

Topeka Independent Living Resource Center
 501 SW Jackson St., Suite 100
 Topeka, KS 66603-3300
 Address Service Requested.

Presorted Standard
 US Postage
 PAID
 Topeka, Kansas
 Permit No. 515



Volume 20 No. 1

A Publication of ADAPT

Winter 2003-2004

Ain't Gonna Let Nobody Turn Us Around Gonna Keep on Marching... Marching on to See MiCASSA Pass

Why are we doing this? It's because, segregation from our society is wrong. Locking people away because they have a disability is wrong. It's almost like, we get locked away, so, it doesn't cause hurt to somebody else. You know, it hurts them to see us, so let's put us out a sight and out a mind. That's wrong. In America everybody deserves the choice and the right to be free. — Ben Barrett

A city of over 200 people that packed up, moved and unpacked itself every day; that was how several people characterized the Free Our People March. A city with rows of tents with wheelchair accessible "streets" between, erected in



photo by Tom Olin

Support the work of ADAPT! Become Inciteful!

Incitement comes out on a quarterly basis. With all that is going on it is so important that you give all you can. Even though there is no mandatory subscription, it does cost money to keep the information flowing. Your contribution keeps the activist voice of ADAPT speaking out.

Yes! I support ADAPT. Here is my contribution for *Incitement*:

\$10 ___ \$15 ___ \$25 ___
 \$35 ___ \$50 ___ \$75 ___
 \$100 ___ \$500 ___
 Other _____

Your contribution is tax deductible.

Make checks payable to: Topeka Independent Living Resource Center

Name _____
 Address _____
 City _____ State _____ Zip _____
 Phone _____
 e-mail _____

Send to:
 TILRC/*Incitement*
 501 SW Jackson St
 Topeka, KS 66603

**INCITEMENT
INCITEMENT
INCITEMENT**

ADAPT/Incitement
1339 Lamar SQ DR #101
Austin TX 78704
(512) 442-0252 v/TTY
(512) 442-0522 FAX

Incitement is produced from the offices of Topeka Independent Living Resource Center (TILRC). Articles, letters, compositions, displays and photos are encouraged. Please contact Tessa Goupil for deadlines for submission of materials. The Editor reserves the right to edit or omit any material that is submitted. For more information, contact Tessa Goupil at TILRC or Stephanie Thomas at ADAPT.

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



photo by Tim Wheat

church parking lots, state police headquarters, and open fields. A city that managed to charge over 80 motorized wheelchairs off a generator every evening so they could make the 10 - 16 miles of marching each day. A city with portable toilets that not only moved from campsite to campsite, but stopped for a lunch break every day too. 200 people traveling by the side of the highway in all kinds of weather with only specified breaks due to traffic control. A city that lost no one despite breakdowns of chairs, messed up catheters and colostomy bags, despite oxygen tank changes and sprained legs and terrible blisters. Even Erik von Schmetterling's stroke or a couple of other folks hospital visits could not hold the group down for too long. Dead batteries and broken casters were simply tests to find another way to get on down the road!

It was a city with a troubadour, mechanics, engineers, trash collectors, laundry, attendants, divas, an evolving kitchen crew, portable media station, drivers, artists and more. One of the most interesting things about the whole event was all the kinds of folks it took to make it happen, in all the places, with all the talents, all the limitations and enthusiasms.

Wild geese and bees were our most constant companions, not counting the relentless traffic that pounded by us every day. Was there a message in the fact that these are creatures that live communally and work together for the good of the group, creatures who take care of one another and each contribute to the support of the others?

Perhaps the most telling part was, though we had planned for over a year, over 200 of us were willingly launching ourselves into something we really had no idea what we were getting into. Every day brought it's own set of challenges, which we met and dealt with. Trust and commitment to one another made a bond we knew would carry us through. And it did.

Weather was not particularly our friend. We started in a tremendous rainstorm with a press conference — between the Liberty Bell and the Constitution — right in downtown Philadelphia and in the end we headed out through rain so hard it was literally difficult to see where we were going. In Baltimore too we rallied in a dreary drizzle, and of course in DC though the rally day was lovely, a hurricane loomed over all and shut down the federal government the day we were to visit Congress! Wilmington's Rally was the exception to the rule with a beautiful day. For the most part, when it was sunny the light somehow reflected off the black asphalt of the road and burned into our skin. Sometimes it was so hot folks would literally doze off as we moved along the side of the road!

Folks flew in (a few drove) from around the country the day before we started and gathered that evening for a meeting to explain the logistics. We would rise on a schedule, use the toilets on a schedule, march and take breaks on a schedule and go to bed on a schedule. No one was in love with regimentation, but to make it work we made concessions. When we got to Baltimore a second set of march-



photo by Tim Wheat

ers joined us, and quickly got in the rhythm of it all.

The support from the public was overwhelming. All along the march people waved and clapped and stared at this bizarre apparition of hundreds of people of all abilities and disabilities — we even had a couple of athletic types in tow — heading down the highways and byways. They would come up to talk about the issues and were amazed that the bill had any trouble passing, given the logic and importance of the issue. When we stopped at night our hosts would come to visit. Some catered magnificent meals; some let us use their rest rooms (you would be amazed how good a public restroom sink and flush toilet can look!) E-mails and phone calls from across the nation sent support for the March and for MiCASSA!

The days of the march each held their own unique events: the church that could not hold us all — even dorm style — the first night (so some used tents), the 16 mile march of the second day, the Rally in Wilmington and the horrible bridge of holes on day 3, camping at the Delaware state troopers' headquarters and the McMullen-Powell family pig roast on the fourth night, the steep hills of Delaware

(who knew?) and the incredible Church of the Nazareen camp with it's blocks and blocks of cabins and most hospitable staff and volunteers. The sixth day was highlighted with the shuttle over the Susquehanna River, a tremendous boost from e-mails from around the world that we read that night and the excitement of see other ADAPTers and their friends who brought dinner! Our halfway day was joyfully celebrated with a proclamation of support from Aberdeen City Council President Myra Fender

and Council Member Gina Bantum and the Knights of Columbus and St. Francis de Sales Church warmly welcomed us that evening. On the eighth day the steep hills of Maryland felled many chairs but we were able to rejoin each other once we arrived at our field campsite beside the Cowenton Church in Whitemarsh. Next was our fateful night in the skating rink where we went from the fabulous feast (courtesy of the Father Robert of St Elizabeth of Hungary Church and his brother) to the sickening green mist and the incredible engineering feat of hooking up to the generator that night. Day ten our reinforcing new crew of marchers joined us for a wet rally at the Inner Harbor and went on the volunteer fire department and an al fresco dinner courtesy of the local independent living folks. By day 11 who remembers where we are or what's up, just keep moving and stay in line! Our biggest trial came on day 12 when a sudden rain storm soaked the chargers and the generator and tremendous effort and personal reserves were required to get even some of the chairs charged in a local fire department. The next day we arrive in DC by hook or by crook - and for some it was pretty damn crook - and were greeted by Capitol Area ADAPT with a homemade feast and a most welcoming church.

The great culmination though was coming into downtown DC the next morn-



photo by Tim Wheat

ing to the train station where the 300 Freedom Train Riders and hundreds of others joined us for our last few blocks to the rally site at the park. Entering the park and seeing the thousands gathered there to greet us was a reminder of all that went into make the march happen, both by those on the road and those not on the road with us! The party that night found new folks and old codgers, long missing faces and friends and family members reveling together amid music, pictures, and even a fill-in-your-piece-of-the-ADAPT-history timeline.

In Delaware, MiCASSA Co-sponsor Senator Biden joined us for our rally, and in DC Senators Harkin and Spector and Congressmen Davis and Shimkus, the main MiCASSA cosponsors all joined us, pledging added support. We even had Representative Dennis Moore bring his guitar and serenade the crowd with *This Land Is Your Land*. In Tennessee advocates were so inspired by the march they literally flooded Senator Frist's office with thousands of faxes until he agreed to meet with ADAPT and they rallied in Solidarity on September 17. Folks in Jackson MS and Raleigh NC, and St. Louis MO held solidarity rallies too. In Chicago op-ed and letters to the editors helped spread the word.

The March was to recommit ourselves and any that would join us to the goal of passing MiCASSA, making the Money Follows the Person a reality, and to get real Medicaid reform and Olmstead implementation so that people have a guarantee to be able to choose to live in the community, in their own homes instead of nursing homes or other institutions. In the march when we left Baltimore in another blinding downpour, Anita Cameron lead us in the song "Ain't Gonna Let Nobody Turn Me Around."

Now our challenge is to continue the push! We must push for hearings on

MiCASSA by March of 2004, for passage of the Money Follows the Person at the federal level and state by state implementation in the meantime. There are there are over 250,000 people that even the nursing home industry admits want out, and that does not even address folks in other types of institutions.

If there is one lesson learned in ADAPT's last 20 years, it is that things worth fighting for are rarely won in a single round. The energy that went into the march reaped a huge harvest of commitment to these goals, but we must ensure that the harvest is not wasted.



photo by Tim Wheat



What you can do to continue to getting/keeping folks out of institutions and reverse the institutional bias:

1. Continue to push your Senator(s) and Representative(s) to be co-sponsors of MiCASSA (S. 971 and HR. 2032);
2. Passionately tell them you want hearings on MiCASSA by March 31, 2004 in the Senate Finance and House Energy and Commerce Committees;
3. Continue to push your Senator(s) to be a co-sponsor of Senator Harkin's "Money Follows the Person" bill, S. 1394;
4. The Bush Administration has still not introduced its "Money Follow the Person" legislation (NFI Medicaid Demonstration Act of 2003). Make it clear to the White House and Congress that "Money Follows the Person" will help people get out of nursing homes and other institutions and assist states in implementing the Olmstead decision.

Please continue your grassroots advocacy!!

Memories from 20 Years of Activism

Remember: 20th Anniversary

At the party in DC this fall folks put up a timeline of ADAPT actions for the last 20 years and invited all to write down their memories and put them up on the wall on the timeline. Here are some of the memories people shared...

- ♦ DC '84: The Preacher! The redheaded quad screaming: "they broke my fucking leg!" All of us plopped down in the middle of Pennsylvania Ave blocking buses in front of the White House.
- ♦ Los Angeles '85: Going into the Bail Bondsman's office with Wade and seeing the picture of Dr. King over his desk. Seeing all the vans arriving and everyone coming to chant for the release of 2 of our folks. "Can you hear us, on the inside, can you hear us!" Dana said. And it worked!
- ♦ Edith grabbing onto the bus' windshield wiper as she blocked it!
- ♦ Cincinnati '86: we delayed start of the REDS baseball game 50 mins.
- ♦ Cincinnati?: Jim Parker rolling out to stop the buses carrying the APTA folks to the dinner at the Football Hall of Fame. We thought he was road hash! But no, he stopped 3 buses of them. (The APTA folks in wheelchairs had to ride on a segregated paratransit bus.)
- ♦ Tulsa '86: They can take us to jail, but they can't take us to work.
- ♦ Detroit '86: Running through the streets of the city to deliver the newspaper to Gilstrap when we got out of gym/jail. Frank McComb's "here comes the judge!" Tapping at the windows of the formal dinner at the Ford Foundation and checking wedding IDs of people coming in for another function there.
- ♦ Atlanta '86: We captured 15 Greyhound buses!
- ♦ San Francisco '87: We blocked San Francisco cable cars.
- ♦ San Francisco 87: Evan Kemp and Janine Betram lost ADAPT virginity (1st action).
- ♦ St. Louis '88: making a line from one end of the arch to the other. The cops wearing the ADAPT headbands Arthur Campbell made. Running around in the train station mall blocking APTA while tourists shopped till they dropped all around us.
- ♦ Canada '88: The streets of Montreal and sneaking through the parking lots in the rain and sneaking in through the basement of APTA's hotel. Wheelchairs flying up from the basement? What the?
- ♦ Montreal '88: Lockdown at the Tanguay Women's prison. Julie Farrar and Frank Lozano zipping out of the police pen and up to the front door of the APTA hotel in the pouring rain.
- ♦ Atlanta '89: We took over the Federal Building for 2 DAYS. President Bush I letting us back in the building and sending his people to meet with us.
- ♦ DC '90: Crawling up the steps of the Capitol.

- ♦ DC '90: Crawling up the Capitol steps!

- ♦ My first action! Being arrested in the Capitol Rotunda and getting written up at work (an independent living center in San Antonio) for being arrested. — Terri Stellar

- ♦ Baltimore '91: Blocking Social Security HQ. That place is big!

- ♦ Orlando '91: Cops on the rooftops watching us.

- ♦ Occupying the Republican National Headquarters - being trapped between two desks.

- ♦ San Francisco: Jimmi & Erik married by Wade.

- ♦ Nashville, TN '93: My first national action was Nashville TN! Deborah Russell ADAPT of Philly.

- ♦ Nashville, TN 93: Photo Op with Oakridge Boys

- ♦ '94 Philly LRI: HUD/Greyhound

- ♦ Las Vegas '94: Rev. Willie at the crossroads. The furniture warehouse jail.

- ♦ Lansing MI October '95: It happened this way - Our friend Governor Engler left his front gate open and 5 minutes later there were about 200 people in wheelchairs on the front lawn. They say we hurt the Engler babies by our noise; well I guess that was a lie because they are just fine! Free Our People! Bill Earl, East Lansing MI

- ♦ Atlanta 96: AHCA The Marriot Marquee atrium - Sounds of ADAPT - Speaking truth - My second arrest on my first action. "Free Our People Now!"

- ♦ Atlanta '96: Going to Atlanta Bell at 11pm and then Jail. Stephie's speech which inspired me to go. Later getting to know Cassie in the Jacuzzi. The rest is history. JC.

- ♦ '97: Greyhound shut down. That dirty dog!

- ♦ DC '97: My first action and Waiting for Newt to come out. Deb Stewart

- ♦ DC '97: Singing "tear down the walls" outside Newt Gingrich flat in DC on a megaphone.

- ♦ DC '98: National Governor's Association HQ. Take those garage doors! Till we get out - Last Metro out when we get out of jail back to the hotel. "Free Our People"

- ♦ DC: Crawled under police cars at Hubert H Humphrey HHS Building

- ♦ Memphis '98: Took over Governor's office and spent the night.

ADAPT



20 Years of

Freeing Our People!

♦ DC '99: Sleeping on the steps of the Supreme Court the night before Olmstead was heard

♦ April '99: The Supremes hear "Olmstead" it's real cold sleeping on the sidewalk. Thomas (the Judge) sleeps through the whole thing, then gives the dissenting opinion - BUT in June we have mostly a victory!!!

♦ Columbus '99: Marched through a snow storm.

♦ Columbus '99: I don't want your fucking cookies!

♦ DC '00: The first time I came to Washington DC. It was exciting. Before that I have never been out of state. Now I make friends every time I come here! Patricia Taggart, Rochester NY

♦ DC '00: I feel like I am somebody! Pam T, Rochester NY

♦ DC: Watching Sparky and Myra and all the others crawling across the checked plaza in front of the Old Executive Office building. They looked like pieces in a giant chess game. Listening to the drumming of the Kansas folks while they held their doorway.

♦ Fall '01: After 9/11 we got married in SF and shut down the four corners!

♦ Fall '01: Something about a wedding and me being terrified!

♦ DC '02: The day we shut down PA Ave. during rush hour

♦ DC '02: Rooming with Erik V & Jimmi

♦ DC '03: All of ADAPT meeting with the

DOJ guy in the street. Awesome. And that BANNER WOW. We shut down the Justice Dept.

♦ Fall '03: Seeing my mom in her lil' orange vest, looking 144 miles more tan than me! Alma Padilla, El Paso, TX

♦ Fall '03: "No more PBJ" beats out "no more cold McDonald's French fries."

How much fellowship and community I felt when the marchers came around the corner. I felt they represented all of us with their courage.

♦ May 2003 The Rally in Washington DC! Free Our People!

♦ My first action I was afraid as I stepped out into the road to block traffic. I got hit by a car on the crosswalk, which is what disabled me. Since then I have been handcuffed to vans, blocked off a police car so that ADAPT could get through, and this week traveling along superhighways for MiCASSA. I'm very privileged to be part of ADAPT.

♦ We are people not animals! Let our people go! Dave

♦ MiCASA Hearings - Trying to webcast a Press Conference and Failing Miserably! MJR

♦ Wayne Cook of San Antonio transit authority saying "lifts on buses over my dead body!"

♦ Throwing up on our lawyer during our hunger strike at the Reno/Sparks jail. They were going to sentence ET to much longer jail time, but the courtroom erupted (sounded like a zoo!) and by sticking together no one was left behind.



Some Important New Information for MICASSA Supporters**

By Mike Oxford

Across the nation, advocates are asking Congress to support MiCASSA (S. 971/ HR 2032) the bill which would free millions of people of all ages from the specter of entering nursing homes and other institutions against their wishes. Many members of Congress, both House and Senate, when asked why they don't support the bill answer that they like the bill, but are concerned about the cost. In the past, an earlier version of the MiCASSA was priced at 10 to 20 billion dollars per year. Since then MiCASSA has been rewritten to help clarify what it does and does not cover, and clear up some of the misunderstandings that caused the bill to be priced so high. Long term services and supports do cost money and many people in this country are clearly not getting the long term support and services they deserve, and that MiCASSA would provide. Now, however, thanks to researchers at the University of California at San Francisco (UCSF), there is reliable new evidence that the cost of MiCASSA, the price of freedom for millions facing the despair of nursing homes and institutions, is only a fraction of the earlier figure.

This is good news, folks. MiCASSA at an affordable price. Lawmakers need not fear too high a cost for a bill our country cannot afford not to pass.

No more excuses.

Relevant background cost information:

- Home and community programs serve over 400,000 more people than nursing homes (NFs) and Intermedi-

ate Care Facilities (ICFs - the institutional program for people with developmental disabilities). Yet even though home and community programs serve 25% more people than their institutional equivalents, they get only get 30% of the total money while institutions get 70% of the funding.

- Medicaid Waivers on average cost \$17,000 per person. Nursing homes cost between \$40,000 and \$50,000 per person.
- In the past seven years occupancy rates in the nursing homes have declined by 7% or 126,000 fewer people. At the same time costs have risen 46%!

In addition to the funding bias, there are other institutional biases built into the system:

- 33% of states have more restrictive financial eligibility rules for community programs than for nursing homes (NFs) and 42% have stricter rules than required by the Federal government.
- Residential care (aka assisted living) experienced a 98% increase in the past ten years.
- 158,000 people are on waiting lists for services post Olmstead. Examples include: Indiana has 7,300 people waiting, Georgia has 9,400 people, Wisconsin has 20,000, New

Mexico has 6,300 and Texas has 74,000 people waiting.

- ❑ Medicaid Waiver funding is not evenly distributed across populations. MR / DD programs serve 39% of the people and get 74% of the money. TBI and mental health programs serve 1% of the people each and get 1% of the money each. AIDS programs serve 2% of the people and get 1% of the money. Aging and disabled programs serve 60% of the people and get 24% of the money.

There is a myth that only the very elderly enter nursing homes these days. The truth is that there has been a 16% increase in working age people going to nursing homes in the past five years while the

elderly population has stabilized. Fully 10% or 170,000 of nursing home residents are working age. In addition, in states where Money Follows the Person is being tested, over half those moving out are over 65 years old.

And they say this system is ok? That it is regulating itself? That there is no need for long term care reform in Medicaid, that there is no need to PASS MICASSA NOW!?!

WE who care about budget integrity, about freedom and fairness and liberty for all say:

PASS MiCASSA NOW.

**Many statistics provided by UCSF, Charlene Harrington. Some information extrapolated by the author.

Where do the Presidential Candidates Stand on MiCASSA?

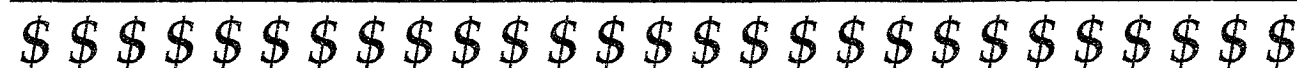
ADAPT has sent a detailed survey to all of the Candidates and will share the results once they are in. However, so far ADAPT has found:

- ❖ Dean supports MiCASSA
- ❖ Senators Edwards and Kerry, and Representatives Gephardt and Kucinich are all MiCASSA co-sponsors.
- ❖ Leiberman vaguely supports community based services but has not come out in support of MiCASSA.
- ❖ General Clark and Moseley-Braun have also recently published statements

supporting MiCASSA.

- ❖ Sharpton has not yet taken any position that we have found.
- ❖ Bush does not support MiCASSA but has taken some steps through his New Freedom Initiative to implement some related programs. In addition, however, he has proposed some Medicaid reforms that would gut Medicaid as we know it, turn the program completely over to the states and ruin any opportunity for MiCASSA!

Will keep you posted as we get more details!



What's Up With the Administration's "Money Follows the Person" Initiative?

Last February the President unveiled his budget and included in it was an Initiative to create demonstration programs to test the Money Following the Person. Yet here we are nine months later and the Administration's bill seems to have disappeared from the face of the earth.

The White House braved the threatening hurricane to meet with ADAPT members on the morning of September 18th. Their staff claimed to have sent language up to Capitol Hill for a bill: the New Freedom Initiative Medicaid Demonstration Act of 2003. Administration members said they were talking with members of the Senate Finance and House Energy and Commerce Committees to introduce the bill right away and want to see it passed before Congress closes for 2003 (estimated to be in mid-November). This bill would include the Money Follows the Person, setting aside \$1.75 Billion over the next 5 years to help states do demonstration projects to implement this concept. Also to be included in the White House bill were demonstration projects on: Respite Care for Caregivers of Adults, Respite Care for Caregivers of Children with Substantial Disabilities, Home and Community Based Alternative to Psychiatric Residential Treatment Facilities for Children, Address Shortages of Community Service Direct Care Workers, Presumptive Eligibility [for

community services] for Certain Elderly and Disabled Persons, and Medicaid Eligibility of Spouse of Individual who Performs Substantial Gainful Activity Despite Severe Medical Impairment.

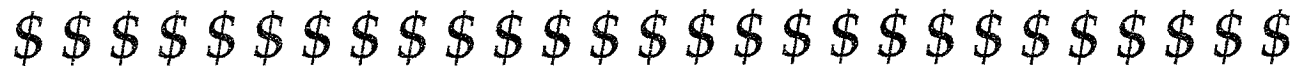
Lip service is what the Bush Administration seems to have mistaken for attendant services.

Or are the Republicans in Congress stonewalling the President and refusing to introduce or support the bill?

As the year closes, finger pointing and vague reassurances seem the best any of them can offer.

Equally unhelpful is the knee-jerk lefty assumption that the Money Following the Person is some kind of stalking horse for Medicaid Block Grants.

Fortunately, while this bill would have helped kick start Money Follows the Person in many states, the concept can be done even without the federal demonstration grants. Texas has now moved over 2,200 people out of nursing homes using Money Follows the Person policy (for which they got no extra federal dollars, but were able to save the state millions. Kansas has a demonstration policy which is moving people out. Maryland passed legislation to "make it so" last spring. Utah, Pennsylvania, Colorado and New York are all wising up and looking at following suit!



ADAPT Demands Hearing on MiCASSA by March 31, 2004

Congress finally recessed for the holiday season after taking action on a Medicare prescription drug bill that will make getting needed drugs more difficult and/or expensive for people with disabilities.

Congress' focus on this Medicare prescription drug bill and on an energy bill (that did not pass) delayed MiCASSA and reform of the institutionally biased long term care system until 2004.

Don't Mourn...ORGANIZE! Let's tell our Senators and Reps what we want.

ADAPT is calling for the Senate Finance and the House Energy and Commerce Committees to hold hearing on MiCASSA (S.971, H 2032) before March 31, 2004. (see box with members).

Senators Harkin and Specter, MiCASSA co-sponsors in the Senate, have both called for hearings in 2004. House Co-sponsors Davis and Shimkus are also supportive of hearings.

All bills must have committee/Subcommittee hearings before they go to the "floor" of Congress for a vote.

Hearings will give us an opportunity to bring the facts to Congress on how corrupt and harmful the current long term care system is to the lives of people with disabilities and older Americans, and how MiCASSA will reform the system.

Since 2004 is a Presidential election year, MiCASSA faces tough sledding. However, if we continue our aggressive advocacy we will Free Our People in 2004.

ADAPT is pushing for hearings on MiCASSA by March 31, 2004 before the Senate Finance Committee and the House Energy and Commerce Committee.

Below are the members of those committees. The members with *** next to their name are members of the Subcommittee(s) that would hear the bill.

House Energy and Commerce Committee (57 Members)	
Republicans (31)	Democrats (26)
*** <i>House Energy and Commerce Health Subcommittee (31 members)</i>	
Republicans (17)	Democrats (14)
<p>Billy Tauzin, Louisiana CHAIR John Dingell, Michigan *** Michael Bilirakis, Florida Chair Subcommittee *** Henry Waxman, Calif *** Joe Barton, Texas Ed Markey, Massachusetts *** Fred Upton, Michigan *** Ralph Hall, Texas Cliff Stearns, Florida Rick Boucher, Virginia Paul Gilmor, Ohio *** Edolphus Towns, NY *** Jim Greenwood, Pennsylvania *** Frank Pallone Jr., New Jersey Chris Cox, California *** Sherrod Brown, Ohio *** Nathan Deal, Georgia *** Bart Gordon, Tennessee *** Richard Burr, N Carolina Peter Deutsch, Florida *** Ed Whitfield, Kentucky Bobby Rush, Illinois *** Charles Norwood, Georgia *** Anna Eshoo, California *** Barbara Cubin, Wyoming *** Bart Stupak, Michigan John Shimkus, Illinois *** Eliot Engel, NY</p>	

- *** Heather Wilson, New Mexico
- Albert Wynn, Maryland
- *** John Shadegg, Arizona
- *** Gene Green, Texas
- *** Charles Pickering, Mississippi
- Karen McCarthy, Missouri
- Vito Fossella, New York
- *** Ted Strickland, Ohio
- Roy Blount, Missouri
- *** Diana DeGette, Colorado
- *** Steve Buyer, Indiana
- *** Lois Capps, California
- George Radanovich, California
- Mike Doyle, Pennsylvania
- Charles Bass, New Hampshire
- *** Chris John, Louisiana
- *** Joseph Pitts, Pennsylvania
- Thomas Allen, Maine
- Mary Bono, California
- Jim Davis, Florida
- Greg Walden, Oregon
- Janice Schakowsky, Illinois
- Lee Terry, Nebraska
- Hilda Solis, California
- *** Ernest Fletcher, Kentucky
- *** Michael Ferguson, New Jersey
- *** Michael Rogers, Michigan
- Darrell Issa, California
- C.L. Otter, Idaho

Senate Finance Committee Members (21 members)	
Republicans (11)	Democrats (9)
Independent (1)	
*** <i>Senate Finance Health Care Subcommittee (19 members)</i>	
<p>*** Charles Grassley, Iowa CHAIR *** Max Baucus, Montana *** Orrin Hatch, Utah *** John Rickerfeller, WVirginia *** Don Nickles, Oklahoma *** Tom Daschle, South Dakota *** Trent Lott, Mississippi *** John Breaux, Louisiana *** Olympia Snowe, Maine Kent Conrad, North Dakota *** Jon Kyl, Arizona Chair, SubCmttee *** Bob Graham, Florida Craig Thomas, Wyoming *** Jeff Bingaman, New Mexico *** Rick Santorum, Pennsylvania *** John Kerry, Masseurhusetts *** Bill Frist, Tennessee *** Blanche Lincoln, Arkansas *** Gordon Smith, Oregon *** Jim Bunning, Kentucky *** Jim Jeffords, Vermont</p>	

Slashing and Burning in the States

Disability advocates across the nation are facing some of the greatest opposition in over a decade. States, facing grave financial crises, and powerful antitax lobby movements, are looking to slash services. And experts forecast next year will be worse.

Medicaid is one of the biggest and fastest growing cost issues for states, and so it has a big target painted right on it's heart. While nursing home services are mandated, there is not such protection for community services - so cuts are threatened most deeply here.

All the more reason we need Real Choice: MiCASSA and Money Follows the

Person. We need to stay vigilant because in this environment the Bush Administration or Congress may propose block grants. Governors may become more supportive of this as Medicaid costs continue to rise. States could write mega-mother of all-Medicaid Waivers to make it happen from the bottom up! Block grants give states "budget certainty" something Governors and state legislatures crave. Block grants could give us waiting lists and diminished service.

States rights are the watchwords of these times, and it seems once again, states rights will be opposing individual and human rights.

How Many People Want Out of a Nursing Home in Your State?

The Minimum Data Set, MDS, is a report each nursing home must fill out quarterly and turn into the feds. One of the questions they ask is about the residents discharge potential (Resident Expresses/Indicates Preference to Return to the Community). Here are the results from the last quarter ending September 2003.

Remember, these are conservative numbers because they are as reported by the nursing homes. Still they are useful as advocacy targets when talking to your states about Olmstead, the Money Follows the Person, and Real Choice issues in general.

MDS stats as of 9/30/03

State	# of People who want out	% of total
Alabama AL	3,255	14%
Alaska AK	160	26.6%
Arizona AZ	3,083	24.7%
Arkansas AR	2,733	15.2%
California CA	22,566	21.6%
Colorado CO	3,356	20.9%
Connecticut CT	5,523	19.8%
Delaware DE	882	22.6%
Washington DC	460	16.7%
Florida FL	16,866	23.9%
Georgia GA	4,910	13.8%
Hawaii HI	571	15.4%
Idaho ID	1,128	24.4%
Illinois IL	15,286	19.6%
Indiana IN	7,062	17.5%
Iowa IA	4,536	16.7%
Kansas KS	3,361	16.3%
Kentucky KY	3,757	16.7%
Louisiana LA	2,917	10.3%
Maine ME	1,376	20.5%
Maryland MD	5,376	21.6%
Massachusetts	8,110	18%
Michigan MI	9,618	23.2%
Minnesota MN	6,518	18.7%
Mississippi MS	1,547	9.8%
Missouri MO	7,654	20%
Montana MT	1,188	21.2%
Nebraska NE	2,308	17.5%
Nevada NV	843	20.6%
New Hampshire	1,078	15.3%
New Jersey NJ	8,163	19%
New Mexico NM	1,345	21.7%
New York NY	19,992	18%

State	# of People who want out	% of total
North Carolina	6,739	17.8%
North Dakota ND	825	13.6%
Ohio OH	16,856	21.8%
Oklahoma OK	3,328	15.6%
Oregon OR	2,196	26.3%
Pennsylvania PE	12,627	6.1%
Rhode Island RI	1,458	17.4%
South Carolina	2,609	16.3%
South Dakota SD	1,002	15%
Tennessee TN	6,257	18.8%
Texas TX	13,429	15.1%
Utah UT	1,466	28.1%
Vermont VT	638	19.8%
Virginia VA	5,679	20.7%
Washington WA	4,735	24.2%
West Va. WV	2,129	20.8%
Wisconsin WI	7,018	19.8%
Wyoming WY	532	21.7%
Puerto Rico	115	66.5%
Virgin Islands	14	37.8%

To look this up on the web in the future go to www.cms.hhs.gov/states/mdsreports/ at the bottom of the page select Report Type and scroll to choose MDS Active Resident Information Report. Next select the report date of September 30 2003 (or whatever) and then on the long list, scroll down till you get to Q1a Discharge Potential and Overall Status. Click there you will get a list by states.



ROCHESTER, NY BY BRUCE DARLING

November 17th, 40 Rochester and Syracuse ADAPTers marched to meet Vice President Cheney who was in Rochester to attend a \$1,000 a plate luncheon fundraiser for the Bush re-election campaign. MiCASSA, Money Follows the Person and Real Choice have disappeared from the Administration's radar and the goal was to correct that!

We were told the police would be setting up a secure perimeter to prevent protesters from getting too close, we chose a route that took us really close without attracting too much attention, crossing at the lights and arriving over an hour before the VP was scheduled to appear. Mounted patrol officers apparently didn't notice the single file line of 40 people in brightly colored ADAPT shirts. We blocked the doors, pulled out our signs and started chanting.

An officer approached the group and said he would call the "paddy wagon" and take people to jail if they stayed in front of the doors. We told him, "Do what you need to do." Our leadership team was negotiating with a more senior officer, whom we told to give our demand list to the Vice President and asked that we meet with one of his staff.

We had thousands of flyers and began leafletting people on Main Street. We were joined by the Rochester Campus Action Network (RCAN). Several protesting nuns joined the action; a young social worker picked up a sign and just started chanting. By now, a couple hundred people had joined the protest. The others were surprised when 40 ADAPT people were louder than 200 anti-war protesters.

Working with the other progressive groups helped make all of our work more effective. They were able to get very useful information and ADAPT helped strengthened the action. It was also an opportunity for ADAPT to educate these groups about our issues and perspective. At first they

looked shocked when we chanted, "Hey Hey Ho Ho Nursing homes have got to go!" But they began to understand our issues and joined in.

The entire ADAPT group moved to the main doors, where things got a bit heated. After the luncheon ended, ADAPT headed over to the Federal Building. While ADAPT and RCAN chanted outside the Federal Building, our representatives took the demand list up to Rep Louise Slaughter's office where they faxed it to the White House.

ADAPT's message, covered by radio, TV and newspaper was loud and clear, "ADAPT expects the administration to keep its word!"

FAST FOR FREEDOM IN MENTAL HEALTH BY BOB KAFKA

The core hunger strikers in the Fast for Freedom in Mental Health declared victory on September 6, 2003 in their 22 Day battle against the American Psychiatric Association, APA. The hunger strike was organized by MindFreedom Support Coalition International.

After forcing a meeting with APA, MindFreedom Executive Director David Oaks said "The public has a right to know that the APA basically concedes the main point of the hunger strike — that there is no reliable scientific evidence such as laboratory tests to back up the domination of the biological model in mental health today."

Advocates said the next step, given the general "stonewalling" attitude by key leaders in the psychiatric industry, is a campaign against the psychiatric drug industry by demanding that Congress investigate the psychiatric drug industry and exposing their corrupting influence of the mental health system.

The battle for freedom from coercion and forced treatment continues. To join the struggle: www.mindfreedom.org/mindfreedom/hungerstrike47.shtml

Words from the Marchers and Ralliers!

(Excerpts from a short video by Jim Glozier)

Marchers rolling on street (singing):

Oh when ADAPT, comes rolling in. Oh when ADAPT, comes rolling in. Oh when ADAPT Comes Rolling in Oh I'm proud to be in that number when ADAPT comes rolling in.

Jo Ann Donnell: We're here on this march of 144 miles from the Liberty Bell in Philadelphia to Washington DC to promote passage of the Medicaid Community Attendant Services and Supports Act. What this means to people with a disability is right of choice. Nursing home service is an entitlement, and community based service is optional. Whenever cuts occur it's always the optional stuff that gets thrown away, and that means people are forced to live, I won't even say live, exist in nursing homes. Not live with right of choice, or ability to be taxpayers, or to live with their families and be productive members of society. We must free our people now and promote MiCASSA. The Senate and Congress must listen to us and make this a law

Marchers: Its called equality for all, not just for some.

Ron Ford: Were marching to Washington D.C. to promote the passage of MiCASSA, Community Attendant Services and Supports Act. This will provide services for people so they can live in their own homes rather than live in a nursing home. Using the same money that will keep you in a nursing home to provide you personal attendant services in your home, where you can have your choice of when you want to go to bed, what you want to eat, and where you want to go. I am also a member of the Ohio Brain Injury Association Board of Trustees, as a survivor of acquired Brain Injury.

John Hoffman: I've been disabled from birth. I was a thalidomide baby, born

in 1961. I'm here to get this bill passed, MICASSA so that the money can follow the individual and disabled people won't be incarcerated in nursing homes, the way that they are now, and end the institutional bias that the nursing homes have bought, through their huge lobbying effort. What it means to me personally to be here? In all truth, is an opportunity to have camaraderie with my old friends.

Anita Cameron: We're on our way to DC to set our people free. Set'em Set'em Free Set'em Free.... I have multiple disabilities and I wanted to live alone, by myself, which I had been doing. I have epilepsy and it was getting out of control, losing some sight, and they decided that it was too dangerous for me to live alone. And they dragged me into a court certified me for up to sixty days and I spent a year trying to fight to get out of this institution. Got out, went traveled around, what not, for a few months. Came back home to Chicago and I joined ADAPT.

Bob Kafka: People were e-mailing, calling from all over the country, to send regards to all the marchers

Nancy Salandra: Everybody, each day, is doing terrifically. Hanging in there, even though they're more tired each day. And the response from the public is just incredible. I think the strange thing for us is that on September 1st, Labor Day was the Jerry Lewis Telethon and we started September 4th. And I think the public just didn't quit know what to do with this, because THEY'RE HEARING you know, the Telethon, and "My kids can't do anything" and then seeing mostly disabled people in wheelchairs doing this incredible march and going to Washington and people I think, they were just floored, that we were actually marching that far.

Ben Barrett: I am now ten years post pedestrian versus a freight train. I was run over by two locomotives and four cars. They put me back together at the University of Wisconsin Madison, but when they were gonna release me from the rehab center... my house wasn't accessible so they were making plans for me to go live in a nursing home for eighteen months, or for no six months while the frost was in the ground so they could build me a ramp after the frost was gone. I had some friends build me a ramp and I got free. The reason I'm doing this is I know too many people that have been put away, for no reason other than their disability and that's wrong. Tell you about a girl I knew when I was young. I saw her get hit by a car when I was ten years old. You know they took her out of my neighborhood. For thirty years, I didn't see her. She was in an institution at five hundred and something dollars a day. In 1995 she got out. In 1998 I stood up with her at a wedding of another friend. She is working at Wal-Mart. She's a taxpayer. What a gift. Every time I see her, she's full of smiles. Just imagine. There's so many people with these gifts. And what do we know that the rest of you don't. Why are we doing this? It's because, segregation from our society is wrong. Locking people away because they have a disability, is wrong. It's almost like, we get locked away, so, it doesn't cause hurt to somebody else. You know, it hurts them to see us, so let's put us out a sight and out a mind. That's wrong. In America everybody deserves the choice and the right to be free.

Bernadette Franks Ongoy: It really is about all of us, and the thing about it is it could happen to any of us in a split second. So many of these folks were able bodied — you and me today we could be in a chair tomorrow... you just come to an ADAPT action because this is really the cross section of America, because you have everything. You do have all the races you


can possibly think of here. You got disabilities, from people that are blind, to people that are in chairs to people that have cognitive disabilities, all sorts of physical disabilities. And what is really kinda cool is that we can cohabitate together in this tent city, and move across you know what three or four different states to make a point and really be making history. This is, the face of America.

Linda Anthony: We talk about liberty and we talk about give me liberty or give me death. Well Mister President and Congress, and the rest of America we want to say to you: Give them liberty but please don't give them death.

John Gladstone: We made it and were gonna pass MiCASSA.

Stephanie Thomas: In my state just less than six months ago they were planning to dump over a hundred thousand people off of community services because they said they had budget problems. These were tight times, and everyone had to tighten their belts. Well guess who was tightening their belt the most: community services. Tell your Senators and Representatives: If Newt Gingrich can get behind this bill, if Ted Kennedy can get behind this bill, you can get behind this bill!

Barb Toomer: We wanted lifts on those busses. We did, and we won that in 1990 with the Americans with Disabilities Act. Then it dawned on us in 1990 we had to get people out to use that transportation that we had fought so hard for. And since then we have appealed to two Presidents, Housing and Urban Development Health and Human Services, the Department of Justice and Congress to pass MiCASSA. They still haven't done it.

Senator Tom Harkin: You're here, your leading the charge; we have to get this passed. To put that next element in there. To back up the ADA. To make sure, that not only is the door open, but that every person has the choice. 

Passages

Jo Ann Donnell

You know they say that only the good die young... Jo Ann was one of the best.

She was the strongest person I know. Jo Ann never let anything get in her way.

When a hurdle came about, she would jump it, when a barrier was in front of her, she would break it down.

Jo Ann was always there. Singing to the oldies, chanting in her bullhorn, toting around her massive backpack in which she always had stuff to share: aspirin, life savers, lighters, kazooos....

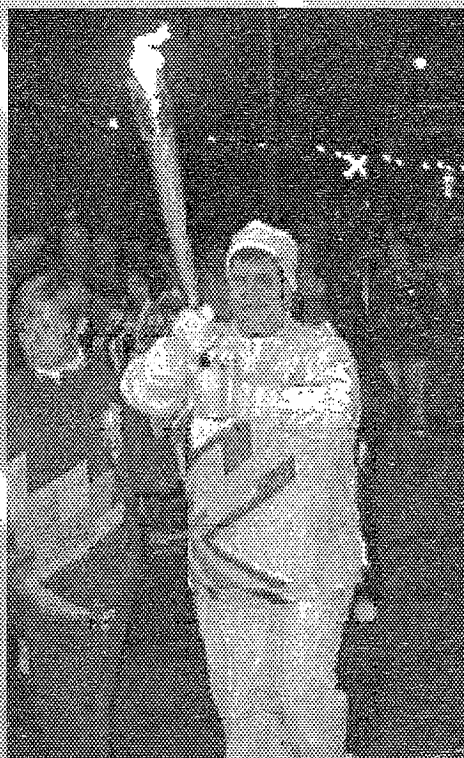
She shared so many good times with so many of us, that it would be impossible to name just one. She brought a certain playful innocence into my world of harsh realities. We'd play truth or dare, quarters, throw ice at each other and shoot each other with waterguns. Jo Ann's aim was unbelievable. She could hit you from 20 feet away!

I am going to miss that sly snicker of hers when she knew something that she probably shouldn't have. The way she'd wrinkle up her nose and giggle quietly. The way she'd sing Bad, Bad Leroy Brown, and get involved in all of my conversations. I'm going to miss taking long drives with her, hanging out in hotels, fighting side by side at ADAPT.

Jo Ann was bound and determined, no matter what, to do EVERYTHING that everyone else did then go above and beyond that, like the day she drove a pontoon boat, carried the Olympic torch, marched from the Liberty Bell to the United States Capitol. Her determination has made her a leader in the community as well as in America. She fought for Freedom and Independence. Not only her own, but for yours and mine as well.

If there is one thing I know that Jo Ann would want to say, it's "lead on, stay strong, be united, and for God's sake... get MiCASSA passed!!!"

We're going to miss you Jo Annie!
Rhoda Smith



Maria Valenzuela

Rochester lost one of its long time ADAPTers on November 14th, 2003. Maria Valenzuela passed away after an extended battle with Diabetes and Renal Failure.

As a child and young woman, Maria lived for many years in a state run institution until during a strike by the state workers, Maria and one doctor provided personal care to the residents who needed assistance. The doctor recognized that Maria "did not need to be there" and Maria moved out of the institution. She lived in her own apartment for three decades and became a fierce advocate for herself and others. Maria loved participating in ADAPT actions and would complain loudly if an action was scheduled on a day she needed dialysis.

In 2002, she fell and broke her hip. The hospital told Maria she would have to go into the nursing home, where she'd be "safe"; Maria told them to "go to Hell" instead, refusing to sign any discharge paperwork which would send her to a nursing home. Ultimately,

the hospital filed for guardianship on Maria, claiming she could not manage her life if she thought she could live in the community. After a two day hearing, a deal was negotiated which would allow Maria to return to her own apartment with community-based services and support from several neighborhood ADAPTers.

To get the funding for some of these services, Maria personally confronted New York State's Commissioner of the Office of Mental Retardation and Developmental Disabilities. During his visit to Rochester, she asked him why he was trying to force her into a nursing home by delaying approval of her services. He immediately agreed to resolve the problem... and did.

Maria loved her freedom, and she died a FREE woman.

Rochester ADAPT... and the NYS Troopers... will miss her.

Spring ADAPT Action

The Spring Action will be in DC from MARCH 20 -25. We will be focusing on *MiCASSA* and *Money Follows the Person* as well as related issues.

Call Tisha in Denver for reservations 303/733-9324.