



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

I Want to Talk About ME! What I want-What I need and how do I get it!

In one of his recent hit country songs, Toby Keith sings, “I Wanna Talk About Me”, expressing his frustration about not being given the opportunity to talk about issues important to him, while the person the song addresses talks incessantly about herself. Advocacy can sometimes be this way. Everyone talks about things that concern him or herself, but often fail to listen to what others are saying. This can be extremely frustrating, especially if what is being said impacts the needs and wellbeing of a person with brain injury.

Advocacy can take many forms, but caregivers of persons with brain injury often become multifaceted advocates. They often are advocates for themselves and for brain injury awareness and supports as a whole. Many persons with brain injury cannot effectively advocate for themselves, thus it can become the role of the caregiver to also become a surrogate “self-advocate” for the needs of the one they care for.

Nancy Johnson, Director of a Masonic Learning Center for Children in Columbus, Ohio, defines self-advocacy as “the ability to understand and effectively communicate one’s needs to other individuals.” She further states; “Learning to become an effective self-advocate is all about educating the people around you.” (www.wrightslaw.com) While this sounds easy, it may not be so easily done.

In order to advocate successfully the facts must be presented in an organized manner. There are several steps that can help lead to effectively self-advocacy.

The steps include;

- Understand exactly what is necessary to meet the need or make the circumstances better.
- Research the best source(s) for getting what is needed and understand the application process to access the appropriate service.
- Support the request with documentation and written records, where possible.
- Assemble documentation before approaching the source of help or service provider.
- Articulate exactly what is needed, why, and the projected end result.
- Respect knowledge, but do not be intimidated by professional titles, positions or degrees.
- Be prepared to communicate upward within an agency or organization if access to the services needed is denied by the front line employees.
- Create a log and document all contacts and communications, whether by phone, in person, or written. This will help in follow-up and in future contact or negotiations.
- Take another person to meetings as an observer. They need not participate, but can provide corroboration on meeting content if it is needed later.
- Thank the people who assist with each step of the effort with a written thank you note. This helps to build alliances and insure future assistance.

Being an advocate for a person with brain injury takes determination. Service systems are sometimes difficult to navigate and there is a shortage of appropriate services. Many professionals in the service systems are unaware of brain injury and their potential need to provide services.

This brings us to the best advice for advocates, words, that ironically, come from another country song. The words “Say It Loud, Say It Clear”, say it all, and this is the best advice we can give.

Partners in Policy Making offers a online training course to help advocates learn how to prepare their case to present it to policymakers. This site includes tools to help individuals with disability and their families make changes that impact their lives through advocacy. The website for Partners in Making Your Case is <http://www.partnersinpolicymaking.com/makingyourcase/index.html>

Advocacy Opportunity

An Open Letter from the Arc of North Carolina

The Division of MH/DD/SAS has been working on the new waivers. The current CAP-MR/DD waiver expires in August 2008 and the Legislature has mandated the development of tiered waivers. The state has requested and is expected to receive authority to extend the current waiver until the end of December 2008 in order to have adequate time to develop a waiver plan that best meets the needs of North Carolinians.

The development of tiered waivers will mean that the waiver that a person receives will be based on their support needs; i.e. Tier 1 will support people with greater independence and less support needs while Tier 4 will serve people with medical fragility and significant behavioral support needs.

The Arc continues to advocate for more flexibility in the waivers, the ability for families and individuals to self direct their supports and services, and for more ability for the Local Management Entities (LMEs) to manage the waivers. To date, the Division has been receptive to input and is attempting to make the waivers user-friendly.

We want to continue to provide positive and rational feedback on how to make the waivers work best for individuals and families. To that end, we really want to know your thoughts. The feedback that would be most helpful is your thoughts on what is currently working, what is hopelessly broken, and what needs to be repaired with the current waiver. Please let us know what you want to see in the new waivers so that we can formulate our advocacy position.

Send an e-mail to lguzman@arcnc.org with what you would like to see with new waivers. Your ideas and suggestions will be used to shape our positions and advocacy as the new waivers are developed.

As drafts of the new waiver plan begin to emerge we will make sure you have the information and we'll make sure you know how to provide your input and feedback. For those of you who are not familiar with the waiver, we have created an Information Page on our website. go to our home page: <http://www.arcnc.org/> and you'll see a link to Service System Information.

Thank you again for your advocacy!

To read the latest information on the CAP MR/DD Tiered Waiver Developments Implementation Bulletin from North Carolina Department of Health and Human Services visit the DHHS website and read Bulletin #39.

<http://www.dhhs.state.nc.us/mhddsas/servicedefinitions/servdefupdates/index.htm>

AGENCY SPOTLIGHT...

Reprinted from Spring 2007

North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) oversees the state's public system of services to persons with Traumatic Brain Injury (TBI).

North Carolina general statute includes traumatic brain injury in the definition of developmental disability. A developmental disability is defined as a severe, chronic disability of a person which:

- Is caused by a mental or physical impairment or a combination of mental and physical impairments.
- Occurs before the person is 22 years of age, unless the disability is caused by a TBI and is sustained after the age of 22.* (**Traumatic Brain Injury services fall into this designation regardless of the age of the individual at the time of onset.*)
- Is likely to continue indefinitely.
- Results in difficulties in three or more areas of major life activities such as self-care, language/communication, living independently, learning, mobility and working.

In North Carolina support is available for eligible individuals of all ages with TBI.

The first step in determining eligibility for services is to contact your Local Management Entity (LME) referral and information line. Intake coordinators will ask questions to, assess needs and the urgency. They may also ask for medical records which document the TBI. This will help determine eligibility for services.

Once eligibility is determined those eligible will be assisted with choosing a service provider in their community who can provide services to meet the needs of the person with TBI. This provider will then work with the individual and family members to determine a personalized service plan.

Person Centered Planning explores what an individual's needs are and ways to address these needs. Some examples of services include in-home support, residential services and assistance with finding a job.

Services may vary in some areas due to the limited services and service provider options available. The local LME will work with eligible individuals to reach the best service options available.

To locate the Local Management Entity or area program that serves your community visit www.dhhs.state.nc.us/mhddsas/tbi or call 919-715-5989.

If there is not a support group that meets near your home, you can contact the closest Regional Family and Community Support Office of the Brain Injury Association of North Carolina for assistance with starting one.

Raleigh 1-800-377-1464 Charlotte 1-877-962-7246
Asheville 1-866-890-7801 Greenville 1-800-697-3115

UPCOMING EVENTS

The National TBI Caregivers' Conference

June 7, 2008

Williamsburg, VA at the distinguished Hospitality House Hotel

The National Resource Center for TBI is proud and pleased to join with other leading organizations in presenting a national conference for caregivers of persons with brain injury. Please share this information with colleagues and friends to help us get the word out about this exciting event.

Conference Name: The National TBI Caregivers' Conference

Location and Dates: Williamsburg, VA June 7, 2008 at the distinguished Hospitality House Hotel adjacent to the historic area.

Description: Family members and caregivers play a crucial role in helping survivors recover after and before discharge from health care settings. With the needs of caregivers in mind, this one-day national conference is designed to provide extensive practical information on achieving recovery. Panel presentations, lectures, discussion sessions, and workshops will cover a wide range of topics including community and home-based rehabilitation, finding and accessing services, recovery, effective advocacy, and rebuilding relationships. Presentations will also cover behavior management, safe driving, return to work and school, emotional recovery, avoiding burnout, and how the brain works. Conference presenters will include experienced caregivers, survivors, and nationally known rehabilitation professionals.

Registration Fee: The fee is \$65 for caregivers who register before April 30th and \$85 afterward. The fee is \$95 for professionals who register before April 30th and \$120 afterward. The registration fee covers the cost of attendance along with lunch, snacks, and refreshments.

Audience: Family members and caregivers of persons with brain injury and other neurological disorders; professionals who provide support and other services to family members and caregivers.

Sponsors and Co-Sponsors: Virginia Commonwealth University, Brain Injury Services, University of Alabama at Birmingham, Memorial Hermann/TIRR (TX), National Resource Center for Traumatic Brain Injury, Brain Injury Association of Virginia. For additional information contact: Linda Lee, llee@braininjurysvcs.org; Phone 703 451-8881

Source: National Resource Center for Traumatic Brain Injury Announcement
<http://www.neuro.pmr.vcu.edu/announce/Training.htm>

More Upcoming Events

- March 10** NC Council of Community Programs- Considerations for Statewide Consumer Organizations: A Symposium for those who utilize Mental Health/Developmental Disability/Substance Abuse Services Who are interested in strengthening the consumer movement by learning new approaches to Leadership. Registration by March 5. For information www.NC-COUNCIL.ORG
- March**
Various dates and times BIANC Walk & Roll-a-thons will be held at six locations across NC. These events raise awareness of brain injury and help raise funds to help the Brain Injury Association of North Carolina serve persons with brain injury and their families. For details contact BIANC at 1-800-377-1464 or visit the BIANC website at www.bianc.net
- June 5-6** Williamsburg Conference- Adult and Child with Brain Injury – Williamsburg, VA www.biausa.org
June 7 National TBI Caregivers Conference – Williamsburg, VA www.biausa.org
- June 6-8** Camp Carefree Brain Injury Survivors Camp for persons with brain injury and their families is hosted by the Brain Injury Association of NC. The camp is located in Stokesdale, NC. This fully accessible camp is a great way to make new friends or to catch up with old ones. To Register: 1-800-377-1464
- June 8** Brain Injury Association of NC Annual Open Board Meeting. This meeting offers persons with brain injury and others the opportunity to address concerns and comments to the board of directors. To request inclusion on the agenda at this meeting please contact BIANC at 1-800-377-1464
- June 21** Annual Waterskiing and picnic at Lake Norman. For additional information contact Project STAR at 704-355-4354

Contributed Article

News from the Statewide TBI Advisory Council

By Marilyn Lash, Chair

I officially became the new Chair at the December meeting of the NC Statewide Brain Injury Advisory Council. Our new Vice Chair is Jo Perkins from the NC Division of Vocational Rehabilitation. I am asking for your help as we enter 2008.

There is a lot going on regarding the "state of the State of North Carolina" when it comes to services and funding for brain injury. Some of it is good news and some of it not so good. It is clear that this is the year when all of us need to speak up and become involved to be sure that we are heard by everyone - legislators, policy makers, lead agency staff and community advocates.

The Advisory Council has gone through an extensive process of analyzing data, reviewing policy needs, examining gaps in services, and discussing reports from needs assessments. This is the year that we will be putting this work into recommendations for action by the Legislature, the Governor and the Division of Mental Health in a written report

The major issues that we are working on include...

- Increasing commitment and funding for brain injury services and programs by the Division of Mental Health.
- Broadening the definition used by state agencies from "traumatic" brain injury to "acquired" brain injury to insure that persons with non-traumatic injuries such as brain infections, brain tumors, loss of oxygen due to cardiac arrest or near drowning have access to services.
- Establishing neurobehavioral services for crisis care, consultation and training.
- Exploring creation of a Trust Fund with dedicated funds for services for individuals with brain injuries and their families.
- Creating definitions for brain injury services for payment by Medicaid.

None of this will happen without a lot of hard work, support and advocacy from our brain injury community. You are the most important members of that community and I will be asking for your help as we move forward.

WWW. HELP!
finding information to help family caregivers

Family caregivers often struggle to find the support and information they need. With the volume of information available on the internet, there are more resources and information available than ever before. Many of the websites are interactive and allow family caregivers the opportunity to communicate and share ideas with other caregivers. These websites offer a wealth of information to benefit, not only the person receiving care, but also the family member who is providing care.

The websites listed below are some examples of the type of interactive web support that is available.

Caregiver.Com Magazine Website

<http://www.thefamilycaregiver.org>

The National Family Caregiving Association (NFCA)

<http://www.familycaregiving101.org>

National Alliance for Caregiving

<http://www.caregiving.org>

The National Caregivers Library

<http://www.caregiverslibrary.org>

TBI Help Desk for Caregivers

<http://www.tbihelp.org>

NC Family Caregiver Support Program

<http://www.dhhs.state.nc.us/aging/fcaregr/fchome.htm>

Tips and Tidbits

A TOOLKIT TO HELP UNDERSTAND MEDICAID FROM ALLIANCE OF HEALTH REFORM

Have you had a difficult time understanding just what Medicaid is and how works? In November of 2007 the Alliance of Health Reform issued a toolkit on Medicaid designed to help journalists understand government health care funding programs during the 2008 elections. This toolkit is not only a valuable tool for those in the media, it can also help caregivers and health care advocates of persons with disability understand the Medicaid funding streams. The toolkit will help people understand who the Medicaid program covers, how it is financed, how it differs from Medicare, how states can alter Medicaid through federal waivers, and what the future holds for the program.

To download this toolkit or to read it on line, visit the website for the Alliance For Health Reform at <http://www.allhealth.org/publications/Medicaid/Medicaid Toolkit 75.asp>

Camp Carefree Photo Album

Photos from Camp Carefree over the years. Plan to add YOUR PHOTO to the 2008 Album



Pictures from Camp Carefree supplied by The Brain Injury Association of NC

Contact BIANC to reserve
YOUR space
1-800-377-1464

RESOURCES **LOOKING FOR HELP?**



Finding resources and information can be like looking for a needle in a haystack. While there are many agencies and resources that can help meet the needs of persons with brain injury and their caregivers, locating the right service can at times be challenging. Some communities offer services that are unavailable in others, but state and federal agencies serve all areas.

The Brain Injury Association of North Carolina has created a Brain Injury Resource Guide to help persons with brain injury in North Carolina locate resources that may meet their needs.

The resource guide lists state and local services and agencies that serve persons with TBI and is available on the Brain Injury Association of North Carolina's web site at www.bianc.net, or you can request a printed copy by contacting The Brain Injury Association of North Carolina at 1-800-377-1464.

Information shared in contributed articles does not necessarily reflect the opinions of Project STAR or Carolinas Rehabilitation. Websites and other information sources are intended to be used at the readers discretion and inclusion in this publication is not intended as an endorsement or recommendation.

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