



# Developmental Disabilities Hospice & Palliative Care

## E-Newsletter

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### News

#### **Feelings of Mistrust and Preference for Curative Treatments Influence Blacks' Perception of Hospice Care**

According to a Keiser Report released on February 1, 2008, Black Americans reported distrust of and lack of access to the health care system, as well as perceived cost of hospice services, as factors influencing racial disparities in the use of hospice. In another finding, researchers discovered that African Americans tended to prefer continued treatment, even if the chances of treatment actually helping were slim. For more information, please visit <http://www.Keisernetwork.org>.

#### **Ageing: Growing Older is Found to Hurt Decision Making**

A January 29th article in the *New York Times* reported the findings of a University of Iowa study on the effects of aging on judgment and decision making, making older adults more vulnerable to fraud and con-artists (a situation often faced by people with developmental disabilities who are living in the community). With the many decisions to be faced during life-threatening illnesses and at the end of life, this area of research bears watching. To read the article, visit <http://www.nytimes.com/2008/01/29/health/research/29agin.html>

#### **New University of Illinois at Chicago Center to Study End of Life Transitions**

The UIC Nursing College recently received funding to create a Center End-of-Life Transitions. This center will study the transitions people must make as they near the end of their lives. Among other important research work, Teresa Savage, assistant professor of nursing, will conduct a project to address end-of-life issues for people with intellectual/developmental disabilities. Focus groups will be conducted with people with I/DD, their families, and paid caregivers. The *I/DD Hospice and Palliative Care* Newsletter will feature updates on this important research as the study progresses. For more information, please visit the UIC web site at [www.uic.edu](http://www.uic.edu).

#### **Founding Members Still 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***

### **Annals of Internal Medicine releases Recommendations for Treatment of Seriously Ill Patients at or Near the End of Life**

The Annals of Internal Medicine released an evidence-based set of recommendations for the end-of-life care. High quality information about palliative and end-of-life care remains limited, and the recommendations and peer-reviewed articles on evidence based interventions may be a major milestone for persons nearing the end of their lives and those who care for them! For more information, visit <http://www.annals.org>. If you have difficulties finding the information, please contact [Anna Zendell](#), and she will send you copies once she has them electronically (*on order at the time of this newsletter*).

### **Hospice Foundation of America Joins AGIS' Ask the Expert Section**

The Hospice Foundation of America is partnering with AGIS to provide expert advice and information on end-of-life issues related to caregiving, including grief and loss, preparing for death, emotional pain, and other complex situations associated with the many stages of preparations for death. To see this new resource, please visit them at [www.agis.com/community/Ask-The-Experts/hfa/](http://www.agis.com/community/Ask-The-Experts/hfa/)

### **AAIDD Aging and End of Life Issues Forum Materials Now Available On-line**

The American Association on Intellectual and Developmental Disabilities (*formerly the AAMR*) has placed materials from its Aging and End of Life Issues Special Forum on the AAIDD web site. Information specific to end of life and palliative care is available in power point format on issues such as: policy perspectives in end of life care, consumer directed care, housing, quality of care, and principles of palliative care for persons with I/DD. To access these materials, please visit <http://www.aamr.org/Events/aging.shtml>

### **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. For our inaugural forum, guest expert, Terry Clark, from The Community Hospice in Albany, is joining us beginning February 11, 2008 to **discuss team building approaches between palliative care and developmental disabilities**. She brings with her strong expertise in palliative 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**

- **RRTI's Geriatrics and Developmental Disabilities Nurse Training Program.** Trainings will include many aspects of aging among people with developmental disabilities, including end of life issues. Sessions are held all across New York to improve access for nurses who wish to participate. Past participants have found this training invaluable in their day-to-day practice with older adults with developmental disabilities. An informational [brochure](#) is available for download. Register today at [www.rrti.org](http://www.rrti.org); seats are going fast!
- 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](http://www.aamr.org/Events/gas.shtml)
- **HPCANYS'** (Hospice and Palliative Care Association of NYS) **28<sup>th</sup> 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](http://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](http://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.

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