



217 South Street  
Waltham, MA 02453  
781-891-6270, ext. 102

[www.afamaction.org](http://www.afamaction.org)    [office@afamaction.org](mailto:office@afamaction.org)

Electronic Newsletter  
March 2017

### **Message from the Chairman:**

As we approach the end of winter, I'm sure you are delighted by how well we fared this season -- compared to two years ago when we were dealing with towering snow mounds. With the coming of spring, we are getting ready to host our annual Autism Awareness and Acceptance Day at the Massachusetts State House. This year we will gather in the Great Hall at the State House on Monday, April 10th. The theme of the program is "**Advocacy Across the Lifespan.**"

As a parent of an adult son with ASD, I'm sure that most other parents have had that anxious experience of accessing services for your loved one and the potential challenges that presents. This year, AFAM will take advantage of Autism Awareness and Acceptance Day to showcase to you and our elected officials some of the challenges facing families. We will also present AFAM's legislative and budget priorities to support and assist families and individuals touched by autism who seek to access services and supports for both children and adults. Most importantly, it is your opportunity to speak to your elected officials and tell them about your hopes and dreams for your loved one in regard to a broad range of services and supports. Please join us on April 10th for this extremely important day of lobbying at the State House. While we have accomplished a lot in past years, our work is just beginning. Please help us, yourselves and your loved ones in this effort!

Michael J. Borr, AFAM Chairman

### **Autism Awareness and Acceptance Day 2017**

Please join us on **Monday, April 10** in the Great Hall of the State House for AFAM's annual advocacy day. The theme of this year's Autism Awareness and Acceptance Day is **Advocacy Across the Lifespan**. The program will focus on the many issues confronting people of all ages with autism and their families and the critical role *you* can play in advocacy. State Representative John Scibak will be the recipient of the "Distinguished Legislator of the Year" award. The event begins at 9:30 a.m. and includes light refreshments. At the end of the program (around 11:30 a.m.), you'll have time to visit your own legislators to encourage them to support legislation and funding for services that help individuals on the spectrum and their families. Advance registration is not required. Visit our website [www.afamaction.org](http://www.afamaction.org) for updates on the program.

## **AFAM's Bill Priorities 2017-18**

### **1. Housing (Accessory Apartments) SD585/HD986**

*Senator Barbara L'Italien*

*Representative Kevin Honan*

An Act relative to accessory dwelling units. For legislation relative to the development and preservation of affordable housing for persons with disabilities and the elderly; is designed to encourage creation of long-term housing stock for people with disabilities and seniors in the form of 2-bedroom accessory apartments.

### **2. Inclusive Concurrent Enrollment SD931/HD456**

*Senator Barbara L'Italien*

*Representative Sean Garballey and Representative Pat Haddad*

An Act related to higher education for persons with autism and other intellectual or developmental disabilities. This bill allows persons with autism or I/DD to access the Commonwealth's state colleges and universities to gain skills necessary to work and live as independently as possible as adults.

### **3. Police Training in Autism HD2107**

*Senator Jennifer Flanagan*

*Representative Kimberly Ferguson*

An Act related to criminal justice training regarding autistic persons. This will require training of law enforcement officers and correction officers in the Commonwealth in appropriate interactions with persons on the autism spectrum, and also shall develop guidelines for law enforcement response to individuals on the autism spectrum who are victims or witnesses to crime, or suspected or convicted of crime.

## **AFAM's FY'18 Budget Ask**

**There are 37,000 individuals and families on the Dept. of Developmental Services (DDS) caseload. Families are the largest group of caregivers. Family support, Turning 22 and related supports comprise a lifeline for these families and their loved ones.**

- Families are our greatest asset, representing 60% of individuals served yet just 3.5 % of the budget
- Caregiving can mean 24/7 support, giving up jobs and can affect the entire family
- With meaningful supports, families who have loved ones with autism can remain together and part of their community

**AFAM requests that the House and Senate accept Governor Baker's Turning 22 proposal in its entirety. As the graduating classes have grown from 630 in 2010 to 975 in 2018, no new formula was set for those turning 22 years old who need DDS assistance, forcing families to leave jobs and few opportunities for young adults. The House and Senate revised the**



investigate the range of services and supports necessary for them to achieve their full potential across the lifespan. Issues to be investigated include those related to public education, higher education, job attainment and employment, including supported employment, provision of adult services, post-secondary education, independent living, community participation, housing, social and recreational opportunities, behavioral services based on best practices, to ensure emotional well-being, mental health services and issues related to access of families of children with autism and adults who are from linguistically and culturally diverse communities.

The Commission is also required to investigate the prevalence of autism over the last 30 years and to develop “plans of action” to address the needs of individuals with autism for employment and housing respectively.

In addition to considering new recommendations, the Commission is required periodically to report on the progress of implementing the 13 recommendations from the 2013 Report. The Commission is expressly required to report each year to the Governor, the Legislature’s Joint Committee on Children, Families and Persons with Disabilities and the Legislature’s Joint Committee on Healthcare Financing with respect to unmet needs and trends in autism services, supports and treatments, including recommendations for regulatory and legislative action to provide or improve such services. Here is the link to the Commission’s Report filed in December 2016, which describes the work of the Commission since its convening in September of 2015 and the status of action on the recommendations from the 2013 Report as of December of last year: [December 2016 Report](#).

The Commission is comprised of 35 members. These members include members appointed by the House and Senate, Secretary of Education, commissioners of a number of state agencies, and 14 members appointed by the Governor. Advocates of Autism of Massachusetts is one of the organizations which has a statutorily designated representative on the Commission. Christine Hubbard currently represents AFAM on the Commission. She can be reached through the AFAM office ([afam@yahoo.org](mailto:afam@yahoo.org)) if you have comments or concerns you want to bring to our attention. The names of all the individuals currently serving on the Commission are listed at page 2 of the [December 2016 Report](#).

The Commission is chaired by the Secretary of Health and Human Services, Mary Lou Sudders. The Commission is staffed by an executive director, Carolyn J. Kain, and two assistants. Ms. Kain can be reached at [carolyn.kain@state.ma.us](mailto:carolyn.kain@state.ma.us). Information about the Commission can be found on its webpage, [Autism Commission](#). Meeting schedules, materials presented at Commission meetings and other materials, and meeting minutes are posted there.

Much of the work of the Commission is being done through eight subcommittees: At the December, 2016 meeting of the Commission the Executive Director provided an update on the work of the subcommittees which includes the names of individuals who serve on the subcommittees and a description of the discussions that had occurred through December in subcommittee meetings. Here is a link to that Power Point presentation, “Sub-committee Work May 2016-December 2016,” which is posted on the Autism Commission website under the “Meeting Materials” for the December 13, 2016 Commission Meeting: [Subcommittee Update](#)

All meetings of the Commission and its subcommittees are open public meetings.

## **News and Announcements**

Join **Autism Housing Pathways** at **Dancing with the Celebrities, March 18<sup>th</sup>** "Celebrities" pair off with members of the MIT Ballroom Dance Team in a competition to support Autism Housing Pathways. MIT dancers will also perform showcase numbers, and lead a group lesson. There are also some opportunities for social dancing. Live and silent auctions, finger food, and a cash bar round out the night. Dancing with the Celebrities takes place at the St. Mary's Parish Hall in Winchester, Saturday, March 18th, from 7-9 pm. For tickets and more information, go to <http://autismhousingpathways.org/dancing-celebrities/>

**The Arc of Massachusetts and the Massachusetts Developmental Disabilities Council** will hold its **39<sup>th</sup> Annual Legislative Reception** on Monday, March 27 in the Great Hall of the State House from 10:30 a.m. to Noon. This year's theme is "Embracing Our Rights: It Takes All of Us."

**The Charles River Center** invites you to join them for their next **Wings for Autism** at Logan Airport on Saturday, April 1<sup>st</sup>, 2017 at 9:30 a.m. This event is FREE! The Charles River Center's **Wings for Autism** program is designed specifically for families with children with autism to help ease the stress of flying. At this free, half-day event, children and their families are able to familiarize themselves with airport and travel procedures. They experience: entering the airport; the check-in process and checking bags; security screening; boarding the plane; preparing for take-off; and exiting the plane.

**Registration is required!** <http://www.charlesrivercenter.org/what-we-do/wings-for-autism/>  
For additional information, please contact [wingsforautism@charlesrivercenter.org](mailto:wingsforautism@charlesrivercenter.org).

**Autism Connections** (previously Community Resources for People with Autism) will hold its **27<sup>th</sup> Annual Autism Conference** on Tuesday, April 11 at the Log Cabin in Holyoke, MA. Dr. Karen Levine, keynote speaker, will discuss her book *Attacking Anxiety*, a step-by-step guide to an engaging approach to treating anxiety and phobias in children with autism. The program also includes Ron Suskind, author of *Life Animated*, which was made into an Academy Award-nominated documentary. For further information and registration, visit their website: <https://pathlightgroup.org/programs-and-services/autism-connections/> or call 413-529-2428.

**HMEA** will hold its **3<sup>rd</sup> Annual Central Massachusetts Autism Summit** on Tuesday, April 11 from 8:30 a.m. to 3:15 p.m. at The College of the Holy Cross in Worcester. The theme of this year's summit is **Hire and Higher: Leveraging the 'Autism Advantage' to Meet the Region's Workforce Demands**. The event will focus on strategies for helping employers recognize that many individuals with autism possess unique and valuable skills that can allow them to be productive and successful in highly specialized positions. This is increasingly referred to as the "autism advantage" as it offers employers access to an expanded labor pool and a competitive differentiator in the marketplace. Keynote speaker is John Elder Robison, Neurodiversity Scholar in Residence at The College of William and Mary, who is author of some of the most widely read stories of growing up on the autism spectrum and living with Asperger's syndrome. The day's program includes speakers and workshops, as well as lunch. For more information and registration, visit [www.hmea.org/autismsummit2017](http://www.hmea.org/autismsummit2017) or call 508-298-1100.

**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 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 \$35 per person/family. Registration is required: phone 781-860-1700.

## **Research**

**Participants wanted for fMRI Study!** The psychology laboratory of Dr. Liane Young at Boston College is looking for participants aged 18 and up with autism spectrum disorder for a study that will help us understand how you perceive yourself and others. You will be asked to undergo an fMRI scan while reading stories and making judgments or decisions on a computer screen. The experiment will be conducted over two sessions, one at Boston College and one at MIT. You will be paid up to \$70 for participating in this study. Transportation costs will also be reimbursed. If you are interested in or have any questions about the study, please contact us at [lypsychlab@gmail.com](mailto:lypsychlab@gmail.com) or at (617) 552-0249.

**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/](http://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](http://www.autismresourcecentral.org)

Autism Connections  
116 Pleasant Street, Suite 366  
Easthampton, MA 01027  
413-529-2428  
[iris.scott@pathlightgroup.org](mailto:iris.scott@pathlightgroup.org)

[www.autismconnectionsma.org](http://www.autismconnectionsma.org)

Family Autism Center  
789 Clapboardtree Street  
Westwood, MA 02090  
[bclark@arcsouthnorfolk.org](mailto:bclark@arcsouthnorfolk.org)  
781-762-4001

[www.arcsouthnorfolk.org/family-autism-center.html](http://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](mailto:Lisa.Connor@tillinc.org)

[www.tillinc.autism\\_support.html](http://www.tillinc.autism_support.html)

Autism Alliance of MetroWest  
1881 Worcester Road  
Framingham, MA 01701  
508-652-9900  
[ADaigle@advocates.org](mailto:ADaigle@advocates.org)  
[PMcKillop@advocates.org](mailto:PMcKillop@advocates.org)

[www.autismalliance.org](http://www.autismalliance.org)

Doug Flutie, Jr. Foundation  
P. O. Box 767  
Framingham, MA 01701  
508-270-8855  
[info@flutiefoundation.org](mailto:info@flutiefoundation.org)

[www.flutiefoundation.org](http://www.flutiefoundation.org)

The Arc of Massachusetts  
P. O. Box 541603  
Waltham, MA 02454  
781-891-6270, ext. 102  
[arcmass@arcmass.org](mailto:arcmass@arcmass.org)

[www.thearcofmass.org](http://www.thearcofmass.org)

Massachusetts Advocates for Children  
25 Kingston Street. 2<sup>nd</sup> Floor  
Boston, MA 02111  
617-357-8431  
[Jlandau@massadvocates.org](mailto:Jlandau@massadvocates.org)

[www.massadvocates.org](http://www.massadvocates.org)

Autism Speaks, Inc. - New England Chapter  
85 Devonshire Street, 9<sup>th</sup> Floor  
Boston, MA 02109  
617-726-1515  
[Russ.Kenn@autismspeaks.org](mailto:Russ.Kenn@autismspeaks.org)

[www.autismspeaks.org](http://www.autismspeaks.org)

Charles River Center  
59 E. Militia Heights Road  
Needham, MA 02492  
781-872-1000  
[ekilicarslan@charlesrivercenter.org](mailto:ekilicarslan@charlesrivercenter.org)

[www.charlesrivercenter.org](http://www.charlesrivercenter.org)

The Arc of Bristol County  
141 Park Street  
Attleboro, MA  
508-226-1445  
mandrade@arcnbc.org

[www.arc.nbc.org](http://www.arc.nbc.org)

**Visit our website: [www.afamaction.org](http://www.afamaction.org)**