

End-of-Life Care for People with Developmental Disabilities Bibliography

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This bibliography is divided into sections: End-of-life care for individuals with developmental disabilities, grief and bereavement, developmental disabilities (aging, healthcare, miscellany), advance planning and healthcare decision making, and end-of-life care—general. Pertinent websites are listed at the end.

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Websites

American Academy of Developmental Medicine and Dentistry (AADMD) is an organization of physicians, dentists, students, and advisory members, whose collective mission is to work together, as clinicians, educators and advocates, utilizing our respective expertise and talents, to improve the overall health of children and adults with developmental disabilities, www.aadmc.org.

American Academy of Hospice and Palliative Medicine (AAHPM) is an organization of physicians and other medical professionals dedicated to excellence in and advancement of palliative medicine through prevention and relief of patient and family suffering by providing education and clinical practice standards, fostering research, facilitating personal and professional development, and by public policy advocacy. www.aahpm.org

American Association on Mental Retardation (AAMR) promotes progressive policies, sound research, and universal human rights for people with intellectual disabilities, www.aamr.org.

American Association of People with Disabilities is the largest national nonprofit cross-disability member organization in the United States, dedicated to ensuring economic self-sufficiency and political empowerment for the more than 56 million Americans with disabilities. AAPD works in coalition with other disability organizations for the full implementation and enforcement of disability nondiscrimination laws, particularly the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973, www.aapd.com

Arc of the United States works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community, www.thearc.org

Center for Practical Bioethics is a freestanding practical bioethics center.

Our vision: A society in which the dignity and health of all people is advanced through ethical discourse and action.

Our mission: To raise and respond to ethical issues in health and healthcare.

Our core value: Respect for human dignity. We believe that all persons have intrinsic worth, and we express this belief by promoting both autonomy and social justice in health and healthcare, www.midbio.org

Center for Self-Determination is not a place. It is a highly interactive working collaborative of individuals and organizations committed to the principles of self-determination. The purpose of the collaborative is to change the nature of the support and service system for individuals with disabilities, using the principles of self-determination to help all persons create the lives they want, connected to and with their communities, www.self-determination.com

Exceptional Parent Magazine provides information, support, ideas, encouragement & outreach for parents and families of children with disabilities, and the professionals who work with them, www.eparent.com.

Last Passages is a Project of National Significance funded by the Administration on Developmental Disabilities and the Project on Death in America, <http://www.albany.edu/aging/lastpassages/> and www.uic.edu/orgs/rrtcamr/endoflife.

National Alliance of Direct Support Professionals. The NADSP is a coalition of organizations and individuals committed to strengthening the quality of human service support by strengthening the direct support workforce. The group has representatives from the fields of mental health, developmental disabilities, child welfare, education, and many others in the human services community. The Alliance has developed a national agenda to address conditions chronicled for 25 years that are harmful to people who rely on human services. These conditions include high staff turnover, low social status, insufficient training, limited educational and career opportunities, and poor wages. These undermine the commitment of the Direct Support Professionals, and have made it very difficult to recruit and train qualified and committed individuals in direct support roles in every area of human services, www.NADSP.org

National Hospice and Palliative Care Organization (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 is to lead and mobilize social change for improved care at the end of life. www.nhpc.org

National Institutes of Health State-of-the-Science Conference on Improving End-of-Life Care, December 6-8, 2004, <http://consensus.nih.gov/ta/024/024EndOfLifepostconfINTRO.htm>.

Not Dead Yet is a national disability rights group that leads the disability community's opposition to legalization of assisted suicide and euthanasia. Founded in 1996, Not Dead Yet's mission has expanded to leading opposition to other forms of legalized medical killing. They oppose efforts to expand the definition of "terminal" and to easing restrictions and safeguards on surrogate decision-making regarding the withholding of food, water, and medical treatment, www.notdeadyet.org.

NYSARC, Inc., the largest not-for-profit organization serving individuals with mental retardation and other developmental disabilities and their families. NYSARC has a rich history of providing advocacy and services throughout New York State, www.nysarc.org.

Quality Mall, a website where you can find lots of free information about person-centered supports for people with developmental disabilities. Each of the "mall stores" has departments you can look through to learn about positive practices that help people with developmental disabilities live, work and participate in our communities and improve the quality of their supports, www.qualitymall.org.

Rehabilitation Research and Training Center on Aging and Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago. The RRTCADD promotes the successful aging of adults with intellectual (mental retardation) and developmental disabilities (I/DD) in response to physical, cognitive, and environmental changes. Its coordinated research, training, and dissemination activities promote progressive policies and supports to maintain health and function, self-determination, independence, and active engagement in life. The RRTCADD is a national resource for researchers, people with intellectual and developmental disabilities, their families, service providers, policy makers, advocacy groups, students, and the general community. The RRTCADD is committed to Participatory Action Research. Its active consumer and family advisors and its national advisory board of major disability, aging, and advocacy organizations help insure that the RRTCADD's research is relevant and is responsive to culturally diverse populations, www.uic.edu/orgs/rrtcamr.

State of the States in Developmental Disabilities Project, University of Colorado, established in 1982 to investigate the determinants of public spending for mental retardation/developmental disabilities (MR/DD) services in the United States, the project maintains a 26-year longitudinal record of revenue, spending, and programmatic trends in the 50 states, the District of Columbia, and the United States as a whole. Analysis of the rich detail of the data base reveals the impact over time of federal and state fiscal policy, and illustrates important service delivery trends in the states in community living, public and private residential institutions, family support, supported employment, supported living, Medicaid Waivers, demographics, and related areas. These financial and programmatic trends are presented in *The State of the States in Developmental Disabilities: 2004*, by Mary C. Rizzolo, Richard Hemp, David Braddock, and Amy Pomeranz-Essley, www.cu.edu/ColemanInstitute/stateofthestates.

TASH: Equity, Opportunity and Inclusion for People with Disabilities since 1975, is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm, www.tash.org.