

2008 Life Threatening Public Policy Workshop Series

Purpose of the Series:

This series is designed to address growing acceptance of public policies that threaten the lives of people with disabilities. These policies include for example “altruistic filicide” where a parent kills his or her child with disabilities, “growth attenuation treatment” undergone by Ashley X of Seattle in early 2007, “suicide tourism” in Switzerland, ethical arguments that parents should have a right to withhold food & hydration from newborn children who have disabilities, pre-natal genetic testing leading to the widespread practice of selective abortion, adoption of the Gronigen Protocol in the Netherlands that enables “death by committee” where a team of doctors select people with severe disabilities for “euthanasia,” & official tolerance for the use of painful, potentially deadly, aversive electric shock programs on people.

The series will heighten understanding of the vulnerability of people with disabilities to such life threatening public policy, & invite participants to respond. This series is intended to help identify & promote values & ideas that are crucial to the overall well-being of people with disabilities, challenge values that pose a threat to the well-being of people with disabilities, & provide thoughtful examination of matters of value.

Who Should Attend:

The series is directed at members of ethics committees & patient advocates in Connecticut’s hospitals; self-advocates, parents, providers, & the public are invited to participate in many of the workshops. The workshops are free. *Registration is required.*

For More Information:

Please contact Ed Preneta at Ed.Preneta@ct.gov

March 5, 2008: Citizen Advocacy

2:00 p.m. to 4:00 p.m.

Farmington Public Library, Farmington, CT

Tom Kohler, Savannah, GA, is a coordinator of Chatham-Savannah Citizen Advocacy. Citizen advocates are unpaid & independent of human services. They create relationships with people who are at risk of social exclusion & whose lives are being diminished because of prejudice toward disability. Tom will encourage participants to understand, respond to, & represent the interests of vulnerable people, look for ways to bring the gifts & concerns of

vulnerable people into community life, & build a constituency of allies to broaden & sustain action on the behalf of vulnerable people.

**March/April 2008: Disability & Medical Decision Making:
Ethical Issues in Policy & Practice**

Time & Place To Be Determined

Judy Heumann has been involved on the international front working with government officials around the world to advance the human rights of people with disabilities. Judy is currently Director of the Department on Disability Services, Washington, DC. Invited to present is Adrienne Asch. Adrienne is the Edward & Robin Milstein Professor of Bioethics at the Wurzweiler School of Social Work, & Professor of Epidemiology & Population Health at the Albert Einstein College of Medicine. A panel of responders, including clergy, a physician, individuals with disabilities, parents, & an attorney, will follow the presentations.

March/April 2008: Genetic Screening: Decisions Regarding Selective Abortions, Genetic Traits, & The Insurance Industry.

Time to be determined. Location will probably be the State Capitol/Legislative Office Building, Hartford, CT.

Robert Greenstein, MD, Director, Division of Human Genetics, UCONN Health Center. Dr. Greenstein is interested in the development of public health genetics programs that bring new genetics technology advances into clinical usefulness. Robert Perske is widely known for his books about community inclusion, & in recent years for his writing & work on people with intellectual & developmental disabilities in the criminal justice system.

April 11, 2008: A Lesson From History: The German Euthanasia Program & Its Echoes In Our Own Day

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.

Jack Yates, Associate Trainer, Social Role Valorization Implementation Project, Worcester, MA. He will focus on the systematic killing of people with impairments by the medical establishment in Germany during World War II. Participants will examine the origins of the German euthanasia program, its opponents, & its parallels today in genetic testing & selective abortion.

April 25, 2008: Social Devaluation & The Killing Thought

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.

Jo Massarelli, Director, Social Role Valorization Implementation Project, Worcester, MA. She is a member of the Medical Safeguards Project, a group of nurses & doctors in Massachusetts who are committed to safeguarding the health & lives of people with disabilities with significant medical needs. She will explore why people treat each other so poorly, even to the point of wishing the other dead. This workshop is particularly directed at members of hospital ethics committees; self-advocates, parents, providers, & the public are invited to participate.

May 2, 2008: Common Life Experiences Of Human Service Recipients Which Can Contribute To Their Deaths

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.

Jo Massarelli will trace the common “wounding” life experiences of people who are recipients of human services. If one is devalued in our society, one is likely to be a recipient of human services, which tends to bring with it patterns of life experiences that are limiting, wounding, & even life threatening. Issues raised will include how segregation & congregation can threaten lives, & the lethal effects of negative imagery, social isolation, & life-wasting activity. This workshop is particularly directed at members of hospital ethics committees; self-advocates, parents, providers & the public are invited to participate.

May 16, 2008: An Exploration Of Fundamental Issues Of Restraint As A Human Service Technique

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.

Marc Tumeinski, Trainer, Social Role Valorization Implementation Project, Worcester, MA. He is a consultant to Citizens Against Restraint, Ontario, Canada. Marc will explore the reality of the extreme vulnerability of those likely to be restrained & the troubling moral questions raised by the use of restraints in human services. Deaths from the use of restraints has been widely publicized at the same time that restraint is increasingly being accepted, taught & used in a wide variety of fields. This workshop is particularly directed at members of hospital ethics committees.

May 30, 2008: Quality Of Life & Medical Deathmaking

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.

Jo Massarelli will analyze the concept of “quality of life” & the ways in which current medical practice has used it to endanger the lives of people with disabilities. Modern medicine has

become a paradox. On one hand, medicine is heralded for life saving treatments &, on the other hand, it is complicit in abbreviating the lives of those whom it deems to have a poor “quality of life.” This workshop is particularly directed at members of hospital ethics committees; self-advocates, parents, providers & the public are invited to participate.

June 13, 2008: Euthanasia & Physician-Assisted Suicide

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.

Stephen Drake is a person with “invisible” disabilities related to a brain injury at birth. Physicians told Stephen’s parents he’d be better off dead. He has been actively involved in *Not Dead Yet* since 1996. He will address the growing climate of acceptance for self-inflicted death especially if it is done with the help of a medical professional, death brought about through surrogate decision-makers on the basis of “she/he would have wanted,” & how redefining personhood, humanness, futile care, medical treatment, death, & end-of-life heighten dangers to people with disabilities. This workshop is particularly directed at members of hospital ethics committees; self-advocates, parents, providers & the public are invited.

June 27, 2008: Constructive Responses To Life Threatening Public Policy

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.

Jo Massarelli & Jack Yates will draw together the themes of the Life Threatening Public Policy series’ topics & look for patterns among the patterns. Suggestions will be made for constructive responses & ways of standing in the way of life threatening public policies with examples of organizations which have taken stands.

July 18, 2008: Too Late To Die Young

2:00 p.m. to 4:00 p.m.

Farmington Public Library, Farmington, CT

Harriet McBryde Johnson has defended her right to live against Princeton University’s bio-ethicist Peter Singer. She is a lawyer in solo practice in Charleston, SC, has been a disability rights activist & advocate for more than 25 years, & is active in a variety of political & disability organizations. Harriet will defy & debunk every popular assumption about disability. Children & adults are encouraged to attend.

September 19, 2008: Culture Of Death

10:00 a.m. to 2:00 p.m.

Institute of Technology & Business Development, Central Conn. State University, New Britain.



2:00 p.m. to 4:00 p.m.

Farmington Public Library, Farmington, CT

Wesley Smith is a senior fellow at the Discovery Institute, an attorney for the International Task Force on Euthanasia & Assisted Suicide, & a special consultant for the Center for Bioethics & Culture. Wesley will address the dangers of the modern bioethics movement. He is a prolific author. His articles have appeared nationally & internationally in many newspapers & other publications. He is actively involved in the struggle against assisted suicide & euthanasia, & is also a prominent critic of mainstream views on bioethics.

October 17, 2008: Free To Live (working title)

Time & place to be determined.

Invited to present is Nat Hentoff. Nat is an American historian, novelist, & columnist for *The Village Voice*, *JazzTimes*, *Legal Times*, *Washington Times*, *The Progressive*, *Editor & Publisher*, *Free Inquiry*, & *Jewish World Review*. His views on journalistic responsibility & the rights of Americans to write, think, & speak freely are expressed in his weekly column, & he has come to be acknowledged as a foremost authority in the area of First Amendment defense. In the 1980s, Nat developed views opposed to abortion, voluntary euthanasia, & the selective medical treatment of severely disabled infants.

September/October/November 2008: Protecting The Lives Of Hospital Patients

Time, date & place to be determined.

Jo Massarelli & Joe Osburn will present an all-day workshop focused on protecting the lives of hospital patients. Joe Osburn has worked in human services since 1964 in a variety of direct service, administrative & consultative positions. He regularly provides support to a few small communal organizations that practice hospitality, life-sharing or other forms of solidarity with socially vulnerable families & individuals.

September/October/November 2008: Understanding Vital Organ Donation

Time, date & place to be determined.

Jo Massarelli, Jack Yates, & associates will address the potential dangers to people with disabilities in the vital organ donation process. This workshop is particularly directed at members of hospital ethics committees; self-advocates, parents, providers & the public are invited to participate.