

Developmental Disabilities Hospice & Palliative Care

E-Newsletter

October 2008 Vol. 2(10)

[October is Disability Awareness Month](#)



The Disability Resource Center at the Hudson Valley Community College in Troy, NY is conducting disability awareness events throughout the month of October. Please click on this [link](#) to get a complete list of planned events.

[Remember - November is National Hospice Month!](#)

Visit [NPHO](#) to find outreach tools and resources to help increase awareness!

[In the News](#)

I/DD Hospice and Palliative Care Issues

► On September 8th-10th the NY Association on Independent Living (NYAIL) and the NY State Independent Living Council conducted a conference entitled, '*Taking Action for Independence: Confrontation and Controversy*' in Albany, NY. One key goal of the conference was to develop strategies for advocacy around a variety of systemic issues, including ensuring all folks with disabilities of all kinds can live and receive services in the most integrated setting. Governor Patterson gave the opening address for this conference. You can view the address by following this [link](#) and then scrolling down to: [09.08.2008 Governor Paterson addressing the New York Association on Independent Living](#).

► The Wall Street Journal recently asked the question, *Should Patient Bracelets Announce End-of-Life Choices?*

The use of colored bracelets has been suggested for use in New York City's 11 hospitals in an effort to alert hospital staff to patients' end-of-life choices. The practice has put into place in a few other states, and remains controversial. The idea is running into trouble in New York City, with detractors citing concerns about branding patients by their end-of-life choices, or inadvertently broadcasting those choices to family and friends who have not been consulted. Read the entire article as well as the community comments and opinions by following this [link](#).

► A recent ***New York Times*** article highlights how children with developmental disabilities and their families received national attention after the Republican convention last month when Sarah Palin appeared onstage with her son, Trig, who has Down syndrome. Governor Palin made a pledge to the families of special needs children stating that, "if we are elected you will have a friend and an advocate in the White House." Disability advocates state that the last time a candidate explicitly appealed to families of the disabled at a national convention was 20 years ago, when the presidential nominee, George H. W. Bush, endorsed the Americans with Disabilities Act. Yet the NY Times reports that many remain divided over what Palin's pledge of advocacy would really mean. To read the entire article click on the link below:

[*Parents of Special-Needs Children Divided over Palin's Promise to Help*](#)

► A study recently published in '*The Journal of the American Medical Association*' highlights the benefits and importance of end-of-life conversations for individuals and their caregivers, both before and after the death of their loved one. Investigators show that patients who reported having end-of-life discussions with their physicians did not feel more depressed, worried, or sad than those who did not. Science Daily spoke with the authors who noted that, "*Our results suggest that end-of-life discussions may have cascading benefits for patients and their caregivers...the way people die has a profound impact on the way their loved ones live on afterwards.*" To read the entire article click on the link below:

[*Benefits of End-of-life Conversations*](#)

► Although end-of-life communication is beneficial, researchers at the Dana-Farber Cancer Institute report that physicians who frequently care for individuals at the end of life, are not routinely provided training in effective communication or in conducting compassionate end-of-life conversations. One recent study, published in the Journal of Psychosocial Oncology, reports that participation in a program designed to foster communication skills can have a positive and lasting effect on the physician's delivery of end-of-life care. To read more about the program click on the following link:

[*End Of Life Physician-patient Communication*](#)

Public Policy & Advocacy Opportunities

Developmental disability and end of life policy as such, is not the kind of thing you're likely to hear very much about in an election season. The mainstream media does not often report on it, and the candidates were not questioned on these issues during their debates.



Yet in the final debate, while no mention was made of end-of-life issues, the topic of developmental disability policy was discussed by both presidential candidates! This may be a recognition that this is a subject of profound importance to millions of Americans, including the more than 37 million individuals with disabilities that are eligible to vote in this country, as well as the countless other family members, caregivers, advocates and professionals who are in service. We felt that it was important to provide some information with regard to the policy views of each of the 2008 presidential candidates.

~Unfortunately, while each candidate has presented a position with regard to Developmental Disabilities, neither has publicly presented a position on end-of-life issues~

▶ On July 26th, in Columbus, Ohio, the disability community hosted an historic, non-partisan '**National Forum on Disability Policy.**' The forum featured time slots for the presidential candidates to individually present their visions for the future of disability policy in America followed by questions by the moderator, Judy Woodruff. Senator John McCain agreed to participate and spoke with attendees via satellite webcast from Arizona. Unfortunately, Senator Barack Obama was not able to participate, but asked Senator Tom Harkin to attend as his surrogate for the forum. Reviewing this forum will give you a good idea about the positions and policy implications of each candidate.

This forum was webcast and can be viewed in its entirety by using this link [National Forum on Disability Policy](#).
The forum is also available in written form; follow this link to download a transcript of the event in PDF form: [National Forum on Disability Policy](#)

▶ The 'American Association of People with Disabilities' (AAPD) has provided a very useful, one-stop shop, informational web-page that will provide viewers with key information about the positions of each candidate (and their running mates) on developmental disability policy with links to their respective websites, press releases and party platform synopses. To view this resource, simply click on the names of either of the presidential tickets below:

~~ [Barack Obama & Joe Biden](#) ~~ "*We must build a world free of unnecessary barriers, stereotypes, and discrimination....policies must be developed, attitudes must be shaped, and buildings and organizations must be designed to ensure that everyone has a chance to get the education they need and live independently as full citizens in their communities.*"

~~ [John McCain & Sarah Palin](#) ~~ "*When men and women with disabilities are excluded from joining fully in the life of our nation, that is an injustice to them and it is a loss to America...The offer of assistance in living with a disability should not come with the condition of perpetual confinement to an institutional setting. The great goal here should be to increase choices, to expand freedom, to open doors, and to allow citizens with disabilities to live where they want and to go where they wish.*"

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▶ In the Capital District area, **Assemblyman Roy McDonald** has been very vocal about his intentions to lead the effort on disability awareness. As the grandfather of two autistic children Roy has taken the issue to the assembly with the proposal of '**The Better Focus on Autism Now Act of 2007.**' Roy recently announced his intention to run for the Senate seat, left vacant by retired Senator Joe Bruno. The 43<sup>rd</sup> Senate District includes Rensselaer County and part of Saratoga County. To learn more about his proposed legislation, or to contact Roy simply follow this link: [Roy McDonalds Proposals](#)



**Hospice legislation update** – Last month we reported on the planned. Hospice rate cuts to be implemented on October 1st, 2008, and asked readers to contact their representatives in support of the **Medicare Hospice**

**Protection Act**, a bipartisan effort meant to delay the reduction of the wage index that would significantly impact hospice reimbursement rates that Medicare had put forth earlier this year. As a result of such Advocacy, 119 members of the House and Senate have cosponsored the Medicare Hospice Protection Act since September 11<sup>th</sup>, 2008, however Congress has since adjourned without resolution to the issue. Follow this [link](#) to keep updated on the progress of this important act!



### **Direct Support Professionals Fairness and Security Act of 2007**

This Act calls for the amendment of the Medicaid Program (Title XIX of the Social Security Act) to provide additional State funding in order to increase wages for direct support professionals serving people with disabilities under the Medicaid program. This act was introduced in March, 2007 and has now been co-sponsored by 129 House Representatives. Follow this [link](#) to read about the current status of the bill or to take action for support. For a better understanding of the Act use this [link](#) to read a fact sheet created by ARC.

## **Information and Resources**

► The [Hospice Foundation of America](#) has announced that it is accepting applications for *'Children and Adolescence Grief Grants'*

The foundation will provide grants of up to \$5,000 for program-related expenses (including but not limited to purchase of equipment or materials, publications, or other curriculum-related materials). *"Priority will be given to programs that offer innovative programs for both children and adolescents, as well as programs that focus on outreach to diverse populations."*



Click on the Hospice Foundation logo to get complete information about the grant and the application process.

### **"Variability in Access to Hospital Palliative Care in the United States"**




There has been rapid growth of new, innovative palliative care consultation services in the nation's hospitals. More than half of the 50-bed or larger hospitals in the U.S. offer palliative care services to ease pain and suffering for seriously ill patients and their families. However, according to a study published in the October 2008 issue of the peer-reviewed, *Journal of Palliative Medicine*, the availability of these services varies widely across geographic regions. The study is available for you to view online, simply click on the journal logo to access the article.

► The [Journal of the American Medical Association \(JAMA\)](#) has recently published two articles on the topic of end-of-life communication. Both articles are summarized and presented below for you to view.

- **"End-of-Life Conversations: Evolving Practice and Theory"**


This article examines the evolution of and need for "end-of-life conversations." Barriers to end-of-life discussions that have been identified in patients and families, health care professionals, and health care systems can seriously interfere with the quality of remaining life for terminally ill patients. Strategies for enhancing end-of-life discussions are most

productively linked to (1) physicians' interpersonal communication skills, (2) a patient-centered model of care, (3) a focus on quality of remaining life, and (4) innovative clinical models for implementing these discussions earlier in the care process. The article concludes that end-of-life conversations must become a routine, structured intervention in health care and that advance care planning is best viewed as one component in a series of ongoing end-of-life discussions.

 Follow this link to the article

- **“Ensuring Competency in End-of-Life Care: Communication and Relational Skills”**

This article presents a 7-step approach for physicians for structuring communication regarding care at the end of life. These 7 steps can be used in situations such as breaking bad news, setting treatment goals, advance care planning, withholding or withdrawing therapy, making decisions in sudden life-threatening illness, resolving conflict around medical futility, responding to a request for physician-assisted suicide, and guiding patients and families through the last hours of living and early stages after death. The Effective application of these steps, as part of core end-of-life care competencies, is likely to improve patients' and families' experiences of care. It may also enhance physicians' professional fulfillment from satisfactory relationships with their patients and patients' families.

 Follow this link to the article

**Developmental Disabilities Hospice & Palliative Care Online Discussion Forum** is an online discussion forum is a collaborative initiative by NYSARC Inc. and The Hospice and Palliative Care Association of New York State, with funding provided by the NYS Developmental Disabilities Planning Council.



~~The forum was developed to provide a safe and accessible platform that would encourage a learning dialog to take place between the developmental disabilities and the hospice/palliative care service provider communities and advocates. The goal of the forum is to improve end of life care for persons with developmental disabilities through greater utilization of hospice and palliative care services.

~~ The forum features a professionally facilitated discussion board where registered members are able to post questions and concerns and then receive answers from experts and/or their peers on a specific topic. Each of you have a wealth of experience to share, and together this can be a thriving community with shared ideas to improve end of life care for persons with developmental disabilities and all who are close to them.

- There is still time to join our current discussion, '*Issues of Dementia in Palliative Care.*' To view this topic, just follow this [link](#).
- Next month our topic will be '*Holistic Care and Alternative Therapies in Palliative Care*' please consider joining us for this fascinating discussion.

Not yet a member?

**Joining is easy!** Simply visit the forum's registration page [Here](#) and register today!

## Upcoming Events ~~ Mark your Calendar

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| <p><b>Oct. 20 -23, 2008</b><br/> <b>Monday -Thursday</b></p> <p>HVCC<br/>             80 Vanderburgh<br/>             Ave Troy, NY<br/>             12180-6096</p>                                                            | <p style="text-align: center;"><b>Disability Film Series and Assistive Technology Demonstrations</b></p> <p>The Disability Resource Center at Hudson Valley Community College will be showing a variety of films related to various disabilities. This film series is to educate, promote and increase awareness among individuals in our society.</p> <p style="text-align: center;">For more information, visit the <a href="#">Hudson Valley Disability Resource Center</a></p>                                                                                                                                                                                                                                                                                                                       |
| <p><b>October 27-29, 2008</b><br/>             Monday-<br/>             Wednesday</p> <p>Stony Point Center<br/>             17 Crickettown<br/>             Road<br/>             Stony Point, NY<br/>             10980</p> | <p style="text-align: center;"><b>Workshop and Disability Conference</b></p> <p>The 2008 Worship and Disability Conference, "Being Whole in the Eyes of God," will be held October 27-29 at Stony Point Center, a national conference center of the Presbyterian Church (U.S.A.) in New York. The theme, "Gathered at the Table: A Safe Haven for All," will focus on worship life.</p> <p>For a brochure and registration, visit: <a href="http://www.stonypointcenter.org">http://www.stonypointcenter.org</a>.</p>                                                                                                                                                                                                                                                                                    |
| <p><b>Oct. 30 - Nov. 1, 2008</b></p> <p>Albany Marriot<br/>             Hotel<br/>             189 Wolf Road,<br/>             Albany, NY</p>                                                                                 | <p style="text-align: center;"><b>18<sup>th</sup> Annual Self-Advocacy Association of NYS Statewide Conference</b></p> <p>This annual conference brings together people with developmental disabilities, their families and caregivers and offers a variety of workshops and focus groups to learn together and share their experiences with self-advocacy.</p> <p style="text-align: center;">For information and registration call: (518) 458-8444<br/> <i>**Scholarship funds are available for support staff**</i></p>                                                                                                                                                                                                                                                                               |
| <p><b>November 24th, 2008</b></p> <p>Desmond Hotel<br/>             and Conference<br/>             Center in Albany,<br/>             NY</p>                                                                                 | <p style="text-align: center;"><b>12<sup>th</sup> Annual Alzheimer's Association Conference for Caregivers</b></p> <p>This annual conference is a wonderful opportunity to hear from leaders in the field of Alzheimer's disease and learn about the latest in research and treatment options. At the conference you can attend a variety of workshops, experience the Virtual Dementia Tour, and visit with the more than 30 exhibitors who will be there to showcase their products and answer your questions.</p> <p style="text-align: center;">For more information:<br/>             Call Gretchen at: 438-2217 ext 208<br/>             Email: <a href="mailto:gretchen.moore-simmons@alz.org">gretchen.moore-simmons@alz.org</a></p>                                                             |
| <p><b>May 28-29, 2009</b></p> <p>Saratoga Hilton<br/>             534 Broadway<br/>             Saratoga Springs,<br/>             NY</p>                                                                                     | <p style="text-align: center;"><b>HPCANYS' 29th Annual Interdisciplinary Meeting and Seminar<br/>             "Embracing Change...Transforming the Future"</b></p> <p>This annual event promises to be as amazing and deeply thought provoking as in years past. It is designed to provide opportunities for networking, education, and thoughtful discussion about end-of-life care.</p> <p style="text-align: center;">If you can make it, it's well worth the trip.</p> <p style="text-align: center;"><b>HPCANY is providing one free registration to this conference!</b></p> <p style="text-align: center;"><i>~~This opportunity is <u>only for those forum members who have posted on at least one discussion board</u>. The lucky recipient will be chosen in a random drawing raffle~~</i></p> |

## ***Newsletter Contributions Welcome!***

We welcome suggestions on content for our monthly newsletter! Do you have a story to tell? A best practice to share? If any of our alert readers come across any news, advocacy opportunities or policy issues they would like to share, or if you have a specific topic that you would like addressed in the newsletter or in a forum discussion, click [here](#) to send it along to the newsletter editor.

You are receiving this newsletter because you subscribed through the **Developmental Disabilities and Palliative Care Forum**. If you no longer wish to receive this newsletter, please click [here](#) to e-mail the newsletter editor. Be sure to put unsubscribe newsletter in the subject line.