

Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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Reporting on I/DD Hospice and Palliative Care Issues

In the News

On March 23rd, 2010 the Health Care Reform bill was signed into law and as the news reflects this event has been a cause for celebration, questions, expectations and uncertainty.

Below are a couple of current news stories that help to illuminate how the passing of this bill will affect end-of-life care as well as persons with disabilities.

Of course, NYS politics is also in the news, with discussions regarding the 2010 state budget still going on concerns over the funding of programs for persons with disabilities continues to be in the news.

► **Health Care Reform** has passed, but what does it mean for end-of-life care? The National Hospice and Palliative Care Organization (**NHPCO**) has been active in advocating and educating for quality end-of-life care and has put together a very simple explanation of what the legislation passed on March 21st, 2010 will mean for providers as well as patients of all ages and their families. They have created a very readable summary of inclusions pertinent to end-of-life care in general and Hospice in particular. This is a very useful tool for any provider who remains unclear to the content as well as the benefit and/or concern of the bill for their organization. Follow the link below to take a look at this summary.

[A Closer Look at the Health Care Reform Provisions Impacting Hospice](#)

► Bob Joondeph, a contributor to the **Disability Rights** website of Oregon, provides a succinct overview of what the HealthCare Reform legislation will mean to the status quo of health care for persons with disabilities. While acknowledging that changes will be coming in the future Bob states that, "the legislation is filled with compromises which reflect our nation's diverse interests and concerns. For those who feel that their financial and political interests are put at risk, the battle is far from over. We will see legal and media attacks for months and years to come. But for now, the disability community has much to celebrate." Use the following link to read his comments and summary.

[Health Care Reform brings promise of more freedom for individuals with disabilities.](#)

► **Disability Scoop** published several articles this week regarding how the health care reform bill and the reconciliation process will affect persons with disabilities, two of these articles are summarized here. Use the title links below to read them.

[Obama Signs Health Care Bill, Enhancing Access for Those With Disabilities](#)

"I think everyone in the disability community is thrilled because everything that we fought for was included," said Liz Savage, director of health and housing policy at the Disability Policy Collaboration, a joint lobbying initiative of The Arc and United Cerebral Palsy.

[Final Health Care Votes Bring Boost for People with Disabilities](#)

There has been some concern that a number of Medicaid patients are already unable to find a physician to take Medicaid because of poor reimbursement rates, but on Thursday, March 26th the 'reconciliation measures voted on in the Senate and finalized in the Congress will grant doctors higher reimbursement rates for care of Medicaid patients in 2013 and 2014, while increasing federal funding to states to meet this cost. The reconciliation bill also includes a funding boost for community health centers and federal money to help states meet the cost of a Medicaid expansion spelled out in the initial health care reform legislation.

► **Kaiser Health News Report** recently published part two of a five part series that examines the ethical, financial and political dilemmas of managing the rising cost of end-of-life care within a health care industry that is rife with technological achievements, advancements and possibilities for prolonging life. Part of the dilemma, however, is what Bioethicist Arthur Caplan calls a '*strong cultural trend*' in America that believes there is always hope for a miracle regardless of the diagnosis, the prognosis or the failing treatments. Laurie Jacobs, a gerontologist at Montefiore Medical Center in New York City expresses the concern on the other side of this trend as states that "*this is no way to die, with every technology imaginable being deployed, and a patient in pain in their finals days or weeks.*" The article goes on to describe the current American health care experience as, "*an experiment to see how far a society can go towards making people if not perfect, then at least as healthy as possible, in spite of the sometimes self-destructive behaviors that undermine good health.*" Whatever your position is on the health care reform debate, this is a powerful and important article that will translate to care providers across the spectrum.

Read this entire article by using the following link: [What Price for Medical Miracles? High Costs at End Of Life Still Part Of National Health Debate](#)

► The **New York Times Article** published February 22nd, 2010 entitled, '[Murky Path in Deciding on Care at the End](#)' summarizes an article from the *New England Journal of Medicine* that debates the ethics of aggressive resuscitation efforts and futile treatments for patients who "are not going to be restored to health" when family request that everything should be done for their loved one. The article looks at the dilemma from a number of different views which are voiced by the physicians and medical staff who have treated these patients and their families. This is a very interesting and thought provoking article particularly because the discussion revolves around actual case studies. There is the case of a young child who was severely brain-damaged from a birth defect, and despite surgery "would never have any meaningful neurological development." Nevertheless, when his heart stopped his parents wanted everything done to keep him alive, and the medical team complied. "I don't think we hurt the little boy at all by doing it. Looking back, for better or worse, this family was able to walk out of the hospital with a feeling of wholeness."

There are dissenting opinions however, referring to this same case Dr. Norman Fost, a pediatrician and ethicist at the University of Wisconsin states, "If you can't say no to things that won't work, God knows what the limit is," Dr. Fost said. The notion that doctors owe it to families to try resuscitation "is a perversion of what medicine is for." This is an interesting and

thought provoking article that is important for all professionals who have occasion to work with families or individuals at the end of life. To read the entire article, use this [link](#).

► The **New York Times article** published March 17th, 2010 entitled, '[No Single Path for Cancer Care in Elderly](#)' tells the story of Elliot, an 83 year old man diagnosed with prostate cancer whose doctors opted for treating the cancer aggressively with hormone and radiation therapy five days a week. Despite his advanced age, Elliot responded very well to the treatment and is now considered cancer free, but as Author Jane Brody points out, *"To the distress of some families, decisions (about treatment) are too often based more on a patient's chronological than physiological age."* The article does a good job of engaging the reader in the medical discussion of whether or not it is appropriate or beneficial to aggressively treat cancer in older persons. The debate centers on the fear that the side effects of cancer treatment would hasten an older patient's death or destroy the quality of their remaining years. The outcome then is that doctors are often under-treating older persons, which may be hastening their death unnecessarily. Dr. Yates, national vice president for research at the American Cancer Society Treatment shares his views on the issue stating that, *"decisions should be influenced by patients' physical and mental health, of course, but also by their financial status, living situations, family support systems and ability to get to and from the treatment facility."* As the title suggests, there is no single path for these decisions for families, patients or physicians but as Brody points out, *"the outcome for Elliot is a direct assault on the oft-given advice that most cancers affecting people his age be left to take their course."*

Use this [link](#) to read the entire story.

► The **New York Times article** published March 24th, 2010 entitled, '[Social Networks a Lifeline for the Chronically Ill](#)' condenses a report released by the Pew Internet and American Life Project and the California HealthCare Foundation that discusses how technology can provide a way of communicating and connecting with others who are living with a chronic health condition or disability. The author notes that while social networking is often perceived as a bit of fun for many, but for persons living with chronic diseases or disabilities, they often become more important and can play a vital role in their lives; this is where they can receive perspectives on their illness or disability from others who can understand what they are experiencing. The author reports that although persons with a disability or those fighting a chronic illness are less likely to have internet access, once they do get online they are able to find practical tips about living with their disease or disability that doctors and family members, having not lived with it themselves, cannot provide. The article quotes John Linna, a social networker who passed away earlier this year as he describes what this form of communication and connection meant to him. John states, *"That day my little world began to expand. "Soon I had a little neighborhood. It was like stopping in for coffee every day just to see how things were going."* The article also provides links to a number of online communities that are useful for specific diagnosis or disabilities.

Use this [link](#) you would like to read the article in full.

► Last week the **Democratic and Chronicle** (a Rochester, NY newspaper) published an article warning that the current NYS budget proposals may have an adverse effect on children with disabilities who are living at home. The change that is causing the biggest concern is a 10 percent decrease in rates paid to providers for home-based services, which the article states is where most early intervention takes place- the child's natural environment. The change means that parents must now contribute on a sliding scale based on their income. This is an interesting article, use the link below to read it in it's entirety.

[New York State special needs children may lose out due to budget](#)

Public Policy News / Advocacy Opportunities

► **Family Health Care Decisions Act (FHCDA) passes after 17 years!**

Until the Legislature's action to pass this bill, New York remained one of two states in the nation lacking legislation or case law to permit close family members to make health care decisions for incapacitated patients. Last month, the New York State Senate finally passed the bill by a vote of 55-3, empowering family members and others close to the patient to make health care decisions, including decisions about the withholding or withdrawal of life-sustaining treatment, on behalf of patients who lose their ability to make such decisions and have not prepared advance directives regarding their wishes.

For the past 17 years, the Hospice and Palliative Care Association of New York State (HPCANYS), has joined with other supportive organizations in the *Family Decisions Act Coalition* to mobilize the Legislature to pass the FHCDA. According to Kathy McMahon, President and CEO of (HPCANYS), "*The Legislature is to be lauded for the long-awaited passage of the Family Health Care Decisions Act. This is a significant move that will help make hospice and palliative care more accessible to New Yorkers with a life-limiting illness that lack decision-making capacity.*" It is important to note that even with the passage of the FHCDA, New Yorkers are still encouraged to prepare a health care proxy, which allows an agent to make health care decisions on behalf of an individual if he or she later loses capacity.

New York Times article published on March 17th elaborates on what exactly the bill contains and a little bit about what held up the passage for so many years. Use the following link to read the article in full: [Law Dictates Who Decides on Care for the Incapable](#)

► The **Health Care Reform** bill signed into law last week also includes some long awaited legislation that constitutes one of the most comprehensive federal efforts to fight elder abuse, neglect and exploitation of our most vulnerable populations.

The legislation includes the long-sought **Elder Justice Act**, which devotes hundreds of millions of federal dollars to elder abuse for the first time. The provisions are to be used to support the Long-Term Care Ombudsman Program and the establishment of an Elder Justice Coordinating Council. Its companion, the **Patient Safety and Abuse Prevention Act**, also included in the legislation, creates new protections for those in long-term care facilities such as a national program of criminal background checks for persons seeking employment in these care facilities. For a little more about the legislation use the following links:

[Health Care Reform Will also Improve Long Term Care](#)
[Obama signs Elder Justice Bill into Law](#)

► **S. 700 / H.R. 1708.** This bill, "**Ending the Medicare Disability Waiting Period Act of 2009**," was introduced in the Senate as S.700 by Senator Jeff Bingaman (D-NM) and in the House by Representative Gene Green (D-TX-29). The bill would amend Title II of the Social Security Act to phase out the 24-month waiting period for disabled individuals to become eligible for Medicare benefits, to eliminate the waiting period for individuals with life-threatening conditions, and for other purposes. The introduction of the bills received a rousing cheer from over 120 organizations in the [Coalition to End the Two-Year Wait for Medicare](#). To read more about the bill, contact your representatives about the bill, request email alerts to action on the bill or to share the bill use the following links: [Senate Bill 700](#) and [H.R. Bill 1708](#)

Information and Resources

▶ **Experts Examine Components of Health Care Reform**

On January 28, the Engelberg Center for Health Care Reform at the Brookings Institution hosted a forum to discuss strategies for improving care for older Americans across a spectrum of institutional and community-based settings. The Health Care reform bill includes a range of new payment and delivery system reforms intended to improve the overall care for patients with complex health needs and chronic conditions that merit discussion. Diane E. Meier, MD joined a panel of experts and key stakeholders to examine the components of health care reform most likely to influence the care this population receives. Participants also outlined specific, practical strategies that policymakers and government agencies can consider when transitioning from legislative action to implementation so older Americans benefit directly from innovations in care delivery. You can read the background paper for Health Care Reform that outlines some of the pieces discussed by the panel using the following link: "[Health Care Reform and Older Americans: Achieving Better Chronic Care at Lower Costs](#)," If you are interested, use the following link to view a video of all four panel discussions, or to download the transcripts: [Health Care Forum and Panel Discussion](#).

▶ **New Website Dedicated to Advancing Funding for Palliative Care**

The Collaborative to Advance Funding for Palliative Care (CAFPAC) is a growing group of funders, from across the U.S., who are committed to advancing funding for Palliative Care. They have recently announced the launching of a new website as part of an initiative to share palliative care grant-making concepts and success stories, and to stimulate higher levels of funding in palliative care. The site provides a 'Snapshot Report' of original research on the state of palliative care philanthropy across the country over a two-year period as well as recommendations for engaging more private foundations in palliative care grantmaking. There are also profiles of some of the funders who have been working in palliative care, and resources such as the 'Palliative Care Grantmaking Toolkit,' which provides information about Palliative Care, grantmakers who are funded and advice on devising your own grantmaking strategy. This is a very worthwhile site to visit and bookmark if your organization is interested in seeking funding for palliative care research or programming. Visit the site at: www.FundPalCare.org

Professional Development and Education

▶ A recent **Medscape Today** article titled, '[End-of-Life Care in the Setting of Cancer: Withdrawing Nutrition and Hydration](#)' provides an excellent four part discussion regarding making the difficult decisions about providing or withholding life sustaining treatment. The article specifically addresses the issues surrounding the act of withholding or withdrawing artificial hydration and nutritional therapy from patients and the challenges that clinicians face when communicating with patients and families over these concerns. The article also includes information on legal perspectives, the role of the provider as well as the patient's culture and religion in determining the goals of care and making decisions about life sustaining treatments. Overall this is a very comprehensive educational article that is well worth reading.

► **The American Association on Intellectual and Developmental Disabilities (AAIDD)** announces its 134th Annual Meeting. The theme for 2010 is *'Imagining the Future, Celebrating the Past.'* This year **Patrick J. Kennedy**, who represents Rhode Island's First Congressional District in the United States House of Representatives and the late Senator Kennedy's son, will speak about his father's vision and his family's impact on the lives of people with intellectual and developmental disabilities and our field's and association's work. Click [here](#) for more information and registration.

► **"Palliative Care: Essential for the Patient, the Family and Public Health."** Earlier this month, the NYS Department of Health's *'Cancer Support and Survivorship Initiatives'* program partnered with the Hospice & Palliative Care Association of NYS (HPCANYS) and the **School of Public Health** at the University at Albany to present this webinar. The broadcast was intended for physicians, public health professionals, nurse practitioners, physician assistants, nurses, social workers and medical/public health students that work with persons who would benefit from Palliative Care services providing patient and family-centered care and optimizing quality of life by anticipating, preventing and/or treating suffering at any time from diagnosis through the end of life.

The webinar is now archived on the SUNY School of Public Health's, Public Health Live Continuing Education website. If you would like to view the broadcast and/or download the accompanying handout materials use the following link and click on 'Archived Broadcasts' in the upper right hand corner. Note that this broadcast can only be viewed using Real Player SP and you may be asked to download the program or update an existing one.

["Palliative Care: Essential for the Patient, the Family and Public Health."](#)

► **Social Work Network in Palliative and End-of-Life Care Listserv**

The Social Work Network in Palliative and End-of-Life Care is a joint effort of the [Project on Death in America](#) and the Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York. This list provides an opportunity for social workers in such fields as oncology, geriatrics, HIV, hospice, nephrology, and pediatrics to network and discuss multidimensional aspects and issues related to palliative and end-of-life care.

The goals and objectives of this email discussion group are to:

- ✓ Establish links among social work specialists in such areas as oncology, geriatrics, HIV, hospice, nephrology, and pediatrics.
- ✓ Enhance and encourage communication, networking, and sharing of expertise among clinicians.
- ✓ Provide online notification of relevant research, and political and social policy issues.
- ✓ Provide opportunity for feedback and collaboration around clinical, education, research, policy and professional issues.
- ✓ Identify areas of commonality and unmet needs of social workers practicing in the areas of palliative care, pain, and end of life.
- ✓ Reduce isolation of social workers practicing in settings where there is lack of opportunity for collaboration and mutual support.
- ✓ Develop a resource list of experts for referral, teaching and joint project development.

If you would like to learn more about this email discussion group, please contact the list moderator, Terry Taltilio by email at taltilio@chpnet.org. If you would like to join the list, complete and return this [registration form](#) to Terry's attention.

► The annual International Research Summer School at the **International Observatory on End of Life Care in Lancaster, England** announces an 'advanced introduction' to social

research methods relevant to end of life care. The dynamic interdisciplinary course is taught by expert researchers and prior knowledge of research methods is not required.

The Summer School runs over a period of two weeks, participants may attend one or both weeks. The first week focuses on a classroom based learning using diverse teaching methods. During the second week students have the opportunity for group discussions and individual tutorials focused on the development of their own research ideas and projects. The second week also provides opportunities to undertake clinical and study visits and to pursue a program of supervised private study. Participants from a variety of disciplines are encouraged to attend. If interested in more information follow this [link](#), or download the [brochure here](#).

► **The Arc** is sending out a *call for presentations* for their **2010 National Convention, 'A Clear Way Forward.'** The convention will be held in Orlando Florida from November 3rd - 6th. The Arc is seeking dynamic and inspiring speakers or panels who will engage participants with a plan for "A Clear Way Forward." This is an excellent opportunity for the professionals in hospice and palliative care disciplines to submit workshops that would contribute to the dialog between providers in the developmentally disabled community and hospice providers that would lead to greater access to end-of-life care for this population. If you are interested in presenting a breakout or plenary session you can access the online application until April 30th at 5pm eastern standard time. Note that no applications will be accepted after April 30th. Use the following link for application instructions, FAQ's and submission form: [Online Presentation Application](#)

► **The Hospice and Palliative Care Association (HPCANYS)** is holding their 30th Annual Interdisciplinary Seminar and Conference on May 13th & 14th, 2010 at the Marriot Hotel in Albany, NY and they would like to extend an invitation to all professionals who care for or provide services to **persons with intellectual or developmental disabilities**.

There will be a number of workshops during the conference that relate directly to end-of-life issues for those working with this underserved population, including workshops on nutrition and pain therapy concerns at end-of-life, delirium and dementia issues as well as a very much needed workshop on how to create a collaboration between the systems of the developmental disabilities community and that of hospice and palliative care community. For more information about the conference or to register please visit the [HPCANYS website](#).

**Proposals are still being accepted for the 2010
Developmental Disabilities Hospice and Palliative Care Forum
Topics!**

The Developmental Disability Hospice & Palliative Care Forum is moving to a new platform and will resume again in the Spring of 2010. We are happy to announce that we are accepting proposals from professionals in the community who would like to host a forum discussion.



If you are interested in:

- ✓ Educating forum members on cutting-edge topics and ideas related to end-of-life care
- ✓ Highlighting your programs on a statewide platform
- ✓ Presenting important research outcomes
- ✓ Networking with over 350 end-of-life health care professionals
- ✓ Gaining recognition in the hospice and palliative care field

Then please follow this link to [complete the RFP](#) and submit to HPCANYS, or email me at kconnell@hpcanys.org

Upcoming Events ~~ Mark your Calendar

<p>April 12-14, 2010</p> <p>Hyatt Regency Washington on Capitol Hill 400 NW New Jersey Avenue, Washington, DC</p>	<p>AAIDD Disability Policy Seminar The AAIDD asks your help to build bipartisan support on Capitol Hill for high-priority disability issues.</p> <p>The Seminar program will provide you with overviews from Washington’s top policy experts about issues vital to the disability community and will arm you with the tools you need to champion the issues you care about most. On the final day of the event, you will have the opportunity to make your case before your Members of Congress and/or their staff, who want to hear from you about the issues affecting persons with intellectual and developmental disabilities and their families.</p> <p>For more information and registration, please visit the Disability Website: http://www.disabilitypolicyseminar.org/</p>
<p>April 16th, 2010</p>	<p>2nd Annual National Health Care Decisions Day (NHDD)</p> <p>The (NHDD) initiative is a collaborative effort of national, state and community organizations committed to ensuring that all adults with decision-making capacity in the United States have the information and opportunity to communicate and document their healthcare decisions.</p> <p>If you or your organization is interested in learning more, or to download the application or participation form please visit: National Healthcare Decisions Day.</p>
<p>April 17th, 2010</p> <p>Bulmer Communications Center, Hudson Valley Community College, Troy, New York</p>	<p>The Capital Region Caregiver Coalition announces the 2010 Educational Day for Caregivers:</p> <p>Tools for Caregivers: Resources you can use when a senior relies on you There is no cost for this conference! Workshops, Continental Breakfast, Keynote Address, Caregiver Connection Corner and Resource Fair!</p> <p><i>If you think you can’t attend because you’re caring for someone, Free Respite care available at an Eddy Daybreak Adult Day Care site nearby!</i></p> <p>Advance registration is required, so please call 382-8481 ext.1238 for more details!</p>

<p>April 22 - 24, 2010 Omni Shoreham Hotel Washington, DC</p>	<p>NHPCO's 25th Management and Leadership Conference: 'Securing Our Roots, Expanding Our Reach'</p> <p>Each year NHPCO designs new educational programming for the Management and Leadership conference, reflecting the latest trends and innovations in hospice and palliative care and addressing all aspects of management and leadership. NHPCO invites leaders in end-of-life care to attend this conference.</p> <p>To learn more or to register use the following link: NHPCO Conference</p>
<p>May 13th & 14th, 2010 Marriot Hotel 189 Wolf Road, Albany, NY</p>	<p>HPCANYS 30th Annual Interdisciplinary Seminar and Conference <i>Mission – Vision – Reality ... Celebrating 30 Years!</i></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>This year HPCANYS is celebrating its 30th year of service!!! If you can make it, it's well worth the trip.</p> <p>For more information visit: HPCANYS 30th Annual Conference</p>
<p>May 20 & 21, 2010 Holiday Inn 232 Broadway Saratoga Springs, NY</p>	<p>SAVE THE DATE! 19th Annual Third Age Conference Sponsored by the New York State Third Age Committee</p> <p>The Third Age Committee is dedicated to focusing on issues for aging persons with developmental disabilities, they sponsor this annual conference, provide a network of experienced trainers, as well as guidance and feedback to New York State's Office of Mental Retardation and Developmental Disabilities Aging Services.</p> <p>More information about this event will follow, but to learn more visit the Program in Aging and Developmental Disabilities website.</p>
<p>June 9th – June 11th 2010 Providence, Rhode Island</p>	<p>134th Annual Meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD) <i>Imagining the Future, Celebrating the Past</i></p> <p>Patrick J. Kennedy, who represents Rhode Island's First Congressional District in the United States House of Representatives and the late Senator Kennedy's son, will speak about his father's vision and his family's impact on the lives of people with intellectual and developmental disabilities and our field's and association's work.</p> <p>Click Here for more information and registration.</p>

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