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An affiliated agency of People Inc.

Summer Issue • 2014  
Quarterly Newsletter

*Headway is a support  
and advocacy agency for  
persons with brain injury,  
other disabilities and seniors.*

In this issue

501C3 Non-Profit Organization

## NYS MEDICAID WAIVER CHANGES PLANNED...how will this affect YOU?

Do you or someone you know receive services from the NYS Department of Health Traumatic Brain Injury Waiver Program (often referred to as the TBI Waiver) or the Nursing Home Transition and Diversion Waiver? About 5,000 people across NYS do, and that includes over 500 people in the Western New York region. As part of the Medicaid redesign, NYS is planning some big changes to Medicaid which will affect people on these programs.

First, a little background: Early in our history, Headway petitioned the NYS Legislature and the NYS Department of Health for specialized services for survivors of brain injury. We were one of the agencies instrumental in the beginning of a more appropriate Medicaid program. Through our efforts and those of other concerned citizens and groups across the state; the TBI Waiver Program was created to provide more services to individuals with brain injuries. This waiver provides a range of community support services for survivors, enabling them to live in their community and avoid placement in an institution. Headway has helped to coordinate these services in the WNY area since this program's inception in 1995.

Building on their successful experience with the TBI Medicaid Waiver, the NYS DOH created the Nursing Home Transition and Diversion Waiver (the NHTD Waiver) to provide assistance in a similar way for people with all types of disabilities who wish to live more independently in the community. Headway helps to coordinate these services in WNY.

**NYS has stated its intention to close down these programs and to move all TBI and NHTD waiver participants into the Managed Long Term Care (MLTC) Program in September of 2015.**

**The TBI Waiver program was started because NYS agreed that it had been dealing with the care of these individuals without addressing their special needs.** Many were being sent to nursing homes, often in out of state facilities. They did not "fit" well in these settings; it was often detrimental to the individuals, as well as disruptive to an older and frailer general nursing home population.

When the waiver programs were initiated they successfully moved many of these people from institutions into community based care, improved the quality of life for participants and saved money for the state. According to New York's own estimates, from 1999 to 2009, the State spent \$276 million less (on the TBI population alone), that is over \$53 million per year, than it would have spent had these individuals been placed in nursing homes. Moreover, these waivers have been highly successful in supporting individuals with cognitive, behavioral and physical issues, along with their caregivers and their loved ones, in living in their own homes where they are safer, more comfortable, and more productive than in institutions. The waiver has specially designed supports, and specially trained staff to further these specific goals.

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**SAVE THE DATE!  
HEADWAY'S  
WALK, RUN &  
WHEEL EVENT  
SUNDAY, SEPT 7TH  
SEE PAGE 3  
FOR DETAILS**

**Headway  
is a donor designated  
agency of the United Way**

**NYS is attempting a redesign of many Medicaid services with the laudable goal of cost containment.** However, individuals with TBIs are among the most vulnerable Medicaid recipients, requiring highly specialized and unique care delivery. In attempting to change to a new MLTC program, run by private insurance companies, without staff with at least some special training, and possibly without some of the special considerations the waiver program provides (potential for housing assistance, respite services, service coordination as a specialized form of case management, among others) this transition may not be successful for many. Managed care plans run by private insurance companies have the potential to become one size fits all, and may not always meet the needs of individuals who need more nontraditional services and not just the “hands on” (like washing and dressing) kind of care typically provided by home health care agencies. Instead, they may need help with organization, supervision due to issues of judgment or impulsivity, or a behavioral program. The goal is to help brain injury survivors become more independent and better integrated into the community. Many have needed progressively less care from the program, some have “graduated” entirely.

**Headway would like to encourage you to let your feelings known on this matter. Your advocacy, your personal story, can mean a great deal if you make yourself heard.**

**We encourage you to request that the population in these waiver programs NOT be transitioned into managed long term care.** There is a precedent of other states which have kept special populations like TBI and others out of their MLTC transition. If they do include them, we at least want to be sure that special terms and conditions are considered. The transition will not happen this year, but it will happen soon, unless our needs are voiced and are heard. We have to be sure any changes made in 2015 do not push us back into the pre waiver days of the 1980s and 1990s.

*Some information for this article provided by The Alliance of TBI and NHTD Waiver Providers.*

## THIS IS WHAT YOU CAN DO!

**Here are places that need to hear your voice:**

- Governor Andrew Cuomo  
[www.governor.ny.gov/contact](http://www.governor.ny.gov/contact), or mail to:  
NYS State Capitol Building  
Albany, NY 12224
- You can find out how to contact your local state assembly representative at [www.assembly.state.ny.us/member](http://www.assembly.state.ny.us/member)
- You can access your local state senator’s contact information at [www.nysenate.gov/senators](http://www.nysenate.gov/senators). Your local library can also assist you with obtaining this information. They will have a local, as well as an Albany office.
- You can also contact  
NYS Department of Health  
**Deputy Commissioner Mark Kissinger**  
at [mlk15@health.state.ny.us](mailto:mlk15@health.state.ny.us) or write to him, or to  
**Acting DOH Commissioner Howard Zucker** at:  
NYS Department of Health  
Corning Tower  
Empire State Plaza  
Albany, NY 12237

Write or email and let these folks know how important the TBI and NHTD Waiver Programs have been. Let them know how these programs have helped keep people out of institutions and have saved the state money. If possible, tell a little of your story or the story of someone on the waiver to illustrate this.

## VOLUNTEER NEWS

**Dr. Lisa Keenan**, Licensed Health Psychologist at ECMC and Headway Advisory Board member, and **Dr. Ken Sroka**, Professor Emeritus at Canisius College, presented a workshop at the Conference on Acquired Brain Injury in Hamilton, Ontario in May, titled “Companions for Healing: One Page at a Time.” The workshop discussed the pilot project started at ECMC involving reading clubs to assist in the continued recovery of survivors of acquired brain injury, and it was well received. Dr. Sroka also presented the concept of the reading clubs at the 2013 annual meeting of Headway.

**Mark Shaw**, student and leader of a peer support group for survivors of brain injury that meets in Niagara County, was part of a panel presenting at the annual conference of the Brain Injury Association of NYS in Albany in June (see more about Mark and the conference on page 6). The panel topic was “Ask the Experts: So I Have a Brain Injury...Now What?” It was designed primarily for those new to brain injury, to learn about steps and strategies for coping with brain injury.

Mark’s mother, **Shelly Shaw**, was part of a panel at the same conference, “Caring for the Caregivers”, helping to understand caregiving at every stage of life after a brain injury and share tips and strategies for the families and caregivers.



### HEADWAY IS ON FACEBOOK!

Come on, do you “like” us? Friend us on Facebook and receive Headway postings on upcoming news and events! You can also send messages to our youth counselor, Molly, or you can contact her directly at 408-3100.

# SAVE THE DATE!

## 5TH ANNUAL 5K EVENT | SUNDAY, SEPTEMBER 7, 2014



### WALK, RUN & WHEEL

Registration 8:30am

Walk, Run & Wheel 9:30am

Post Walk, Run & Wheel Festivities, including  
AWARDS, LIVE MUSIC, FOOD & BASKET RAFFLE!

11:00 am—1:00 pm

*See registration form enclosed.*

### SPONSORSHIPS ALSO AVAILABLE AS FOLLOWS:

LEVEL	BENEFITS	AMOUNT
Gold	Logo/Name on upcoming print materials, Event T-Shirts, Day of Event Signage & Opportunity to Display Marketing Materials at Event	\$500
Silver	Logo/Name on Event T-Shirts & Day of Event Signage	\$250
Bronze	Day of Event Signage	\$100

For more information or to secure your sponsorship,  
contact Christine at 716-408-3117 or at [cmelchiorre@headwayofwny.org](mailto:cmelchiorre@headwayofwny.org)

## BRAIN INJURY: NOW A PRESIDENTIAL ISSUE

On May 29, 2014, President Obama hosted the first ever White House summit on concussions, a sign that this issue has begun to be taken more seriously.

Attending were scientists and doctors. There were representatives from professional sports leagues like the NFL and Major League Soccer. The president of the NCAA was there. Some of those who had suffered concussions spoke about the impact this had had on their lives.

This was a major step in bringing this issue into the open, but there is still much to be done. Last fall, the Institute of Medicine and the National Research Council published a report that found that there are gaps in our concussion research knowledge, and that there is a startling lack of data on concussions, especially in youth sports. The report also found that there is still a “culture of resistance” among athletes related to the self reporting of concussions and the adherence to treatment plans once they experience a concussion.

As part of the summit, new commitments to research were announced. Among them:

- The **NCAA and the Department of Defense** are jointly launching a \$30 million effort to fund the most comprehensive clinical study of concussion and head impact exposure ever conducted, and they are issuing a Educational Grand Challenge aimed at improving concussion safety behaviors in college sports and the military.

- The **NFL** is committing \$25 million over the next three years to support projects and partnerships aimed at promoting youth sports safety including expanding access to athletic trainers in schools.
- The **National Institute of Health** is announcing the launch of a new research effort to detect, characterize and measure the chronic effects of repetitive concussions
- **UCLA** is beginning a program targeting sports concussion prevention, outreach, research and treatment for athletes of all ages, especially youth.
- The **National Institute of Standards and Technology** will invest 5 million over five years to work on the development of advanced materials that can provide better protection to the athlete and the soldier.

Many other programs were announced to promote education and awareness for parents, coaches and athletes and to educate health care providers.

This is progress. The NFL formed its first committee on concussions in 1994. 20 years later, saving athletes from concussions is at last important enough to be addressed by the President, and there are initiatives started from the White House. It is progress too long in coming for a host of athletes, both professional and students, who have found that “getting your bell rung” is not something to be disregarded, but that **a concussion is a brain injury**, and one that can have far reaching consequences.

# MOONLIGHT ON THE GREEN

The moon was full, the guests arrived with flair, the baskets beckoned and music filled the air.

Headway of WNY's **15th Annual Spring Gala** took place on Thursday, May 15 inside Windows on the Green at the gorgeous Westwood Country Club. A variety of food stations, carefully prepared by Windows on the Green culinary staff, were placed throughout the venue, featuring an array of Italian, Asian & American cuisine.

With over 220 guests in attendance, 216 baskets raffled and 17 Silent Auction items successfully bid on, the event raised over \$32,000 to help ensure that individuals in WNY with brain injuries and other disabilities, and seniors have access to advocacy, resources, and support systems to enable them to live as independently as possible in the community.

One of the main features of the event is the ever popular Basket Raffle, with a vast array of eclectically themed baskets. The crowd enthusiastically participated and the excitement mounted as winning numbers were displayed.

The Silent Auction portion of the evening included a beautiful hand-made wooden bench, jewelry, art, a weekend get-away and a Michael Kors designer set. Bids were made throughout the evening and the winning bids were announced at the close of the evening.

A Special Thank you goes to Chris Van Veghten and her group of volunteers who worked tirelessly in putting together the stunning array of baskets this year. The end result was truly awesome!

Additionally, special recognition goes out to Darlene Robida and her friends who created the stunning centerpieces this year, bringing together several elements of the Moonlight on the Green theme.

**Many thanks go out to all our sponsors, with a special thanks to our Presenting Sponsor, Elmwood Health Center.**



# THANK YOU SPONSORS!

**Full Moon, \$3,500 Phase**  
Elmwood Health Center

**Half Moon, \$2,500 Phase**  
The Landwehr Family

**First Quarter Moon, \$1,250 Phase**  
The Denio Family  
Dolce Panepinto  
Health Force

**Third Quarter Moon, \$500 Phase**  
All Metro Healthcare  
Buffalo Wheelchair  
Erie County Medical Center  
Feroletto Law  
Parkview Health Services  
Venture Forthe, Inc.

**Crescent Moon, \$250 Phase**  
Academic Buffalonias, PC  
Blackburn's Dove Medical  
Merrill Lynch  
Jane and Jerry Piskorz  
Rich Products  
Vision Electronics Group

**New Moon, \$125 Phase**  
Heritage Christian Services  
Martha C. Leung  
Nancy and Mark Reed  
Irene and Illio Toffoli  
Upstate Steel, Inc.

**Theme Decorated Cake provided by Wegmans**

**Thank You to the following for their generosity and support**

Buffalo Press, Inc.  
Ronald Fernandez  
Michael DelMonte  
Headway of WNY, Inc. Staff  
People, Inc. Staff

**Thank You to the Special Events Committee Members**

Darlene Robida, Chairperson  
Maggie Apotosky  
Felice Bumbaco  
John Feroletto  
Diana Landwehr  
Elisabeth Mann  
Christine Melchiorre  
Carrie Mendola  
Kelly Mendola  
Chris Van Veghten  
Mari Warmus  
Bill Warmus



# BIANYS 32ND ANNUAL CONFERENCE

*Uniting as the Voice of Brain Injury*, BIANYS 32nd Annual Conference took place on Thursday, June 5 & 6 in Albany, New York.

The annual conference brings together several hundred individuals with brain injuries, family members, caregivers, health professionals, providers and other interested individuals for learning and sharing.

Headway Volunteer and survivor of brain injury, Mark Shaw (featured in the Spring 2013 issue of this newsletter) presented at this year's conference and shared his experience in the passage below.

*"June 6, 2014 was the day of the conference that I was on a panel of survivors. The group was called "Ask The Experts" We spoke to fellow survivors as well as Family members. Some spoke of their "new lives" and what they do now from writing to public speaking and rally's in DC to writing. I personally used myself as an example and said DON'T GIVE UP! Doctors said that I would NEVER walk again even with a walker and I shouldn't have either long term or short term memory or perhaps both, but I do. I told of going back to school and am now in Graduate School and I said it gives me satisfaction to do thing that I am told it is not likely or possible at all just so I can say "DID IT!" now what? I also told them that Doctors know what they read in a textbook and not the individual or what the individual is capable of. At first I was told 1 year, then 3 years, then 5 years would be the "limit of time" to get back what I am going to get back. In a few days (June15) it will be 10 years since I got sick and I am still making gains. I think that all of the panelists gave hope to those new to TBI. I also threw in there that I liike to look at the glass as half full rather than half empty and that even in what seems like the worst times of ones life, there is still a silver lining there somewhere. It may not be very apparent and you might have to do some searching, but there is one lurking in the shadows. Using me as an example again I said I was mad at the world at first, but eventually I found my silver lining and it was falling into a perfect fitting career path."*

Thank you Mark! We applaud you for all you do to make the world a better place for those around you!

To learn more about the Brain Injury Association of NYS, visit their website at [www.bianys.org](http://www.bianys.org).

# BECOME A MEMBER!

*Support our mission by becoming a Member of Headway of WNY, Inc.!*

Annual Headway Membership helps support our general operating expenses and makes it possible for us to provide valuable benefits to our subscribers. Benefits include invitation to our Fall Annual Meeting; discounts for select special events; free publications, such as a quarterly newsletter filled with informative and inspirational information; and a valuable Resource Guide for services throughout WNY. Membership support also helps subsidize programs for survivors of brain injury and their families. Membership is on an annual basis.

If you are not currently a Headway member and would like to join us, or if you would like to renew your membership, please complete and return the form below:

- 
- Individual \$20  new
- Family \$30  renewal
- Professional \$55
- Supporting \$100
- Lifetime \$250

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

*Please also consider supporting our efforts with a Tax Deductible Donation*

Amount Enclosed

\$ \_\_\_\_\_

Make your check payable to:

Headway of WNY, Inc.  
2635 Delaware Avenue  
Buffalo, NY 14216

## OPPORTUNITY TO CONSIDER



Paid research opportunity from the Center on Brain Injury Research and Training! CBIRT needs help to improve their website for families:  
<http://ow.ly/xHADW>

Are you 18 or older and taking care of an adult family member with a brain injury? Do you have high-speed internet access? If yes, you may qualify for the study and a payment of at least \$50. For more information, please copy and paste this link to the project information page to learn more: [http://www.surveymonkey.com/s/030214\\_030214\\_030214](http://www.surveymonkey.com/s/030214_030214_030214)

# AMERICORPS VISTA UPDATES

Headway is currently wrapping up our first year as a host site through the Americorps Volunteers in Service to America (VISTA) program administered by the Service Collaborative of Western New York. Sarah DePerrior, current Americorps VISTA member, will be finishing her term of service in July of 2014. Sarah has worked on starting up our veterans outreach initiatives over the past year. She has been involved with a variety of different activities over the course of her term of service. Her work has included the following:

- Attending outreach events on behalf of Headway, including VA events and programs, veterans' service fairs, and health fairs
- Participating regularly in community provider organization meetings.
- Collecting and compiling information on organizations in Western New York that provide services for veterans.
- Setting up meetings with relevant organizations in order to learn more about their services as well as share information on Headway and the services we offer.
- Putting together Headway's "Resource Guide for Veterans with Brain Injury," which will be available summer 2014.

- Working on research and proposals for grant funding to allow Headway to expand services for veterans.
- Working with Headway staff and volunteers on event planning, particularly for "Making Your Mark...Moving Forward," a new community arts outreach event for veterans and survivors of TBI.

We are also excited to announce that Headway has been renewed as a VISTA partner site for 2014-2015. Starting in August 2014 we will have a new VISTA member working to continue with our veterans outreach initiatives. New goals for the next year of this project include the following:

- Conducting a needs assessment to determine how Headway can understand and serve the needs of veterans, particularly those with TBI.
- Continuing to network with veterans organizations in the community and producing a second edition of the Resource Guide.
- Engaging veterans as volunteers as part of a "speaker's bureau" as well as building peer mentorship and support opportunities.

## EMPOWERMENT PRESENTATION OFFERED

*Are you looking for an inspirational speaker for your next meeting, support group or event? Sammy Violante's presentation "An Eagle Only Soars When It Flies Against the Wind" offers hope and inspiration on the topic of overcoming adversity. An award-winning investment broker turned inspirational speaker, he offered his presentation at Headway of WNY's Annual Meeting last November and has presented to over 250 groups in WNY over the last several years. His story of personal rehabilitation captures the attention and imagination of the audience and leaves a lasting impression. To find out more about these free inspirational talks, please contact Sammy directly at 634-7294.*

## HEADWAY OF WNY, INC.'S LEAD RRDS OF TBI WAIVER PROGRAM RECEIVES CERTIFICATION

As part of its ongoing efforts to provide the most professional and up-to-date services, Headway of WNY recently sponsored Kristen Hewlett (Lead RRDS of the TBI Waiver program) in becoming a certified Brain Injury Specialist.

She attended the certification training in June, offered through the Academy of Certified Brain Injury Specialists (ACBIS). This national certification is offered to professionals and those working with people who have brain injury. In the process of obtaining this certification, CBIS candidates learn about: epidemiology and incidence of TBI and acquired brain injury, anatomy and brain relationship to behavior, various treatment approaches, family issues, and other related health and social issues.

Ms. Hewlett started working at Headway in 2009 as an assistant Regional Resource Development Specialist (ARRDS) and became the Lead RRDS for the TBI program in December of 2009, reviewing all service plans and authorizing State approval to participants on the program.

## HEADWAY WELCOMES NEW ASSISTANT RESOURCE DEVELOPMENT SPECIALIST

Melisa Granville began working as the Assistant Regional Resource Development Specialist in March 2014.

Melisa has worked in the human services field for 12 years. Prior to employment with Headway, she worked in the Office for Persons with Developmental Disabilities (OPWDD) as a Medicaid Service Coordinator at Sasi, where she helped people with disabilities find housing, recreational activities, medical providers and linkages to work programs. She also held a Team Leader position at Sasi, and worked for 8 years as a Program Coordinator at Baker Victory Services, where she had oversight of ICF and IRA management staff at several sites.

Melisa has a Bachelor's Degree in Education from Canisius College. She lives in Hamburg with her husband and 2 children.



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**YOU ARE NOT ALONE, MOVE FORWARD WITH HEADWAY.**

## HEADWAY'S

### SUPPORT GROUPS FOR SURVIVORS OF BRAIN INJURY AND THEIR FAMILIES

All meetings, except as noted, will take place at Headway  
2635 Delaware Ave., Suite E, Buffalo, NY 14216/716-408-3100  
*(Please take note of Changes to Dates and Times of Support Groups)*

#### PEER SUPPORT

Enter at Suite B  
1st & 3rd Tuesday  
6:30 PM to 8 PM

#### CARE GIVERS SUPPORT

Enter at Suite E  
1st Tuesday  
6:30 PM to 8 PM

#### WOMENS SURVIVOR'S SUPPORT

Enter at Suite E  
1st Tuesday  
1 PM to 2:30 PM

#### YOUTH SUPPORT BY PHONE

Direct contact with Youth Counselor  
Please phone us  
408-3100

DeGraff Hospital  
Dining Conf. Rm/Gr. Fl.

#### PEER SUPPORT IN RURAL COMMUNITIES

3rd Tuesday  
6:30 PM to 8 PM

#### VETERANS/ CARE GIVERS SUPPORT BY PHONE

408-3100

St. Paul's Lutheran Church  
4007 Main Street, Eggertsville, NY  
**COMPLEX REGIONAL PAIN SYNDROME SUPP.**  
4th Monday  
7:00 PM

#### PLEASE NOTE:

*If the Buffalo Schools are closed due to inclement weather, support meetings listed here are also cancelled.*