



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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Editor: *Kimberly Connell*

Reporting on I/DD Hospice and Palliative Care Issues

Editors' Note: This Newsletter is now published quarterly

In the News

► **A New York Times article entitled, [Palliative Care Extends Life, Study Finds](#)** relates the results of an interesting new study published in the *New England Journal of Medicine* that shows the effect of palliative care when it is provided throughout the continuum of care for advanced lung cancer. Early integration of palliative care with standard oncologic care in patients with metastatic non–small-cell lung cancer resulted in survival time that was prolonged by approximately 2 months as well as clinically meaningful improvements in quality of life and mood. Dr. Jennifer S. Temel, an oncologist and author of the paper, states that there is sometimes tension between medical specialties, since surgeons and oncologists often view cancer as a battle, while palliative care specialists are seen as “giving up.” Doctors and patients “traditionally see palliative care as something extended to a hospitalized patient in the last week of life,” *We thought it made sense to start them at the time of diagnosis.* And we were thrilled to see such a huge impact. It shows that palliative care and cancer care aren’t mutually exclusive.” If interested, Dr. Mark Kris from the Memorial Sloan-Kettering Cancer Center in New York summarizes the results of this study in a video on Medscape using the following link (*You will have to sign up as a member – but it is free*): [Palliative Care: A New Component of Optimal Cancer Care?](#)

If you are a registered member of the [Developmental Disability Hospice & Palliative Care Forum](#) site you can access the *New England Journal of Medicine* research article by Dr. Temel under the '[Resource](#)' section. (*If you are not yet a registered member but would like to be, simply [click here](#) to register on the home page*)

► **A NY Times article published last fall entitled, [In Cancer Therapy, There Is a Time to Treat and a Time to Let Go](#)** discusses the tough decisions cancer patients and their families face when conventional treatments are no longer resulting in reversal of the disease and becomes what is termed 'futile care'. When interviewed, Dr. Thomas J. Smith, an oncologist and palliative care specialist at the Massey Cancer Center of Virginia Commonwealth University, suggests that while there is no official definition of futile care, “*it represents care that is “very unlikely to help and likely to harm.”* However, Smith acknowledges that patients are sometimes reluctant to relinquish treatment because they are terribly afraid of dying, of being alone and cut off from care; patients may fear, with some justification, that if treatment stops the doctor will abandon them. When faced with a patient who says, “I’ll do anything to live two

minutes longer,” Dr. Smith says the doctor should ask: “What is your understanding of your illness? What would you like to do with the time remaining?” He suggested that doctors “put everything in writing — here’s what you have, what we can do for it, what will happen with treatment and without it — so that everyone is on the same page,” eliminating the risk that wishful thinking colors what patients hear. To read the entire article using use the title link above.

► **Disability Scoop** reports on how President Obama’s proposed budget will affect people with disabilities calling it a mixed bag. Ari Ne’eman, president of the Autistic Self Advocacy Network says, “There’s a lot of stuff that’s very concerning, everybody recognizes that these are difficult fiscal times but we need to make sure that we aren’t sacrificing the long-term rights and opportunities for people with disabilities.” To read the entire article, use the link below: [Obama Budget Brings Mixed Bag for People with Disabilities](#)

► **HBO’s ‘Temple Grandin’ Offers inside Look at Autism:** The HBO biopic airing February 6, tells the story of autism self-advocate, Temple Grandin, who is arguably the most well known person living with autism, having written and lectured extensively about her experiences with the disorder. The film (which has won 5-emmys and a Golden Globe) was shot from Grandin’s perspective focuses on her upbringing and depicts how she thinks in pictures. Earlier this month, Disability Scoop interviewed Temple about her life experiences living with autism, the movie and Claire Danes who portrayed her ~ if you would like to read that interview and view a trailer of the movie use the following link: [Temple Grandin’ Offers inside Look at Autism](#)

► **On February 14th the Philadelphia Enquirer** published an article entitled, “[End of life in group homes: Some guidance](#)” that relates the story of why Abigail Sandler’s *‘has fought for clearer rules on who calls the shots when a group-home resident becomes deathly ill.’* We learn that when Abigail’s sister Amiee, a woman with developmental disabilities who was a resident of a group home, was hospitalized, had stopped eating and diagnosed as terminal, was given a feeding tube at the request of the group home despite Amiee’s legal guardians expressed desire to not give her the tube. Sandler calls for more definitive guidelines regarding *‘who has the legal upper hand if families disagree with care providers, who often have sought all-out medical care for their intellectually disabled charges.’* Although this case took place in Pennsylvania, these are issues that resonate with families in every state who are legal guardians for loved ones who are living with an intellectual or developmental disability.

► **New Yorker magazine** article entitled, “[Letting Go: What Should Medicine Do When It Can’t Save Your Life?](#)” written by surgeon Dr. Gawande is a thoughtfully written story that skillfully presents the value of conducting end-of-life and advanced care planning discussions with patients before a moment of crisis. The article reports that based on surveys of patients with terminal illness, people have concerns besides simply prolonging their lives; top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. Unfortunately Gawande states that these top priorities are not often realized when end-of-life preparation is not completed. *‘Spending one’s final days in an I.C.U. because of terminal illness is for most people a kind of failure. You lie on a ventilator, your every organ shutting down, your mind teetering on delirium...The end comes with no chance for you to have said goodbye or “It’s O.K.” or “I’m sorry” or “I love you.”* To read the entire article using use the title link above.

The PBS show ‘Need to Know’ interviewed Dr. Gawande about the content in this article; the

interviewed included discussion of end-of-life counseling and health care reform. You can view the video of this interesting interview using the following link: [Need to Know](#).

► **A few months ago, the NY Times published an article entitled, [End-of-Life Care for Patients with Advanced Dementia](#)** which discusses the dilemma doctors and family caregivers face when a patient or loved one diagnosed with dementia declines and yet a determination for hospice cannot be made because there simply isn't a satisfactory way to identify which patients are likely to die within six months (*the Medicare regulation for a Hospice referral*). The article states that nationally, only 11 percent of Americans who died in hospice care last year had a primary diagnosis of dementia, while nationally, by way of comparison, more than 40 percent of Americans who die each year are in hospice care. Unfortunately the article also cites a study published last November in the Journal of American Medical Association (JAMA) that reports the results of a prognostic tool developed by researcher called A.D.E.P.T. The hope was that this tool could more effectively predict the six-month mortality, but the results show that in only 67 percent of the time was it reliable, which is to say that it failed a third of the time. Efforts to look at the Medicare Hospice certification requirements and additional tools are solutions offered. To read the entire article, please use the title link above.

If you are a registered member of the [Developmental Disability Hospice & Palliative Care Forum](#) site you can access the JAMA article under the '[Resource](#)' section. (*If you are not yet a registered member but would like to be, simply [click here](#) to register on the home page*)

► **NPR reports on a functional brain scan that could help identify developmental problems.** The technique, called functional connectivity MRI, shows which parts of the brain are communicating which could help doctors identify children whose brains are not developing on schedule, and may eventually explain what goes wrong in the brains of children with autism. Nico Dosenbach of Washington University explains why the technique is more useful for detecting developmental disorders than the traditional MRI scans that many children with behavioral or learning problems receive. *'The traditional scans usually appear normal because the problem isn't usually with the brain structures themselves. Instead, the trouble comes from the way those structures are communicating with each other.'* You can read or listen to this story here: [Determining 'Brain Age' With a Simple Scan](#)

► **The January 4th, NY Times article, [U.S. Alters Rule on Paying for End-of-Life Planning](#)** reports that the Obama administration officials cited procedural reasons for removing a Medicare regulation allowing billing for doctors in order to discuss advanced care planning with patients as part of the annual physical examination. *"We will amend the regulation to take out voluntary advance care planning,"* the official said. *"This should not affect beneficiaries' ability to have these voluntary conversations with their doctors."* This is not the first time that such a benefit and a billing allowance has been proposed and then eliminated – read the entire story using the title link above.

[Public Policy News / Advocacy Opportunities](#)

► **Bill Removing 'Mental Retardation' From Law is passed and signed into law October 5th, 2010.** [Disability Scoop](#) announces that the bill known as 'Rosa's Law' was unanimously passed mandating the removal of the terms "mental retardation" and "mentally retarded" from all federal education, health and labor laws and replacing them with the words "intellectual

disability.” The bill, called “a perfect example of citizen advocacy” by one of the bill’s sponsors, Senator Barbara Mikulski from Maryland, was proposed because many Americans feel after years of misuse the word ‘retarded’ now qualifies as hurtful speech.



New York Palliative Care Information Act (PCIA)

On August 13th, 2010 Governor David A. Paterson signed the [New York Palliative Care Information Act](#) into law. The law, which went into effect on February 9th, 2011 requires physicians and nurse practitioners treating patients diagnosed with a terminal illness or condition to offer the patient or their surrogate representative information and counseling on the available options for palliative care and end-of-life care including aggressive pain management and hospice care as well as the possibilities for further life-sustaining treatment. The New York Times recently wrote an interesting article on this new law which you can read here: [‘Frank Talk about Care at End-of-Life.’](#)

► **Disability Scoop** reports that in October, Sen. Chris Dodd from Connecticut and Sen. Richard Burr from North Carolina, introduced a revised [‘Restraint and Seclusion Bill’](#). The legislation is similar to HR 4247, *Keeping All Students Safe Act*, but will allow schools to include restraint and seclusion in students’ individualized education plans (IEPs) if students have a two-year history of behavior that could create “imminent danger of serious bodily injury in school.” We will keep you apprised of the progress of this bill, if congress does not review the bill in this congressional session, it will have to be introduced again at a later date. Disability Scoop published a series of articles detailing the history of the bill from January 2009 until the present; to view that page, use this [link](#). If you would like to track the progress of this bill you may use the following link: [Open Congress](#).

► **Kaiser Health News article reports on the Pediatric Palliative Care Act pilot projects:** [‘New Law Could Help Hospice Patients Continue Aggressive Medical Treatments’](#). The new law instructs Medicaid, the state-federal program for the poor, to cover simultaneous hospice and curative care for children with terminal illnesses immediately. And it directs the federal Medicare program, which covers seniors and disabled people, to launch up to 15 pilot projects around the country to test the concept. If the experiment is deemed successful and doesn’t increase costs, then Medicare could make the benefit available to everyone in hospice. Palliative Care services within the hospice benefit include a team of doctors and nurses devoted to easing physical pain and symptoms, and social workers and clergy who help patients and their families accept death. *Concurrent treatment sites: Aetna and United Healthcare already allow their hospice patients who are insured through private plans to pursue curative treatments. Randall Krakauer, who oversees Aetna’s Medicare and concurrent-care programs, says the change did not increase the program’s costs.* Read the article using the title link above.

► **April 16th, 2011 is National Healthcare Decisions Day:** The National Healthcare Decisions Day (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. On April 16th, you and/or your organization have the opportunity to join Americans across the country to talk to others about your future healthcare decisions and to complete your advance directives. For more information about participation use the following link:

[National Healthcare Decisions Day](#)

► **Federal Government Infuse Millions to Expand Respite Care:** Grant awards totaling \$2.25 million in 2010 have doubled the size of the Lifespan Respite Care Program, which was established by Congress in 2006 to improve respite services for caregivers of those with special needs. Already in 12 states, the new grants will allow programs to be created in (12) additional states including New York. The NYS project is supported by the New York State Office for the Aging (NYSOFA) in collaboration with the Statewide Caregiving and Respite Coalition of New York (SCRCNY). NYS Project objectives include: 1) development of a coordinated system of accessible, community-based respite services for people of all ages/across all needs; 2) identify and facilitate development of respite services for underserved populations; 4) identify current programs that train informal caregivers and provide a methodology to link caregivers to programs; 5) determine good practices and establish linkages to recruitment and training of volunteers; 6) raise public awareness about caregiving and the value of respite; and 7) develop a strategic approach to ensure sustainability. For additional information use the following link: [Lifespan Respite Care Program](#)

Information and Resources

► On January 21st, 2011 The **Office of Persons with Developmental Disabilities (OPWDD)** announced that, *“Effective immediately, (OPWDD) has approved the use of the newly revised [Medical Orders for Life-Sustaining Treatment \(MOLST\) form](#) for the individuals served in the OPWDD system.”* The MOLST form has been approved by the Office of Mental Health (OMH) and the Office for People with Developmental Disabilities (OPWDD) for use as a nonhospital DNR/DNI form for persons with developmental disabilities or persons with mental illness, including persons who are incapable of making their own health care decisions or who have a guardian of the person appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate's Court Procedure Act. However, the MOLST form must be accompanied by and attached to the OPWDD approved '[Checklist for Individuals with Developmental Disabilities](#)'. Use of the Checklist ensures that the appropriate statutory standards have been met prior to use of the MOLST process and assures that the form can be used for persons with developmental disabilities who are incapable of making their own health care decisions or who have a guardian of the person appointed pursuant to Article 81 of the Mental Hygiene Law or Article 17-A of the Surrogate's Court Procedure Act. This means that the MOLST form may only be completed after the Health Care Decisions Act (HCDA) process has been completed for an individual. Use of the Checklist ensures that the appropriate statutory standards have been met prior to use of the MOLST process. *Please note that use of the [MOLST form](#) is optional.*

► **Announcement:** Intellectual and Developmental Disabilities Research Centers 2011 grant opportunity. The *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)* invites applications for Center Core Grants designed to advance the diagnosis, prevention, treatment, and amelioration of intellectual and developmental disabilities (IDD). This Funding Opportunity Announcement (FOA) seeks applications from institutions that meet the qualifications for a program of IDD research. The grants fund core resources to support interdisciplinary research and research training. Funds for the research projects using these core facilities come from independent sources including Federal, State and private organizations. To access the full text announcement and award and submission information use the following link: [Center Core Grants](#)

► **Support for Caregivers:** the Veterans Administration has redesigned the [VHA Caregiver Support Website](#) with the caregiver in mind. The site has been designed to make it easier for caregivers to find valuable services and benefits as well as a number of valuable resources which will help the caregiver balance their life and ease the burden of providing daily care for loved ones. Additionally, on February 1st, the VHA launched the **National Caregiver Support Line** devoted to Veterans' Caregivers. The toll-free number (1-855-260-3274) is available to family members, loved ones, or friends who provide care for Veterans living with the effects of war, disability, chronic illness, or aging.

► The **Wall Street Journal** recently published an article announcing the introduction of new 'apps' available to smart phone users designed to assist busy, overburdened caregivers manage the challenges of tracking their care recipient's medical appointments, medication management, nutritional requirements and other daily caregiving related responsibilities. The author explores several available free or low-cost caregiver applications available to smart phone users. Read the article here: [Apps to Help Track Seniors' Medical Needs](#)

► **NPR's Fresh Air's** Terry Gross recently interviewed Dr. Atul Gawande about his research and writings on end-of-life care. Dr. Atul Gawande is a surgeon at Brigham & Women's Hospital and the Dana-Farber Cancer Institute as well as a staff writer for The New Yorker. Gawande tells Gross that he began his research of end-of-life care because he didn't know how to broach the subject of death with his terminally ill patients'. Gawande believes that patients want to avoid suffering and that they would like to spend their last days doing things that they care about not just taking in more treatments that may lead to more suffering. He also believes that medical professionals need to begin building a system that focuses on how to help dying patients achieve what's most important to them at the end of their lives; *"as we face an incurable disease, what can we do to make it more likely that you've identified what's important to you and how you want those final months to go — and then help you achieve it?"* This powerful interview can be found online at using the following link: [Make End-of-Life More Humane](#)

► The **American Academy of Hospice and Palliative Medicine** (AAHPM) has just released a new two and a half minute video called *"You're Sick. It's Serious."* The video, posted on YouTube is a social marketing tool intended to increase awareness of the medical specialty of Hospice and Palliative Medicine. You may view the video using the link above and are encouraged to share it when and if you believe it is appropriate or useful.

► The Center to Advance Palliative Care (CAPC) has launched the [IPAL-ICU Project](#), a new initiative to improve Palliative Care in the ICU. Developed by experts in both critical care and palliative care with a goal of promoting *"a paradigm shift in the way that critically ill patients, and their families, are cared for in the ICU,"* the resource is intended to be central hub for shared expertise, evidence, tools and resources in the U.S. Diane E. Meier, MD, Director of the Center to Advance Palliative Care (CAPC) says that she is thrilled to join with the National Institute on Aging to support this pioneering project, *"We expect to see an enormous positive impact on the care of the critically ill, who are the sickest and most vulnerable patients in America's hospitals."* You can access this exciting new resource here: [IPAL-ICU Project](#)

► **Autism NOW: Resources, Not Cure, Focus of New Developmental Disability Center.** In September, 2010 the ARC and a few additional disability organizations joined forces to establish a national resource center to assist people dealing with autism and other developmental disabilities. The group was awarded \$1.87 million from the Administration on Developmental Disabilities, to start the new initiative known as Autism NOW: The National Autism Resource and Information Center. Although the name emphasizes autism, those behind the center say it will offer resources for people with all types of developmental disabilities. Guided by the principles of inclusion, integration, independence, and self-determination, the center will gather, organize, and make publicly available readily accessible, high-quality resources and information related to community-based services that support independent living and self-determination, treatment protocols that promote community-based experiences (e.g. education, employment, recreation, transportation, early intervention and child care), and evidence-based interventions.

Autism NOW celebrated its opening on January 18 and a new website launch is to be announced soon. If you wish to be notified of when the site goes live simply register on the site using the following link: [Autism NOW](#)

Professional Development and Education

► **Hospice Social Work: Linking Policy, Practice, and Research:** In March, 2010 the Social Work Policy Institute (SWPI) convened a think-tank symposium, *Hospice Social Work: Linking Policy, Practice, and Research*, to explore the connections between hospice social work services, the mission of hospice, federal requirements, professional standards, and the current state of hospice research by social workers. Attendees included practitioners, administrators, regulators, researchers, educators, policy-makers and national leaders. The full report includes the recommended action steps to enhance excellence in hospice care, highlights strategies that can be undertaken by multiple stakeholders as well as an extensive APPENDIX with information on federal regulations and quality improvement efforts as well hospice social work credentials, standards, continuing education, research and researchers. The report from the symposium can be accessed here: [Social Work Policy Institute Report](#)

► A recent article published in the **Journal of Palliative Medicine** entitled, '*Disability Perspectives on Health Care Planning and Decision-making*' reviews the literature addressing the significance of developmental and intellectual disability on health care decision-making, advance care planning, and end-of-life care. Special attention is provided to assessing the life values or preferences of persons with intellectual disability with limited decisional capacity. The article concludes with suggested recommendations for more inclusionary dialogue, research to better inform palliative care services, and new planning models for individuals with limited capacity.

If you are a registered member of the [Developmental Disability Hospice & Palliative Care Forum](#) site you can access the entire article under the '[Resource](#)' section. (If you are not yet a registered member but would like to be, simply [click here](#) to register on the home page)

► The **Journal of Social Work in End-of-Life & Palliative Care** has put out a call for manuscripts for publication in a special thematic issue on *Pediatric Issues in Palliative and End-of-Life Care*. Manuscripts submitted for consideration could include a range of issues involving children and families dealing with chronic or life-limiting illnesses, such as 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, family members' anticipatory

grief/ bereavement; children's grief/bereavement related to sibling or parent death, suicide or other traumatic death; and unique developmental issues for children who are dying. Submissions should also address practice implications for social work/mental health professionals. Deadline is June 31st, 2011. Questions and submissions should be sent to Ellen L. Csikai, PhD at ecsikai@sw.ua.edu

► In recognition of the importance of spirituality in end-of-life and palliative care practice the **Journal of Social Work in End-of-Life & Palliative Care** has put out a call for manuscripts for publication in a special thematic issue on *Spirituality in End-of-Life and Palliative Care*. Submissions addressing a broad range of related topics are encouraged including, quantitative and qualitative research studies, theoretical approaches, model programs, related ethical issues, policy development, Inter-professional team functioning and team training and belief systems of death that may affect clinical work. Deadline is June 30th, 2011. Questions and submissions should be sent to Ellen L. Csikai, PhD at ecsikai@sw.ua.edu.

► **Book Review:** *'Last Acts of Kindness; Lessons for the Living from the Bedside of the Dying'* is a collection of life stories that asks the reader to think deeply about death as a spiritual experience rather than a medical failure. Author and self described midwife to the dying, Judith Redwing Keyssar, writes from her heart about her extensive experience in the field of palliative care, providing nursing expertise along with emotional and spiritual guidance and support for people in hospitals, residential facilities, and in their own homes. You can preview the book and read several chapters at Amazon: [Last Acts of Kindness](#)

► **Book Review:** The Journal of the American Medical Association reviewed Dr. David J. Casarett's book, *'Last Acts: Discovering Possibility and Opportunity at the End of Life'* calling the book "part memoir, part scholarly exploration, and part handbook for clinicians caring for patients at the end of life." Casarett, a Palliative Care physician and researcher asks, *'what would you do if you or a loved one only had a few days, weeks or months to live?'* Casarett describes his experiences in caring for approximately 50 terminally ill patients and creates a "Taxonomy of Last Acts", which is his way of classifying the responses patients have when they realize they are dying. He has "distilled" his approach to terminally-ill patients into three open-ended questions: "(1) Who in their lives is most important to them? (2) What would they want to do if they could do anything? (3) What would they most regret not doing?"

This book can also be previewed at Amazon: [Last Acts](#)



We would like to thank everyone who participated in our latest forum discussion:

"Obtaining Hospice for Patients without Capacity or Guardians: The Challenges, Benefits and Restrictions of the Surrogate Decision Making Committees (SDMC) Consent Process"

This was a topic that generated a great deal of interest and will remain an open thread on the [Developmental Disabilities Hospice & Palliative Care Website](#) so that ongoing questions and concerns can be addressed and additional resources can be posted as well.

**As always, proposals are being accepted on an ongoing basis for the
2011
Developmental Disabilities Hospice and Palliative Care Forum Topics!**

If you have a topic that you would like addressed please email me at
kconnell@hpcanys.org

To submit an RFP follow this link to [complete the simple application](#) and submit to me at
kconnell@hpcanys.org

Upcoming Events ~ ~ Mark your Calendar

<p>May 19-20, 2011 Desmond Hotel Albany, New York</p>	<p style="text-align: center;">SAVE THE DATE!!</p> <p style="text-align: center;">The Hospice & Palliative Care Association of New York State's (HPCANYS) 31st Annual Interdisciplinary Seminar and Meeting An event designed to provide opportunities for networking, education, and thoughtful discussion about end-of-life care.</p> <p style="text-align: center;">This year's theme is 'Leadership for a Caring Community' will offer workshops designed to provide participants with the tools to navigate the changes in the challenging years ahead.</p> <p style="text-align: center;">Registration will begin soon at HPCANYS.org</p>
<p>September 16-19, 2011 Sheraton Downtown Denver 1550 Court Place Denver, Colorado</p>	<p>The Arc's 2011 National Convention will once again bring together self-advocates, families, chapters, members, staff and professionals.</p> <p>Dr. Temple Grandin, the real-life inspiration the biopic which recently won Claire Danes an Emmy and a Golden Globe award, is scheduled to be the keynote speaker at The Arc's National Convention in Denver, CO in September.</p> <p>Dr. Grandin is a woman with autism who became one of the top scientists developing groundbreaking methods for the humane treatment of livestock.</p> <p>Make your plans now to attend the Convention this fall. Early registration begins soon at www.thearc.org.</p>

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