



National Hospice & Palliative
Care Organization/
Office of Disability

**End-of-Life Care Initiatives:
Available Resources & Training**



The Architect of and Catalyst for Social
Change to Advance Care at
the End of Life.

- **NHPCO's Vision**
A world where individuals and families facing serious illness, death, and grief will experience the best that humankind can offer.
- **NHPCO's Mission**
To lead and mobilize social change for improved care at the end of life.

www.nhpc.org




Office of Disability/Last Passages

Increase Access to Hospice &
Palliative Care for Individuals with
Developmental/ Intellectual
Disabilities and their Families


- **Identification of Promising Practices**
- **Development of Educational
Materials**
- **Encourage Collaboration**

www.albany.edu/aging/lastpassages



Promising Practices: Cross-Training & Collaboration


- Nationally
- Oklahoma
- California DDS
- Massachusetts Collaboration
- New Jersey Health Decisions
- New York: NYSARC's Continuing Efforts
- Washington DC



Person-Centered Planning

An on-going planning process which emphasizes the person's gifts, strengths, talents, needs and supports, and which includes as primary sources of information the person, their family and others who know and love the person best (even if they're not paid to provide support), in addition to professional involvement.


Leigh Ann Kingsbury, 2005



The Role Of Person-Centered- Planning

- Identify elements of the person's life that are important and should not be forgotten or ignored when he/she is dying
- To help clarify what is important *to* the person and what is important *for* the person
- Identify rituals that may bring comfort to someone who is dying or is grieving
- To communicate well ahead of time the people, documents, places, rituals, etc. the person wants in place at his/her death

Leigh Ann Kingsbury, 2005



The Role Of Person-Centered Planning

- To help staff sort through and define their roles and responsibilities
- To maintain autonomy at a time when there are many, many professionals involved
- Informed decision-making for the person

Leigh Ann Kingsbury, 2005



Unifying Concepts Between DD Systems, Hospice and the Process of Person-Centered Planning

- Autonomy for the person
- Dignity and respect as defined by the person
- Inclusion of family and friends
- Individualized approaches
- Cultural competency

Kingsbury and Botsford, 2005



Office of Disability

Next Steps

- Identification of Needs
- Educational Materials
- Continued Collaboration
- Conferences/Publications
- Disability Groups and End-of-Life Care



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