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Electronic Newsletter  
June 2017

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

All of us at AFAM were saddened to learn that DDS Commissioner Elin Howe will be retiring on July 17, 2017. During her 10 years in that vital position, she has been a stalwart supporter of services for people of all ages who are challenged by an autism spectrum disorder as well as other intellectual and developmental disabilities. Families have known that they could trust her to “fight the good fight” on behalf of their loved ones.

Over the past ten years, we have met with her on many occasions to discuss issues of great importance to the autism community. Her door has always been open, and she has not shied away from facing challenging questions. While we have not always agreed, we recognized early on that she brought compassion and integrity to her work. She embodies the best of public service, and does so with class and dignity.

We wish her well as she moves into a new phase of her life, and we thank her for all she has done to improve the lives of our loved ones.

Michael J. Borr, AFAM Chairman

### **AN URGENT MESSAGE TO PEOPLE WITH AUTISM AND THEIR FAMILIES FROM AFAM**

Do you or your loved one with autism depend on: A day hab program? Adult foster care funding? Home and community based waiver services from the MA DDS? Medical care and dental care from MassHealth? Residential services from DDS? SSDI payments? Children’s Autism Waiver services in your home? Special education services at your child’s school?

While these services are delivered to you by the State of Massachusetts or your city or town’s school district, they are funded in significant part by the Federal Government through Medicaid and other programs. The Federal Government contributes roughly 50 cents of every dollar Massachusetts spends on Medicaid services.

## **So you need to know what's happening in Washington, D.C.**

The House of Representatives recently passed the American Health Care Act (AHCA) (the bill to repeal and replace the Affordable Care Act (Obamacare)). According to the [Congressional Budget Office \(CBO\)](#), the AHCA:

- Slashes Medicaid funding by \$834 billion over the next decade and results in an estimated 23 million people losing their health insurance by 2026 due to higher premiums and a fundamental restructuring of the Medicaid program to block grants and per capita caps
- Shifts primary funding to states; will force state officials in Massachusetts to make difficult decisions regarding allocations of funding of care among multiple vulnerable populations (e.g., the elderly vs. the disabled)
- Increases insurance coverage rates for people with pre-existing conditions, including those with disabilities, resulting in loss of care for families who simply cannot afford high premiums
- Allows states to opt-out of funding essential health benefits, including rehabilitative and habilitative services and devices and preventative and wellness services on which our families rely

## **The devastating impact of what the bill proposes on our loved ones with autism and their families cannot be overstated! But that's not all!**

The budget plan just announced by the President proposes: an **ADDITIONAL \$610 billion** in Medicaid cuts; more than **\$70 billion in cuts to Social Security Disability benefits**; \$5.79 billion in cuts to the National Institutes of Health, the lead agency for federal research on autism; \$47 million in cuts at the Health Resources and Services Administration, eliminating all its autism programs, including training for health care professionals to screen and diagnose autism; and \$35 million in cuts to the National Center for Birth Defects and Developmental Disabilities, which leads the autism surveillance efforts at the Centers for Disease Control.

## **If these changes and cuts are adopted, Massachusetts will not be able to make up the difference!**

The Senate leadership is now working on changes to the House-approved version of the AHCA. The time for **action is now!** Here is what you can do:

**Call your Senators today (202-224-3121) and tell them to oppose cuts to Medicaid. Share personal impact stories about how Medicaid helps you and your loved ones. Reach out to friends and family in other states to call their Senators on your behalf. Thank you!**

## **Adult Services**

**We are looking for a pro-active, committed person to join AFAM's Adult Service Committee and head up our Employment Task Force**

Services for adults with autism exist in Massachusetts, but unlike school services, they are not mandated, and there are fewer of them. In light of the dramatic growth in the numbers of children with ASDs and the aging of these children into adulthood, *we are facing a crisis and advocacy is*

*essential*. The AFAM Adult Services Committee advocates to encourage Massachusetts to adopt a proactive strategy for developing community, residential and employment supports geared for adults with ASDs – those who are adults currently in need of such services and the hundreds of children with ASDs who will soon be reaching adulthood.

The AFAM Adult Services Committee consists of volunteers who are members of the AFAM Executive Committee and other self-advocates, parents, and professionals from across the state who are advocates for and providers of services to people with autism. AFAM has divided the Adult Services Committee into three task forces to advocate for housing, employment, and day hab and community-based day services and supports for adults with autism.

**What Does AFAM's Employment Task Force Do?** The AFAM Employment Task Force advocates for increasing paid employment opportunities for people with autism in Massachusetts by providing for a range of job training, job development and employment opportunities.

**The members of AFAM's Employment Task Force are:**

Brittany Collins, Doug Flutie, Jr. Foundation for Autism & Flutier Enterprises  
Jessica Flannery, sibling  
Anke Kriske, parent  
Michelle Labadini, parent  
Heather Lomartire, BCBA, Vice President of Employment and Day Supports, Charles River Center  
Eric Olson, parent  
Daphne Romanoff, parent  
David Rosenzweig, self-advocate

**What's Required of the Chair of the Employment Task Force?**

The Employment Task Force meets every month to six weeks, at the discretion of its Chair. Its meetings can be held in person at The Arc of Massachusetts offices in Waltham or virtually by teleconference (or a combination of both). The Chair is responsible for scheduling Task Force meetings, setting the meeting agenda in consultation with Task Force members, following issues concerning employment of people with autism at the state level, and reporting about the activities of the Task Force to the Chairs of the Adult Services Committee. Occasionally, the Chair may be asked to attend a meeting of the AFAM Executive Committee to discuss Task Force initiatives. Background knowledge about the employment situation for people with autism, state employment supports, and the state legislative and regulatory process would be helpful, but is not required. A passion for advocacy, a willingness to learn, and a pro-active attitude are required!

**If you are interested in taking on this opportunity to engage in and shape advocacy for employment for people with autism in Massachusetts, please email the AFAM office at [AFAMoffice@yahoo.com](mailto:AFAMoffice@yahoo.com).**

**Opportunity to Comment to the FDA**

The Food and Drug Administration (FDA) has announced an opportunity for public comment on Patient-Focused Drug Development for autism. Patient-Focused Drug Development is part of FDA's performance commitments made as part of the fifth authorization of the Prescription Drug User Fee Act (PDUFA V).

The comments are intended to allow the FDA to obtain patient perspectives on the impact of autism on daily life as well as patient views on treatment approaches for autism. In conjunction with this effort, a public meeting was held on May 4, 2017 at the FDA in Washington, D.C.

Comments must be submitted either electronically or in writing by **July 5, 2017**. See the SUPPLEMENTARY INFORMATION section of the FDA announcement document at [Details on Commenting](#) for details on how to file or mail a comment. See comments filed to date at [Comments](#).

### **Background:**

As part of Patient-Focused Drug Development, FDA will obtain input of patients and patient representatives on the symptoms of autism that matter most to patients and on current approaches to treating autism.

FDA has approved products for irritability related to autism including risperidone and aripiprazole. In addition to pharmacological treatments, behavioral and educational interventions are also common treatment options.

FDA is interested in the perspectives of patients with autism and caregivers on 1) symptoms and the daily impacts of their condition, 2) current approaches to treatment, and 3) decision factors taken into account when selecting a treatment.

### **Specific Questions posed by the FDA:**

#### **Topic 1: Disease symptoms and daily impacts that matter most to patients**

(1) Of all the symptoms that you/your child experiences because of the condition, which 1-3 symptoms have the most significant impact on your/your child's life? (Examples may include behavioral symptoms, difficulty with motor coordination, difficulty sleeping, difficulty concentrating, seizures, etc.)

(2) Are there specific activities that are important to you/your child but that you/your child cannot do at all or as fully as you would like because of these symptoms? (Examples of activities may include sleeping through the night, daily hygiene, eating, dressing, participation in sports or social activities, etc.)

(a) How do these symptoms and their negative impacts affect daily life on the best days? On the worst days?

(3) How has your/your child's condition and its symptoms changed over time?

(4) What worries you/your child most about your/your child's condition?

#### **Topic 2: Patients' perspectives on current approaches to treating**

(1) What are you/your child currently doing to help treat the condition or its symptoms?

(Examples may include prescription medicines, over-the-counter products, and other therapies including non-drug therapies such as behavioral interventions)

(a) How has your/your child's treatment regimen changed over time, and why?

(2) How well does your/your child's current treatment regimen treat the most significant symptoms of the condition?

(a) How well do your/your child's treatments address specific activities that are important to you/your child's daily life?

(b) How well have these treatments worked for you/your child as the condition has changed over time? Which symptoms are not addressed as well?

(3) What are the most significant downsides to your/your child's current treatments, and how do they affect your daily life? (Examples of downsides may include bothersome side effects, interacts with other medications, time devoted to treatment, etc.)

(4) What specific things would you look for in an ideal treatment for your/your child's condition?

(a) What would you consider to be a meaningful improvement (for example symptom improvements or functional improvements) in your/your child's condition that a treatment could provide?

(5) What factors do you/your child take into account when making decisions about selecting a course of treatment?

(a) What information on potential benefits of these treatments factors most into your/your child's decision?

(b) How do you/your child weigh the potential benefits of these treatments versus the common side effects of the treatments? (Common side effects could include headache, nausea, fatigue, weight gain)

(c) How do you/your child weigh potential benefits of these treatments versus the less common but serious risks associated with the treatments? (Examples of less common but serious risks are infections, organ damage or failure, suicidal thoughts)

## **Government Affairs**

AFAM is grateful to the House and the Senate for the FY 2018 budget and the support for persons with autism through the DDS line items. At press time, the budget is in Conference Committee.

AFAM's main budget priority is to support the Turning 22 line items and our graduates with autism through three other line items: Day/Employment, Residential, and Transportation. The goal of the funding is to address the needs of all students with autism who are turning 22 years old.

During Conference Committee budget negotiations, AFAM is strongly encouraging maintenance of the following line items to support families and individuals throughout the lifespan: Family Support, Autism Kids Waiver, DESE-DDS funding, and Adult Autism Omnibus.

AFAM is also advocating for the Adult Foster/Family Care program (Adult Family/Foster Care EHS 335 Line Item 4000-0601).

We are asking the Conference Committee to ensure rates for AFC are not lower than those in effect for fiscal year 2016. This program is a cost effective way to keep individuals with autism in our communities and thriving by supporting families and providing opportunities.

Lastly, we are moving quickly into hearings for our top three bill priorities. The bills include Inclusive Concurrent Enrollment Initiative, Accessory Units for Housing, and Police Training in Autism. Please be in touch with Maura Sullivan at [sullivan@arcmass.org](mailto:sullivan@arcmass.org) if you are interested in bill advocacy, providing testimony or testifying at the joint committee hearings.

### **News and Announcements**

**You can now make secure online donations to AFAM via PayPal! Just visit our website** ([www.afamaction.org](http://www.afamaction.org)) and click on the DONATE button.

**HMEA's Autism Resource Central** will hold its annual **Golf Tournament** on Friday, August 18<sup>th</sup> at the Cyprian Keyes Golf Club in Boylston, MA. The event will raise funds to support families in central Massachusetts with a loved one with Autism Spectrum Disorder. Registration is now open. You can register as an individual or as a foursome. If you don't have a team, they will match you with others to complete a foursome. Cost is \$125 per person or \$500 per foursome. Sponsorship opportunities are also available. For more information, call 508-298-1607 or visit their website: [www.autismresourcecentral.org/](http://www.autismresourcecentral.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 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.

**Six scholarship opportunities are available** for those diagnosed with Autism Spectrum Disorder! Black Wynn Personal Injury Lawyers, the Feldman Law Firm, the Kelly Law Team, the Law Office of David P. Shapiro, RJT Criminal Defense, and Dentistry by John Barras have each donated a \$1,000 scholarship to be used at any college or technical school within the United States. Applicants are encouraged to apply to each of the scholarships!. The application forms and further details can be found by visiting the scholarship links found below:

<http://www.bwphoenixpersonalinjurylawyers.com/2017-autism-scholarship/>

<http://www.afphoenixcriminalattorney.com/autism-scholarship>

<https://www.jkphoenixpersonalinjuryattorney.com/autism-asd-scholarship/>

<https://www.davidpshapirolaw.com/autism-scholarship/>

<http://www.sandiegocriminallawyerrt.com/2017-autism-scholarship/>

<http://www.johnbarrasdds.com/2017-autism-scholarship/>

Questions should be directed via email to Breanna Armour at [breanna@archesolutions.com](mailto:breanna@archesolutions.com)

## Research

**The Benson-Henry Institute for Mind Body Medicine at Massachusetts General Hospital is seeking participants for a research study: Resiliency Intervention for Parents of Children with Autism Spectrum Disorder.**

This is an 8-session, 1-1/2 hours a week virtual-delivery resiliency program for parents of children with ASD. The program teaches relaxation techniques, stress awareness, and problem-solving skills to help cope with the stressors of parenting children with ASD. Participants will receive up to \$40 worth of gift cards. If you join this study, you will be asked to participate in a virtual resiliency program and complete surveys to monitor your progress in resiliency training. If you are interested in participating or would like more information, please contact [ParentalStressStudy@partners.org](mailto:ParentalStressStudy@partners.org) or call 617-643-6036.

**The Center for Autism Research Excellence (CARE) at Boston University** invites your family to participate in our exciting studies for children and young adults (ages 4-21) with autism

spectrum disorders. Our Autism Center for Excellence Study is exploring the following research questions:

**Children 5-12 years old: Can a novel language intervention prove effective for minimally verbal children with ASD?**

**Adolescents 8-21 years old: Which brain systems might explain why some people with ASD do not acquire fluent speech?**

**All ages (4-21): What are the language, behavioral, and cognitive profiles of minimally verbal children and adolescents with ASD?**

We offer free parking and compensation for all your visits to our facility. Our staff members are committed to making your child's research experience fun! We make every effort to accommodate your family's schedule and your child's specific sensory and stress-reducing needs.

Contact us today to find out more! Contact Brittany Dorer at 617-358-5910 or email her at [care@bu.edu](mailto:care@bu.edu).

### **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  
[karen.serra@pathlightgroup.org](mailto:karen.serra@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  
PMcKillop@advocates.org

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

Doug Flutie, Jr. Foundation  
P. O. Box 767  
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508-270-8855  
info@flutiefoundation.org

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

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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

[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

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

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59 E. Militia Heights Road  
Needham, MA 02492  
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mandrade@arcnbc.org

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