



THE INDEPENDENT

*the hardest battle is to be nobody-but-yourself
in a world that is trying to make you like everybody else.*

e.e. cummings

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**PLEASE COMPLETE AND RETURN
THE SURVEY CONTAINED IN THE
NEWLETTER. THE INFORMATION
WILL HELP US SERVE YOU MORE
EFFECTIVELY.**

TRAUMATIC BRAIN INJURY ACCOMMODATIONS IN THE WORKPLACE:

According to the Brain Injury Association (2005), a traumatic brain injury (TBI) can be caused by a hard hit or jolting impact to the head (closed head injury) or by a penetrating object, such as a bullet (open head injury). Specific statistics of interest include:

Although not all insults to the head result in a TBI, approximately 1.4 million people experience a TBI every year;

The majority of individuals affected by TBIs, 79%, receives medical attention and are subsequently discharged from the emergency department;

Seventeen percent of individuals with TBIs are hospitalized for further treatment and rehabilitation, while the remaining four percent

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(about 50,000) do not survive.

The most common causes of TBI include falls, motor vehicle accidents, motor vehicle/pedestrian accidents, and assaults; Children from birth to age four and adolescents aged 15-19 are most at risk, with males being more likely than females to sustain a TBI;

African Americans suffer more deaths from TBI than any other group; and Military personnel frequently experience TBI from blast injuries inflicted by Improvised Explosive Devices (IED's) (Brain Injury Association, 2005).

Depending on the severity of the injury, a TBI survivor may not have any limitations, while another may struggle with daily living. Even if two people have the same type of brain injury, their outcomes may differ based on physical health and cognitive ability prior to the injury, the quality and duration of rehabilitation services, and family support.

Specific limitations hinge on what part of the brain was damaged by the injury, and any bodily system may be impaired as a result. Some survivors may have impairments related to gross motor limitations (walking, balancing, coordination), fine motor limitations (handling, fingering), bowel and bladder control; handling stress and emotions; and speech impairments.

Cognitive limitations may involve difficulty with memory, problem solving, math, reading, or “executive functions”, such as planning/organizing/prioritizing/decision-making. In some cases, because the parts of the brain that process auditory and visual information were damaged in a TBI, a person may have trouble comprehending what is seen or heard despite intact vision and hearing.

Accommodations for employees with TBI depend on the nature of their limitations, what bodily systems are affected, and essential job functions. Suggestions for accommodating cognitive deficits, psychological issues, motor impairments, sensory deficits, and speech difficulties due to TBI can be accessed at www.jan.wv.edu or by using the Searchable Online Accommodation Resource (SOAR) at www.jan.wv.edu/soar/.

Information appeared in Job Accommodation Network’s (JAN) *JAN E News*, Volume 6, Issue 1, First Quarter, 2008. Author-Laura K. Artman, MS, CRC, Graduate Research Assistant.

Reprinted in NYS E-Bulletin, April, 2008

**NATIONAL STROKE ASSOCIATION
OFFERS WEB-BASED RESOURCE
DIRECTORY**

Recovery from stroke is a challenging journey that can last a lifetime. It can also be a new beginning with many unexpected positive benefits. Whether managing life at home or in a care facility, finding the right services and programs makes an important difference in quality of life.

For stroke survivors and families, situations, needs and finances often change. The key is to determine what you need, learn about the types of resources available, and then find those resources. National Stroke Association

wants survivors and caregivers to achieve the best quality of life possible, and is here to help make the recovery journey easier.

Starting April 15, 2008 National Stroke Association invites you to visit its new web-based Resource Directory at <http://www.stroke.org/> to learn about different types of resources as well as find numerous regional and national resource links.

Information appeared in the National Stroke Association’s *Brain Alert Newsletter*, April, 2008 which can also be found at their web site www.stroke.org.

**SPEAK OUT AGAINST
DANGEROUS LEGISLATION
TO LIMIT ACCOUNTABILITY
FOR POOR MEDICAL CARE**

There is legislation in both the NY Senate and Assembly that seeks to drastically limit the ability of people who have suffered injury due to poor medical care from seeking redress in court. While there are many fine caregivers in New York State, there are, unfortunately, some "bad apples" and it is crucial that people who have been victims of poor care have the ability to seek adequate compensation for the harm they have suffered and their losses.

This not only provides a means to help compensate them for their suffering, it also provides a very important deterrent for those medical practitioners who are not otherwise motivated to provide good care.

Please send a message to your leaders in Albany and your local news media to protect the rights of victims of medical negligence

Information appeared in the April 2008 issue of the Long Term Care Community Coalition's e-newsletter which can be read at <http://www.assisted-living411.org>.

RAYMOND'S ROOM BOOK OF THE YEAR FINALIST; RELEASED IN BRAILLE

Raymond's Room: Ending the Segregation of People with Disabilities by Dale DiLeo has been named a book of the year finalist by *Foreword* magazine. The book also has been released in Braille by the National Library System (NLS), one of 650 books chosen nationally.

Foreword is a national magazine that features reviews of books from independent publishers. It reviewed *Raymond's Room* last spring. The tenth annual Book of the Year Awards "represent some of the best work coming from today's independent press community," according to Whitney Halberg, associate editor of *Foreword*. The program was designed to discover distinctive books across a number of genres. *Raymond's Room* is a finalist in the family and relationships category.

Raymond's Room: Ending the Segregation of People with Disabilities is published by Training Resource Network, Inc., and can be ordered at <http://www.raymondsroom.com>, 800-280-7010, amazon.com or your local bookstore. Cost of a hard copy is \$25.00

DISABILITY SAVINGS ACCOUNT

Senator Christopher Dunn (R-Conn.) has introduced the Disability Savings Act of 2008. The purpose of the proposed legislation is to

encourage individuals with disabilities and their families to save private funds for disability-related expenses to supplement, not supplant, benefits provided by other sources (including Medicaid and private insurance) so that people with disabilities can maintain health, independence, and quality of life.

This legislation encourages individuals with disabilities and their families to save personal funds for their unique disability-related needs in Disability Savings Accounts (DSAs). The establishment of DSAs will promote the investment of private funds in the long-term well-being of individuals with disabilities through tax-advantaged savings tools, including a refundable tax credit for low-income savers, while protecting the beneficiary's access to critical public supports.

DSAs will provide a tax-advantaged mechanism for individuals with disabilities to save money.

Funds expended from the DSA for specific services such as education, medical services, employment training and support, transportation, and other related services will be tax-free.

Interest on accounts with a balance of \$250,000 or less is tax free.

Low income earners will receive a refundable matching tax credit of up to \$1000 for their contributions to the DSA.

Funds from college savings plans and special needs trusts for the same beneficiary can be rolled into the DSA without penalty.

Beneficiaries of the account must be determined to be blind or disabled by the Social

Security Administration or the Disability Determination Service of a state and be under the age of 65. The account can be held and managed by the beneficiary, their spouse or family member, or a legal guardian through a financial institution. The DSAs are designed to be easier to manage and set up than current savings mechanisms, which often require the expensive services of an attorney. Beneficiaries or their representative can expend funds directly from the account for services. Assets held in the fund will not be counted against eligibility for Medicaid and SSI or other federal support services.

For more information, go to <http://dodd.senate.gov:80/index.php?q=node/4316/print>

INFORMATION APPEARED IN PROGRAM DEVELOPMENT ASSOCIATES WEBLETTER News and Information for Disability Professionals Volume #12 – 47th Edition April 4, 2008

TRAUMATIC STRESS

Families and friends of returning services members often wonder what to expect after their loved ones come home from a combat zone. Read about how to help family members in this fact sheet from the Center for the Study of Traumatic Stress at:

<http://www.healthyminds.org/docs/CSTSHelpingYourLovedOnes.pdf>

If you cannot access it via computer, call Chris and she'll mail you a hard copy of the 2 page document.

AAPD URGES U.S. SENATE TO CONSIDER 21ST CENTURY COMMUNICATIONS AND VIDEO ACCESSIBILITY LEGISLATION FOR PEOPLE WITH DISABILITIES

The American Association of People with Disabilities (AAPD), the largest cross-disability membership organization in the U.S., was pleased with the outcomes of the May 1st hearing held on Capitol Hill by the U.S. House Subcommittee on Telecommunications and the Internet chaired by Representative Edward Markey (MA) The hearing focused on draft legislation, "Enhancing Access to Broadband Technology and Services for Persons with Disabilities."

AAPD now urges the U.S. Senate to consider similar legislative steps to ensure equal access to technology for people with disabilities.

Hearing witness Jamaal Anderson, defensive end and 2007 first round draft pick of the NFL Atlanta Falcons whose father is a leading deaf educator and former board member of Gallaudet University, testified.

Another witness, Russell Harvard, a deaf Hollywood actor provided his testimony through sign language, asking the Committee to require accessible user interfaces and controls on TV sets and players.

Sergeant Major Jesse Acosta, a Purple Heart army veteran whose vision was severely injured by mortar attack in Iraq, offered his testimony in support of the thousands of veterans with vision disabilities, including those returning from Iraq with eye injuries.

These witnesses' statements support the legislative and regulatory agenda of the Coalition of Organizations for Accessible Technology (COAT).

But other witnesses had objections to the legislative proposal. Dane Snowden, representing the Cellular Telecommunications & Internet Association (CTIA), stated that it "was well intentioned but would lead to potentially inflexible regulations." Ken Nakata of Disability Initiatives and Government Compliance BayFirst Solutions, though agreeing on the need for legislation, suggested that there should "be procedural safeguards." Chairman Markey called industry objections "eerily similar" to earlier opposition to enact the original closed captioning law in 1990.

Larry Goldberg, Director of the Media Access project at WGBH-TV in Boston, MA, presented information on technological feasibility.

As I write this, the proposal has not been reported out of committee or assigned a bill number. The archived [video of the hearing](#), including the witnesses' statements, can be found on the House Subcommittee's website. At http://energycommerce.house.gov/cmte_mtgs/110-thrg.050108.Disabilities.shtml. As of June 19, there was no text available on the site.

The only NY member of subcommittee is Eliot Engel representing Bronx, Westchester and Rockland. He can be contacted at 2161 Rayburn HOB, Washington, DC 20515, Phone: (202) 225-2464; (202) 225-1904 (House TTY number); Fax: (202) 225-5513. E-mail him through his website at <http://engel.house.gov/>. Click the contact button.

Subcommittee on Telecommunications and the Internet members can be contacted at Sub Committee on Telecommunications and the Internet, 2125 Rayburn House Office B., Washington, DC 20515; 202-225-2627(v); (202) 225-1904 (House TTY number).

Edward Markey (D-MA), subcommittee chair can be e-mailed through his web site at <http://engel.house.gov/>

Contact subcommittee members and ask that the proposal be reported out of committee.

<p>HEARINGAID ASSISTANCE TAX CREDIT ACT – H.R. 2329/S. 1410</p>
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You most likely know someone who has a hearing loss. Whether it affects a relative, child, friend or co-worker, or even yourself, hearing loss is a prevalent and often neglected concern. Hearing loss affects over 30 million Americans or 1 in every 10 people; in fact, it's the second most common birth defect. Despite these staggering numbers and the fact that hearing aids could treat 95% of all hearing loss, Medicare and most insurance policies expressly exclude coverage, making treatment an expensive endeavor. The Hearing Aid Tax Credit (H.R. 2329 and S. 1410) is legislation drafted with these real concerns in mind. If enacted, it would provide a \$500 tax credit per hearing aid available once every 5 years for dependents and for those aged 55 and older.

With an average cost of \$1,800 including fitting and follow-up, hearing aid treatment can result in unexpectedly high costs for the average American. The tax credit would help millions of people seeking hearing aid treatment since \$500 can make the difference when deciding

whether you can afford treatment. The tax credit has wide bi-partisan support, is supported by nearly every hearing health organization and advocacy group, and addresses a real and too often ignored healthcare need. Your support is needed, however, to let your Senators and Representative know that the Hearing Aid Tax Credit would make a real difference in your life. So please, contact your Congressmen and tell them how the Hearing Aid Tax Credit could help you.

The House bill H.R. 2329 is in the House Ways and Means Committee. Our Representative Brian Higgins is a member. Contact him at 2 East Second St., Suite 300, Jamestown, NY 14701, 484-0729 or 431 Cannon House Office Bldg., Washington, DC 20515. (202) 225-3306 (v); (202) 225-1904 (House TTY number).

Senator Clinton is one of the co-sponsors of the Senate version, S. 1410. Contact her at United States Senate, 476 Russell Senate Office Bldg., Washington, DC 20510;(202) 224-4451 (V); (202) 224-6821 (TTY).

The Senate bill is in the Senate Committee on Finance. The committee's address is 219 Dirksen Senate Office Building, Washington, DC 20510-6200, (V) (202) 224-4515. Max Baucus is the chairman. I was not able to find a tty number for him.

Contact Max Baucus and Brian Higgins and tell them you want these bills to clear their respective committees.

HEALTH 08.ORG

Voters have identified health care as the leading domestic issue for the government to address and for the presidential candidates to discuss in the 2008 campaign. In particular, voters would

like to hear the candidates' positions on reducing the cost of health care and health insurance and expanding coverage to the 47 million uninsured Americans.

This side-by-side comparison of the candidates' positions on health care was prepared by the Kaiser Family Foundation with the assistance of Health Policy Alternatives, Inc. and is based on information appearing on the candidates' websites as supplemented by information from candidate speeches, the campaign debates and news reports. The sources of information are identified for each candidate's summary (with links to the Internet). The comparison highlights information on the candidates' positions related to access to health care coverage, cost containment, improving the quality of care and financing. Information will be updated regularly as the campaign unfolds.

To view information, go to <http://www.health08.org/sidebyside.cfm>

ELECTION DAY

An historic presidential election is coming up. Barack Obama the Democrat's presumptive nominee is the first Black candidate of a major political party. His web site includes a recorded message on inclusion of people with disabilities.

John McCain, a decorated Vietnam War veteran has long been known as a maverick, often breaking from traditional Republican Party principles. The list of issues on his web site does not have a specific category "disability". However, it lists his concerns about autism research and availability of health insurance for people with pre-existing conditions.

Regardless of your political views, it's imperative that **YOU MAKE YOUR VOICE**

HEARD! You can't vote often, as the old joke about Chicago politics goes, but you can and must vote!

The General Election is November 4. Mail registration applications must be postmarked no later than **October 10** and received in Mayville no later than **October 15** to be eligible to vote in the general election. Helen has voter registration forms. Come in or call her at 661-3010 if you need one. Forms are available on line at the NYS Board of Election's web site at <http://www.elections.state.ny.us/>. You can also find your polling place there.

You may register at your local board of elections or any state agency, including our office, participating in the National Voter Registration Act, on any business day throughout the year but, to be eligible to vote in the general election, **your application must be received no later than October 10**, except if you have been honorably discharged from the military or have been a naturalized citizen since October 10, you may register in person at the board of elections up until **October 24**.

Notices of change of address from registered voters received by **October 15th** by the county board of elections must be processed and entered in the records in time for the general election.

October 28 is the last day to postmark application or letter of application for ballot. **November 3** is the last day to apply in person for an absentee ballot. It must be received by the board of elections no later than **November 11**.

November 4 Last day to deliver a ballot in person to the board of elections.

NEW YORK STATE INCLUSIVE RECREATION CENTER ANNOUNCES NEW WEBPAGE

SUNY Cortland was funded by the DDPC to establish the Inclusive Recreation Resource Center. The mission of the center is to promote and sustain participation by people with disabilities in inclusive recreation activities and resources throughout the state.

The Center's website provides an easy entry point for people with disabilities seeking inclusive recreational opportunities in New York State. It features an online database of recreational amenities and assessments of those amenities that have been conducted by volunteers trained by the center. It also features information on training offered by the Center on becoming an Inclusivity Center and on how to be an Inclusion Advocate. There is also a recreation referral service offered through the Center that assists participants with disabilities to meet their recreational needs.

To visit the Inclusive Recreation Center's website please visit the following link: www.cortland.edu/nysirrc

Information appeared in *NYS E- bulletin*, June 2008.

TRANSPORTATION FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Through a grant from the Western New York Developmental Services Office, Southwestern Independent Living Center provides FREE evening and weekend wheelchair accessible transportation to Chautauqua County residents who are living with family members. This

service is not exclusively for people living with parents. Riders can live with their parents, spouse or their own children. Riders can use this transportation service throughout the county for recreational purposes. Riders must provide documented proof of disability.

For more information, call Helen at 661-3010.

THIS NEWSLETTER CAN BE MADE AVAILABLE IN ALTERNATIVE FORMATS- LARGE PRINT, BRAILLE, TAPE AND E-MAIL. FOR MORE INFORMATION, CALL CHRIS AT 661-3013(V/TTY) OR E-MAIL ME AT chris@ilc-jamestown-ny.org

MEDICAL ASSISTANCE GRANTS

The UnitedHealthcare Children's Foundation is offering support to meet the needs of children across the United States with assistance grants for medical services not fully covered by health insurance.

Parents and caretakers across the country will be eligible to apply for grants of up to \$5,000 for healthcare services that will help improve their children's health and quality of life. Examples of the types of medical services covered by UHCCF grants include speech therapy, physical therapy, and psychotherapy sessions; medical equipment such as wheelchairs, braces, hearing aids, and eyeglasses; and orthodontia and dental treatments

Any child 16 years old or younger living in any UnitedHealthcare region of the United States (all 50 states) and in need of financial assistance for healthcare services will be considered eligible for a grant. Families must meet

economic guidelines, reside in the U.S., and be covered by a commercial health insurance plan. Highlighted criteria for applying: The income max is based on "per individual" in the household, family Adjusted Gross can't exceed \$80,000. Visit their website at www.uhccf.org/ and learn more about it. They also have a great Frequently Asked Questions Section.

Criteria (modified from their website www.uhccf.org/criteria.html)

*Any child, 16 years old or younger

The applicant must be covered by a commercial health insurance policy and limits for the requested service are either exceeded, or no coverage is available and/or the copayments are a serious financial burden on the family.

*Consideration will be given, but not be limited to, criteria such as the potential of the intervention to significantly enhance either the clinical condition or the quality of life for the child, the financial status of the family and the severity of the child's illness.

*Financial need of the child's family should be documented through information provided on the application and by submission of a copy of the most recently filed tax return. Generally, awards will be granted to individuals in families whose adjusted gross income per individual does not exceed \$20,000. If you have 4 people in your family AGI cap would be \$80,000. Other financial resources to meet the health care need are not available.

*The amount awarded to an individual within a 12-month period is limited to either \$5,000 or 85% of the fund balance, whichever amount is less. Awards to any one individual are limited to a lifetime maximum of \$7,500. An application must be submitted prior to the child's 17th birthday.

To apply visit: www.uhccf.org/

Information appeared in NYS E-bulletin, May 2008

CONSUMER SATISFACTION SURVEY

PLEASE CHECK IF YOU AGREE OR DISAGREE WITH THE FOLLOWING:

1 .Southwestern Independent Living Center's staff I met or spoke with assisted me willingly and promptly.

AGREE _____ DISAGREE _____

2. The staff I met or spoke with had the knowledge and the skills necessary to assist me.

AGREE _____ DISAGREE _____

3. The staff I met or spoke with presented the information clearly.

AGREE _____ DISAGREE _____

4. The staff made an effort to understand my specific needs.

AGREE _____ DISAGREE _____

5. I was able to count on the staff to do what they said they would do.

AGREE _____ DISAGREE _____

6. The staff treated me with respect and courtesy.

AGREE _____ DISAGREE _____

7. I felt satisfied overall with the Southwestern Independent Living Center.

AGREE _____ DISAGREE _____

8. All Southwestern Independent Living Center programs/resources are accessible to me.

AGREE _____ DISAGREE _____

9. Southwestern Independent Living Center's programs and resources enhance my ability to live, learn or work.

AGREE _____ DISAGREE _____

10. I always felt in charge of my own services.

AGREE _____ DISAGREE _____

11. I would recommend Southwestern Independent Living Center to others.

AGREE _____ DISAGREE _____

General Comments:



TRANSITION NEWS



NEW GUIDANCE FOR HOMELESS STUDENTS WITH DISABILITIES

In April, the Office of Special Education and Rehabilitative Services of the U.S. Department of Education issued a Question and Answer Document (at <http://www.ed.gov/about/offices/list/osers/index.html?src=mr;> put homeless in the search box) for guidance on implementing the Individuals with Disabilities Education Act (IDEA) in conjunction with the McKinley-Vento Homeless Assistance Act to serve homeless children with disabilities.

The McKinney-Vento program is designed to address the problems that homeless children and youth have faced in enrolling, attending, and succeeding in school. Under this program, state educational agencies (SEAs) must ensure that each homeless child and youth has equal access to the same free, appropriate public education, including a public preschool education, as other children and youth. Homeless children and youth should have access to the educational and other services that they need to enable them to meet the same challenging state student academic achievement standards to which all students are held. In addition, homeless students may not be separated from the mainstream school environment. States and districts are required to review and undertake steps to revise laws, regulations, practices, or policies that may act as a barrier to the enrollment, attendance, or success in school of homeless children and youth.

This document included significant language suggested by the National Law Center on Homelessness and Poverty (NLCHP) and its partners, the National Association for the Education of Homeless Children & Youth and the National Center on Homeless Education.

This guidance provides questions and answers relating to homeless children and the general requirements to educate children with disabilities, the “child find” requirements of the IDEA, evaluations for special education services, eligibility and individual education plans, schools of origin for homeless students, unaccompanied youth and surrogate parents, early intervention services for infants and toddlers, and coordination between McKinley-Vento and Special education services.

NLCHP and its partners are continuing to work with the Department to ensure all students receive the services to which they are entitled. Groups interested in collaborating on comments should contact NLCHP Children & Youth attorney Eric Tars through their web site, www.nlchp.org, or can send comments directly to OSERSguidancecomments@ed.gov (put the word “Homelessness” in the subject line of your e-mail).

