



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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Editor: *Kimberly Connell*

Reporting on I/DD Hospice and Palliative Care Issues

In the News

► A recent **Medscape Today** article summarizes a study published in the April, 2010 *New England Journal of Medicine*, on the efficacy of completing written advanced directives prior to a hospitalization, terminal illness or life limiting event. Reported findings of this nationally-representative study found that 67.6% of participants who lacked the capacity to make required decisions at the time of death had established an advance directive. Authors call the results a clear demonstration that talking about the goals of medical care so that patients or their surrogates can determine what care they will receive when they are no longer competent, has become acceptable to a large majority of those Americans who need it most. What is not clear from this study is the effectiveness of written advanced directives since their effectiveness is often limited by inattention to them and by decisions to place priority on considerations *other than the patient's autonomy*.

To read the entire article, or to listen to the accompanying audio report by Dr. Hagga, Deputy Director of the Division of Behavioral and Social Research at The National Institute on Aging in Maryland, use the link below:

[‘Advance Directives Again Shown Useful for End-of-Life Care.’](#)

► The **CBS Sunday Morning** show with Charles Osgood will feature a segment on *Palliative Care* this weekend, **Sunday, May 2**. The segment will include interviews with Diane E. Meier, MD, director of the Center to Advance Palliative Care (CAPC), and Robert Pardi, husband of the late Dr. Desiree Pardi, recently featured in the *New York Times* article, [‘Helping Patients Fight Death, She Fought to Live.’](#) The CBS Sunday Morning airs Sundays from 9-11 AM, check your [local listings](#) for air time and channel.

► **Disability Scoop recently** published an article discussing the addition of Lauren Potter, a 19 year old young woman with Down syndrome to the cast of *Glee*, a popular television show on the Fox network. The article also reprints an interview conducted with Lauren about her role on the show as well as her experiences on the set and in her everyday life. Use the following link to read the article: [Down Syndrome Takes Center Stage on Fox’s ‘Glee’](#)

► In a recent **Huffington Post** article entitled, [‘Five years after Terri Schiavo’s death: What have we Learned.’](#) palliative care physician David Casarett asks, “Have we, as a nation, become more thoughtful about end-of-life decisions? What have we done to prevent such public catastrophes in the future?” Casarett discusses his views on the advance care planning clause that was originally in the national health care reform bill and sparked the ‘death panel’ debate. He believes that the clause, which should have been viewed as a straightforward mechanism to promote choice and autonomy, was included to prevent the sort of family disputes that made Terri’s care so difficult, but that the "death panel" label left him feeling, “very much the same way that I felt as the nation watched Terri Schiavo’s story reach its conclusion in 2005...Looking back on those events, it’s difficult to believe that we’re any closer to an open dialogue about death and dying than we were five years ago.” The idea of bringing end-of-life planning to the nation is an interesting concept and whatever your views on the inclusion or exclusion of the clause, or on the need for legislation to encourage physicians to take the time to talk to patients about the choices that are available to them, this is an interesting and thought provoking article.

Use the title [link](#) above to read the entire article.

Public Policy News / Advocacy Opportunities

► Governor Patterson has proposed **expanding amber alert to persons with intellectual and physical disabilities**. A [press release](#) from the New York State Office of the Governor states that under the Governor’s proposal, the same system now used to disseminate missing child alerts to police agencies, broadcast networks, Thruway service areas, lottery terminals, airports and bus terminals would be deployed when adults at particular risk go missing. The bill is intended for adults who have a mental disability, cognitive disorder or physical disability that prevents them from assisting in their own recovery, as well as missing adults who have disappeared under circumstances that indicate they are in imminent danger of harm, such as those were abducted or who are suicidal. The bill is currently in draft form; if you would like to read a copy of Program Bill No. 233, follow this [link](#).

► **H.R. 4247 Restraint & Seclusion Legislation Passed the House, 262-153:** The legislation which addresses the appropriate use of physical restraint and seclusion also encourage states to provide support and training to better protect students and staff and prevent the need for emergency behavioral interventions. The bill, now called the *Keeping All Students Safe Act*, will now move to the Senate, where its companion bill S. 2860 has only one sponsor, Senator Chris Dodd (D-CT). It is imperative that the Senate secure more co-sponsors of the legislation if the bill is going to be moved through to a vote. If you, or your organization, are interested in advocating for the bill, use the following link to ask your Senator(s) for their support: [Keeping All Students Safe Act](#). If you would like to read more about the bill use visit the Council for Exceptional Children (CEC) [Legislative Action Center](#).

► Earlier this month, the **Arc of the United States 2010 Disability Policy Seminar** took place in Washington DC with over 500 advocates for disability rights gathered to hear from government officials, policy experts, advocates and others; the entire day was focused on health care reform. Jeffrey Crowley, Director of the Office of National AIDS Policy and Senior Advisor on Disability in the White House, addressed the participants saying that health care reform is a major advancement for disability policy.

On the second day of the seminar, attendees heard presentations on employment, education, housing and the ABLE Act. [The ABLE Act of 2009 \(Achieving a Better Life Experience\)](#) would give individuals with disabilities and/or their families access to savings

accounts that would allow individual choice and control while protecting eligibility for Medicaid, SSI, and other important federal benefits for people with disabilities.

Among those attending were past Arc President, Leo Berggreen and his son Robert who met with a number of Congressional Representatives. In a letter to The Arc, Berggreen wrote, *“It went extremely well in both sessions. As we know, our best advocates are self advocates. Robert stole Congressman Melancon’s heart, he insisted on having a picture taken with him and said that the [ABLE Act](#) (was) legislation with which they could agree and that the Congressman agreed to co-sponsor.”*

Information and Resources

► The ***Oncology Times***, April 2010 issue published an article detailing the conclusions of study in the March 17 issue of the ***Journal of the American Medical Association***. The article entitled, [“US Palliative Care Programs Shown to Vary Widely, Face Multiple Barriers,”](#) points out that while most cancer centers in the U.S. have palliative care programs there is a large degree of inconsistency with which palliative care is administered, practiced and integrated into pain care plans within the oncology units. The article also points out that this study, like many others, has found that when cancer patients are referred for palliative care, it is often too late in their disease course to receive truly integrated, high-quality palliative care. In an effort to introduce Palliative Care earlier and consistently in cancer centers across the nation, the American Society of Clinical Oncology has recommended that palliative care be integrated into cancer care as a routine part of comprehensive care by the year 2020.

Lead author and medical oncologist Dr. David Hui states that, “there is a connection between palliative care and death,” and that *“branding is a problem.”* Stating that when he and his colleagues asked the recipients of their survey, “What is the name of your program?” many cancer care executives said they were moving away from the term “palliative care and toward using “supportive care” instead, since the impression is that patients find “supportive” a less distressing term than “palliative.” “Oncologists should be encouraged to make early palliative care referrals and to participate regularly in family conferences and palliative care educational rounds,” Dr. Hui and his colleagues wrote, and in addition “palliative care specialists should start attending interdisciplinary cancer treatment rounds.”

► The ***John Hopkins Gazette*** reports that a team of researchers at Johns Hopkins University have received a \$1 million, two-year ‘Challenge Grant’ from the National Institute for Nursing Research to “develop and test innovative training methods that will include video documentaries of patients and families that are geared toward integrating palliative care into chronic pediatric diseases.” *The research will focus on specific disabilities including Duchenne muscular dystrophy and blood disorder sickle cell disease.* The researchers said they believe that the project will make caregivers more compassionate and respectful, with a better understanding of what their patients’ lives are like,” and it will address caregivers’ emotions in dealing with the “tremendous feeling of inadequacy because of not being able to fix what is not fixable.” Research team member and professor of medicine in the John Hopkins School of Medicine, Gail Geller states that, “Palliative care generally has been associated with end-of-life care,” Geller said. “This is one of the first studies to remove palliative care from [that] limited context and to say, what can we learn from the principles of pediatric palliative care in the context of chronic diseases?” If you would like to read more use the following link: [Pediatric palliative care initiative launched](#)

► **The Center to Advance Palliative Care (CAPC)** has published a new analysis of palliative care programs in the US has been conducted by the Center to Advance Palliative Care in conjunction with the National Palliative Care Research Center. The analysis found that large hospitals and not-for-profit hospitals were more likely to have programs than other hospitals, but that the number of programs in hospitals is growing ~ facilities dedicating 50 or more beds to palliative care increased 125.8% between 2000 and 2008. In an interview with Medscape Today, Diane E. Meier, MD, director of the Center to Advance Palliative Care, states that there are a number of factors driving this trend towards the growth of Palliative care programs.

These include:

- ♦ the increase in the number and needs of the chronically ill with co-morbidity and functional impairment in hospitals
- ♦ growing evidence of poor quality of care and high levels of physical and psychological distress in these patient populations and in family caregivers
- ♦ a rising body of evidence demonstrating that palliative care delivered at the same time as all other appropriate curative or life-prolonging treatments improves patient-level outcomes and enhances the likelihood of patients completing their medical treatment and remaining independent at home

Read the entire Medscape Today article:

[Palliative Care Programs Continue to Increase in American Hospitals](#)

To read or print the CAPC report, use the following link:

[2010 Snapshot of U.S. Hospital-Based Palliative Care Programs](#)

► A recent **Medscape** article summarizing a study April 15, 2010 - Despite the distress of learning that their disease is terminal, most cancer patients prefer to know the truth, and to hear it from their physicians. This conclusion is from a Korean study reported in the April 10 issue of the Journal of Clinical Oncology. The majority of patients with terminal cancer and their family caregivers preferred disclosure, and patients who were aware of their diagnosis had a lower rate of emotional distress and a higher health-related quality of life, the researchers report. They found that patients were more likely than their caregivers to prefer to know the truth about their terminal status (78.6% vs. 69.6%).

The results showed that patients who were told about their prognosis directly, either by a physician or a family member, had a significantly better quality of life, including physical, emotional, and cognitive functioning, than patients who reported guessing about their condition or learning about it by chance. Patients who were told directly about their terminal status also reported fewer symptoms, such as fatigue, pain, appetite loss, and financial problems.

► Last month **BMJ**, an open access medical journal, published the results of a study in which hospitalized patients over age 80 received either usual care or an intervention for advance care planning. The intervention, facilitated by a nurse or allied health worker, provided formal assistance with documenting the patients' end-of-life treatment wishes, and with designating a surrogate decision maker or health care proxy. Among other outcomes, the article reports that patients receiving the intervention were almost three times more likely to have those wishes followed (86% versus 30% in usual care) and that the family members of patients in the advance planning intervention reported significantly less emotional trauma afterward. Overall study outcomes follow:

- ♦ End of life care is poor and needs to be improved / Coordinated advance care planning improves end of life care
- ♦ Focusing on the completion of advance directives *alone* does not improve end of life care

- ◆ Involving surrogates in discussions on advance care planning improves the likelihood that they will know the patient's end of life wishes
- ◆ Advance care planning reduces the incidence of anxiety, depression, and post-traumatic stress in surviving relatives

If you would like to read or print the study use this link:

[The impact of advance care planning on end of life care in elderly patients](#)

► The **Dying Matters** Coalition was developed in 2009 by the National Council for Palliative Care (NCPC) to promote public awareness of dying, death and bereavement; their mission is "to support changing knowledge, attitudes and behaviors towards death, dying and bereavement, and through this to make 'living and dying well' the norm". The Coalition understands that accomplishing this mission will involve a fundamental change in society in which dying, death and bereavement will be seen and accepted as the natural part of everybody's life cycle, but believes it is in everyone's interest to talk about it, before it's too late. The Dying Matters Coalition is working to address this by encouraging people to talk about their wishes towards the end of their lives, including where they want to die and their funeral plans with friends, family and loved ones. To encourage such discussion they have created a website designed to help start those conversations, called [Dying Matters](#). While the coalition and the site originated in the Britain this site is well worth visiting and sharing with others; use the link above to visit the site.

Professional Development and Education

► **Call for Manuscripts:** The Journal of Social Work in End-of-Life and Palliative Care is preparing a special thematic issue on '**PEDIATRIC ISSUES IN PALLIATIVE AND END-OF-LIFE CARE**' and has put out a call for manuscripts to all social work and mental health professionals. Manuscripts could include a range of issues involving children and families dealing with chronic or life-limiting illnesses and should address practice issues. *Suggested topics include:* the use of palliative care or hospice care, pain management issues with children; plan of care/decision-making issues; working with children and families of diverse cultural populations; children's grief/bereavement related to sibling or parent death, unique developmental issues for children who are dying, their siblings and the impact on family development.

- ✓ **Questions** regarding whether your topic area is appropriate should be directed to Ellen L. Csikai, editor at 205-348-4447 or ecsikai@sw.ua.edu
- ✓ The **deadline for submission** is September 15th, 2010 and should be sent electronically to: Ellen L. Csikai, Ph.D ecsikai@sw.ua.edu

► **The Administration on Aging (AoA)** announces the availability of approximately \$2.25 million for **Lifespan Respite Care Programs** that will enable states to establish, enhance or expand Lifespan Respite Care systems, including new and planned emergency respite services, training and recruitment of respite workers and volunteers and assist caregivers with gaining access to needed respite services. Funded projects will serve all eligible respite recipients, including family members, foster parents, or other adults providing unpaid care to adults needing care to meet basic daily needs or prevent injury and to children who require care beyond that required to meet their basic needs. Over the course of these projects, states will work to expand and enhance respite care services to family members; improve the statewide dissemination and coordination of respite care; and provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.

- ✓ The deadline for submission of a letter of intent to apply for funding is Friday, May 7, 2010. Letters should be submitted to Greg Link at greg.link@aoa.hhs.gov.
- ✓ To learn more about this opportunity, please visit [AoA Funding Opportunities](#).

▶ **The 2010 National Lifespan Respite Conference** has extended its deadline for submitting a proposal until May 17th. The goal of the conference is to showcase the creative ways in which Lifespan Respite Care can be delivered throughout the nation. We expect attendance of 600 to 800, representing parents, family members, life partners, older adults, grandparents, social workers, case managers, program managers, nurses, advocates, direct support staffs, health professionals, policy developers, advocates, respite and crisis care providers, state respite coalitions, community leaders and elected officials.

▶ **Developmental Disabilities Alliance of Western New York (DDAWNY)** announces the 22nd Annual *Developmental Disability Awareness Day*. This year the event will be held this year on **Thursday May 27, 2010** at the Buffalo Convention Center. Registration Deadline is May 21st, 2010, so act fast!

✓ For registration details as well as information about the workshops, speakers and other special events logon to the DDWANY website and download the [Registration Brochure](#).

▶ 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](#).

▶ **Hospice & Palliative Care Association of NYS (HPCANYS)** is **Celebrating 30 Years!** To celebrate, [HPCANYS](#) is hosting a Gala Celebration at the Marriott Hotel in Albany, NY during the Annual Interdisciplinary Meeting and Seminar. HPCANYS welcomes staff and friends from hospices across the State as well as the public. This event will feature **gourmet cuisine**, live and **silent auctions** and an **off-Broadway production of "180 Days,"** currently sold out in its first off-Broadway run. This is a one woman show by Taren Sterry; actor, comedienne and Hospice Volunteer Program Manager. In '180 Days' Taren takes the audience on an intensely personal and surprisingly funny journey through her first six months as a hospice volunteer. Hoping to help patients find meaning at the end of life, through unexpected and humbling events, she discovers hidden qualities in herself that give her own life purpose.

✓ For more information, to purchase tickets or to make a donation, simply follow this [link](#).

**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 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 application](#) and submit to HPCANYS, or email me at kconnell@hpcanys.org

Upcoming Events ~~ Mark your Calendar

<p>Thursday, May 13th, 2010 8:00 AM - 3:00 PM</p> <p>Immaculate Conception Center Douglaston, NY</p>	<p align="center">1st Annual Spring Conference Queens Council on Developmental Disabilities</p> <p>Keynote Speaker: Jill Gentile, Acting Associate Commissioner, OMRDD SDIS Region 2 Registration Fee is only \$22 Continental Breakfast and Buffet Lunch included</p> <p>You may register by email: ygross@psch.org Please include your name, agency, address and phone number</p>
<p>May 13th & 14th, 2010 Marriot Hotel 189 Wolf Road, Albany, NY</p>	<p align="center">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 align="center">This year HPCANYS is celebrating its 30th year of service!!! If you can make it, it's well worth the trip.</p> <p align="center">For more information visit: HPCANYS 30th Annual Conference</p>

<p>May 20 & 21, 2010 Holiday Inn 232 Broadway Saratoga Springs, NY</p>	<p style="text-align: center;">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 style="text-align: center;">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>
<p>October 24th – 27th, 2010 Sheraton Baltimore City Center Hotel Baltimore, Maryland 21201</p> <p style="text-align: center;"><i>Save the date!</i> <i>More information will follow</i></p>	<p style="text-align: center;">2010 National Lifespan Respite Conference <i>Respite: Create It!</i> Hosted by the Maryland Respite Care Coalition, Inc. (MRCC) In Partnership with the ARCH National Respite Network and the National Respite Coalition</p> <p>This conference is intended for everyone who supports family members and caregivers of individuals across the lifespan. Every person who is affected by life altering conditions due to illness or disability has a stake in this significant issue. (<i>i.e. Alzheimer's disease, mental illness, developmental disabilities, Parkinson's, ALS, autism, HIV, AIDS, multiple sclerosis, etc.</i>),</p>

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