



## E-Newsletter

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### News

#### **Declaration of Health Parity for Persons with Intellectual and Developmental Disabilities**

The American Association on Intellectual and Developmental Disabilities (AAID--formerly the American Association on Mental Retardation) has just released its declaration on health parity specific to people with I/DD. This two page declaration provides a great philosophical cornerstone for agency, community, regional, state and national policy advocacy. To download a copy of the declaration, please visit:

<http://www.aamr.org/pdf/HealthDeclarationFinal.pdf>

#### **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 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/surveya07e27o7cdxfacwxcxz/start> to complete a brief on-line membership form. Member fees are \$50 for professionals and \$25 for students.

#### **Hospice and Palliative Care in the News**

Palliative care has become widely-discussed in our national news, as well as academic journals. Here is a sampling of what was featured in the past month's news.

A January 2, 2008 article on ABC News entitled Whites Get More Pain Meds than Minorities, Study Says discusses the part that prejudices play in Emergency Room pain drug dispensing. The article is based upon a longitudinal research study conducted from 1993-2005 on emergency room visits, comparing dispensation of opioids, a common pain medication, between white and non-white ER patients over the 13 year period. The article discusses reasons for the variations in prescription dispensing, including lack of physician education on pain treatment, inadequate supplies of opioids in non-white community pharmacies, and pain complaints of women and minorities, and seniors receiving less attention than complaints of white males. For a copy of the article, please visit <http://www.abcnews.com>. If you cannot acquire the article, please feel free to contact Anna Zendell at [ag0814@albany.edu](mailto:ag0814@albany.edu), and request a hard copy.

A *Washington Post* article from 12/11/07 on Time is Money? Not for Docs discusses the importance of medical providers spending time with families and doing other care duties, many of which are not reimbursed by Medicare. The importance of time spent with persons and their families dealing with end of life issues and care cannot be underestimated. To access this article, please visit <http://www.washingtonpost.com/wp-dyn/content/article/2007/12/07/AR2007120702090.html> If you cannot access this section, feel free to contact Anna at [ag0814@albany.edu](mailto:ag0814@albany.edu), and request a hard copy.

A powerful article on the ways in which the hospice movement has influenced access to and quality of end-of-life care can be found in the *Idaho Press-Tribune* from 12/27/07. The article, entitled Hospice Changes End of Life Experiences elucidates the benefits of hospice, as well as giving an historical time line of the hospice movement. To access this article, please visit <http://www.idahopress.com/?id-2715> .

Finally, in somewhat older news relevant to end of life care for persons with developmental disabilities and their families, an article from the *Chicago Tribune* (9/19/07) discusses long term care for baby boomers with developmental disabilities. This article, entitled An Incredibly Bleak Picture (*taken from a quote by an advocate interviewed for the story*) shares the struggles family members have to access long term care, particularly when family caregivers are nearing the end of their own lives and fearing for the quality of life for their own aging children. The writers chronicle the difference that timely intervention with families by disabilities providers can make in both quality of care and peace of mind for family caregivers. To access this article, please visit [http://pqasb.pqarchiver.com/chicagotribune/results.html?st=advanced&QryTxt=&type=current&sortby=REVERSE\\_CHRON&datetype=0&frommonth=01&fromday=01&fromyear=1985&tomonth=01&today=04&toyear=2008&By=Olkon&Title=An+incredibly+bleak+picture&Sect=ALL](http://pqasb.pqarchiver.com/chicagotribune/results.html?st=advanced&QryTxt=&type=current&sortby=REVERSE_CHRON&datetype=0&frommonth=01&fromday=01&fromyear=1985&tomonth=01&today=04&toyear=2008&By=Olkon&Title=An+incredibly+bleak+picture&Sect=ALL). If you cannot access this article, please feel free to contact Anna at [ag0814@albany.edu](mailto:ag0814@albany.edu) and request a hard copy.

## ***Information and Resources***

### **Palliative Care: Specialized Care for Serious Illness**

This article appeared in *The Safety Net* magazine, published by the National Association of Public Hospitals and Health Systems, and provides an excellent philosophical overview of navigating palliative care services in the health care system. If you would like a copy, contact [ag0814@albany.edu](mailto:ag0814@albany.edu).

### **EPEC Online Learning**

The complete EPEC (Education in Palliative Care in End of Life Care) curriculum is now available as on-line courses for CEU's and CME's. Courses are geared toward physicians, nurses, and other health care professionals working in palliative care education and practice. EPEC courses are generally \$30 each. For detailed information on the wide variety of courses, please visit

<http://www.epec.net/EPEC/Webpages/Ecommerce/categoryDetail.cfm?categoryID=module&CFID=89562&CFTOKEN=61036146>.

### **Palliative Care Education Center**

Excelsior College in Albany has a Center for Palliative Care Education, which combines its expertise in distance education with its renowned health care faculty. This is an excellent place for people who need Continuing Education Units (CEU's). For more information, please visit the site at <http://www.excelsior.edu>

### **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!**

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!

We anticipate beginning targeted discussions on topic areas of interest to the hospice and developmental disabilities provider communities in the near future. If you have a specific topic that you would like addressed, please let Anna Zendell know ([ag0814@albany.edu](mailto:ag0814@albany.edu)).

If you have not yet signed up for the forum, please do so today! Each of you has a wealth of experience to share, and together this will be a thriving community with shared ideas to improve end of life care for persons with developmental disabilities and all close to them.

## 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)
- **American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association Joint Annual Assembly.** This annual conference is being held January 30-February 2, 2008 in Tampa Bay, FL. For more information, please visit <http://www.aahpm.org/>
  - **National Hospice and Palliative Care Organization (NHPCO) Audio Web Seminars.** The NHPCO has another excellent round of audio web seminars listed on its web site. They can be accessed through [www.nhpc.org/i4a/pages/Index.cfm?pageID=5065](http://www.nhpc.org/i4a/pages/Index.cfm?pageID=5065)
- **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).

## 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.