena, Kalispell, Great Falls, and Billings. Missoula marchers began with a rally at noon at the Missoula County Court House. Marchers in all sites delivered keys to Sen. Baucus' Montana offices to say "Don't Throw Away the KEY to Long Term Care: Include the Community Choice Act in Health Care Reform and End the Institutional Bias."

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## **Kansas ADAPT is still fighting to keep the buses rolling in Topeka, *by Kevin Siek***

We have been battling Topeka Metropolitan Transit Authority (TMTA) since the beginning of February, when they announced they were eliminating the Evening and Sunday bus service. We demanded that they hold a series of public meetings to get the community's input before they made any cuts and worked with Topeka Independent Living Resource Center to organize a coalition of about 50 social service agencies and small business called Topekans in Support of Public Transit. The coalition got the City Council to temporarily raise the mil levy for TMTA to try and maintain the existing bus service.

Unfortunately, TMTA wouldn't work with us or the City Council to agree on how much money they needed. TMTA wanted more than what the City Finance department said they needed and said they would cut services if they didn't get everything they wanted. We called their bluff and told City Council we advocated for the mil increase to maintain the bus service and if TMTA was going to take the extra money and cut services anyway, we didn't think they should get the increase.

The Council did vote to give them an increase, but they are threatening to cut services again. We are building support for a community-wide forum to address the problems with TMTA and what the community can do to insure the long-term viability of a transit system that meets the needs of the entire community. The Struggle Continues!

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## **Indiana Transit Update *from Teresa Torres***

ADAPT Indiana continues to press for compliance with the consent decrees issued in the class action lawsuit against Northwest Indiana transit providers. They've been playing the whole 'something is better than nothing' song, but although hit hard by the cessation of county-wide demand response services in a community with seven separate systems, our people have been keeping the pressure on as much as possible. Along the way, we've aligned with some union drivers.

The Regional Bus Authority, which was created by a shell game some thought would enable the defendants to duck their legal obligations, is largely made up of the very same people against whom the lawsuit was

filed. Each initial defendant, none of whom have met even a fraction of the terms of the consent decrees, was just notified by our attorney that they're about to be taken back into federal court for non-compliance.

Meanwhile, the bogus Indiana SILC – which that has been written about on dimenet, in the Mouth and Ragged Edge for years – which has never allowed any discussion about the trans suit even though the Indiana Department of Transportation was one of the defendants – which has a policy prohibiting t-shirts that say mean things – and which continues to have people hauled off by police for asking questions - has invited the state's department of transportation staff to talk with them about ways to work together.

On a related note, here are some thoughts about a legal rip-off that's happening all across the country.

Since the standards for demand-response services aren't as stringent as complementary para-transit, many communities simply pay local non-profit organizations (it used to be primarily sheltered workshops, now it's Area Agencies on Aging) to run them. After they are given vehicles, operating and maintenance money, these private entities are then free to use those resources for profit-generating trips. In Northwest Indiana, only 20% of the rides provided by 'public transportation' providers were actually 'public rides.'

Through contracts with Voc Rehab or by Medicaid payments, they prioritize people for whom they can make as much as 10 times as much to get from Point A to Point B, causing everybody else to wait as long as 2 weeks for a ride. People think they're getting a good deal, because they don't have to pay, until their caseworker says sorry, we've already spent too much on you, so you can't get (fill in the blanks).

So if you want to go from 100 Main Street to the doctor's office at 7500 Broadway, you can ride free – they'll set you up immediately, then bill Medicaid as much as \$150 for the trip (counting the maximum wait time). But if you want to go from the same address to the movie theater next to the doctor's office, you'll have to plan two weeks in advance to pay your five bucks.

Indiana's Medicaid guidelines require that the least expensive mode of transportation be used for all 'medical billing – that's been interpreted to mean the least expensive private provider. In the wake of 'funding cuts' to public transportation services, an army of 'medical transport' companies sprang up to buy vehicles determined to no longer be safe for the road, only to put them right back on the road.

The state can then report Medicaid transportation costs that are 300 times greater than they need to be, thus jacking up the Medicaid budget and making it difficult to have any discussion about community supports.

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## **Chicago ADAPT and Vice President Biden**

On Friday, July 31, Vice President Biden was scheduled to speak before the National Urban League Conference, which promotes power and success for African Americans and other people of color. Four of us went down to the conference venue and passed out 200 fliers explaining nursing home disparities between black people and white people, and why the CCA is so important. Thanks Larry, Zorytza, Tim, and also Nancy, Denerale and German from Philly.

### **Protesters hault [sic] trains to make statement, *By Katherine Scott, ABC Channel 6, Philadelphia, PA, August 06, 2009***

30th STREET STATION - August 6, 2009 (WPVI) -- You could say it was gridlock along the Market-Frankford El today thanks to a protest by dozens of riders in wheelchairs who were determined to get their message across, even if it meant shutting down service.

Disabled riders are calling on SEPTA to bridge the gap.

"On 30th Street El, there's a big gap between the platform and the train, people using wheelchairs get stuck in that gap," German Parody of ADAPT said.

So today, over thirty protesters got stuck on purpose, holding up eastbound and westbound trains on the Market Frankford El at 30th Street Station for nearly an hour and a half.

Disability rights activists from the group ADAPT are demanding SEPTA enforce the policy of providing a bridge plate to wheelchair-bound riders when needed.

"We're sick and tired of not being able to gain access to the El," Zachary Lewis of ADAPT said.

A SEPTA spokesperson says service was disrupted for probably thousands of people, but protesters tell Action News drastic measures were needed to orchestrate change.

But a SEPTA spokesman counters this issue could have been resolved by a meeting or phone call.

"We've had no complaints either through our customer service office or in writing that this has been a problem and if it has been we will address it immediately," SEPTA spokesman Richard Maloney said.



As protesters stayed stuck, other straphangers were diverted to shuttle buses; some sympathizing more than others.

"Maybe they should make things better for the disabled people," passenger Lashonda Lindsay said.

"They're disrupting my service, other people's service. No. Do it another time," passenger Mary McGroarty said.

Eventually it was all aboard for the protesters with assurances that SEPTA was onboard with their plight.

Watch the video at: <http://abclocal.go.com/wpvi/video?id=6952431>

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## **Desert ADAPT demands accessible route at Cielo Vista Mall, by Efrain "Frank" Lozano, 07/09**

On Wednesday, July 29, 2009, thirty El Pasoans protested Simon Properties' continuous refusal to create an accessible pedestrian pathway at Cielo Vista Mall. Local media coverage was obtained from the majority of the city's major newspapers and television stations. We held an 11am press conference at the Eastside Bus Terminal bordering the mall.

With bandanas on our foreheads, posters taped up to wheelchairs (some being carried by some of our people), and florescent construction vests, we traced the route where we want Simon Properties to make the accessible pathway (from the theater to the mall), with a moving picket. After a couple of minutes of having the moving picket on Sunmount Street, we divided our people into three color teams.

As our teams marched from Sunmount Street to the mall, we made a quick stop at the movie theater located on the property and flyered it. An event that caused impact on some of our people was when a child that was by the theater entrance asked his father what all those [people in] wheelchairs were doing yelling so loud. His father then explained that we were there fighting for access and that sometimes people had to do protests like that to get what we needed.

... When we got inside the mall, each team separated and that's when the work began. After each team was done, we all met at the east boundary of the mall. Our action resulted in 50+ stores flyered and several people within the mall were also made aware of the issue. ...

... At the geographic center of El Paso we can not accept being forced into moving traffic just trying to shop or go to the movies.

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## **Biden comes to Philly and faces ADAPT, July 28, 2009, by Cassie Holdsworth**

The Vice-president came to Philly today! We found out in plenty of time to get to City Hall and the room he was in. We were stopped by the police three times on different elevators, but finally we found one policeman who believed us when we said we had a pass, which we did, we found it on the ground. Three of us went up the elevators and others remained outside.

We were right there and the secret service man said they would let us in if the Vice-president staff would approve us; well they would not, so we went outside.

We all came back together outside; we knew where he would come out and he was in view of the group and in hearing distance. He sat on top of his car, but never acknowledged that we were there! We held up our sign which said, "End the institutional bias and pass the Community Choice Act, our homes not nursing homes." We chanted on the bullhorn but he just sat there, not the friendly guy he used to be! We all had on orange shirts, but guess what, there was another group a block away and they all had orange shirts on, so we looked much bigger than we were. We only had seven people with us but a block away all you could see where orange shirts. I have no idea who they were, but hopefully Vice-president Biden thought they were us too! Denied access again to what must have been a public event, since other people were getting upstairs.

Well, just when we thought we had a President who was a community organizer, and a Vice we saw as a friend, my how things change when we make real demands for real people suffering in nursing homes for no other reason than the Vice-president and our President find it easy to overlook our issues, broke their promises to us, and charge us a lot of money to fight for our rights!

I hope after camping at the DNC they discover who they are dealing with. We have fought for years to get and keep our community out of institutions and nothing they do will stop us. We would rather go to jail than



*Desert ADAPT demands access for all at Ceilo Vista Mall.  
Photo by Jose Lara.*

die in a nursing home!

End the institutional bias! You can sign any international bill of rights you want, but until you give people in America a real choice to receive services in their own homes, regardless of disability or age, we will find where you are at and let the world know that you will promise anything, but in the end you do what you want! Now an orange T-shirt means you will turn us away from a public event and ignore our civil rights to go to bed and get up when we want to choose where we live, to have assistance in dressing and bathing and to have help with cognitive tasks when needed.

Our plan is cheaper than yours President Obama. We can free up to 3 people for the price of putting one away! I would love to know how much money you get from the nursing home industry, especially since I understand they will get a rate increase in your health care bill going from 2004. We voted for you because we believed that you would keep your promises to implement the Community Choice Act, and we will follow you everywhere until you do what you promised. There is no health reform without the Community Choice Act! And I hope all our friends the Democrats know that we expect them to stand up for us as well as they do for the middle class, so expect to see ADAPT everywhere you turn up and our legislators need to do more than sign on they need to fight for our civil right to freedom.

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## **At Sestak Town Hall, Disability Activists Draw Their Own Red Line on Long-Term Care Funding, *By Daniel Denvir, The Huffington Post, August 28, 2009***

I scanned the aisles for mustachioed presidential portraits and Obamacare warning-signs at a health care town hall with Rep. Joe Sestak (D-PA) in Philadelphia. "Before we get started," intoned the understated moderator, "we know that these meetings here in the Commonwealth have been somewhat heated."

Yesterday's meeting was hosted by [Liberty Resources](#), an organization that promotes independent living for disabled people, and the Philadelphia chapter of [ADAPT](#), a seriously militant disability rights organization.

But the town hall with Sestak, who is challenging Republican-turned-Democrat Senator Arlen Specter in the party primary, went uninterrupted, the ground rules unchallenged.

No teabaggers showed up. No screaming. No fearful questions about "death panels" or socialism, national or otherwise. Yet the nearly 200 disability rights activists that showed up were mad.



For disability rights activists, the public option--which they do support--isn't the only red line that Democrats shouldn't cross. Activists say they will oppose any bill that fails to include the core provisions of the [Community Choice Act](#), legislation that gives in-home long-term care the same funding priority as nursing home care. These people want to live independently--an option that, fiscal watchdogs be advised, turns out to be almost three times cheaper than institutional care.

As I wrote in a piece this June about the [situation in Pennsylvania](#):

Federal and state Medicaid law requires that disabled people receive a state-granted waiver to get reimbursed for homecare, making the system highly biased toward placing people in institutions. This is the system's default setting, especially for the elderly disabled.

The Community Choice Act would change what activists call the "institutional bias" in long-term care funding. This is the "rationing" that actually takes place under our current system. While the House legislation didn't include these long-term care provisions, activists are hopeful that Senate allies will come through and that a comprehensive bill will make it out of conference.

In a debate dominated by crazed, gun-toting teabaggers and a series of incoherent Democratic proposals, disability rights activists present a different--and undercovered--angle on health care reform. The room full of people with chronic health care needs offered a poignant counterpoint to the crazies who have terrorized politicians over the past weeks, people more concerned with obscure and tenuous historical comparisons (circa 1933) than an everyday person's very real problems.

ADAPT was out in full force in orange shirts emblazoned with their trademark logo of a person in a wheelchair breaking free of her chains. Indeed, ADAPT says they secured the meeting after they blockaded a Sestak town hall two weeks back (although I wasn't able to confirm this independently), protesting the fact that the event wasn't accessible. These are amazing political activists, people who excel in chaining their wheelchairs to things in order to get a point across.

But Specter is also a cosponsor of the Community Choice Act, so Sestak--who claimed that he was the first congressman to put Braille on his business cards--had the big challenge to put some daylight between the two on disability rights issues.

A few healthcare workers showed up, too, some members of AFSCME and SEIU locals.

Henry Nicholas, President of the National Union of Hospital and Health Care Employees (AFSCME), was one of the first to speak. "I'm one-hundred percent committed to single-payer health care, its less complicated and its the way to go"--but, he said, he thought a public option was the second best scenario, and hoped that Sestak would support it.

Sestak spoke out forcefully in favor of a public option, [but refused to vote](#) against a bill that did not include it. An aide told me he didn't want to have his hands tied when a final bill came up.

I ran into a friend from the *Philadelphia Weekly* on her way out of the event. She confessed that she had hoped to catch a bit of drama at the town hall--and I had to agree. The state of American politics is such that people painting Hitler mustaches on photos of our president get more attention than a grassroots movement to provide sensible, humane and cost-effective long-term care to people with disabilities. What a shame.

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## **Sebelius and Specter meet Philly ADAPT on health care reform, 08/09**



*Philly ADAPT at the townhall meeting.*

Philly ADAPT attended a town meeting on health care reform with Health and Human Services Secretary Kathleen Sebelius and U.S. Senator Arlen. They asked Sec. Sebelius why there was nothing in Obama plan about ending the institutional bias, and principals of Community Choice Act. Originally, she thought they were talking about the CLASS Act, but once they set her straight she said she thought it should be and that she has always supported rebalancing.

Senator Specter voiced his support for including the Community Choice Act in the Senate version of Health care reform. He said he agreed with Senator Harkin that people should not be forced into nursing homes, that it is all about choice and that he believes that it will be in the Senate version with a federal mandate!

The article from the Philadelphia Inquirer about the event mentioned the "people in wheelchairs wearing orange T-shirts" and included the picture above of Cassie, Marsha and Erik at the meeting.

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## **Disabled demonstrators take Westside corner to protest reduction in accessible apartments, *September 4, 2009, by David Crowder for Newspaper Tree***

A proposal going before the El Paso City Council on Tuesday sparked a protest Thursday afternoon by about 30 employees and members of two organizations for the disabled, the Volar Center for Independent Living and Desert Adapt, and their supporters.

The group, including 18 people in wheelchairs, occupied four corners of the intersection of North Mesa and Festival, chanting and waving signs against the proposal to reduce the percentage of handicapped-accessible units in future apartment buildings.

In the face of a shortage of as many as 8,000 new apartments to meet the expected demand by incoming Fort Bliss troops and their families, the City Council has already approved property tax breaks for apartment complex developers.

But developers, led by El Paso apartment builder Tom Bohannon, have told the city they need one more concession to successfully lure national developers to El

Bohannon told City Council that accessible apartments, with wider doorways and halls, bigger bathrooms with roll-in showers and lower counters have long been hard to rent because there is too little demand by disabled renters and able-bodied renters don't like them.

Since the late 1980s, El Paso has required that 5 percent of new apartments in major complexes be handicapped-accessible apartments, and the developers want that reduced to 2 percent. *[This sentence was changed at 11 a.m. Sept. 5 to correct the proposed percentage.]*

But after two decades of apartment building under the 5 percent rule in El Paso, the protesters claim they and others who confined temporarily or permanently to wheelchairs cannot find accessible apartments to rent.

And when they do, they say, they find those apartments aren't really accessible because the city has not been enforcing the standards.

"Some apartments advertise that they have accessible apartments but when you find them, they have grab bars in the showers and that's it," said Jose Lara, who was part of the street-corner protest. "That doesn't mean they are accessible."

"There are 20,000 troops and 50,000 people coming, and we have people with disabilities looking for apartments to rent. We need to increase the number to 10 percent instead of 2 percent."

The protesters staged their demonstration at Mesa and Festival because that was as close as they could easily get to The Point apartments at Festival and Stanton where, they said, Bohannon has his office.

Bohannon has said there is plenty of demand for new apartments in El Paso because income levels in El Paso simply aren't high enough to attract the big out-of-town developers.

As the biggest El Paso apartment builder, he said he has complied with the city's requirements but has been unable to rent his accessible apartments to the disabled and had had to offer those apartments to others at a discount.

Luis Enrique Chew, Volar's executive director, was among the protesters Thursday and said people with disabilities can't find apartments to rent.

"We need the city ordinance to stay like it is," he said referring to the 5 percent requirement. "The trend nationally is to improve access. New York has a standard of 10 percent while Texas has a 2 percent requirement.

"El Paso has always been progressive and has thought about the future," he said. "They've promoted El Paso as a city to retire in because of the weather. If we reduce the number of accessible apartments, there will be problems."

Chew, who is confined to a wheelchair, accused the city of approving plans for new apartment complexes where accessibility standards are not met.

"I have visited apartments owned by Bohannon that supposedly met the city standards but the light switches are too high and the bathrooms are too small for a wheelchair."

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**Western PA ADAPT visits Congress after Labor Day, September 11, 2009, by Kathleen Kleinmann**



The three ADAPT Chapters in Western Pennsylvania teamed up to win US Representative Glenn Thompson's Support for CCA. In August, 20 ADAPters made an unscheduled visit to his home regional office in Warren, North Central Pennsylvania. A scheduled follow up visit was made by 30 ADAPters to the Washington DC office.

The Congressman was willing to meet with all of us in the Canon Building hallway. The expected 10 minute meeting with 5 people turned into a meeting with 30 lasting over one hour. We told the Representative that his reputation with the disability community was suffering because he was one of only two PA Representatives who have not yet signed onto CCA.

The Representative appeared truly concerned with this dilemma. After listening to all of our stories and the history of HB 1670, the Representative stated that he would read the bill, and he let us know soon if he could sign on. He told us about his prior work history in the health care field, and how he felt all 50 states should have a mandate to provide community care instead of nursing homes.

ADAPT talked about our current drive to include the Community Choice Option for states in the current drive for health care reform. Representative Thompson said he respected our decision to compromise to make progress, and he told us that he looked forward to joining us in the fight for community care in all 50 states in the future. We are waiting for the confirmation that Representative Thompson will sign on to the Community of Choice Act.

This week coincided with the reconvening after recess of Congress and the renewed commitment of the Senate Finance Committee to produce their version of the Health Care Reform bill. ADAPT of Western PA decided to visit all the members of the Senate Finance Committee and to urge them to build in the Community Choice Option.

Senator Rockefeller's, WV, was first on our list since we had been working with our neighbors in West Virginia. After hearing the usual "fire hazard" routine for so many wheelchairs in their office, we were able to meet with aides for a boisterous hallway meeting. We definitely had the Senator pinned down but he was "too busy" for us.

ADAPT relented only because of our need to visit Finance Chairperson Baucus, MT, who was assembling the 6 Representatives in his office for the Finance Committee's first talk on Health Care Reform.

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## **SEPTA ordered to install elevators for disabled, *By Allison Steele, The Philadelphia Inquirer, September 13, 2009***

After six years of legal wrangling, a judge has ordered SEPTA to install elevators for disabled passengers at two major stations.

Ruling Friday in a lawsuit by Disabled in Action of Pennsylvania, U.S. District Judge Gene E.K. Pratter ordered SEPTA to build elevators in the courtyards at 15th and Market Streets and in the center of City Hall. Those areas have staircases or escalators leading to the Market-Frankford and Broad Street lines.

"This is, purely and simply, about civil rights and equal access," Steve Gold, the attorney for the disability-rights organization, said yesterday. "Disabled Americans have the right to access these stations."

SEPTA spokesman Gary Fairfax said yesterday that he had not seen the ruling and could not comment yet.

Nancy Salandra, president of DIA's board, said she was thrilled. "The judge did the right thing," she said. "This was a very frustrating process for us."

The lawsuit argued that SEPTA should have installed elevators in 2002 and 2003, when escalators and stairways in those areas were replaced. SEPTA argued that disabled passengers could get to the 15th and Market station by taking an elevator on 16th Street between JFK Boulevard and Market Street, which takes passengers down to a concourse.

That elevator is about 340 feet from the station, DIA argued, meaning that disabled people would have to travel significantly farther than other passengers.

"When you're talking about equal access and discrimination, it's not a money issue," Gold said.

According to the ruling, SEPTA's director of engineering said installing the elevator at City Hall would cost about \$2 million and said in a deposition that as far as he knew, it could be done.

Disability-rights organizations have been battling SEPTA over compliance with the American With Disabilities Act since the law was enacted in 1990. In 1993, a group of people in wheelchairs sued SEPTA because buses were not always equipped with working lifts. In 2001, a judge ordered the agency to improve access to its paratransit vans, which transport disabled passengers and seniors, and implemented steep fines if SEPTA failed to provide a rider with a requested trip.

**CONGRATULATIONS DIA & PHILLY ADAPT!**

## Chicago Mayor Tells Obama, Illinois Congresspeople: I Support CCA, 09/09

On September 8, Chicago Mayor Richard M. Daley sent letters supporting the Community Choice Act to President Barack Obama, Illinois US Senators Durbin and Burris, and Illinois US Representatives Rush, Jackson, Lipinski, Gutierrez, Quigley, Roskam, Davis, Bean, Schakowsky, Kirk, Halvorsen, Costello, Biggert, Foster, Johnson, Manzullo, Hare, Schock, and Shimkus. The Mayor thanked those who have supported the CCA, and asked for the support of those who have not yet signed on.

Chicago ADAPT thanks Mayor Daley for his support on this critical civil rights issue, and we also thank the Mayor's Office on People with Disabilities, headed by Commissioner Karen Tamley, for their work to help the Mayor send these letters. The letters are in response to a direct action by Chicago ADAPT on the Mayor's office on July 21. Thank you to all who went to City Hall that day, and especially thank you to Monica Heffner and Larry Biondi for serving as our negotiating team. We hope that these letters serve as a spur towards 100% CCA support from the state of Illinois, dead last in community supports for people with developmental disabilities in the nation.

FREE OUR PEOPLE in the land of Lincoln!

The text of the letter from Mayor Daley to President Obama follows:

Office of the Mayor  
City of Chicago  
September 8, 2009

Richard M. Daley, Mayor

The Honorable Barack Obama  
President of the United States



*Chicago ADAPT Demonstrators outside Mayor Daley's office at the July protest.*

The White House  
1600 Pennsylvania Avenue, NW  
Washington, DC 20500

Dear Mr. President:

As Mayor and on behalf of the City of Chicago, I write to ask for your support of the Community Choice Act (S. 683; H.R. 1670). The Community Choice Act, sponsored in the House by Congressman Davis, and cosponsored by Congressmen Jackson, Gutierrez, Schakowsky and Senators Durbin and Burris, would provide Americans with disabilities equal access to community-based services and supports. Specifically, the legislation would require state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals, allowing those in nursing homes and other institutions to choose where and how they receive personal assistance.

Nearly half of all funding for long-term services and supports is provided through Medicaid for which there continues to be an institutional bias. Medicaid requires states to provide nursing home services, yet community-based services remain optional. As a result, almost two-thirds of Medicaid long-term dollars are being spent on institutional services and only one-third are spent on community-based care. Accordingly, I am very concerned that the State of Illinois ranks 51st among all states and the District of Columbia in serving people with developmental disabilities in small integrated settings.

In these times of budget crises for our nation's cities and states, it should also be noted that the cost of providing services at home or in the community is much lower than in an institutionalized setting. The annual cost for an individual in a nursing home is \$23,000. Providing home and community-based care allows more people to be served and can slow growth in Medicaid spending.

Individuals with disabilities need and deserve these critical community services. I have supported the Community Choice Act or similar legislation for many years and I urge your support for this important legislation. Thank you in advance for your consideration.

Sincerely,

Richard M. Daley  
Mayor

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**Youth Activism Pays Off!, by Dallas Hathaway, 09/09**



In the summer of 2007 Jeremiah O'Dell and myself had the great opportunity of attending ADAPT's Youth Summit in Chicago. We learned a lot about grassroots organizing, and self advocacy, among many other things. One of the tasks that was given to all of us was to identify an issue back in our own communities that we could work on making right. As soon as the task was proposed I told Jeremiah I had the just the task for us. I had been trying to get my high school to make a restroom in the science building accessible for wheelchairs. Not only so I could use them and quit wasting my class time going to the next building, but also the students who come after me who have the need for an accessible restroom. For the first couple of years when I needed to use the restroom while in science class I had to go to a completely different building on campus because I could not get my wheelchair through the door of the restroom in the science building.

I contacted my school officials, and told them the issue. They didn't seem to really care. Instead of getting discouraged I got organized.

A couple of weeks after I had gone to the administration, I noticed the assistant principle was in a wheelchair. She had fallen and broke her leg and was using a wheelchair. I went and talked to her about the situation with the science building restrooms again, this time I asked her to accompany me to the restrooms, she agreed. We went to see if she could enter the restroom in her wheelchair, she took a quick look at the doorway and said she wasn't going to even try. She didn't want to get stuck in the doorway.

We then went back to her office and talked some more. She asked me if I would help draft up a proposal to give the school board to address the restroom problem. I told her I would help her as much as I could in drafting up the proposal. Being new to self advocating, and I still wasn't real familiar with the accessibility laws covered by the ADA, so I wasn't sure how much help I could really be. Being unsure of the accuracy of my proposal and not quite sure of all of the available resources in my community, I contacted my local center for independent living and asked if they could assist me. I soon realized that it was the administration's job to draft the proposal to rectify the problem, not mine.

I again went to the administration at my school and reminded them of the issue and to see where the assistant principal was on her proposal. She informed me that she hadn't even started. She thought I was taking care of it, but said she would contact the appropriate people to have the situation fixed.

This was at the end of the school year. I assumed that during the summer the proposal would have been drafted and the issue rectified. So on the first day of the school year I went and checked out the restrooms in the science building. Much to my surprise NOTHING had been done!

That's when I remembered something we were taught while at the youth summit, never take people at their word - get everything in writing, which I hadn't done. By this time I had read up on the ADA some, and had identified available resources in the community that could help me.

After compiling a list of resources, I contacted my local youth representative on the Topeka ADA Advisory Council, who just happened to be my friend Jeremiah, and talked over possible avenues to get the ball rolling on the situation. After getting a couple of other advocates opinions we decided to contact the ADA coordinator for the school district.

After telling him my problem and what had been told to me by the administrators at my school he said no one ever contacted him or anyone in his office about an issue with restrooms at any school. He went on to say that the behavior shown by school officials was very unacceptable. He immediately got a crew over to my school to check out the accessibility issues, and to get a bid on making the restroom accessible. After about two and a half years of asserting my right to use the restroom at school and three weeks of construction I finally have seen what the inside of the science building restroom looks like and don't have to waste valuable class time to go to the next building to use the restroom.

So to all of you young people out there, who think they cannot make a difference or their voice isn't heard when they speak, just look at how a sixteen year old disabled individual went toe to toe (so to speak) with a school district, and with determination, organizing, and utilizing community resources accomplished a big victory for all the students now and in the future who may need to use an accessible restroom while in the science building. So just keep your head high and remember, you can do anything you put your mind to with the voice you were given and a little bit of organizing and determination. Never give up!

Dallas Hathaway,  
FREE OUR PEOPLE!!

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*Dallas enjoying the fruits of his labor.*

# Passages ...ADAPT Family News

## Bertha Coward

With deep sorrow I am writing this to tell ADAPT my mother (Bertha Coward) has died from cancer. Many may recall her first supportive role during the Columbus Ohio action as well as local actions. She was major supporter to Capitol Area ADAPT providing transportation, handing out flyers, PCA for members, attending meeting to advocate for consumer directed care and going to the extreme to show the mayor and city council how it's done. For National ADAPT she transported luggage and members from the airport and provided rides for ADAPT members arriving on business to support CCA. She also cooked and served food during FREEDOM MARCH upon arrival to the church in DC. SHE WAS VERY PROUD TO WEAR THE ADAPT COLORS. *Bobby Coward*



*Bertha Coward*

## Rayford Smith



*Rayford Smith with his Wife Debbie*

ADAPT has lost yet another warrior. Rayford Smith of Michigan passed away last Wednesday, February 11, at Arbor Hospice in Ann Arbor, Michigan. Ray and his beloved Debbie participated in a number of national ADAPT and Not Dead Yet actions. Some folks may remember Ray from the 1998 ADAPT action in Memphis when he was part of the group that took over Gov. Sundquist's office. Ray's PA hung his feeding tube from the ceiling... not a common site at actions. At a national Not Dead Yet action, Ray, who had CP and was not easily understood by many people, went from blocked door to blocked door in his willingness to be arrested, only to be basically turned away by the police because they didn't know how to communicate with him. Rayford

was tenacious and funny and engaging. He was also one of the first people in Michigan to move into his own home with 24 hour support, after surviving many years in a nursing home where he was abused. Once freed from the hated nursing home, he was a shining example of what's possible- living a free, self-determined life, marrying Debbie, and fighting for the freedom of his brothers and sisters still behind the nursing home walls. Rayford will be greatly missed.

## **Bill Skellie**

Just wanted to let the ADAPT community know that Bill Skellie has passed. He had developed Alzheimer's over the past few years and then had a major heart

I sometimes try to imagine being totally blind, having no hands, one leg, and using a wheelchair in the middle of a national ADAPT action. I KNOW that in Bill Skellie I saw true courage and trust in one's brothers and sisters. Really think about it for a minute and I feel you'll know what I'm talking about. He was gruff and crude and fearless in the face of bureaucratic bullshit. He had no tolerance for that which oppressed us. I miss him so much. *Sandi Weber*

## **Wayne Spahn**



*Wayne Spahn*

I am so sorry to have to tell you that long time ADAPT warrior Wayne Spahn passed away on March 22nd, 2009. Wayne, born in Kentucky, moved to Beaumont and then to Austin in the early 1980s. His activism with ADAPT, UCP of Texas and other disability organizations helped to ensure accessible public transit, a more accessible Austin and passage of the Americans with Disabilities Act, ADA. An initial member of ADAPT of Texas, Wayne gave yeoman's service on Capital Metro's M.I.S.A.C. (Mobility Impaired Service Advisory Committee) and mentored many self-advocates. He taught us to be persistent, flirt, laugh out loud, accept help, listen and that anything worth saying is worth saying, over and over...until they get it. His advocacy at both the Austin City Council and Texas legislature helped bring about many advances for Texans with disabilities. Wayne will be greatly missed. *Stephanie Thomas*



*Bill Skellie*





**ADAPT/Incitement**  
**1640A E 2nd St, Ste 100**  
**Austin TX 78702-4412**  
**(512) 442-0252 V/TTY**  
**(512) 442-0522 FAX**

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Topeka Independent Living Resource Center, Inc.  
501 SW Jackson St., Suite 100  
Topeka, KS 66603-3300  
(785) 233-4572 V/TTY  
(785) 233-1815 TTY  
(785) 233-1561 FAX

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