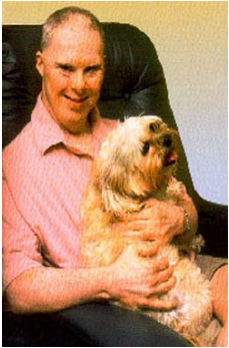



LAST PASSAGES
Sharing Information and Promising Practices to Enhance End-of-Life-Care for Persons with Developmental Disabilities





By Angela King, MSW
Volunteers of America

Participating Organizations

- Volunteers of America
- Center for Aging, NYS OMRDD
- Center for Disabilities Studies and Community Inclusion, University of Southern California
- University of Chicago
- Center for Excellence in Aging Services, University at Albany
- Center for Intellectual Disabilities, University at Albany
- Center for Life's Journeys

- Center for Practical Bioethics
- Creative Living Options, Inc.
- InLeads (Innovations in Leadership and Supports)
- Massachusetts Department of Mental Retardation
- National Hospice and Palliative Care Organization
- New Jersey Health Decisions
- Oklahoma Department of Human Services, Aging Services Division
- Oklahoma Department of Human Services, Developmental Disabilities Services Division
- Orange Grove Center, Chattanooga, TN
- ResCare, Inc.

Completed Surveys

- Multi-focus surveys to providers, local ARCs, professionals, and self-advocates
- Survey of state DD directors through NASDDDS of policies, needs and problems in end of life care for people with developmental disabilities in the state
- Pre and post test surveys of attendees of end of life care training sessions

Results of Surveys

- A recognition of the need for end of life care policies, particularly in the areas of Medicaid, guardianship and investigations
- Identification of the need for staff training in end of life care, particularly nurses, casemanagers and direct support staff
- Need for improved collaboration with hospice providers

National Advisory Board

- Hospice providers
- Health care professionals
- State DD officials
- Family members
- Providers
- Self-advocates-representing Not Dead Yet
- Medical ethics professionals
- Academics/Researchers
- Other interested parties

Training Sessions

- State wide training in Oklahoma which resulted in on-going model
- Training at the national conference of DDNA, (Developmental Disabilities Nurses Association)
- Training sessions in Tennessee, Louisiana, Kansas, Nebraska, California, and several others

Presentations

- Presentations at numerous state and local conferences, including
- NHPCO: National Hospice and Palliative Care Organization
- National Association of QMRPs
- YAI conference in New York
- TAMR

Importance of End-of-Life Care

- Improved access to health care
- People are aging in a variety of home, social and work settings
- Staff and families are more frequently faced with end-of-life care issues
- Increased medical options and length and intensity of care available to older people with intellectual disabilities at the end-of-life



Pro-Disability Attitude

- Right to life, despite the level of their disability
- Right to choose curative care
- Right to the full range of choices available to other community members
- Right to high-quality palliative care

Beliefs & Attitudes

- Each person is unique in his or her needs
- Each person is of equal value and deserving of respect
- Expectations can either challenge or limit the growth of individuals
- Each person deserves quality services and is deserving of our best efforts
- We must learn to perceive and understand the thoughts, feelings, wants and needs of people at the end stage of life

Unique Barriers to End of Life Choices

- Dependent conditions, family members and guardians making decisions on behalf of the person
- Legal decision making authority is in question
- Living with a chronic disability

Guiding Principles

- Respect for the autonomy of the person
- Do not harm
- Do what is good
- Justice



What Are We Planning

- Treatment options
- Burial
- Wills/Distribution of personal belongings
- Funeral homes
- Religious/cultural rituals

End of Life Care Planning

- Talking with the individual about their attitudes toward life and how they want to live it
- Talking with the person about their attitude toward pain and how they want to manage it
- Assisting in preparing advance directives
- Assisting in identifying and preparing someone to act as his/her health care agent.

Planning For End of Life Care

- Getting accurate, adequate information for decision-making
- Talking with family about their concerns, relationship with the individual, their values, religious and cultural views on the end of life
- Talking with medical professionals about treatment options

Planning Process

- One step at a time
- Small, intimate conversations
- Get good information from health care professionals
- Consider the person's life in totality when discussing options

Medicaid System

- Funding to support the use of hospice or related services within the person's normal living environment
- Natural deaths must be treated with dignity and respect
- Flexibility for a person to exercise their choices regarding end of life care

Policy Implications

- Death must be treated as a natural occurrence
- Guardianship laws must recognize the need for the full range of end of life care choices
- People with disabilities should have the right to make choices concerning end of life including the right to curative or hospice care

Resources

- Web sites
- <http://www.albany.edu/aging/lastpassages/>
- <http://www.uic.edu/orgs/rrtcamr/>

Training Resources

- End of Life Care Resource Guide available through NYSARC
- Policy paper on the website
- Trainers available for presentations and longer sessions contact amking@voa.org or lizc@indra.com
