



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

March 2008 Vol. 2(3)

News

Recently Published Articles

The current edition of *Social Science and Medicine* has released a new article, **Communicating a terminal prognosis in a palliative care setting: Deficiencies in current communication training protocols**, on the journal's website. This is an excellent article, particularly given our on-line forum discussions on disclosing end-of-life related news. A copy can be found on www.elsevier.com/locate/socscimed. If you cannot retrieve it, please contact the [newsletter editor](#) and a copy can be forwarded to you.

The Journal of Palliative Medicine's most recent issue has an interesting article on **Team, Diversity, and Building Communities**. This may be of particular interest to those of you who participated in or read the postings in our on-line forum with guest expert, Terry Clarke. For more information, visit <http://www.aahpm.org>. If you cannot find the article, you can also contact the [newsletter editor](#) and a copy can be forwarded to you. [Reference: Muir, J.C. (2008). Team, diversity and building communities. *Journal of Palliative Medicine*, 11(1), 5-8.]

Health System Struggles with Spiritual Care

One of our readers shared the following article with the DD Hospice and Palliative Care Newsletter team. A USA Today article from February 15, 2008 discusses the importance of spirituality for many people who are terminally ill. Among findings, people receiving end-of-life care reported that spirituality is at least somewhat important, that they felt their spiritual needs went largely unmet, and that people who felt supported in their spiritual needs experienced a higher quality of life overall. To access this article, visit http://www.usatoday.com/news/health/2007-02-14-spiritual_x.htm.

Last Call: Founding Members Sought for the Social Work Hospice and Palliative Care Network (SWHPN)

The recently founded organization, SWHPN, is the first organization here in the US to unite social workers, consumers/patients, and stakeholder agencies in the fields of hospice, palliative, and end-of-life care. This organization is now seeking founding members to influence the development of SWHPN to promote the role of social work in the growing field of hospice and palliative care, as well as the role of palliative care in social work as a profession. This represents a unique opportunity to influence a national end-of-life care

agenda for persons with developmental disabilities. If interested, please visit <http://survey/constantcontact.com/surveya07e27o7cdxfacwcxcz/start> to complete a brief on-line membership form. Member fees are \$50 for professionals and \$25 for students.

Information and Resources

Call for Papers

The 2009 SSWR (Society for Social Work Research) Annual Conference organizers have issued a special call for papers on the topics of grief, loss, trauma, and other end-of-life topics. This is an international conference that is attended by thousands of professionals! The call for papers provides an excellent opportunity to share the unique needs and issues around end-of-life care for persons with developmental disabilities and those who care for them. For more information, visit www.sswr.org or e-mail Crystal Moore at cmore@skidmore.edu.

Developmental Disabilities Hospice & Palliative Care Forum!

The DD Hospice and Palliative Care Forum is up and running now! We have an exciting line-up of guest experts coming on to the forum to share expertise and engage in lively discussions with you and others interested in hospice and palliative care for persons with I/DD. Guest expert, Dr. Geraldine Abbatiello, is joining us beginning March 17, 2008 to discuss when to make the decision to let go and seek palliative or hospice care. She brings with her a strong clinical, research and academic expertise in palliative and end-of-life care for persons with I/DD and will be available to answer member questions for 2 weeks.

This forum is a collaborative initiative by NYSARC Inc. and The Hospice and Palliative Care Association of New York State, with funding provided by the NYS Developmental Disabilities Planning Council and is in direct response to a series of training workshops on palliative care and the ensuing demand for more information and collaborative opportunities. These workshops which took place across New York State brought together developmental disabilities, hospice/palliative care service providers, and advocates to collaborate and learn more about innovative ways to improve end of life and supportive care for persons with developmental disabilities, their families, and their paid caregivers. Staff, families, and advocates who participated in these workshops formed local and regional collaboratives aimed at sustaining improvement in end of life and supportive care. This forum was created to offer an on-line opportunity for these groups to continue to pursue service and care improvements. Come join the forum and use this as a platform to share ideas, challenges, and questions. Joining is easy. Simply visit the forum's registration page at <http://www.ddhospicepalliativecare.org/register.cfm> and register today!

Upcoming Events

- The 2008 Disability Policy Seminar, **Advancing Disability Policy in an Election Year**, sponsored by the AAIDD, will be held on March 2-4, 2008 in Washington, DC. Many policies advancing health and quality of life for persons with developmental disabilities and their families will be considered by our Congress this year. This conference will discuss these and ways to get involved and make a difference at a more policy-based level, as well as the individual work being done in your agencies. For more information, visit www.aamr.org/Events/gas.shtml

- **HPCANYS'** (Hospice and Palliative Care Association of NYS) **28th Annual Interdisciplinary Seminar and Meeting** will be held May 15-16, 2008 in Saratoga Springs, NY. The theme this year is Threads in the Fabric: Working Together. For more information, please visit www.hpcanys.org.
- **NYSARC's 2008 Aging Symposium** will be held April 23-24, 2008 in Saratoga Springs, NY. The theme is Live Long and Prosper: Healthy Aging for People with Intellectual and Other Developmental Disabilities. For more information, please visit www.nysarc.org.

Newsletter Contributions

We welcome suggestions on content for our monthly newsletter! If you have an item you would like to submit, such as news, resources, or upcoming events, please click [here](#) to e-mail Anna Zendell, newsletter editor.

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