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Electronic Newsletter
June 2011

Message from the Chairman:

Each year, April is Autism Awareness month and again this year we marked the month by gathering at the Massachusetts State House. AFAM sponsors this annual Autism Awareness Day to acknowledge the special efforts of special people, to talk about issues significant to our community, and to make our lawmakers aware of budget and legislative priorities that AFAM's member organizations believe are critical to individuals and families touched by an autism spectrum disorder. Advocacy is an ongoing process that I believe has taken on a heightened sense of urgency for our community. The numbers of individuals with ASD in need of services is growing and the funding budgeted by our state to serve those individuals is, for the most part, either status quo or being reduced. In short, we are fighting for a larger piece of a smaller pie.

While I admit my message to you may seem redundant, there is a good reason for repeating it often. The fact is, **your voice counts and you need to reach out NOW to your legislators to advocate for more funding that is critical for our community.** I am also urging you and all our members – self-advocates, families and friends impacted by ASD -- to reach out to the organizations and agencies that serve individuals with ASD and ask them what their vision is for people impacted by ASD. Where do they see their programs and the services they do or don't offer but should, in five years? In ten years? Are they prepared to serve the increased numbers of people with ASD who have already begun to age into the adult system? Equally important, you need to then ask *yourselves* what you can do to participate in helping them plan the future of the people you care about!

Michael J. Borr, Chairman
AFAM Executive Committee

Government Affairs Committee

Thanks to everyone who helped make ***Autism Spectrum Awareness Day*** at the State House on Thursday, April 14th such a success! It was wonderful to see so many families make the trip into Boston to come learn about our legislative priorities and go and meet with elected officials to press for more services for children and adults with Autism Spectrum Disorder. Special thanks to

WBUR's **Sacha Pfeiffer**, host of *All Things Considered*, for serving as our Emcee and to **The Massachusetts Developmental Disabilities Council (MDDC)**, **The May Institute**, and **Autism Speaks, New England** for sponsoring the refreshments at the event.

Congratulations to our **legislators of the year**, State Rep. Ellen Story and State Senator Steve Tolman. We greatly appreciate their commitment to the autism community.

The **budget process for Fiscal Year 2012** is ongoing. We are pleased that there is increased funding for the DESE/DDS program which provides funding for children with severe disabilities requiring intensive supports to continue to live at home. The Governor and House proposed \$6 million, an increase of \$2.5 million for this program. The Senate appropriation was for \$4 million. Fortunately, the amendment for an additional \$2.5 million for the program proposed by Senator Clark passed. It also contained language which requires DDS to fully expend the entire amount appropriated as intended. The House budget appropriated \$3.0 million for the for the line item for the Division of Autism including the Children's Autism Medicaid Waiver Program The Senate budget appropriation did not include the \$500,000 increase and amendment to increase the appropriation filed by Senator Creem did not pass. Due to the different appropriations, the matter will now be decided in Conference Committee. A Senate budget amendment to increase funding for the Day Habitation program by \$4 million passed. An amendment proposed by Senator Rodrigues to restore a significant portion of the \$14 million in Family Support funding cut by the Senate failed. The Senate's figure for Family Support is \$9 million less than what was proposed by the House. Due to the different appropriations, the matter will now be decided in Conference Committee. An attempt to increase funding for the Day and Employment Line Item by \$1 million did not succeed in the Senate. AFAM will continue to keep you updated on budget developments as work begins in the Conference Committee. It is still possible to make improvements to the line items. Please take a moment to read all of the AFAM Alerts and make calls to elected officials when asked to do so.

Ann Guay, Co-Chair
Government Affairs Committee

Insurance Committee

I was recently asked to present an update on ARICA to the Governor's Special Commission Relative to Autism. Highlights from the presentation "Early Returns – The First 100 Days" were as follow:

- Implementation is ongoing at a pace that is consistent, or perhaps a bit faster than the experience in other states that have enacted similar laws
- Consumers and providers have lots of questions:
 - Covered treatments
 - Credentialing procedures for insurance companies
 - Co-pays, deductibles
 - Medical vs. Educational

Some of these questions are starting to get clarified, others are raising need for further discussion. My summary observation is that, based on the early returns, ARICA is working pretty much the way it was intended. As with any new legislation, there are some “square pegs and round holes” that we will be continuing to resolve.

For people whose insurance policies are not subject to ARICA (mainly self-insured or “ERISA” plans), we have been working hard on outreach to advocate for employers to include this coverage in their 2012 plans. If you are interested in more information and assistance, please contact us.

For people who have Mass Health, even though Mass Health is not subject to ARICA there are many ways to access some of the treatments in ARICA. One avenue is to purchase a private insurance policy through the Premium Assistance Program. It is important to note that the **Commonwealth Choice Open Enrollment period runs from July 1-August 15**. Further information can be obtained from our FAQ sheet, and we are happy to assist with questions.

By the end of June we will have provided over 20 training sessions across Massachusetts to numerous groups and organizations. We will not be holding any trainings in July and August, but the Autism Insurance Resource Center is working on a webinar that will be rolled out during this time frame. We will resume trainings in the Fall – if your group is interested, please contact us.

Amy Weinstock, Chair
Insurance Policy Committee

Adult Services Committee

AFAM’s Adult Services Committee asks for your help with a “mission critical” project that will benefit you and others in our community. If you are a young adult (14 years or older) or an adult with ASD, AFAM needs your participation in a broad-based survey to help us:

- document how many individuals over 14 have been diagnosed with ASD in Massachusetts;
- understand what supports young adults may need, especially when they finish school;
- advance understanding of both the similarities and differences of needs within our community;
- increase AFAM’s ability to advocate for the most appropriate services; and
- expand awareness and support for ASD among lawmakers, service providers, and affiliated groups within Massachusetts.

The survey, which you can find on our website (www.afamaction.org) just takes about 10 minutes to complete and it will help us tremendously in our advocacy efforts. Thank you so much!

This spring we welcomed new members to AFAM’s Adult Services Committee. We have been fortunate to be joined in our work by Martha Ziegler, long time advocate, Chapter 766 pioneer and the mother of an adult daughter on the spectrum, David Specht who until his recent retirement was the long-time director of Community Resources for People with Autism in Easthampton, and

Anke Kriske, who represents the Autism Society of America, Massachusetts Chapter on AFAM's Executive Committee and is the mother of a teenage son with autism.

Over the summer we will continue to follow the work of the Autism Commission and share information with the working group/subcommittee on adults on the spectrum, which is chaired by Ann Guay and Dave Harmon, and look forward to its recommendations for ways in which Massachusetts can better meet the needs of adults with ASDs.

Thanks to a grant from the Danny Foundation, we are planning a legislative briefing for the early fall where we can report the results of our survey and continue to educate state representatives and senators about the needs of adults with ASDs in Massachusetts.

As always, please share your stories, experiences, and ideas with us about the ways in which we can advocate for young people and adults across the spectrum and change the landscape for their futures in our state. We can be reached via email at office@afamaction.org. (Please note in the subject line that you would like the email to be directed to the Adult Services Committee.)

Chris Hubbard, Chair
Adult Services Committee

News and Announcements

The Asperger's Association of New England has moved to a new location: 51 Water Street, Suite 206, Watertown, MA 02472. Phone and fax numbers are unchanged.

The Asperger's Association of New England, in cooperation with MGH YouthCare and UMass Medical Center, are combining resources to address a poorly-understood aspect of living with Asperger Syndrome in a conference on **Sexuality, Relationships, and Asperger Syndrome**. The conference will be held on Friday, June 10 & Saturday, June 11 at the LaCava Center at Bentley College (175 Beaver Street, Waltham). Registration is limited, so contact AANE as soon as possible. Phone 617-393-3824 or email Lisa Graffeo (lisa.graffeo@aane.org).

SNCARC Family Autism Center will be starting a Bike Club in June for individuals ages 12 and over. Participants must bring a bicycle and a helmet of their own to the club and be able to balance, pedal, and have the basic skills involved in riding a bike. (Training wheels are okay!) RSVP is a must, and a parent or caregiver must stay with the participant during the club. The SNCARC Bike Club will meet on Monday evenings from 6:00 to 7:00 p.m., June 13th-September 19th at their facilities located at 789 Clapboardtree Street in Westwood. Please contact Betsy Roche eroche@sncarc.org or 781-762-4001 Ext. 310 for more details. You must register in advance to participate.

The final session of the **Lurie Center/LADDERS of MGH Program's 2010-11 Roger A. Bauman Parent Lecture Series** will take place on Thursday, June 16 from 6:30 to 8:30 p.m. in the Paul D. Merritt Building at the Charles River Center (59 E. Militia Heights Road, Needham (located at the top of Dwight Road, off Central Street)). The topic is "Comorbidities and Autism Spectrum Disorders," presented by Dr. Gagan Joshi, Psychiatrist, MGH Bressler Clinic. To register, please

contact Julie O'Brien, Family Support Clinician, LURIE CENTER LADDERS of MGH for Children at 781-860-1726 or jobrien20@partners.org This is the last program of the 2010-11 series. The program will resume again in September.

The Asperger's Association of New England is having a yoga fundraiser, **Get Down (dog) with AANE**, on Saturday, June 11 from 5:00 to 6:30 p.m. at Jai Yoga (871 Washington Street, 3rd Floor, in Braintree. The class will be taught by Brian Culkin, owner of Jai Yoga. All proceeds will benefit AANE programs and services. For information, contact AANE (617-393-3824).

The May Institute is hosting an **Open House for Professional Educational Advocates** on Thursday, June 23 from 9:30 a.m. to 12:30 p.m. at the 41 Pacella Park Drive in Randolph. Topics will include how to access autism services through the ARICA insurance coverage law, and an overview of the National Standards Project, which identifies treatments shown to be effective for individuals with autism spectrum disorders. Lunch will be served. If you wish to attend, you must contact Jen Charron at jcharron@mayinstitute.org or 781-437-1248 by June 6.

Family Autism Center will host a **car wash** on Saturday, July 23 at 399 Neponset Street in Canton, MA from 11:00 a.m. to 2:00 p.m. All proceeds will benefit FAC's participation in The Rodman Ride. Come out, get your car washed, and show your support for Family Autism Center!

Join **Family Autism Center** at Showcase Live in Foxboro for "**1964**" **The Tribute** on Friday, August 19. "1964" The Tribute takes their audiences on a musical journey to an era in rock history that will live in all of our hearts forever. They are hailed by critics, fans, as well as prestigious publications such as Rolling Stone Magazine, as the #1, the most authentic and most popular Beatles tribute on the planet. Purchase a ticket through Family Autism Center and they will receive a portion of each ticket sale. Ticket includes a light dinner (Chicken skewers, crudites platter, mac and cheese balls, taquitos) before the show. Raffle prizes and silent auction items will be available as well. Tickets are \$45.00 each. Please contact Betsy Roche to purchase tickets eroche@sncarc.org, 781-762-4001 Ext. 310. All proceeds from this event will benefit Family Autism Center's participation in The Rodman Ride for Kids. We look forward to seeing you there!

AANE's Annual Conference for Adults with AS will take place on July 23 in Boston, with keynote speaker Rudy Simone. For further information, call 617-393-3824.

The Autism Alliance of MetroWest and the **Autism Support Center** are sponsoring **Especially for Me! Free Evening at the Discovery Museums for Families with Children on the Autism Spectrum** on Saturday, August 6 from 5:30 to 8:30 p.m. Come join the fun at the Discovery Museums (located at 177 Main Street/Route 27 in Acton) during this special free evening for families with children on the autism spectrum. Please contact Amy Spencer at : aspencer@discoverymuseums.org or 978 264-4200 ext 28 for more information or to register for the event.

AANE's Cape Cod Summer Conference for Educators, Professionals and Parents will be held on Thursday, August 11 at the Cape Codder Resort & Spa in Hyannis. This year's theme is "Practical Solutions for Addressing the Behavior Needs of Individuals with asperger Syndrome," with keynote speaker Brenda Smith Myles, Ph.D. For further information, call 617-393-3824.

Community Autism Resources will hold its annual **Hearts & Hands Walk for Autism** (as well as a Family Fund Day) on Saturday, September 24 from 9:30 a.m. to 1:30 p.m. at Bristol Community College. The event raises funds to help support families in the everyday challenges of living with ASD. Community Autism Resources provides FREE services to children and adults with ASD and their families in the South Shore, Cape Cod and Islands, and most of the southeastern region of Massachusetts. For more information, visit their website: www.community-autism-resources.com

The Autism Consortium is offering a free resource, **Transitioning Teens with Autism Spectrum Disorders: Resources and Timeline Planning for Adult Living**. It is available as a download on the Autism Consortium's website: <http://www.autismconsortium.org/empowering-families/transitioning-teens-with-autism-spectrum-diso-2.html> (There is a link on the right side of the page to download the whole thing.)

Research Study

The Wall Lab at Harvard Medical School has created a shortened diagnostic survey. Because autism varies widely in severity, making an accurate diagnosis can be difficult. Autism can be diagnosed through the use of a behavioral exam named the "Autism Diagnostic Interview – Revised" or ADI-R. However, because this survey is long – it has 93 questions and can take up to 2.5 hours to complete – the diagnosis process can be prohibitive.

We have designed a substantially shorter exam of 7 questions that we believe may be as effective as the ADI-R at diagnosing autistic children. Should this prove to be true, our exam would help healthcare providers diagnose autistic children more rapidly and enable children to receive valuable therapy that is more in tune with the timing of their development and more likely to have a positive outcome. One big way to determine if our abbreviated exam *is* effective is to get your help.

If you are a care provider for a person with autism, your answers to the few questions in the survey will tell us whether our exam actually works. The survey can be accessed at <http://autworks.hms.harvard.edu/community/survey>. We greatly appreciate your help!

For additional announcements, please visit the websites of our Founding Organizations

Autism Support Center
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www.ne-arc.org/autism

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car@community-autism-resources.com www.community-autism-resources.org

Autism Society of America, Massachusetts Chapter
47 Walnut Street
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asamasschapter@hotmail.com www.massautism.org

Community Resources for People with Autism
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