

# MASS NEWS

Massachusetts Advocates Standing Strong



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## LETTER FROM THE CHAIR ~ WE DID IT! DDS

John Anton

In the month of June many celebrations were held across the state by hundreds of self-advocates, families, and regional offices to celebrate changing the name of the agency who serves us to the Department of Developmental Services.

On June 30, at the DDS with our Commissioner, Elin Howe, we had the official celebration for this event honoring those who were involved in the early years when Massachusetts Advocacy Standing Strong started and had changing the name as their priority and also those who continued to support us throughout the years. There were many unsung heroes who helped us. It was always about respect and dignity and not being stigmatized.

Massachusetts was one of the last states to be changed and we are proud of our accomplishments which we achieved through partnerships with legislators, agencies, and self-advocates like you who made phone calls, wrote letters, attended rally's, and made visits to the State House.

Our work is not over as we address the challenges of cuts in the budget which will affect all of us. We must continue to concentrate on changing attitudes and perceptions and educate each other on issues which affect us both financially and personally. One of our top priorities in the coming year will be self-determination and person-centered planning where the money will follow the person if they change their program or residence.

We invite you to join us in our efforts and encourage you to become a paid member of M.A.S.S and to invite new members to your local and regional groups. There is strength in numbers and we believe we can achieve more with your help. Thank you for your time and effort and having your voice heard.



# SELF-ADVOCACY AND MRS SPEAKS OUT

Submitted by: Joseph K., Tom K., Tristan J., Karen C.

Self-advocacy is about speaking up for ourselves and for others who cannot or may need help speaking up for themselves. Self-advocacy is letting others know how you feel, what you want, and what is important to you.

We are members of a self-advocacy group called MRS Speaks Out. The first meeting of the group was almost 3 years ago. There are now about 17 members and we meet two times each month. We learn about our rights and speaking up for ourselves. We are also members of Massachusetts Advocates Standing Strong (M.A.S.S.), the statewide self-advocacy group.

MRS Speaks Out has been busy. During the past year we went to the State House two times; in March we attended a Legislative Reception; in June we went to a rally and hearing on the Change the Name of DMR (House Bill H1876). During

one of our visits to the State House, we met Governor Patrick. Many members went to the Human Rights and M.A.S.S. conferences. Some members completed a first aid class. We wrote a satisfaction survey and met with most self-advocates at MRS. Kellie Ward came to one of our meetings, we talked about some issues, concerns, and some things that are important to us. We held a car wash and raised \$171.

During 2008 we plan to do more fundraising, go back to the State House, continue to help others learn about self-advocacy, and work to "Change the Name of DMR."

By letting others know what is important to us, we can help make positive changes in our lives.



## BLUE TEAM AT MINUTE MAN ARC

The Blue Team is about advocating for our needs.

Once a month about 25 people attend.

January was self-advocate awareness month.

We made t-shirts and signs at residences and baker.

The signs talked about what self-advocacy meant to people.

Notices went home to parents about self-advocacy.

February and March will be library awareness months.

Posters are being made about what you can do at a library.

We are going to make and wear pins.

Staff at all programs is going to take people to register for library cards.

People who have library cards will go and use things at the library.

April and May will be Health and safety months.

We are making a list of trainings we are offering to the self-advocates.

First Aid and CPR, Universal Precautions, and Fire Safety, were some ideas.

June and July will be Fitness and Exercise.

We have a steering committee that meets once a month.

Each program has a staff and a self-advocate on the committee.

The purpose of the committee is to make things happen all over the agency.

*Written by Susan Carvalho*

02-11-09

## SHARE THE POWER

Now that you are all experienced self-advocates, and know how to speak up for your rights and how to fight for the changes you want. We need to open up and make sure other folks learn how to do the same. One way to do this is to make sure more people know about MASS. We are working on a new brochure that explains who we are, what we do, and how to join. Remember, the more of us there are, the stronger we are.

We need your help. – what do you like about being in MASS? What is important about being a Self-Advocate? How would you explain what we are to someone who had never heard of us? Please think about this yourself, or with your local group, and send MASS your answers to the newsletter, or to your regional board representative.

**Thank you**

# ADAPT ACTIVISTS BEGIN THIRD DAY OF PROTEST AT DEMOCRATIC NATIONAL HEADQUARTERS

Washington, DC - As dawn breaks in the nation's capitol, approximately 30 disability rights activists, most with disabilities, from ADAPT continue their vigil on the sidewalk surrounding the headquarters of the Democratic National Committee (DNC).

On Tuesday, July 21, 2009, in 25 cities across the nation, ADAPT groups took their message to Democratic Party offices and its leaders. Forty ADAPT members in Washington, DC protested in the DNC headquarters, and were physically removed by law enforcement from the building at approximately 6:00 PM, although no arrests were made.

The protesters were demanding that the Democratic National Committee:

1. Apologize for creating Medicaid's institutional bias which has forced millions of seniors and individuals with disabilities needlessly into nursing facilities and other institutions;
2. Issue a public statement calling for elimination of the institutional bias in 2009 either as part of healthcare reform or as separate legislation, known as the Community Choice Act (S 683/HR1670); and
3. Facilitate a meeting between ADAPT and Democratic leaders, including Representative Henry Waxman, Senator Max Baucus, and Valerie Jarrett of the White House to develop a plan to pass the Community Choice Act.

In most cities, the Democratic committees agreed to relay ADAPT's demands to the DNC. In some cities, the staff committed to working with ADAPT to influence the leadership of the DNC to support ADAPT's goals. "Our state party leaders really worked with us to identify how they could help us influence the national leadership," said Nadina LaSpina, an ADAPT organizer in New York City.

However, in our nation's capital, the DNC still refuses to meet any of ADAPT's demands. During the vigil's second day, ADAPTers chanted and distributed informational materials. "We even were able to meet with Members of Congress right here on the street who expressed interest in becoming co-sponsors of the Community Choice Act," said Cassie James, an ADAPT organizer from Philadelphia.

As darkness fell, the vigil continued and many of the protesters went to sleep in reclining lawn chairs and sleeping bags, some in tents and others under a lean-to constructed from PVC pipe and plastic tarps in front of the DNC. Several large banners throughout their sidewalk encampment show the group's support for the Community Choice Act.

The ADAPT members in Washington, DC are committed to maintaining their presence in front of the DNC offices in an attempt to pressure Democratic leaders to work with ADAPT to discuss plans to pass the Community Choice Act.



## MRS SPEAKS OUT UPDATE

(September-November)

We are having our meetings two times each month. We have been busy. We have a few new members in our group.

Mary Jo and Liz, from the Regional Training Department gave us training in "Diversity" and "How to Run a Meeting". We had a good time, fun, and we laughed a lot at the training. We learned a lot about different people from around the world like Haiti, Africa, Jamaica, Puerto Rico, Peru, and Australia. Everyone was given a Diversity book and a certificate. We had a nice lunch with macaroni & cheese, salad, lasagna, chips & salsa, rolls, soda, and apple pie for dessert. We also celebrated 3 birthdays: Geralyn, John, and Michael.

On November 15th, many members went to Annual Massachusetts Advocates Standing Strong Conference in Worcester. There were a lot of people at the conference.

We had a good time; we made some new friends. There was music in the afternoon. There were workshops about Abuse Awareness, Dating, and Housing. Commission Howe spoke at the conference.

Some members went to a training given by the Erica, from the League of Women Voters held two meetings to talk about the election. We talked voting, the candidates, and the questions. Most members of MRS Speaks Out voted on November 4th.

*Submitted by Tom, Scott, and Karen*

# THANK YOU • THANK YOU • THANK YOU • THANK YOU

I use the state's PCA(Personal Care Assistant) program for my support staff. This means I am the boss and have to do my own hiring. Recently I advertised for a new person in the paper.

A lot of people answered by calling my number. With the bad economy, a lot of people thought \$10.84 an hour sounded good.

As always many of the people sounded really good, and were ok with down sides of the job. Several prospects were no longer interested when they heard I needed to get o Whitinsville once a month, and that the PCA program did not reimburse for gas and mileage.

Of the rest, I made interview appointments with about 25 of them.. Some people showed up late for their interview, one person showed up 2 hours early (which is as much a problem for me, as being late is ) A couple smelled heavily of cigarettes (even though they told me on the phone that they didn't smoke). Some more people called to cancel, because they changed their mind. Others just didn't show. A couple of people talked down to me. Some people started trying to rearrange my schedule before they had the job.

It became clear to me that being a direct care worker sounded like an easy gig for a lot of people who didn't have the maturity or job readiness skills to get and keep other jobs

SO:

To all the hard working staff who show up.. Every day. On time. And help us live our lives with respect and affection, and even go the extra m and even go the extra mile to do things on their own time because they want to see us succeed. - I say, **"thank you!"** on behalf of us all.

I.

PS I did finally find a driver, and still prefer to be my own boss even with all the work an employer has to do..

*Do you know someone friend, family, staff who did something special for you?*

*Write to us and tell us about it.*

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## M.A.S.S. Schedule for Regional Meetings

REGION	DATE	TIME
West	First Tuesday	6:30 PM – 8:00 PM
Central	Second Tuesday	5:00 PM – 7:00 PM
Southeast	Second Thursday	6:00 PM – 8:00 PM
Metro	Third Thursday	6:00 PM – 8:00 PM
Northeast	Third Wednesday	6:30 PM – 8:00 PM

## DO YOU (*REALLY*) KNOW WHO YOUR LEGISLATORS ARE?

Remember all that hoopla back in November? All the excitement and commercials and news time. That's right, the elections We turned out and voted.

Well, that was not only for the president of the United States. (Barack Obama won, in case you hadn't heard)

Many places also voted for state legislators. We were able to change the name because we developed good relationships with our state reps and state senators. Hopefully you thanked those people by voting for them.

Of course, yours wasn't the only vote. If we are lucky, the "good guys" who support our movement are still there on Beacon Hill. If not, then it is VERY important that you go and create a new, powerful relationship with whoever is now in office (maybe they're "good guys", too)

**FIND OUT** who is now representing your district and go tell them about MASS and your life.

### There are 3 easy ways to find out who won the November elections

- (1) Call the *town Clerk's Office* in your town. They are used to people calling and asking this question, so don't feel embarrassed.
- (2) Call the *State House* directly – 617 – 722 – 2000 and ask for the Division of Elections
- (3) Go on the *web* at [www.wheredoivotema.com](http://www.wheredoivotema.com) you will find a place where you just type in your address and zip code, and they will list ALL the political positions for your area both state and federal and even some positions you probably didn't even know existed



## THE OLMSTEAD DECISION

In 1995, Lois Curtis and Elaine Wilson, two self-advocates just like us, were living in a state hospital. In Atlanta, Georgia They wanted to leave and live in the community. Everyone agreed they were ready to do that, but there were no spaces open in their DDS programs. They were told they had to continue living in the hospital. Did that stop them? No, it did not! They fought back. They sued the state of Georgia for not putting enough money into their community support programs. They said it was the law under the Americans with Disabilities Act to put them in a hospital when they didn't need it. Their lawyers directed the lawsuit at Olmstead, who was the head of Georgia's Human Resources Department (like our Health and Human Services program) So the name of the case was "L.C. and E.W. versus Olmstead" We usually call it "Olmstead" for short.

The first judge who heard the case agreed with the women - yippee, hooray- but the State of Georgia appealed the case (they asked for another judge to decide) This time the case went all the way to the US Supreme Court. This was important because decisions at the Supreme Court can affect the laws in the United States and then.... The Supreme Court agreed that Title 2 of the ADA guaranteed people with disabilities to receive help in the "most integrated"; least restrictive setting. And because it was the Supreme Court saying so about a law that already existed, all states are supposed to be spending more money on housing, agencies, transportation, Dayhab, and employment services., so that no person with a disability has to live in an institution, unless they want to.

(Hooray!! Yippee!! lots of dancing and celebrating )

*Lois and Elaine moved into their own apartments are very happy.*

# PRESIDENT OBAMA'S GOALS TO EMPOWER PEOPLE WITH DISABILITIES

*(Taken From Disability Issues Winter 2008 –2009)*

When Barack Obama was running for president , he made a lot of promises about what he would do to improve the lives of PWD (people with disabilities).

Now that we voted him into office we have to make sure that his administration keeps those promises. Here are some goals to watch out for. and for you to choose to follow up with your federal senators (Kerry and Kennedy) and your congressmen (different people depending on where you live) We've seen what persistent lobbying can do – we changed the name at the state level!- so lets put our experience to work

- (1) **Universal Genetic Screening** all states will test infants for 29 disorders
- (2) Supporting the **Genetic Information Non-discrimination Act** this act will prohibit employers and health insurance companies from using the above information to discriminate against people.
- (3) Guaranteeing **Health Care Coverage** for PWD who lose their Medicaid when they get a job, but still don't make enough money to pay for health insurance they can get a subsidy to help afford it. This plan also prevents insurance companies from denying coverage for pre-existing conditions.
- (4) Strengthen Specialty care in **the Veteran's Administration** improved services for Traumatic Brain Injury and Post-Traumatic Stress Disorder as well as Spinal Cord Injuries ,and other issues
- (5) **Transportation** increasing options for accessible transportation **for PWD**
- (6) **Autism** funding for services, research and treatment development
- (7) Support the **Fostering Independence through Technology Act** which offers 21st century solutions like home monitoring and communications

You may not like all of these goals, choose the ones important to you, and –fight on!

*Q Who Runs MASS?* ? ? ? ? ? ? ? ?

*A Actually, YOU run MASS. Many people think Ed Bielecki, our state coordinator, makes all the decisions and sets the direction for MASS but the Board of Directors, all the people you vote for as your regional representatives, hire Ed to help them carry out what they want to do. And the regional reps bring back the ideas and desires YOU have.*

*There are a million and two things MASS could work on to make your life better. Changing the Name was only the first goal MASS developed when we first got together 10 years ago. We've worked on lots of other, smaller improvements along the way, and now we want to make sure we are going after the fights that are important to you( better jobs, relationships, transportation, what? ) We really want to know from you. Talk it over in your local groups, think about it the next time you get frustrated. You can let us know here, at the newsletter, or email Ed directly(mass1998@earhlink.net), or tell your Board rep at the regional meeting. You've learned not to let others make decisions for you about your life, now, don't let others make decisions about your organization*



# **MASSACHUSETTS ADVOCATES STANDING STRONG**

*Our Mission is to empower self-advocates through education so we make choices that improve and enrich our lives.*

## *What we believe:*

- **Everyone has the same rights.  
Rights and responsibilities go together.**
- **Everyone should be treated equally.**
- **People should have the same opportunities to make their own decisions and choices.**
- **People should have the support they need.**
- **Everyone is important.**
- **We speak out for ourselves and each other.**
- **We stand by each other and make things better in our lives.**

# SAVE THE DATE!



The 12<sup>th</sup> Annual

M.A.S.S. STATE SELF-ADVOCACY CONFERENCE

will be held on

## November 21, 2009

At the Crown Plaza in Worcester Massachusetts

RETURN SERVICE REQUESTED

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