

LAST PASSAGE Partners



End-of-life care refers to the plans, preferences, and expectations that an individual envisions for his or herself with the realization that life does not go on forever. It is not necessarily initiated by any medical or health event, condition, or consequence but simply by the common understanding that life ends and we should be able, to the best of our ability, with support, to have a say in its actualization.

Organizations Represented by People on the Advisory Board

- Center for Aging, NYS OMRDD
- Center for Disabilities Studies and Community Inclusion, University of Southern California
- 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
- Center for Rights of Parents with Disabilities of the Colorado Cross-Disability Coalition
- College of New Rochelle
- Creative Living Options, Inc.
- Hospice Foundation of America
- InLeadS
- Marist College
- Massachusetts Department of Mental Retardation
- National Hospice and Palliative Care Organization
- New Jersey Health Decisions
- NYSARC, Inc.
- Oklahoma Department of Human Services, Aging Services Division
- Oklahoma Department of Human Services, Developmental Disabilities Services Division
- Orange Grove Center, Chattanooga, TN
- ResCare, Inc.
- Volunteers of America of Oklahoma
- Volunteers of America, Inc.

LAST PASSAGES

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



In 2001, Volunteers of America, Inc. initiated **Last Passages**, a three-year national demonstration project with four goals:

- To establish a national baseline of the needs and care available to people with an intellectual disability and their families regarding end-of-life care;
- To identify and evaluate promising strategies for improving end-of-life care;
- To disseminate education and resources, examples of best practices, and models of innovative agency and state policies to professional and provider organizations throughout the country; and
- To advocate on behalf of individuals with an intellectual disability and their families for more effective and compassionate end-of-life care practices and policies at national, state, and individual agency levels.

Volunteers of America, Inc. initiated **Last Passages** in response to the increased longevity of people with an intellectual disability, and to the growing number living with their families, by themselves, or in individual or group housing in the community, receiving community-based healthcare and facing the challenge of obtaining quality end-of-life care within their communities. While hospice and palliative care have significantly transformed end-of-life care for the general population, people with an intellectual disability and their families have not benefited to the same extent. In addition, formal and informal caregivers for people with an intellectual disability typically lack training and access to resources for enabling dignity and quality during care at the end of life.

Partners in the **Last Passages** initiative include Marist College, New York State ARC, Inc., New York State Office of Mental Retardation and Developmental Disabilities, and the University at Albany.

Over the three years of the grant, **Last Passages** accomplished the following:

- Convened an advisory board of national leaders from major public and private provider organizations, hospice and healthcare, bioethics, self-advocacy groups, families, and interdisciplinary professionals.
- Conducted a national survey of the status of end-of-life care as well as promising practices and policies among major provider organizations.

- Produced a statement of core principles and philosophy on end-of-life care for adoption by service provider organizations and professional associations.
- Replicated a staff training program, originally developed by the New York State ARC, Inc., with 250 trainees in Oklahoma and evaluated its effectiveness in increasing the staff's knowledge and confidence.
- Developed, conducted, and evaluated a train-the-trainer program to provide trainers in end-of-life care.
- Provided educational programs at major state, national, and international conferences including the Council on Social Work Education; the Gerontological Society of America; the Developmental Disabilities Nurses Association; the American Association on Mental Retardation; the Young Adult Institute; the National Hospice and Palliative Care Organization's Clinical Team Conference; the Center for Hospice, Palliative Care and End-of-Life Studies; the World Congress of the International Association for the Scientific Study of Intellectual Disabilities; the National Association for Qualified Mental Retardation Professionals; the Tennessee Department of Mental Retardation Services; the Texas Association on Mental Retardation, as well as local presentations in Louisiana, Montana, and numerous other venues.



- Disseminated research findings, recommendations, and resources in articles in professional journals and publications including the *American Journal of Mental Retardation*, the *Journal of Intellectual Disability Research*, the *Journal on Disability Policy Studies*, the *Frontline Initiative*, and *Executive Perspectives*.
- Disseminated information to parents and physicians through a series of articles in *Exceptional Parent*, a magazine widely distributed to parents of individuals with an intellectual disability and their physicians.
- Established a website with research findings, best practice examples, policy models for improving state and agency policies, guidelines and recommendations, resources, and links to related sites.
- Supported NYSARC's development of a training manual and CD as a resource for public and private provider organizations to provide staff education and development.
- Development of *Precepts of Advance Care Planning, Healthcare Decision-making, and Palliative Care for People with Disabilities* (December 2004).
- Distributed a detailed report on the outcomes and recommendations of the **Last Passages** initiative.
- Established an agreement with the Rehabilitation Research and Training Center on Aging and Developmental Disabilities at the University of Illinois at Chicago to continue dissemination of project information and materials on its website and through its clearinghouse.

The resources developed by the **Last Passages** initiative continue to be available and accessible to interested individuals and providers. For more information, visit: http://www.uic.edu/orgs/rrtcamr/end_of_life/

Or contact Angela King, Volunteers of America, amking@voa.org.

For copies of the NYSARC monograph, resource manual and training resources, contact Nancy Cannon, NYSARC, Inc., cannonn@nysarc.org.

For copies of research papers, program evaluations, and reports, contact Anne Botsford, Ph.D., A.C.S.W., Marist College, anne.botsford@marist.edu.