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Electronic Newsletter
December 2009

Message from the Chairman:

Happy Holidays! As I review AFAM's activities over the last year, I am left with mixed emotions. On a positive note, we have made great progress in two areas where we have begun major initiatives. This past January we filed our first legislative initiative, H3809 - An Act Relative to Insurance Coverage for Autism (ARICA). Our thanks go to Representative Barbara L'Italien and Senator Fred Berry, great friends of our community, who sponsored the legislation. Amy Weinstock, chairperson, and her entire Insurance Committee deserve tremendous credit for their tireless work throughout the year as this bill makes its way through the legislative process.

Chris Hubbard, chairperson of our Adult Services Committee, as well as the rest of her committee are finalizing their work on a survey and paper on the state of adult services for people with autism in Massachusetts. We all owe a debt of gratitude to Amy and Chris, as well as their committees made up of parents, parent-professional, and professionals. These are all volunteers who give their time to help improve the lives of individuals impacted by an autism spectrum disorder and their families. Thank you!

I would be remiss if I did not talk about the substantial budget cuts faced by many of our member organizations who provide direct services to individuals with autism. Make no mistake: currently the autism community is under siege. Our thanks go to Leo Sarkissian, Executive Director of The Arc of Massachusetts, and Gary Blumenthal, Executive Director of Association of Developmental Disabilities Providers, for mobilizing the disability communities' responses over the past year to cuts announced by our state government.

All of the people I have mentioned are all only a small number of what makes up our community. To be effective, we also need your help. We all have busy lives and I appreciate the fact that many don't have the time or resources to give equally. I do ask that in this upcoming New Year, we all take a moment and think

about how we can contribute. Can we give money? Can we volunteer our time? Can we do something as simple as when we see an alert, pick up the phone and call five or ten friends and/or relatives and ask them to help? Please make a commitment to participate -- .we need you!

I wish all of you a happy and safe holiday season.

Michael J. Borr, Chairman
AFAM Executive Committee

Government Affairs Committee

During the month of October, a number of legislative hearings for key pieces of legislation designated as AFAM priorities were held on Beacon Hill:

H. 3809, An Act to Require Insurance Coverage for Autism

This bill requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of Autism Spectrum Disorder. A hearing was held on October 21, 2009. The Insurance Subcommittee has updated you on recent developments. I want to talk a moment to thank all of the parents and professionals who came to press conference, attended the hearing and gave testimony. Your efforts are greatly appreciated.

H. 3804, An Act Addressing Bullying of Children with ASD

This bill amends the Autism IEP Act to clarify that IEP teams must address bullying of children with ASD. A hearing before the Joint Committee on Education was held on October 20, 2009. Compelling testimony in support of the legislation was given by parents, professionals and an adult with Asperger's Syndrome. Additional support for why the legislation is so important was provided by the release of the report Targeted, Taunted, Tormented: The Bullying of Children with ASD by Mass Advocates for Children. The report summarizes the responses of more than 400 parents of children with ASD who completed an on-line survey about the extent to which their children were bullied in school. To view the report in its entirety, go to www.massadvocates.org.

S. 223, An Act to Improve Augmentative and Alternative Communication for Children with Disabilities

This bill will help to ensure that teachers receive training in AAC methods necessary to educate children with disabilities who are nonverbal or have limited speech. A hearing before the Joint Committee on Education was held on October 20, 2009. Parents, educators and a young man who is an AAC user testified in support of the bill.

We hope all of these bills will be reported out favorably from the committees to which they are assigned. AFAM will continue to keep you apprised of legislative

developments and reach out and ask for your assistance in garnering support to help gain passage of these important pieces of legislation in the coming months.

Ann Guay, Chair
Government Affairs Committee

Insurance Committee

Thank you to everyone who came out to support ARICA at our hearing on October 21, 2009. Our presence made a powerful impact on the legislators and our testimony was well received. We are hoping that the Committee rules favorably on our bill, but the timing of when this may happen is unclear at this time. We will be in touch in the interim if there are news updates or if we need direct response from all of you. In the meantime, please continue to remind your legislators that medical insurance for autism treatment is of critical importance to you and your family.

Below is an Opinion piece on ARICA by Doug Flutie which was published in the Boston Globe on October 17.

Amy Weinstock, Chair
Insurance Policy Committee

FILLING THE AUTISM VOID By Doug Flutie October 17, 2009

MASSACHUSETTS MAY have the best health care in the country, but it doesn't cover the treatment for the fastest-growing health threat to children - autism.

Autism affects brain function and impairs communication, social interaction, and sensory modulation skills. The most recent statistics show that 1 in 91 children has autism, with the incidence four times as high in boys.

More than 500 babies born this year in Massachusetts will soon be diagnosed with autism. What their parents will learn first - what my wife, Laurie, and I have learned from our son Dougie - is that while the hopes and dreams for their child may change, they will also intensify.

Parents will learn that, with early intervention, children with autism can make significant strides - a fact backed up by extensive studies. They'll find that their pediatricians and neurologists will prescribe intense one-on-one speech, occupational, physical, and behavioral therapies. And then they'll be dismayed to discover that, though they've always paid their health care premiums, their health plans will not cover these services.

Why don't health plans cover treatments for the fastest-growing health threat to children? There is a contradiction between the role of schools versus that of medicine and health plans. Federal law stipulates that schools provide services necessary to allow all children to "access the curriculum." While critical to helping children with autism excel in the classroom, this in no way replaces their need for therapy to improve long-term brain functioning - not only to get through an average day, but to lay the foundation for the rest of their lives.

School superintendents are powerful in asking health plans to step up to ensure that children with autism, like all others, are sent to school ready to learn. They expect health plans to provide glasses to students with poor eyesight, or even chemotherapy to children with cancer, so they have every right to expect that children with autism will receive out-of-school autism therapy.

Foundations like The Doug Flutie Jr. Foundation for Autism and Advocates for Autism of Massachusetts work hard to fill the gaps in services and opportunities for children with autism. We also work to make up for the absence of the lead player in supporting the treatment of any medical condition: health plans.

In the health plans' absence, parents are left to pay privately or see their children go without autism therapies.

Those of us who can afford it (comfortably or through extreme means) see the incredible difference these services make in our children's ability to communicate, learn, function as part of the family and the community, and simply stay safe.

Those who can't afford it face the pain of being unable to give their child services proven to radically improve their developmental outlook.

Autism coverage isn't just the right thing; it's the financially smart thing. This coverage will cost just \$2.28 per member per month. Alternatively, the average lifetime cost for an adult with autism is estimated at \$3.2 million. Research shows that with effective early intensive intervention, up to 47 percent of individuals can lead independent lives without state-funded supports. Additionally, they will each make an estimated \$1.7 million contribution as taxpayers, bringing the actual savings of autism coverage per person to \$4.9 million. While not all individuals will achieve this outcome, even moderate gains result in significant savings to taxpayers.

The Legislature is considering a bill that requires health plans to treat autism as a medical condition and pay for its treatments. Fifteen states have already passed similar legislation. This state needs to join them in ending insurance discrimination against people with autism.

Doug Flutie is a former professional football player and the cofounder of the Doug Flutie Jr. Foundation for Autism.

Adult Services Committee

As 2009 draws to a close, AFAM's Adult Services Committee is reaching a milestone. The committee is nearly finished its report on the current state of services for adults with Autism Spectrum Disorder in Massachusetts. The report will be presented to the Legislature, State Administration and the community at large in January. The report will also present the results of AFAM's survey on the needs of individuals ages 14 and older who have an ASD and have needs or will have needs for intensive and specialized day, employment, and residential supports when they reach the age of 22.

We'd like to thank all the families who have taken the time to complete the survey. We have had 250 responses to date! We would love to see this number go even higher in the last weeks of 2009. If you have a family member to whom the survey is targeted, please take ten minutes, go to www.afamaction.org, click on the link and complete the survey. Your participation in this survey will not only help you and your family member but others who have similar needs and who are unable to participate. Results will make a difference in our ability to obtain services over time!

We'd also like to thank Ann Jones and Margie Pascetta who have served on the Adult Services Committee this past year and a half, and have had to step down recently due to professional commitments. They provided valuable contributions as we got our advocacy work underway and we are very grateful to them both.

We are fortunate to have been joined by some new members who are volunteering their time and efforts to the committee. These folks include: Linda Cournoyer, the parent of a daughter on the spectrum and long time advocate with the Arc of Massachusetts Board and Government Affairs committee, and professional delivering care to people with disabilities in the central part of Massachusetts; Christine Draper from the May Institute's Adult Services division; Dorothea Ianuzzi, parent to a teenaged son on the spectrum and a clinical social worker helping families with developmentally disabled family members; Deirdre Phillips, mother to a son who has recently transitioned to adult services; and Eric and Setha Olson, parents of a son now in his fifties on the spectrum and long time advocates for services, including advocacy efforts which resulted in c.766 in Massachusetts. We thank each of them for their willingness to serve on the committee.

Christine Hubbard, Chair
Adult Services Committee

How Can You Help?

In a few days you will receive a letter from AFAM encouraging you to make a donation to our organization. As you've read elsewhere in this newsletter, we have intensified our activities on behalf of the entire autism community – working with elected officials on important legislation and joining with other disability organizations to organize vigils at the State House aimed at preventing the loss of millions of dollars of funding for services for individuals with disabilities across the Commonwealth. It is essential that our work must go on – and that's where you come in. If you have supported us in the past, please consider an additional donation at this critical time. If you've never given to Advocates for Autism of Massachusetts, please become a donor now. By doing so, you will help AFAM remain a strong, unified voice advocating for the needs of families and professionals whose daily lives are affected by autism.

Back by popular demand – the AFAM 2nd Annual Wine Sale, just in time for your own holiday needs as well as gift-giving.

To learn how you can purchase private-label wines and benefit Advocates for Autism of Massachusetts at the same time, visit www.grapesurfer.com/afam, where you can order online. Orders placed by December 16 will be delivered by Christmas; orders placed by December 23 will be delivered by New Years. The sale is conducted by Custom Grapes, which has a great track record of working with many charities in Massachusetts and elsewhere. There are six varieties of wine, and you can order individual bottles of multi-bottle gift packs. It's easy to order online, so visit the website now.

Twelve Tips for Helping People with Autism and Their Families Have a Happy Holiday

(Source: Autism Society of America)

While many happily anticipate the coming holiday season, families of people on the autism spectrum also understand the special challenges that may occur when schedules are disrupted and routines broken. Our hope is that by following these few helpful tips, families may lessen the stress of the holiday season and make it a more enjoyable experience for everyone involved. The following tips were developed with input from the Autism Society, the Indiana Resource Center for Autism and the Indiana Autism Leadership Network.

1. Preparation is crucial for many individuals. At the same time, it is important to determine how much preparation a specific person may need. For example, if your son or daughter has a tendency to become anxious when anticipating an event that is to occur in the future, you may want to adjust how many days in advance you prepare him or her. Preparation can occur in various ways by

using a calendar and marking the date of various holiday events, or by creating a social story that highlights what will happen at a given event.

2. Decorations around the house may be disruptive for some. It may be helpful to revisit pictures from previous holidays that show decorations in the house. If such a photo book does not exist, use this holiday season to create one. For some it may also be helpful to take them shopping with you for holiday decorations so that they are engaged in the process. Or involve them in the process of decorating the house. And once holiday decorations have been put up, you may need to create rules about those that can and cannot be touched. Be direct, specific and consistent.

3. If a person with autism has difficulty with change, you may want to gradually decorate the house. For example, on the first day put up the Christmas tree, then on the next day decorate the tree and so on. And again, engage them as much as possible in this process.

4. If a person with autism begins to obsess about a particular gift or item they want, it may be helpful to be specific and direct about the number of times they can mention the gift. One suggestion is to give them 5 chips. They are allowed to exchange one chip for 5 minutes of talking about the desired gift. Also, if you have no intention of purchasing a specific item, it serves no purpose to tell them that maybe they will get the gift. This will only lead to problems in the future. Always choose to be direct and specific about your intentions

5. Teach them how to leave a situation and/or how to access support when an event becomes overwhelming. For example, rather than having a behavioral episode, the individual should be taught ahead of time that they should go to their room when feeling overwhelmed. This self-management tool will serve the individual into adulthood.

6. If you are traveling for the holidays, make sure you have their favorite foods or items available. Having familiar items readily available can help to calm stressful situations. Also, prepare them via social stories or other communication systems for any unexpected delays in travel.

7. Know your loved one with autism and how much noise and activity they can tolerate. If you detect that a situation may be becoming overwhelming, help them find a quiet area in which to regroup. And there may be some situations that you simply avoid (e.g., crowded shopping malls the day after Thanksgiving).

8. Prepare a photo album in advance of the relatives and other guests who will be visiting during the holidays. Allow the person with autism access to these photos at all times and also go through the photo album with them while talking briefly about each family member.

9. Practice opening gifts, taking turns and waiting for others, or giving gifts to others. You might also choose to practice certain religious rituals. Work with a speech language pathologist to construct pages of vocabulary or topic boards that relate to the holidays and family traditions.

10. Prepare family members for strategies to use to minimize anxiety or behavioral incidents, and to enhance participation. Help them to understand if the person with autism prefers to be hugged or not, needs calm discussions, or provide other suggestions that will facilitate a smoother holiday season.

11. If the person with autism is on special diet, make sure there is food available that they can eat. And even if they are not on a special diet, be cautious of the amount of sugar consumed. And try to maintain a sleep and meal routine.

12. Above all, know your loved one with autism. Know how much noise and other sensory input they can take. Know their level of anxiety and the amount of preparation it may take. Know their fears and those things that will make the season more enjoyable for them.

Our hope above all is that you will have a wonderful holiday season!

News and Announcements

The Asperger's Association of New England is offering a series of **Workshops for Parents**. Coming up soon are the following:

“Making Daily Life Work at Home” on December 7 from 7:00 to 9:00 p.m. at the AANE office (85 Main Street, Suite 101, Watertown);

“Making School Work for Your Child with AS” on December 8 from 10 a.m. to Noon at the AANE office;

“Understanding Asperger Syndrome: Interventions and Strategies for Parents” on December 14 from 7:00 to 9:30 p.m. at the AANE office; and

“What Can I Say? What Did You Say? Using Language to Build Social Skills,” a 2-day program on December 10-11 from 8:30 a.m. to 4:00 p.m. at Bentley College in Waltham.

To register, visit the AANE website (www.aane.org) or call 617-393-3824.

Community Resources for People with Autism will co-host a **4-part Transition Series** in the Berkshires, together with Central Berkshire Regional School District – SPED PAC, Berkshire County ARC, United Cerebral Palsy of Berkshire County, Berkshire Family and Individual Resources and the Department of Developmental Services Berkshire Area Office. The first session, “Transition Planning 101,” will be held on Tuesday, January 5 from 6 to 8 p.m. at Nessacus Middle School in Dalton (RSVP by December 28). The second session, “Self Advocacy,” will be held on Saturday, January 16 at the BCARC

Social Development Center in Dalton (RSVP by January 11). The third session, "Guardianship," will take place on Nessacus Middle School on Tuesday, January 26 (RSVP by January 19) and the final session, on "Self Advocacy," will be held on Tuesday, February 23 at Nessacus Middle School. For more information or to register, contact Rhonda Ward at 413-529-2428, ext. 117 or by email at wardr@theassn.org

Community Resources for People with Autism will present **Insight Into Autism Spectrum Disorders** on Thursday, January 7 from 6:00 to 8:30 p.m. at SCAN 360 (11 Wilbraham Road, Springfield), with speaker Jason Litto. This is an interactive workshop designed to introduce families and caretakers to ASD. For more information or to register, call 413-529-2428. Registration deadline is January 4.

Community Resources for People with Autism is continuing its **Educational Advocacy Workshop Series** at the Community Resources office in Easthampton. "Strategies for Effective Communication" will be the topic on Wednesday, January 13. "Strategies for Effective Advocacy" will be the subject on Tuesday, February 9, and "The Hidden Curriculum" is the topic on Tuesday, March 2. All programs are from 6:30 to 8:30 p.m. For more information or to register, contact Community Resources at 413-529-2428. Note that you must register at least a week in advance of each program.

The Autism Support Center is offering a free workshop on **What is the obligation of the public school system to meet the unique needs of children with autism spectrum disorder?** The workshop will be held on Thursday, January 14 from 6:30 to 8:30 p.m. at the Haverhill Public Library (99 Main Street, Haverhill). An Autism Public Information Specialist from Mass. Advocates for Children will conduct the workshop, which will help parents understand the rights and procedures which ensure children with ASD receive educational opportunities which reflect competency and potential. To register, contact Susan Gilroy at 978-624-2302 or sgilroy@nsarc.org

Community Autism Resources will hold its **15th annual Parent Retreat** on February 13-14 at Whispering Pines Retreat Center at the Alton Jones Campus of the University of Rhode Island. The retreat is co-hosted by Dr. Barry Prizant, Dr. Elaine Meyer and Community Autism Resources. If you are interested in receiving more information, or participating in the retreat, please call Community Autism Resources at 508-379-0371, ext. 22.

SAVE THE DATE for the **15th Annual ASD Symposium**, co-hosted by Dr. Barry Prizant and Community Autism Resources. The symposium will take place on March 11-12 at the Rhodes on the Pawtuxet in Cranston, RI. On Thursday, March 11 you can spend the morning with Temple Grandin and the afternoon with Elaine Hall of "Autism: The Musical." On Friday, March 12, spend the day with Dr. Pat Mirenda, whose program is "Beyond Wants and Needs: Using AAC

to Support Social Interactions.” You can register online at www.community-autism-resources.com or call Kelly at 508-965-5705.

Supporting Physical Activity and Recreation in the Community (SPARC): A Research Study is a no-cost, 16-week, community-based walking and physical activity program for teens ages 12-17 with Autism Spectrum Disorders with moderate needs. The program includes: Support and supervision provided by trained staff (1 staff per 2 teens); an individualized *SPARC* plan; and an opportunity to meet new people and have fun! *SPARC* starts on February 21, 2010 and runs to June 10, 2010. Participants will attend 2 days a week and can choose from two sites: Malden YMCA – Sunday 12:30-2pm and Wednesday 4:30-6pm. OR Newton YMCA – Sunday 3-4:30pm and Thursday 4:30-6pm. For more information about *SPARC*, and to see if your child qualifies for participation, call Renee (781-642-0259) or email: shriver.study@umassmed.edu

Help teach doctors how to do a better job explaining things to women with intellectual disabilities! Dr. Joanne Wilkinson in the Department of Family Medicine at Boston University is beginning a research project to interview women with intellectual disabilities about mammography. Our goal is to help teach doctors how to do a better job explaining things to women with intellectual disabilities. We are looking for women ages 40 and over (who are eligible for a mammogram) that would like to talk for 20 minutes about what it's like when you go to the doctor, how the doctor explains things to you when you're going to have tests done, and how comfortable you feel there. We're giving people a \$20 gift card to Target, as a present, for doing the interview. Cristina Deis is a student who will be helping Dr. Wilkinson with the project. If you are interested in meeting with us to talk more about it please call (858) 752-2781 or e-mail at cdeis@bu.edu. Please include your name, age, and phone number. Thank you and we look forward to talking with you!

**Prospective Multisystem Evaluation of Infants at Risk for Autism
Do you have a Child with Autism AND Are you Pregnant? OR
Do you have a NEWBORN Less Than 4 Months Old?**

If so, you may be eligible to join a research study on the early signs of Autism. This study will monitor the development of infants at risk for ASD during 7 follow up visits from 2 weeks to 30 months of age, involving:

- Medical and neurological exams
- Cognitive, behavioral, and developmental assessments
- Examination of biological development and of brain, metabolic, and immune function
- Samples of saliva, urine, hair, blood
- The study is being conducted by: Martha Herbert, MD, PhD and Margaret Bauman, MD

There is no charge for study evaluations and compensation for time is provided.
For more information, please contact us at mghsiblings@partners.org or at 781-860-1760

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

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