



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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In the News

I/DD Hospice and Palliative Care Issues

December 2nd, 2008 marked the deadline to implement the new Medicare Hospice Conditions of Participation (Hospice CoPs)

For the first time since the Medicare Hospice Conditions of Participation were created in 1983, the regulations for Medicare certified hospice providers issued by the Centers for Medicare and Medicaid Services have been *significantly* revised. The new Conditions of Participation (CoPs) have a strong focus on patient centered care that emphasizes quality assessment, performance improvement and patient outcomes. These regulations have been implemented to ensure that patients and family caregivers who are receiving or utilizing hospice and/or palliative care will receive the highest standard of care.

For instance, CoPs states that:

- All services revolve around the plan of care which *is now driven by the needs and wishes of the patient and family.*
- The initial comprehensive assessment will be updated as frequently as the patient's condition requires, but at a minimum of every 15 days.

Of course, these new regulations mean that CMS surveyors will be making the rounds to verify that certified hospice and palliative care service providers are complying.

Is your agency prepared?

NHPCO's Regulatory Team is offering materials to help members with these new regulations. Most recently, a copy of the 'CMS Interim Interpretive Guidelines' was made available to NHPCO members, before it was released to the broader public. NHPCO has made these materials available on the **CoPs Planning for Success** section of their Web site to assist Hospice and Palliative care providers with compliance not only today but in the future as well. NHPCO encourages our provider members to take advantage of these resources ... most of which are free!

Public Policy News

2008 proved to be a very industrious legislative year for improving the lives of the developmentally disabled community, as well as the hospice and palliative care community! We already have reported on a number of important new laws signed in 2008; following are several more that will be of interest to those who work with, advocate for or serve the developmentally disabled, as well as those who work in the hospice and palliative care service community.

► On **July 8, 2008 MOLST** (*Medical Orders for Life Sustaining Treatment*) became Statewide and permanent when Governor Patterson signed the end-of-life program into law. In a recent [press release](#), Michael Rosenberg, M.D., President of the Medical Society of the State of New York said of the law, "*For the first time all New Yorkers will have the comfort of knowing that the wishes of those who are terminally ill can be clearly articulated and that health care providers will have real guidance as to what the patient's wishes are at the end of life.*" Still, there remains some confusion among professionals as to what the difference is between MOLST and other advanced directives such as a Health Care Proxy, a DNR and a Living Will. ***What is MOLST? And what does MOLST mean for developmentally disabled individuals at end-of-life?***

For those who have more questions, the Community-Wide End-of-Life/Palliative Care Initiative, an [Excellus BCBS](#) enterprise, provides an excellent overview of the pilot program's goals, development and outcomes as well as a MOLST training center with centralized information about the MOLST form, capacity determination and requirements, educational materials and videos; follow this [link](#) to visit their web site today to learn more and to help integrate this important tool into the end-of-life care of developmentally disabled individuals.

'**MOLST** is a set of 'actionable medical orders, signed by a physician' that summarizes an individual's/surrogates current treatment preferences and wishes. Depending on those preferences, a physician order for Do Not Resuscitate (**DNR**), Do Not Intubate (**DNI**), and/or other life sustaining treatments, such as CPR or help with breathing can be designated on the MOLST. Perhaps most significant, is that the MOLST form converts the patients/surrogates treatment goals into medical orders, and ensures that the information is transferable and applicable across care settings, including institutional care, emergency medical services, and hospitals.

** Also, January's [DD Hospice and Palliative Care Online Forum](#) Discussion , '*Advanced Directives and the Developmentally Disabled Community*' is an excellent resource to help with any confusion that you may have regarding recent legislation, express concerns over legal issues and ask questions regarding barriers to the utilization of advanced directives in the developmentally disabled community**

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▶ On **July 7th, 2008** Governor Patterson signed, **A.10592/Chapter 194** into law extending the authority of NYSARC, Inc. to issue bonds through the Dormitory Authority of the State of New York until December 31st, 2013. These bonds are a win-win for everyone involved: they provide savings for New York State and, most importantly, essential programs for thousands of people with intellectual and developmental disabilities and their families. To date, NYSARC has issued a total of \$156 million in low-interest debt through the Dormitory Authority. This has made it possible to finance and refinance 343 community development projects across the state serving people with intellectual and developmental disabilities, saving the state \$32 million in financing charges over the past five years.

▶ On **August 5th, 2008**, **A.11550/Chapter 484** was signed into law in NYS, requiring special education teachers and administrators to be trained in the needs of children with autism. This legislation calls for enhanced course work or training about children with autism along with all other certification or licensing requirements.

▶ On **July 21st, 2008** Governor Patterson signed **A.9512A/Chapter 335** into law. This is a law that ensures the screening of young children (birth to age three) for developmental delays, including autism spectrum disorders, becomes a routine practice for pediatric primary care providers. Early diagnosis leads to early intervention, which has been proven to lead to better developmental outcomes for children. These professionals, who have regular contact with young children, are in a key position to recognize early characteristics of autism spectrum disorders.

Advocacy Opportunities

▶ Over the past several months, NHPCO along with many other hospice providers and advocates have joined a nationwide effort against the Centers for Medicare and Medicaid Services (CMS) in an attempt to halt the proposed Medicare Hospice rate cuts. NHPCO is pleased to announce that although the (proposed) rate cuts have not been reversed through these advocacy and grassroots efforts, a bipartisan group of 160 lawmakers in both the U.S. Senate and the U.S. House of Representatives have publicly supported our efforts to protect reimbursement rates for hospice.

To make sure that your voice is heard, contact your Representative in the U.S. House of Representatives or your State Senator. Simply [Click Here!](#) And ask them to support the Medicare Hospice Protection Act. (H.R. 6873 and S. 3484) These bills will delay the implementation of the rule and allow the Medicare Payment Advisory Commission (MedPAC) to continue its review of the Medicare hospice benefit.

▶ The New York State Association of Community and Residential Agencies (NYSACRA) is researching Shared-living options for New York State and is asking for input from both provider agencies and from individuals with disabilities and/or their families. They have created a survey about supported/shared living as an alternative to the traditional models of community residential supports in New York State. There are two versions of the survey; if your agency or the individuals and/or family members you serve would like to

participate, simply follow the links below to the version that is relevant to your or their situation.

- Follow this [link](#) to complete the 'Supported/Shared Living Survey for provider agencies'
- Follow this [link](#) to complete the Supported/Shared Living Survey for People with Disabilities and their Families

Information and Resources

► The revised *Medicare Hospice Conditions of Participation* (CoPs) regulations have placed a stronger focus on care plans driven by patient and family wishes, and require plan assessments at a minimum of every 15 days. These regulations emphasize that effective communication between the patient, the family and health care providers is integral to optimal care planning and execution, which presents challenges to all populations although this may be particularly true individuals within the DD community at end-of-life. A recent article, published in the **BMC Palliative Care Journal** discusses the findings of research that sought to develop multidisciplinary practice guidelines for conducting family meetings in the specialist palliative care setting. Family meetings are commonly recommended as a useful way for health care professionals to convey information, discuss goals of care and plan care strategies with patients and family caregivers. Yet it seems there is insufficient research to demonstrate the utility of family meetings, as well as how to conduct them in order to make the most effective use of them and produce good outcomes for the patient and/or family member.

To read the entire article, follow this [link](#).

► The National Center for Death Education, at Mount Ida College, in collaboration with NHPCO, is offering an online course entitled, ***Spiritual Care for Patients with Dementia and Their Families***. The 4-week course, which is to be facilitated by Dr. Kathleen Rusnak, will run from January 12 to February 6, 2009. The program is offered in a format that is user friendly and requires no special software or advanced computer skills. Participants will be able read lecture notes, download readings, and participate in discussion at their convenience, day or night and regardless of time zone.

For more information visit: www.mountida.edu/ncde or contact NCDE at (617)928-4649

► The NYS Developmental Disabilities Planning Council (DDPC) has made available an abuse prevention training curriculum developed collaboratively by Teacher's College, Columbia University and AHRC of New York City. This training package, titled "***Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment for adults with Developmental Disabilities***" (ESCAPE-DD), includes a CD of training resource materials and a DVD of training scenarios, this resource is intended to be used with people with developmental disabilities to help them identify, avoid, and effectively respond to potentially abusive situations and/or relationships.

To obtain a [free copy](#) of the ESCAPE DVD contact the NYS DDPC at 518-486-7505 or contact Nick Rose at: nrose@ddpc.state.ny.us

▶ On December 11th, 2008 the National Down Syndrome Society (**NDSS**) hosted an evening with William I. Cohen, MD Director, Down Syndrome Center Children's Hospital of Pittsburgh. The event was the second in the Education Series presented by NDSS, a series intended to bring nationally recognized leaders in the areas of Education, Advocacy and Research to New York City to educate with timely information to the Down syndrome community. While this event was free to attend, NDSS has provided a video presentation of the event on their website. To access this video, follow this [link](#) to the NDSS website.

▶ The National Healthcare Decisions Day (NHDD) Initiative is a grassroots 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. National Healthcare Decisions Day is a yearly initiative to encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be. The community wide End of Life/Palliative Care initiative invites you to join their NYS coalition conference call January 15th, 2009. To learn more about the initiative follow this [link](#) to the website.

▶ Members of **Obama's Health Care Transition team**, including former Senator Tom Daschle, solicited comments and recommendations on health care reform through the use of an internet blog on the transition website, [Change.gov](#). The team solicited comments and recommendations on health care reform which makes this a great opportunity to raise the level of awareness and importance of interdisciplinary training of health care professionals and caregivers end-of-life issues within the developmentally disabled community. Although we know they can't possibly read all of the submissions, we understand that the transition team is reviewing comments and using technology to track topical issues and key words. To submit a post, go to the following link: [www.change.gov](#)

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### **Developmental Disabilities Hospice & Palliative Care Online Discussion Forum**

Is a great source of information for those who are interested in creating supportive teams around individuals with developmental disabilities who are at the end of life, and features a series of two-week discussions moderated by noted experts on topics related to end-of-life care for people with developmental disabilities and those who support them.



~~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 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 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.

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Each of you have a wealth of experience and knowledge to share, together we can create a thriving community where knowledge, ideas and experiences are shared to improve end of life care for persons with developmental disabilities and all who are close to them.

~~ Join us online for our January Forum as we discuss the topic of *'Advanced Directives and the Developmentally Disabled Community'* with **Dr. Pat Bomba**, who is a nationally-recognized palliative care and end-of-life care expert and currently serves as the Vice President and Medical Director, Geriatrics for Excellus BlueCross BlueShield – and - **Paul Kietzman**, who was the first General Counsel appointed to the NYS OMRDD and is currently a practicing attorney for NYSARC, Inc.

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The purpose of this month's forum is to discuss ways to ensure that the rights of the DD community at end-of-life are upheld.

Following is an excerpt from the material prepared to frame our discussion:

All persons, including those with intellectual and developmental disabilities and their guardians have the right to ensure their wishes for end-of-life care are heard and honored, but the truth is that this is often not the case. For the developmentally disabled community, one of the biggest barriers to ensuring end-of-life care choices are conflicting State laws and regulations concerning guardianship, informed consent, DNRs and related health care decisions. Yet another barrier to individual choice at end of life for the developmentally disabled community is the sheer complexity of Advance Directive forms.

Although legislation has recently been enacted in New York State intended to address these barriers, there remains some confusion within the professional and service community about the legislation itself, its usefulness in the DD community and the best way to utilize these laws to provide end-of-life care with dignity and compassion.

Here are just a couple of the questions that this topic asks us to consider:

1. Should the differences in capacity required for making one's own decisions and what is required to appoint a health care agent be considered?
2. As an individual's situation changes over time, when/where are the appropriate points for legal intervention?
3. What are the legal and ethical issues to consider when executing an advance care directive for an individual with developmental disabilities?

If you are a member and would like to join the discussion, click (or cut and paste) the following link into your browser:

<http://ddhospicepalliativecare.org/phpbb2/viewtopic.php?t=107>

Want to join in the discussion? Not yet a member?

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

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Upcoming Events ~~ Mark your Calendar

<p>Thursday, January 15th, 2009</p> <p>1:00pm – 2:30pm EST</p>	<p style="text-align: center;"><i>Save the Date</i></p> <p style="text-align: center;">National Health Care Decision Day (NHDD) <i>2009 New York State Coalition Conference Call</i></p> <p>The Community-wide End-of-Life/Palliative Care Initiative is sponsoring local and state-wide networking conference calls to bring together key state leaders with the goal of empowering and coordinating organizations across New York State to plan NHDD activities. This is an excellent opportunity to bring the concerns of the DD Community at end-of-life to the table.</p> <p style="text-align: center;">Join with others in the region to talk to others about your future healthcare decisions and to complete your advance directive.</p> <p style="text-align: center;">Call-in Number: 1-800-747-5150 Passcode: 238-4514</p>
<p>Sunday, January 18th 2009</p> <p>1:00PM – 5:00PM</p> <p>Wilton Emergency Squad</p> <p>(between exits 15 and 16 of the Northway)</p>	<p style="text-align: center;">Down Syndrome Support Group</p> <p>Tri'd and True Friends, (part of the Down Syndrome Aim High Resource Center) will be meeting in Wilton this Sunday. All families of individuals with Down Syndrome are welcome! This will be a time for parents to socialize, celebrate and enjoy adult company and a time for the kids to play together.</p> <p style="text-align: center;">Please contact Joni Rhodes, at 695-4627 or 232-6671 or email her at pcjoni@localnet.com, for more information.</p> <p style="text-align: center;"><i>In case of inclement weather, please call before traveling.</i></p>
<p>January 19th 2009</p> <p>6-8pm</p> <p>O.D. Heck Development Center – Bldg 5 Balltown Rd, Schenectady, NY</p>	<p style="text-align: center;">Fathers Network Meeting</p> <p>The Fathers Network was developed to support fathers who are facing the emotions and challenges of parenting a child with special needs. All dads are invited to join the group and network with other fathers who have ‘been there’.</p> <ul style="list-style-type: none"> ◆ Share stories of success ◆ Share concerns or frustrations ◆ Engage in valuable conversations ◆ Open to dads, uncles, male siblings, grandfathers, step fathers ◆ Join us for coffee, soda, snacks <p style="text-align: center;">To RSVP for this event or for more information please contact Jim Swart at: (518) 381-4350 ext. 26 or jmswart1@verizon.net</p>

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<p>February 2nd – 3rd 2009</p> <p>Empire State Concourse in Albany, NY</p>	<p align="center">NYSRA 2009 Legislative Forum Acting on the State Budget and Priorities for People with Disabilities</p> <p>NYSRA’s highest priority is to advocate for people with differing abilities by ensuring they are offered broad opportunities toward community integration relating to competitive employment, as well as seeing they receive supports to pursue individual interests, to participate in activities within their communities, and to offer their talents and energy as contributing members of their communities. To add your voice to future legislative policies reserve your seats for this forum now.</p> <p align="center">For more information visit DDAWNY at: Developmental Disabilities Alliance of Western NY</p>
<p>April 21-22, 2009</p> <p>Omni Shoreham Hotel, Washington, DC</p>	<p align="center">24th Management and Leadership Conference and the 2009 National Hospice Foundation Gala</p> <p>Early-bird registration is now open for the premier end-of-life leadership conference, NHPCO's 24th Management and Leadership Conference</p> <ul style="list-style-type: none"> • Participate in the development and implementation of advocacy strategies to promote hospice and palliative care • Discuss changes in the regulatory, public policy and healthcare landscapes that impact hospice and palliative care • Examine best practices in advanced operations that distinguish quality programs <p align="center">For more information visit the NHPCO website here: Management and Leadership Conference</p>
<p>May 28-29, 2009</p> <p>Saratoga Hilton 534 Broadway Saratoga Springs, NY</p>	<p align="center">HPCANYS' 29th Annual Interdisciplinary Meeting and Seminar "Embracing Change...Transforming the Future"</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. If you can make it, it's well worth the trip.</p> <p align="center">HPCANY is providing one free registration to this conference!</p> <p align="center"><i><u>~~This opportunity is only for those forum members who have posted on at least one discussion board. The lucky recipient will be chosen in a random drawing raffle~~</u></i></p>

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As Always - We want to hear from you!

We welcome suggestions on content for our monthly newsletter!

Would you like us to list your event?

Do you have a story to tell?

Do you have a best practice to share?

If any of our 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 Kimberly Connell, the newsletter editor.

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