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A Shout Out  
to our Walk  
Teams!  
Over \$3000  
raised!  
Thank You!

# Autism Society of NH

SEPTEMBER 2011



## President's Letter

Dear Friends of ASNH

### It's time to talk about a tough subject -- Money.

Money seems to be in short supply in the Granite State these days: School budgets are tight, our hospitals are cutting staff, and although Developmental Services has every reason to be grateful for the outcome of last year's budget process, young adults with disabilities are once again being told that they have to wait for essential services. Things don't seem to be much better in Washington, and that can only mean more belt-tightening at the state level.

I hate asking hard-working families and providers for money, believe me. I know how much you already do to support someone who lives with an autism spectrum disorder. **The simple fact is, however, that private charities like ASNH are the last line of defense for our children, teens, and adults.**

There are a few opportunities -- and some *serious* threats -- looming in the coming months: The small gains we have made toward insurance reform could be rescinded by HB 479; the move to a managed care model for

Medicaid-funded insurance (think NH Healthy Kids) could either improve care coordination or limit access to health services; revisions to the rules that govern the Children's In Home Support Waiver may make it harder for us to exercise parental choice in designing services.

ASNH has the advantage that NH laws require we have a representative at the table in many of these conversations. ***But we need our modest core funding to keep the phone on and respond quickly when parents call us.***

Let's make this year's [Walk in the Sun](#) the best in ASNH's fundraising history!

### ***Our kids can't wait for the economy to turn around.***

Please help us ensure that existing and better services are available for your family today and tomorrow

Best,

**Kirsten**

Kirsten Murphy  
Interim President



*8th Annual*

## Walk in the Sun

October 15, 2011

Massabesic Audubon Center, Auburn, NH  
Registration at 9 am, Walk begins at 10 am

**Music, Displays, Snacks, and Activities for the Kids.**

*An ASD-friendly quiet room is available.*

***www.nhautism.com*** for registration

## NEWS YOU CAN USE

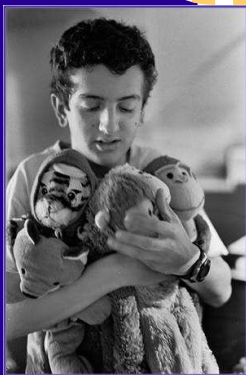
### Bureau Seeks Tighter Guidelines for Children's In Home Supports

The Children's In Home Support Waiver (CIHS) is a Medicaid-funded program designed to help meet the needs of some of New Hampshire's children who experience the most significant challenges due to developmental differences and family need. Of the more than 350 waivers, roughly half have been awarded to children who have an autism spectrum disorder

Recent guidance from federal Medicaid authorities has resulted in significant additions to the state regulation that guides the use of these waiver dollars. Although announced last January, these changes are only now being finalized in state regulations.

Families who access an CIHS waiver for a child on the autism spectrum should discuss these changes with their case manager well in advance of developing their CIHS agreement. New guidelines include the following:

- 70% of IHS budgets must be used for personal care, which is defined as assistance and skills training with basic daily living skills, such as communication, socialization, health and personal safety, and physical functioning.
- Respite should generally not exceed 15% of the IHS waiver budget.
- Therapeutic services that are available under the Medicaid State Plan (that is, through NH Healthy Kids) must be accessed through this health insurance plan, rather than through the CIHS waiver. This applies to consultative services such as speech therapy, occupational therapy, and physical therapy
- There is a \$2,500 limit on fencing as an environmental modification and spending must be base on a specific clinical recommendation.
- Funds for computer or electronic devices have a service limit of \$1,500/year, including software; exceptions my be granted at the recommendation of a licensed professionals or service such as NH ATECH.
- Therapeutic recreation, such as hippotherapy, music therapy, or art therapy is capped at \$1200/year. This does not include camper-ships. Additional funds may be authorized with a recommendation by a licensed professional.



### BDS Announces New Complaint Procedures

In response to consumer recommendations, the NH Bureau of Developmental Services has revised its process for handling complaints about client care. In the past, complaints were handled directly by each of NH' s ten area agencies. Going forward, complaints are to be filed directly with the state and will be investigated by an independent third party. Individuals who receive services in the developmental services system have a right to be free from abuse, neglect, and being taken advantage of. To file a complaint, please call 855-450-3593.

# CARA Passes House on Voice Vote

**September 20, 2011**-- With the clock ticking before an end-of-the-month deadline, the House has passed the re-authorization of funding for the historic Combating Autism Act.

The only appropriations bill specific to ASD, CARA is the source of crucial funding for the NH Leadership Education in Neurodevelopmental Disabilities (LEND) program and other state-level funding opportunities.

Action on the bill now moves to the Senate where the measure cleared the Health, Education, Labor and Pensions Committee on Sept. 7 by unanimous vote. Despite more than 35 Senate co-sponsors, CARA's fate remains precarious in light of strong opposition from a small number of Republican Senators.

In related news, Senator Jeanne Shaheen (D-NH) has become the 36th US Senator, and the only member of the Granite State's Congressional delegation, to co-sign this legislation.

CARA would authorize a total of \$693 million on continued biomedical and treatment research on autism and require further development of an overall strategic plan for the intensification, expansion and better coordination of federal efforts designed to help persons with autism and their families.



*“What is it that individuals and families impacted by ASD should stress to policy makers?”*

## Families Urged to Respond to Managed Care Survey

While budget negotiations occupied advocates throughout last year's session, a less well publicized bill quietly made its way through the legislative process. SB147-FN requires the Department of Health and Human Services to fast track a plan that would change Medicaid coverage from a fee-for-service model to managed care.

DHHS and advocates are urging consumers to fill out a short survey at the DHHS website ([link here](#)). The survey has several open-ended questions where you have the opportunity to raise issues that may be of concern to those who experience autism. Letters may also be sent to the Commission and the planning committee care of: Katja Fox, Office of the Commissioner, Department of Health and Human Services, 129 Pleasant Street, Concord, NH 03301

### Resources to Learn More

- Frequently Asked Questions about Care Management, [link here](#)
- BDS Managed Care Survey, [link here](#) or see: <http://www.dhhs.nh.gov/ocom/care-management.htm>

### Opinion

Do individuals and families impacted by ASD have a stake in NH's Managed Care Debate? *You bet we do!*

By Kirsten Murphy

Passage of SB 147-FN committed New Hampshire to using a managed care model for the delivery of all Medicaid funded services and supports. This sea change in the delivery of acute and long term care has been legislatively fast-tracked. There has been little time for public input, let alone the education that informs effective consumer advocacy. To complicate matters, NH's managed care drama takes place with the backdrop of federal health reform, an as yet poorly understood regulatory environment that will significantly impact the minimum level of benefits that states can offer its Medicaid recipients.

What is it that individuals and families impacted by ASD should stress to policy makers? Without losing the reader in the tall, tall

*Cont.*

## Opinion, *cont.*

weeds of healthcare reform, there are three important issues that should be stressed to policy makers. The best opportunity to make your views known is through the on-line survey available at the Department of Health and Human Services website: <http://www.dhhs.nh.gov/ocom/care-management.htm>. **Note that the survey will close by October 5 at 9 pm.**

1. **“Managed Care” means *coordination of care, not constraining access to care.*** Comprehensive care coordination has been the “Holy Grail” of improved care for those who experience ASD. The 2008 Report by the NH Commission on Autism Spectrum Disorders found that: *“While case management is provided within certain segments of a child or individual’s program (for example, special education, there is no mechanism to develop a coordinated plan of care that addresses needs and takes advantage of strengths across all environments.”*

A management system that creates incentives to reduce the amount of specialty care and therapeutic intervention used by patients will not serve our sons and daughters with ASD well. Thankfully, the legislative charge to DHHS includes a strong emphasis on identifying a “medical home” for each Medicaid recipient. Parents and advocates should insist that under the new managed care plan, primary care providers and their staff receive reasonable reimbursement for the family education and care coordination that are at the heart of the medical home concept.

2. **NH’s new managed care program should align the screening, diagnosis and treatment of ASD with the guidelines established by the American Academy of Pediatrics.** Early Periodic Screening, Diagnosis, and Treatment (EPSDT) is a mouthful of letters that refers to the comprehensive package of children’s health services that Medicaid requires of all states. Since 1967, the purpose of the EPSDT program has been *“to discover, as early as possible, the ills that handicap our children” and to provide “continuing follow up and treatment so that handicaps do not go neglected.”* The importance of early identification and intensive treatment is not lost on parents who have a child with ASD. Yet despite clear guidelines by the American Academy of Pediatrics and other professional groups, NH’s Healthy Kids program does not cover behavior-based therapy. In a managed care environment, one could imagine additional limits placed on speech, occupational, and other therapies.

Federal Medicaid law requires that for children up to the age of 21, states -- regardless of whether they use a managed care or fee for service model -- must cover: *“Other diagnostic, screening, preventive, and rehabilitative services, including any medical or remedial service (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.”* The move to managed care can be seen as an opportunity to bring our state Medicaid Plan into compliance with this requirement. Families should tell DHHS that they expect a full range of therapeutic benefits – including speech, occupational therapy, and ABA – to be provided to Medicaid enrolled children.

3. **Mental health *is* health.** Many individuals with ASD experience co-morbid mental health issues, including anxiety and depression. These may be chronic and require frequent episodes of care to achieve the best possible management of symptoms. When symptoms become severe, individuals may need access to a higher level of care, including hospitalization, for their safety.

It is important for anyone concerned about the needs of individuals with ASD to ask very specific and challenging questions about the incentives and limitations that may be in play in a managed care system: Will yearly mental health benefits for an individual be limited? Will there be a cost or co-payment for treatments or medications? What protocols will be in place to determine if inpatient treatment is appropriate? Families must insist that behavioral health benefits be equal to those provided for any illness.

### To Learn More

Autism Society’s statement regarding federal deficit reduction and Medicaid reform. <http://www.autism-society.org/news/help-the-autism-society-lead-1.html>

DHHS Questions & Answers regarding Managed Care, [www.dhhs.nh.gov/ocom/documents/FAQCareMgt.pdf](http://www.dhhs.nh.gov/ocom/documents/FAQCareMgt.pdf)

## Be Different

**A presentation by John Elder Robinson  
November 3, 2011**

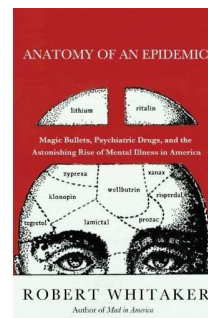
ASNH is pleased to co-sponsor *NY Times* best selling author John Elder Robinson's first Northern New England appearance. The author of *Look Me in the Eye* and *Be Different*, Robinson brings a inspiring message to those who experience Asperger's and other forms of autism. This event will take place in the evening at the McAuliffe-Shapard Discovery Center in Concord, NH.

To register, see [www.spauldingyouth.org](http://www.spauldingyouth.org) or the ASNH calendar. Note that ASNH is offering 50% scholarship support for individual and family registrations upon request. Please call Missy at 603-649-2424 for details.

## 50 Years of Psychotropics, A medical Advance or doing more harm than good?

**By Robert Whitaker  
October 5, 7 pm**

This controversial subject will be explored by the author of "Anatomy of an Epidemic" and an expert panel. Location: Dartmouth College, Carpenter Hall, Hanover, NH. **Free and open to the public.** For more information about Whitaker see <http://robertwhitaker.org>



## Practical Classroom Strategies for Students with ASD

**By Cassie Yakley, PsyD  
October 18, 3:45 to 5:45**

Penacook Elementary School Library

Participants will gain a deeper understanding of the function and meaning of interfering behaviors observed in students with an ASD, as well as tools for addressing these behaviors in a manner that minimizes classroom disturbance and maximizes learning for ASD students. CEU's offered.

Sponsored by Spectrum 46, Merrimack Valley Parent Outreach, and ASDN. **Free and open to the public.**

For more excellent training opportunities  
Please see the ASNH calendar  
[www.autism-society-nh.org/calendar.html](http://www.autism-society-nh.org/calendar.html)

## PLANNING FOR ADULTHOOD

By: Butenhof & Bomster, PC  
e-mail: [office@butenhofbomster.com](mailto:office@butenhofbomster.com)

Is your child approaching the age at which the state considers your child to be an adult for purposes of making independent financial and health care decisions? The age of adulthood in New Hampshire is eighteen (18), even though circumstances may warrant a child remaining in the public school system past that magic age.

For parents of young adults who have special needs, the looming loss of authority to make critical decisions regarding care and the lack of immediate access to information concerning a child may be worrisome. Accordingly, before a child who needs ongoing assistance from a parent becomes an adult in the eyes of the law, you may wish to consult with a special needs attorney to explore various options to ensure your child's needs continue to be met.

### Health Care Decisions

Let us take Caroline, for example, who will turn 18 in a few months. Caroline falls within the autism spectrum but is quite high functioning and rather independent. If Caroline pursues her continuing education away from home and becomes ill or is in an accident, will her parents have the ability to speak with medical providers concerning her condition and treatment? What would happen if Caroline needed surgery and was unable to communicate her wishes concerning her care, could her mother and father step into Caroline's shoes and work with the health care providers directly? Without being granted the legal authority to do so after Caroline turns 18, the answer, generally, is no.

If Caroline has the mental capacity to make her own health care decisions but still would like help from her parents or other trusted adults, like an older sibling, she could sign a release of information form under the Health Insurance Portability and Accountability Act ("HIPAA") naming those individuals as personal representatives to whom doctors, hospitals and other medical professionals may release information, upon request. In addition, Caroline should execute a durable power of attorney for health care. By signing a health care power of attorney, Caroline would authorize another trusted individual, also known as the "attorney-in-fact," to become her substitute medical decision maker were she ever to become unable to make her own health care decisions due to an accident or serious illness. The scope of authority granted to an attorney-in-fact may be broad or limited depending upon the terms of the power of attorney. Thus, the signing of both a HIPAA release and a health care power of attorney keeps in place a necessary support structure that existed before the child turned the age of 18.

What if Roger, unlike Caroline, is turning 18 but does not have the capacity to sign estate planning documents naming attorneys-in-fact to handle medical decisions? In this case, a petition for guardianship would need to be filed in a court in order to name a trusted adult, like a parent, as guardian over Roger's person. The court would evaluate the mental capacity of the child (also called the "ward") and the need for a protective legal mechanism to ensure his safety. Because a guardianship is granted by a court, ongoing reporting requirements are imposed on the persons who have been granted authority to make medical decisions for the young adult. In addition, under most circumstances, the scope of authority granted to a legal guardian over the person is akin to the powers granted to an attorney-in-fact under a durable power of attorney for health care. However, once granted, a child could not remove a guardian as easily as he or she could rename or substitute an attorney-in-fact.

### Financial Decisions

Upon reaching the age of adulthood, a child also has independent control over his or her finances. This power over the purse often is a rite of passage for a child but, as most parents know, the ability to manage finances well only comes with experience. If a young adult needs assistance managing money, one option is for him to execute a durable power of attorney for financial matters. If James turns 18 and is competent to sign a financial power of attorney, he could name a parent or other trusted individual as an attorney-in-fact to help manage his financial affairs. It may be more of a challenge for a young adult to recognize that a parent's assistance may be just as helpful in the financial arena as it is for medical matters. Some examples may be helpful to explain how having a parent at the table proves useful. For

instance, what if James is applying for financial aid for college and needs to coordinate with government agencies, apply for scholarships with the school and file various forms? Wouldn't it be nice if he could share the load and give some of the projects to mom or dad? Also, if James were hurt on the job, he may wish to have his attorney-in-fact deal directly with the employer or the insurance company to resolve a claim. It is important for a young adult, like James, to understand that signing a durable power of attorney does not take away his authority to control his own finances. Rather, the persons appointed to assist with financial matters merely are part of his financial team and only control money matters upon his request or if it becomes absolutely necessary for some reason.

What if Betty, unlike James, reaches adulthood but does not have the capacity to handle finances or sign a power of attorney? In that case, a parent may need to file for guardianship over Betty's "estate" if it is likely that financial matters, like applying for Supplemental Security Income ("SSI"), will be an issue in the future. Once again, when a parent is requesting court permission to handle a child's affairs, the court will evaluate closely the ability of the young adult to understand and manage finances and weigh the same against the need for the appointment of a trusted adult to step in to handle the job. Similar to a guardianship over a person and health care matters, the scope of a guardianship over an estate and finances may be broad or limited.

## Educational Matters

What happens to a parent's ability to participate in a child's educational goals when a child reaches the magic age of majority? Whether the child is enrolled in high school, a technical program or an institution of higher learning, once he or she legally is considered an adult, the parents lose control over the child's education and access to all records, including grades. A parent who is granted guardianship over a child's "person," as may be necessary for Roger and Betty, should have sufficient authority to make decisions concerning appropriate school settings and curriculum, as well as access to necessary records to plan for the young adult's future educational needs.

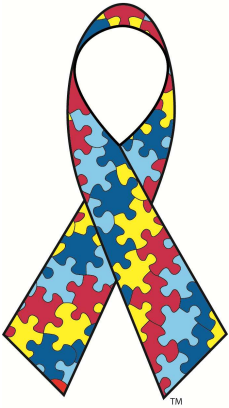
However, how would children like Caroline and James, who are not in need of a guardian, ensure that a parent may continue to help with educational matters? After high school, a young adult often is focusing his or her energy on class work, forming friendships and building connections at school. As a result, he or she may need help navigating the educational bureaucracy and completing necessary paperwork. In this case, a parent may wish to discuss the benefits of having their young adult execute a special power of attorney just for educational matters. This estate planning document takes nothing away from the young adult but continues to give parents the necessary seats at the table in order to provide the helping hands needed to ensure the child's goals are met.

Before a child with special needs reaches the landmark birthday defining his or her legal rights under state law, parents may wish to consider speaking with an attorney who specializes in special needs planning in order to ensure that the best possible foundation is laid for the child's future.



**Butenhof & Bomster, PC**  
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 Phone (603) 296-0428 Fax (603) 296-0430  
 office@butenhofbomster.com

*At Butenhof & Bomster, PC, we focus our practice in the areas of elder law, estate planning, Medicaid planning, special needs trusts planning, guardianships, and probate and trust administration. Simply put, our philosophy is that each client's circumstances are unique and deserving of individualized attention and planning, regardless of whether such planning involves the creation of a complex trust structure or simply the execution of a health care power of attorney.*



## Mission Statement

*The Autism Society of New Hampshire is dedicated to improving the lives of individuals who have an autism spectrum disorder and their families. Through education, advocacy, and support, ASNH fosters unqualified acceptance and genuine appreciation for individuals with ASD living in the Granite State.*

Box 68  
Concord, NH 03302  
(603) 679-2424  
[www.autims-society-nh.org](http://www.autims-society-nh.org)

# Calendar Highlights, cont.

## **Parent to Parent Training Opportunity**

Have you ever considered being a Trained Supporting Parent for another parent who has a child with a disability? Have you ever said to yourself "I don't ever want another parent to go through what I've been through! – all alone!"

Parent to Parent of New Hampshire provides Supporting Parent Training to give you the opportunity to support other parents facing many of the same things you have already experienced raising a child with a disability.

**Saturday, November 5, 2011**

9:00 a.m. - 3:30 p.m. at the Wentworth-Douglass Hospital  
2<sup>nd</sup> Floor – Auditorium C in Dover NH 03820

For information and application

Call 1-800-698-5465 Email: [P2PNH@valley.net](mailto:P2PNH@valley.net)