

AccessLetter

Cambridge Commission for
Persons with Disabilities

MAME Advocates Fight for Access to Meetings

What happens when you make a routine request for a disability accommodation (to which you are legally entitled) and are denied? What do you do when, after appealing the denial, that appeal is first rejected, then your rebuttals ignored, for *five years*? Many of us would just give up. But a small, yet tenacious international advocacy group based in Salem, Massachusetts stuck with the process, and provides a positive example of diligent advocacy resulting in a good ending.



Chronic Fatigue Syndrome (CFS) is the name that is commonly used to refer to Myalgic Encephalomyelitis. MAME (Mothers Against Myalgic Encephalomyelitis) is an umbrella group which advocates not only for people with CFS (PWCs), but also for people with related conditions such as Fibromyalgia and Multiple Chemical Sensitivity.

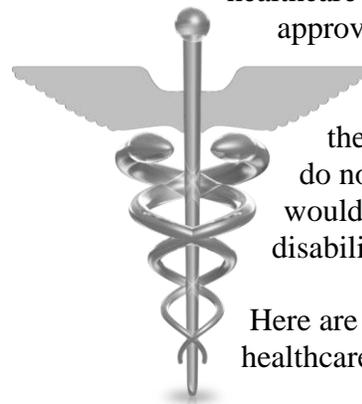
Most PWCs have major mobility and attention-span deficits; most are physically unable to travel to Washington to participate in the quarterly meetings of the CFSAC (CFS Advisory Committee – the committee that makes recommendations to the Secretary of Health and Human Services regarding research and treatment for CFS), and very few are able to sit through a 15-hour meeting held over two days, or to absorb much content if they did.

Yet CFS activists are a rich source of information and resources which would be a real asset to the CFSAC. PWCs are also highly motivated to find effective treatment for their illness. So PWCs and their

(More on MAME Advocates, page 2)

Healthcare Reform: What does it mean for people with disabilities?

As this issue of *AccessLetter* was going to press, a healthcare reform bill was nearing approval in Washington D.C. Amid all the emotional debate and rancor over the legislation, many people do not understand what this bill would mean to people with disabilities and chronic illnesses.



Here are some key elements of the healthcare overhaul legislation:

- Every American will be required to have health insurance
- Individuals unable to afford coverage will receive a subsidy
- Health insurance companies will no longer be able to deny coverage to people with “pre-existing conditions”
- Health insurers will no longer be permitted to cancel coverage for individuals who become sick or disabled
- The Medicare Part D prescription drug coverage gap, often called the “donut hole”, will be phased out over time
- Annual dollar caps and lifetime coverage limits on health insurance claims will be eliminated

Watch for full-length articles on healthcare reform in future editions of *AccessLetter*.

MAME Advocates (cont.)

advocates need to know what is discussed at the CFSAC meetings, to both hear what happens there and contribute to the process. But the CFSAC had never made accommodations for PWCs to attend their meetings.

MAME President Jean Harrison says, "It would be like having the committee that oversees blindness research not providing meeting materials in Braille."

In June 2004, MAME officially requested reasonable accommodations so that PWCs could be included in CFSAC meetings. Since accommodation of people with disabilities is clearly required by Section 504 of the Rehabilitation Act of 1973 (a precursor to the ADA), MAME's request should have resulted in a fairly simple, swift administrative procedure of arranging for the CFSAC meetings to be videotaped and made available either via mailed DVD copies, or via videostreaming over the internet. But the CFSAC refused to accommodate the very people they purport to represent.

In December 2004, MAME filed a formal complaint with the Office of Civil Rights (OCR), the agency that is set up to enforce Section 504.

Finally, in January 2005 (perhaps spurred to action by MAME's OCR complaint), the CFSAC discussed MAME's request. However, it was clear they did not intend to make the accommodation and even brought in a lawyer who fabricated reasons to deny the request. Harrison said, "The reasons given were bogus -- they said they were not required to accommodate us, that taping would disrupt the meetings, might cost too much, and would jeopardize the privacy of people attending the meeting. But the National Institutes of Health (NIH) was already videocasting several other committee meetings at that time."

The OCR denied MAME's complaint. MAME board member (and former board member of the CCPD) David Peterson said, "We were shocked. This is like having been mugged on the street, then going to a policeman who in turn says that the mugging was perfectly legal."

So then MAME rebutted the OCR's denial. By law, the OCR is required to respond to rebuttals within 180 days. But after *three years*, there was still no official response, nor did OCR acknowledge emails or phone calls asking for a response.

Peterson said, "It was not a fair fight -- dozens of able-bodied, salaried government civil servants on the one side, a handful of severely disabled people with limited time, mobility, and resources on the other." Harrison added, "We were not asking for anything special -- we were asking only that existing laws be obeyed."

Movement finally came in April of 2009, when CFSAC was placed under the leadership of Dr. Wanda K. Jones, Deputy Assistant Secretary for Health. MAME member

Pat Fero says, "We told Dr. Jones about our case. She agreed that accommodations *must* be made, and that there was no excuse for the OCR to have ignored us. She then went directly to the OCR with our paperwork in hand and, as a result, videocasting was set up within a few days."

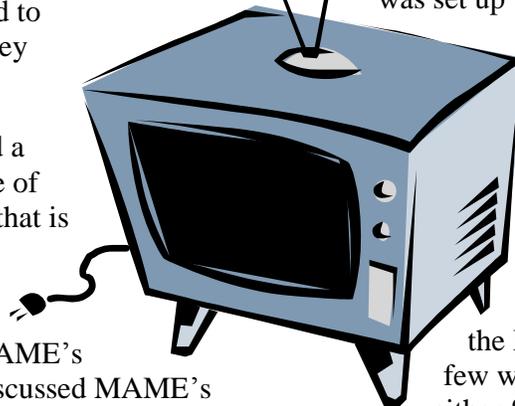
These meetings are now archived on the NIH website so that PWCs all over the world can view what happens at the meetings, and thus contribute their comments, suggestions, ideas, and resources.

Nearly 2000 people watched the video of the May 27-28, 2009 meeting within the first few weeks; thousands more have watched since, either from the NIH website or from copies on YouTube. The videos can also be viewed by CFS researchers, friends and family members of PWCs who might not be disabled but are unable to attend the CFSAC due to other commitments. Dr. Jones has pledged that *all* future CFSAC meetings will be videocast and archived.

After years of grassroots advocacy, one more Federal agency has been brought into compliance with disability law, and as a result the CFSAC will be able to benefit from the participation and feedback from PWCs all over the world.

For more information: MAME (Mothers Against Myalgic Encephalomyelitis)

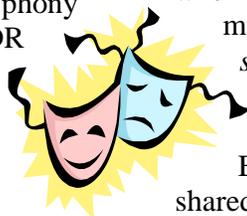
President: Jean Harrison (jeanharrison@mame-net.org)



LOL!

Traversing the Great Divide of Laughter

A few weeks ago, my comedy troupe at Emerson College was asked to perform at an all-troupe show on campus with a “Valentine’s Day” theme. Well, Valentine’s Day also happened to be Presidents’ Day, which was great luck for us. We came up with a phony eHarmony ad featuring Abraham Lincoln and FDR as a devoted couple, accomplishing both themes in one awesome video. Yet when it came time to have our actors play their parts, we realized that having FDR in a wheelchair (which we did) and having Abe Lincoln playfully push him down the hall to “This Will Be” (which we also did), might come across as offensive. How far is too far when humor touches on a sensitive issue like disability?



For many people, comedy is all about context. A disability-related joke shared between people who share similar lifestyles (a group of deaf friends, for example), might be appropriate in that situation, but what happens when a nondisabled individual steps in and tries to tell it? The same joke has suddenly changed from funny to infuriating. We can probably assume that, as long as there’s no malicious intent on his or her part, the nondisabled person was trying to relate to this particular group of friends. Maybe they are someone’s clueless

blind date (yikes!). The intention, whatever it was, is lost in the jarring realization that certain people can’t joke about certain things.

Is this fact divisive, or does it help unite the disability community in some way? For me, it’s always been both.

Nondisabled people will most likely feel out of the loop when such a joke is told in a social setting; their inner monologue probably goes something like this:

should I laugh? If I do (or don’t), is that rude? Should I repeat this joke to others, and if so, to whom? Why did I wear this awful shirt?

But for the individual with a disability who shared the joke and other disabled people around them, this type of humor might encourage camaraderie and effectively “lighten the mood.” After all, life’s no fun unless you can laugh at yourself from time to time.

Laughter should unite people, not divide them. In a perfect world, no one would ever be offended by jokes – in other words, *everything*, even ideas, would be accessible. For now, we (both joke-tellers and joke-listeners alike) must find ways of sharing humor without objectifying any group or individual in a way that can be seen as hurtful. It’s a difficult task, but in our journey to achieve it we may find new ways of joking – of *communicating* – with one another, so that everyone can laugh free of impunity.

-- Opinion by Emily Kane

Upcoming Events of Interest to the Disability Community (See end of Calendar for all weekly/recurring events)

- Apr. 1-30 **NY PORTRIATS, a Photographic Exhibition of Artists with Disabilities in New York City** – this exhibition by Gordon Saski, who himself has a disability, will be on display at the VSA Arts of Massachusetts’ (VSAM) *Open Door Gallery*, 89 South Street, Boston, from January 15-April 30, 2010. For more information, contact VSAM at 617-350-7713 (voice), 617-350-6535 (TTY), 866-552-4796 (Videophone), or see <<http://vsamass.org/gallery.php>>.
- Apr. 8 **Cambridge Commission for Persons with Disabilities (CCPD) Monthly Meeting**—meets on the 2nd Thursday of each month at 51 Inman Street, 2nd floor Conference Room, 5:30 to 7 p.m. with opportunity for public comment. Call 617-349-4692 or email <kthurman@cambridgema.gov> for more information.
- Apr. 13 **When Do We Start to Have Fun? The Pursuit of Leisure** – This event sponsored by the Northeast Arc is an opportunity to learn about recreational activities that are accessible to people with disabilities. There will be representatives from Partners for Youth with Disabilities, Northeast Arc Recreation, YMCA, Outdoor Explorations, and occup. therapist Madelyn O’Reilly. This event is being held at the Northeast Arc, 6 Southside Road in Danvers. Registration required, Cost is \$5, but funding is available. For more information or to register, contact Maria Maniaci at 978-624-2340 or by email at <mmaniaci@ne-arc.org>.

- Apr. 14 **DBSA Presentation: “Recovery Learning Communities: Vital Resource, Place of Transformation and Good Neighbors”** – free presentation by Chuck Weinstein, LMHC, NCC, who is the Director for the Metro Boston Recovery Learning Community. Presentation is from 7 p.m. to 8 p.m., followed by a discussion until 9 p.m. at the Depression Bipolar Support Alliance meeting at McLean Hospital. See DBSA listing under Wednesday recurring events for details.
- Apr. 27 **Turning Three workshop in Boston** – Sponsored by the Federation for Children with Special Needs, this free workshop provides information for parents about the process of transitioning a child from Early Intervention to publicly funded preschool. Discussion includes the required Early Intervention transition planning steps, eligibility for special education, the Team process and the parent’s role in planning, making decisions and monitoring progress for their child. The workshop will be held at the Children’s Hospital Pavillion Dining Room, 300 Longwood Ave, 6:30 p.m. to 8:30 p.m. Pre-registration is required; call 617-236-7210 or register online at <<http://fcsn.org>>.
- Apr. 27 **Showing Your Work: A Clinic on Spaces and Approaches for Studio Artists, a workshop for artists with disabilities** – Sponsored by VSA Arts of Massachusetts (VSAM) and the Museum of Fine Arts, the goal of this workshop is to help participants think about how to best present their work professionally. This is a brown bag dinner with the time to be determined, and will be held in the Community Room on the 1st floor of the NonProfit Center, 89 South Street in Boston. Registration is \$20 and is required no later than April 23. For more information, including a list of presenters, or to register, contact VSAM at 617-350-7713 (voice), 617-350-6535 (TTY), 866-552-4796 (Videophone) or see <<http://vsamass.org>>. For information on financial assistance, contact Bonnie Kaplan at <bsk@vsamass.org>.
- Apr. 28 **DBSA Presentation: “Transcranial Magnetic Stimulation for the Treatment of Depression”** – free presentation by Oscar G. Morales, M.D., Associate Director, Psychiatric Neurotherapeutics Program at Harvard Medical School, from 7 p.m. to 9 p.m. at McLean Hospital. See DBSA listing under Wednesday recurring events for details.
- Apr. 29 **The Do-It-Yourself Guide to Creating Housing Options** – a four-part series of workshops focusing on helping parents explore ways to create supportive living arrangements for their adult children with disabilities. There will be guest speakers and participants will brainstorm together about the steps that need to be taken. The workshops will be held on Thursday, April 29, May 6, May 13 & May 20 from 7-9:00 p.m. at the Family Resource Center, 34 Gould Street in Reading. Registration is required and there is a \$20 fee for the series. Contact Michelle Faugno at 781-942-4888, x4018 or <mfaugno@themark.org>.
- Apr.29-May 1 **Inspiring Minds: Meet Women in Science** – This event is being held at the Museum of Science (MoS) at 9 a.m. on April 29 and 30, and at 10 a.m. on May 1 and is included with Exhibit Halls Admission. Several accomplished women will be present to share their experiences in fields ranging from archaeology and astrophysics to neurobiology and weather forecasting. Guests can also try out experiments at the MoS Technology Tables. For more information, including a list of the scientists and their professions, see <www.mos.org> or call 617-723-2500.
- May 1 **Murderball, another FREE movie presented by Disability Reframed: a Community Film Series** – This documentary about world-class rugby players who smash their wheelchairs into those of their opponents in pursuit of victory is full of action, drama and comedy. In their own words: “We’re not going for a hug, we’re going for a [expletive] gold medal.” Screening and discussion with a guest speaker following the film is from 2 p.m. to 5 p.m. at the Citywide Senior Center, 806 Massachusetts Ave in Central Square, Cambridge. This is a free public event; bring your friends. The site is wheelchair accessible. No need to RSVP. For questions, contact the Cambridge Commission for Persons with Disabilities (CCPD) at 617-349-4692 (Voice), 617-492-0235 (TTY) or <kthurman@cambridgema.gov>.
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- May 12 **DBSA Presentation: “Seasonal Affective Disorder”** – free presentation by David Mischoulon, M.D., Ph.D. from 7 p.m. to 8 p.m., followed by a discussion until 9 p.m. at the Depression Bipolar Support Alliance meeting at McLean Hospital. See DBSA listing under Wednesday recurring events for details.
- May 13 **Cambridge Commission for Persons with Disabilities (CCPD) Monthly Meeting**—meets on the 2nd Thursday of each month at 51 Inman Street, 2nd floor Conference Room, 5:30 to 7 p.m. with opportunity for public comment. Call 617-349-4692 or email <kthurman@cambridgema.gov> for more information.
- May 26 **DBSA-Boston’s Annual Creativity Forum** – members read from their prose and poetry at the Depression Bipolar Support Alliance meeting at McLean Hospital. See DBSA listing under Wednesday recurring events for details.

Weekly & Recurring Events

Ongoing by Appointment

Free Tax Preparation – The Cambridge Economic Opportunity Committee will provide free tax preparation by appointment. They can arrange to meet with you at your home if you are unable to come to their office in Central Square. They also help with signing up for MassHealth and food stamps, offer free financial education, literacy courses, and assistance in paying owed rent and utilities. For more information or to make an appointment, call 617-868-2900 or see <<http://ceoccambridge.org/>>.

Injured Worker Support Meetings – (*previously listed as RSI – repetitive strain injury*) Meetings are scheduled by appointment, often the 1st Wednesday of the month, 5:15 - 6:45 pm. Meetings/appointments usually take place at 650 Beacon Street, Kenmore Square, Boston, 4th Floor Conference Room. Volunteers provide resources and support. For more information or to set up a meeting, call 617-247-6827, or go to <www.rsiaction.org>.

Mondays

NAMI Connection – a support group for adults with mental illness, meets every Monday, 1-2:30 p.m. at the Cambridge Somerville Recovery Learning Community, 153 South St, 2nd Floor in Somerville. The group is free and open to all who self-identify as having a mental illness, regardless of diagnosis. For more information, contact Janel Tan at 617-863-5388 or <tanj@vinfen.org>.

Tuesdays

Boston Voice Users is a group for people who use speech recognition or dictation software. They meet 7:30 – 9:30 p.m. on the 2nd Tuesday of each month at MIT in Building 2, Rm.135. To find out more about meetings and discussions go to <www.bostonvoiceusers.org>.

Wednesdays

Access Advisory Committee to the MBTA meets 1 – 3 p.m. at the State Transportation Building, 10 Park Plaza, Boston, 2nd floor Conference Room #2 on the 4th Wednesday of each month. Call 617-973-7507 voice or 617-973-7089 TTY or email <aact@ctps.org> for more information or to request interpreters. Security measures require proper ID for access to meetings.

DBSA-Boston (Depression Bipolar Support Alliance of Boston) Support Group, (formerly known as MDDA, Manic Depression & Depressive Association) meets every Wednesday evening, 7 - 9 p.m. at McLean Hospital in Belmont (de Marneffe Building, 1st floor lobby). Includes a lecture on the 2nd and 4th Wednesdays. Call 617-855-2795 or see <www.dbsaboston.org> for more information.

Feeling for Form Introductory Tour of MFA for blind & low vision visitors – The Museum of Fine Arts (MFA) in Boston offers a series of introductory one-on-one guided tours to the Museum and its collections for blind and low vision individuals who want to build a deeper relationship with the Museum. Each monthly session focuses on a different collection and includes wayfinding and verbal description of spaces. These tours are given on the 1st Sunday of the month at 10:30 am and the 3rd Wednesday at 6:30 pm. Individuals can attend one or more sessions, whichever interests them. Guided tours can also be scheduled at other times. Pre-registration is not required unless a visitor needs a sighted guide or other access accommodation. Contact Valerie Burrows at 617-369-3302 or <vburrows@mfa.org> to register. Call 617-369-3189 or email <access@mfa.org> or go to <www.mfa.org> for more information. The MFA is located at 465 Huntington Avenue in Boston, 02115 and is accessible by the Green line “E” train to the “Museum of Fine Arts” stop, or the Orange line train to the “Ruggles” stop.

Free introductory tour of MFA in sign language & with assistive listening devices – A new monthly offering at the Museum of Fine Arts (MFA) in Boston for people who are Deaf or hard of hearing. These tours will be given at 6:30 pm on the 2nd Wednesday of each month. No pre-registration is required; meet at the Sharf Visitor Center in the MFA. For more information about accessible programs Valerie Burrows at 617-369-3302 voice, 617-267-9703 TTY or email <access@mfa.org>.

Open Support Group for Adults on the Autism Spectrum – Meets on the 2nd Wednesday of each month, 7-8:30 pm at the offices of the Autism Association of New England (AANE), 85 Main St., Suite 101, Watertown, MA. Hosted by Jamie Freed; a \$5 donation is suggested. RSVP to 617-393-3824, x310 or <Jamie.Freed@aane.org>.

Rainbow Support Group for Adults with Developmental Disabilities – Funded by Massachusetts Advocates Standing Strong and the Department of Developmental Services, and hosted by Cambridge Family & Children’s Service (CFCS), this free group provides an opportunity for gay, lesbian, bisexual, transgender, and intersex individuals with developmental challenges to find their voice, be heard and supported in a safe, friendly environment. Participants must be at least 22 years old. Meets on the 3rd Wednesday of each month, 6:00-8:00 pm at CFCS, 60 Gore Street, Cambridge, which is accessible by taking the MBTA Green Line to the Lechmere station. For more information, contact Peter Montalto at <pmontalto@helpfamilies.org> or 617-876-4210, x122.

Senior Support Group for caregivers over 60 – meets on the 3rd Wednesday of each month at the Family Resource Center, 20 Gould Street in Reading. Share and learn with other seniors who have adult family members with developmental disabilities. For meeting times or more information, contact Judy SantaMaria at 781-942-4888, x4022 or <familysupport@theemarc.org>.

Thursdays

Autism Support Group – meets 3rd Thursday of each month, 6:30 – 8:30 p.m. at the Central Square Branch of Cambridge Public Library, 45 Pearl Street in Cambridge. For more information contact Lorraine Iacopucci at <liacopucci@nsarc.org> or 978-624-2304.

Cambridge Commission for Persons with Disabilities (CCPD) Monthly Meeting – meets on the 2nd Thursday of each month at 51 Inman Street, 2nd floor Conference Room, 5:30 to 7 p.m. with opportunity for public comment. Call 617-349-4692 or email <kthurman@cambridgema.gov> for more information.

DBSA-Boston (Depression Bipolar Support Alliance of Boston) Support Group, (formerly known as MDDA, Manic Depression & Depressive Association) at Mass. General Hospital meets every Thursday, 7 - 9 p.m. in the Schiff Conference Center Room, Suite 4A on the 4th floor in the Yawkey Building. Follow the signs. Meetings are free and open to public. For more information call 617-855-2795 or email <mghgroup@dbsaboston.org>.

“**Piecing the Puzzle,**” a **Parent to Parent Autism Support Group** – meets in Jefferson Park Community Room #1, at Jackson Place in Cambridge every Thursday from 10 am to 12 noon. Purpose is to provide support and understanding to families with children on the autism spectrum and to increase autism awareness in the community. Sponsored by Cambridge Family & Children’s Services in collaboration with the Dept. of Developmental Services (DDS). For more information or to become a member, contact Yevett Fraticelli at <piecing_the_puzzle@yahogroups.com> or 617-876-4210, x105.

Sundays

Feeling for Form Introductory Tour of MFA for blind & low vision visitors –These tours are given on the 1st Sunday of the month at 10:30 am. Pre-registration is not required for the Sunday tours unless a visitor needs a sighted guide or other access accommodation. See Wednesday listing for details.

Cambridge Commission for Persons with Disabilities

The Commission was established in 1979 to act as a clearinghouse on disability and access issues throughout the City of Cambridge. We strive to raise awareness of disability matters, to eliminate discrimination, and to promote equal opportunity for people with all types of disabilities – physical, mental and sensory. The Commission provides information, referral, guidance, and technical assistance to individuals and their families, employers, public agencies, businesses and private non-profit organizations.

The goal of our 11-member citizen advisory board, comprised primarily of individuals with disabilities, is to maximize access to all aspects of Cambridge community life. Our regularly scheduled Commission meetings, which always include an opportunity for public comment, are held at 5:30 p.m. on the second Thursday of each month.

Access Notice: The City of Cambridge and Commission for Persons with Disabilities do not discriminate on the basis of disability. This newsletter is available in e-mail, large print and other alternative formats upon request. To add your name to our mailing list, to inquire about alternative formats, or for information about other auxiliary aids and services or reasonable modifications in policies and procedures, contact CCPD.

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AccessLetter is produced by the Cambridge Commission for Persons with Disabilities,
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51 Inman Street, second floor, Cambridge, Massachusetts, 02139

We welcome your articles, comments, criticisms, and suggestions. Write us!

Read past issues on our website: www.cambridgema.gov/DHSP2/disabilities.cfm

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Cambridge Commission for Persons with Disabilities

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