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Electronic Newsletter
December 2017

Message from the Chairman:

A year ago, the message I wrote expressed the concern that many of us in the autism community felt in the wake of the presidential election. Like many of you, I was worried by the rhetoric expressed by the president-elect during the campaign. At the same time, I also noted that my own “years of experience as a political junkie have taught me not to hit the panic button. Often a candidate's rhetoric changes when faced with the realities of actually holding office and governing.” I went on to “urge all in our community to remain calm and wait to see the actual policies he and his administration put in place.”

Perhaps I was excessively optimistic. What we have witnessed in the past 12 months is certainly concerning as it potentially affects vulnerable populations – not just those in the disability community but millions of others who believe that government has a crucial role to play in creating and sustaining opportunities for everyone. As the parent of an adult son with autism, I am well aware that so much of the supports and services for individuals with ASD are in part funded by federal monies. Not only the president and his administration but many in Congress have different ideas that I believe many negatively impact Medicaid, special education, and existing tax policies that help those whose families include a person with disabilities.

What that means is that it's more important than ever for us – AFAM -- to be vigilant and prepared to advocate for those policies that will support the people we love and who are in most need of help. We need *your* help to do that! The fact is, the success of our advocacy on behalf of those with ASD requires not only dedicated volunteers and committed grass-roots advocates, but funding as well. We are dependent on the generosity of individuals and families – people like you and me -- to enable us to continue our vital work.

Please support us! Your contribution of time or dollars, both equally important, are vital to making sure the voices and interests of individuals diagnosed with an autism spectrum disorder are considered by those in government.

With best wishes to you and your family a happy and safe holiday season!

Michael J. Borr, AFAM Chairman

Adult Services

AFAM's Adult Services Committee is comprised of three task forces. Here is an update on their work:

The **Housing Task Force**, chaired by Karen Mariscal, is focusing its advocacy on the passage of Senate Bill 2132 (formerly Senate Bill 729). This bill, which is one of AFAM's legislative priorities this year, encourages the development of housing for people with disabilities, including autism, and the elderly by permitting the construction of two bedroom accessory apartments as of right (i.e., not requiring a variance or special permit) in cities and towns in Massachusetts.

Sponsored by Senator Barbara L'Italien, Senator Jason M. Lewis, Rep. Jack Lewis, Rep. Denise Provost and other legislators, the bill has been heard by the Joint Housing Committee and is now being considered by the Senate Rules Committee. As the bill moves through the legislative process, the AFAM Housing Task Force will join others, including Autism Housing Pathways and ArcMass, in contacting legislators to advocate for its passage. Please watch for legislative alerts on AFAM's *Facebook* page so you can join in this advocacy and contact your legislator with a request to pass Sen. Bill 2132.

The **Task Force on Day Habs and Community Based Supports**, currently, is closely following changes underway at MassHealth. Many adults with autism rely on MassHealth funding for their healthcare and/or long term services and supports (LTSS) such as day habs and other day programs. MassHealth traditionally has paid healthcare providers on a fee-for-service basis for each visit, procedure, or test. This can result in uncoordinated care and high costs. In March 2018, MassHealth is launching a new system of provider-led organizations called Accountable Care Organizations, or ACOs. These entities are provider led organizations that coordinate care, have an enhanced role for primary care, and are paid based on care outcomes verses the volume of services provided. In addition, MassHealth is making changes to its managed care organization (MCO) program to align with these new goals. These new entities will work with Community Partners, community-based organizations that provide care coordination to ACO and MCO members. To make this happen, MassHealth negotiated a new 5-year "1115 Medicaid Waiver" with the federal government. The waiver includes \$1.8 billion of investment over 5 years to fund this historical restructuring of the way MassHealth works. Changes integrating LTSS into this new system will be rolled out in the next two to three years. The AFAM Task Force has offered and will continue to offer stakeholder comments to MassHealth as this process unfolds.

The Task Force also will offer comments on the "Chapter 115" regulations that the Department of Developmental Services is finalizing with respect to the implementation of Positive Behavioral Supports in DDS day and residential programs. We will provide updates to our autism community about this significant revision and updating of DDS regulations.

The **Task Force on Employment** advocates for an increase in paid employment opportunities for people with autism in Massachusetts, exploring ways to encourage adoption of creative public and private strategies to enhance job training, job development and employment opportunities. The

Task Force is in need of a Chair to guide its efforts. In the meantime, the current members of the Task Force are joining AFAM and ArcMass in advocating for a Supplemental Budget that addresses the \$20 million cut in funding for DDS day and residential programs in the FY 2018 budget (this year's budget). Please join in this advocacy by sending your stories of need for employment supports for people with autism to afamoffice@yahoo.com.

During this giving season, we wish to thank all of our Task Force members for giving of their time, skills and efforts to advocate on behalf of adults with autism in Massachusetts. We wish them, you and all of our families the joys of the season in this mission!

Chris Hubbard, Chair

Government Affairs:

AFAM's Priority Legislation and Policy Advocacy Continues

Hearings have taken place for two of AFAM's top priority bills and the third hearing is due to be scheduled soon. We are hopeful that Inclusive Concurrent Enrollment Initiative (ICEI) will be passed favorably out of the Joint Committee for Higher Education shortly after the New Year. Stay tuned to AFAM's social media for more updates. As we reported in September, our Accessory Housing Units legislation has passed favorably out of the Joint Committee on Housing and is currently being reviewed by the Rules Committee, chaired by Senator Montigny. AFAM is answering questions and advocating for the need for housing creation for people with autism directly with this committee staff.

Our bills have great support from the AFAM community as well as support within the State House and through our partner organizations such as The Arc, Autism Housing Pathways, and Massachusetts Advocates for Children.

AFAM is prepared to testify for Police Training in Autism and will have a panel with the Director of the ALEC (Autism Law Enforcement Coalition) program of The Arc of South Norfolk as well as parent, self-advocate and parent/professional testimony.

AFAM has provided in-person testimony for numerous bills over the years. Planning for hearings involves building panels to testify in front of the Joint Committees. These panels are made up of experts on the bill from many different perspectives. AFAM tries to include a self-advocate, a legislative sponsor, and if possible a community leader. It is important to give the Joint Committee's a wide perspective on the bills. AFAM uses and submits research, searches and prepares for any opposition, and provides written testimony collected from additional stakeholders.

Other bills that will enhance the lives of people with autism and their families that are currently well positioned in the legislative process are; Nicky's Law, Dental Access, Loan Repayment, Hospital Training in Autism, Operation House Call and Prompting and Cueing. Contact Maura Sullivan for more information on AFAM's legislative and policy effort and/or other autism related legislation at sullivan@arcmass.org.

AFAM also has the opportunity to advocate on a policy level for regulatory changes and rate issues. AFAM attends Autism Commission and other agency meetings and provides comments that will influence policy. Recently we have been involved in the stakeholder commentary process for the Positive Behaviors Support regulatory revisions. Important to our testimony is explaining how policy affects families. AFAM appreciates hearing from our community in regards to programs and services. Your stories are the most powerful tool we have to influence policy and legislation.

To learn about our policy advocacy or more about our priority bills, call or email Maura Sullivan at 781 891-6270, ext 113 or sullivan@arcmass.org

SAVE THE DATE! Join us for AFAM's Annual **Autism Awareness and Acceptance Day** at the State House on **Thursday morning, April 12, 2018** from 9:30 to 11:30 a.m. AFAM would like this information posted to everyone's webpages and social media sites as soon as possible.

Watch for details after the new year.

Lift a glass for Autism Awareness: Another way to support AFAM

Looking for a way to shop for gifts (or do some personal shopping) without having to head to the mall? Here's a convenient way to purchase high-quality, attractive wines -- and support AFAM at the same time! With Christmas, Hannukah, and Kwanzaa just around the corner, this is a timely offer.

In cooperation with Benefit Wines, we are offering 6 different varieties of AFAM-branded wines in various packages -- for example, you can choose a red wine package, a white wine package, or a sampler package of 4 or 6 wines, and you can even create your own of 4, 6, 8, or 12 bottles. A portion of your purchase price comes to AFAM and helps fund our ongoing advocacy on behalf of people on the autism spectrum and their families. For more information, visit our website (www.afamaction.org) or order online at BenefitWines.com/AFAM.



The Autism Insurance Resource Center will present a program on **ABA for Adults – Opportunities and Challenges** as part of its series on **Current Developments and Trends in Insurance Coverage for Autism Treatments**, on Thursday, December 7 from 8:30 to 11:00 a.m. at the UMass Medical School (55 Lake Avenue North, Faculty Conference Room S1-342, Worcester). **Please register** by sending an email to audrey.huntley@umassmed.edu
Directions to UMASS Medical School: <http://disabilityinfo.org/ARICA/pdfs/UMass-campus-directions-with-map.pdf>

Join **Autism Connections** for a **Sensory-friendly performance of A Christmas Carol**, on Wednesday, December 13 at 7:00 p.m. at the Colonial Theater (111 South Street, Pittsfield, MA). Tickets for this special performance only are discounted at \$5.00! Please contact Erica.donovan@pathlightgroup.org for further information.

The Family Resource Center of Northeast Arc is offering a **Free Advocacy Workshop: Special Education Basic Rights** on Wednesday, December 20 from 9:30 to 11:30 a.m. at the Northeast Arc Center for Excellence (6 Southside Road, Danvers). Learn about Special Education Laws, Principles, and the Process. Registration is required! To sign up, please contact Karen Bartlett (kbartlett@ne-arc.org or phone 978-624-4317).

The American Repertory Theater (A.R.T.) is offering a **Sensory-Friendly production of Charlotte's Web** on Friday, December 29 at 2:00 p.m. The theater is located at 64 Brattle Street, Harvard Square, Cambridge. It is accessible to persons with special needs and to those requiring wheelchair seating or first-floor restrooms. Environmental adjustments to the show include:

- house lights will remain dimmed during the performance, rather than completely off
- the volume of the performance will be reduced
- a staffed “quiet area” will be available in the lobby for those who need to take a break
- there will be a relaxed and inclusive atmosphere where patrons can enter and exit the theater freely during the performance
- trained volunteers will be on hand to assist with patron needs
- tablets and smartphones will be permitted to help non-verbal children communicate

For further information or to book tickets, contact A.R.T. Ticket Services by phone at 617-547-8300, by email at ticketsservices@amrep.org, or online at americanrepertorytheater.org/access

Save the Date! Stepping Out for Autism will present “A Night at the Museum” – a benefit for **Autism Connections** on January 27, 2018 at the Museum of Springfield History. The event begins at 6:00 p.m. and includes cocktails, dinner, music and dancing, live and silent auctions, and an exploration of all of the museum’s exhibits, which will be open to all attendees. For more information, call 413-529-2428.

Congratulations to Richard Serna, Associate Professor of Psychology at UMass Lowell, who has received a \$250,000 grant from the National Institute of Mental Health to address the acute need for professionals trained in the most effective treatment for children with autism spectrum disorder – behavioral intervention. Serna is collaborating with Associate Professor **Charles Hamad**, a UMass Medical School psychologist, to develop the new training tool. The software will

feature a virtual child, programmed with learning difficulties associated with ASD, who can interact with people training in behavioral intervention techniques.

The Friends of Lurie (the Lurie Center for Autism) present **Coffee Convo**, a presentation and discussion series held on the 3rd Wednesday of the month from 6:30 to 7:30 p.m.

Here are the programs that have been scheduled for December, January, and February:

December 13, 2017: Attend our Lurie Land Party for Patients and Families

January 17, 2018: "Microgila and Autism: So What?" Presented by Staci Bilbo, Ph. D.

February 28, 2018: "Vocational and Career Opportunities Across the Spectrum." Presented by the MGH Aspire Internship Team

Registration is required: Email: LurieCenter@partners.org or call 781-860-1700

For more info about the Lurie Center, visit www.luriecenter.org

Tempus Unlimited (formerly Cerebral Palsy of Massachusetts) has an **Augmentative Communications Support Program** that **funds iPad for consumers**. While MassHealth does cover iPad for individuals with autism who meet their medical necessity criteria, we want to call your attention to this alternative source of funding for AAC devices. For more information, please call 800-924-7570 or visit www.tempusunlimited.org

The Massachusetts General Hospital Lurie Center is offering a series of small-group informational workshops for parents, caregivers and families about **Understanding the Guardianship Process in Massachusetts**. All sessions will take place at the MGH Lurie Center (1 Maguire Road, Lexington). Please Note: These workshops are provided by a parent/professional, are **not** intended to provide legal assistance or advice, rather they are informational only. Referrals to legal experts are provided as needed.

The first series, **Guardianship 101: Learn the Basics of the Guardianship Process**, provides an overview of what guardianship is and how it is determined in Massachusetts; the types of guardianships (including limited, Rogers); how to decide if your child needs a guardian and alternatives to consider; a review of how to begin the process and what the Massachusetts probate court requires; the steps you need to follow and a suggested timeline to prepare for your child turning age 18. Guardianship 101 is offered on the first and third Friday of most months, from Noon to 1:00 p.m. The fee: is \$20 per person/family. Registration is required: phone 781-860-1700.

The second series, **Guardianship 102: Learn the Step-by-Step Process for court required Paperwork**, offers a more hand-on group tutorial and will include: where you are in the process and moving forward; a review of relevant checklists for each attendee; guidance with probate court processes and referral to legal resources as needed; guidance on filling out required documentation (petition, bond, citation/giving notice, care plan); and a question and answer session. Guardianship 102 is offered on the second and fourth Thursday of most months from 11:00 a.m. to 12:30 p.m. The fee is \$50 for individual/family for regularly scheduled group time; \$100 for individual appointments. You must specify at the time you call.. Registration is required: phone 781-860-1700.

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

Autism Support Center
6 Southside Road
Danvers, MA 01923
978-777-9135

www.ne-arcautismsupportcenter.org/

HMEA's Autism Resource Central
71 Sterling Street
West Boylston, MA 01583
508-835-4278
Sloring@HMEA.org

www.autismresourcecentral.org

Autism Connections
116 Pleasant Street, Suite 366
Easthampton, MA 01027
413-529-2428
karen.serra@pathlightgroup.org

www.autismconnectionsma.org

Family Autism Center
789 Clapboardtree Street
Westwood, MA 02090
bclark@arcsouthnorfolk.org
781-762-4001

www.arcsouthnorfolk.org/family-autism-center.html

TILL's Autism Support Center
20 Eastbrook Road, Suite 201
Dedham, MA 02026
781-302-4600
Lisa.Connor@tillinc.org

www.tillinc.autism_support.html

Autism Alliance of MetroWest
1881 Worcester Road
Framingham, MA 01701
508-652-9900
ADaigle@advocates.org
PMcKillop@advocates.org

www.autismalliance.org

Doug Flutie, Jr. Foundation
P. O. Box 767
Framingham, MA 01701
508-270-8855
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617-357-8431
Jlandau@massadvocates.org

www.massadvocates.org

Autism Speaks, Inc. - New England Chapter
85 Devonshire Street, 9th Floor
Boston, MA 02109

617-726-1515

www.autismspeaks.org

Charles River Center
59 E. Militia Heights Road
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781-872-1000
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www.charlesrivercenter.org

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Visit our website: www.afamaction.org

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