



## Overview

### **The Center for Practical Bioethics and Disparities in Health and Healthcare**

The Center for Practical Bioethics formalized its commitment to promote awareness about healthcare disparities in 2000. Since that time, the Center has actively pressed its agenda locally and nationally through its recruitment and programming efforts.

The Center has a program associate dedicated to these issues. Other Center staff have participated in and initiated a number of programs to address issues related to diversity and disparities in the delivery of health care. These activities include programming at the national, regional and communities levels; community service; and scholarship.

#### **Programs**

- **APPEAL (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at the End of Life).** A Robert Wood Johnson Foundation funded project at Howard University to develop a curriculum to supplement existing curricula and educational materials on palliative care and end-of-life care designed to address the unique needs of African American patients and their families. The Center's CEO served as a member of the National Advisory Committee that oversaw this project.
- **Initiative to Improve Palliative Care for African -Americans (IIPCA)** was formed to define and promote a research, education, and policy agenda for the improvement of care for African American patients facing serious illness. This program is currently housed at the Duke Institute for Care at the End-of-Life. The Center was a charter member of this IIPCA, and the Center's CEO serves on the advisory board for the Duke Institute.
- **Last Miles on the Way Home Conference.** This national conference funded by the Robert Wood Johnson Foundation was held in Atlanta, Georgia in February, 2004. The Center's CEO served on the planning committee. At the conference the Center was acknowledged for the work it has done to improve care for African-Americans and was one of five recipients of the **Marian Gray-Secundy SANKOFA Award.**

- **Kansas City Regional Long-Term Care Ethics Committee.** An American Bar Association funded project to recruit, organize, train and make available to all long-term care providers in seven counties in Kansas and Missouri that comprise greater Kansas City, a model multidisciplinary ethics committee to address end-of-life issues of seriously ill and dying residents. The Center partners with the Kansas City Regional Long-Term Care Consortium, Missouri Long-Term Care Ombudsman Program and LIFE Project of Kansas.
- **Last Passages.** A three-year project to identify and share information and promising practices to enhance end-of-life care for people with developmental disabilities. The participants in the project include Volunteers of America, NYSARC, the National Hospice & Palliative Care Organization, and a number of other organizations working in the areas of developmental disability, end-of-life care and bioethics.
- **Layton Lecture,** October 17, 2002: September Williams, MD, MA, nationally known African American physician, clinical ethicist, and filmmaker reached more than 100 Kansas City thought leaders, clinicians, and public about the intersections of media, medicine, and race.
- **Cultural Diversity Summit.** The Center conducted a three-year “active listening” project wherein end-of-life stories from four vulnerable populations (Laotians, Mexican Americans, African Americans, and impoverished Caucasians) were collected. Stories were published along with commentaries and other pedagogical tools for healthcare professionals. A community-wide summit was held on February 22, 2002, in KC’s poorest county to report lessons learned. Summit was attended by more than 200 persons representing 12 area institutions.
- **National Association of Attorneys (NAAG) General 2002-03 Listening Conferences.** The Center worked with the NAAG to host three listening conferences across the country which framed end-of-life care as a consumer protection issue. In planning these conferences special attention was given to the disparities in end-of-life care, especially about good pain management.
- **And Thou Shalt Honor.** In conjunction with the And Thou Shalt Honor Foundation, the Center kicked off the first in a national series of televised townhall meetings focused on caregiving by families for frail elderly people. The Center served as the lead organization for organizing this coalition and providing administrative support. With concerted effort by the Center more than 20% of those who participated were from diverse segments of our community.
- **Pain Advocacy Campaign.** With *Last Acts Partnership*, the Center developed a consumer education program to inform people about the importance of advocating for better pain management and to provide them with tools for doing so. Two special components were developed – one in Spanish for Latino populations and another specifically for African-Americans.

- **Diversity in End-of Life Care.** Two staff members provided a one-day inservice training program for nurses at St. Luke's Hospital. More than 200 clinicians attended.

### **Community Service**

- Developed a person-centered methodology that people with mental retardation use to make advance care plans. Established and chair the Truman Behavioral Network ethics committee, the only institutional ethics committee in Kansas City that is exclusively concerned with ethical issues in community mental health care. Conducted focus group study of the relationship between acculturation and health status of three immigrant populations.
- In November, 2002 two Center staff members helped write the Consensus Statement of the American Bar Association's project on healthcare decision making for the unbefriended elderly.
- Membership on Kansas City's Department of Health "Health Planning and Assessment Committee," a city-wide effort to determine the health needs of Kansas City's vulnerable populations
- Guest lectures at the schools of medicine at the University of Kansas Medical Center and the Kansas City University of Medicine and Biosciences on health and healthcare disparities
- Guest lecture at community forum, with the Midwest Center for Holocaust Education, on eugenics, genetics, and racism; Overland Park, KS, July 2004

### **Scholarship**

- In partnership with the Tuskegee University National Center for Bioethics, guest editing a special issue of the internationally recognized bioethics journal *Cambridge Quarterly of Health Care Ethics* focused on healthcare disparities
- In partnership with the Tuskegee University National Center for Bioethics, guest-edited a special issue of the nationally recognized bioethics journal *Theoretical Medicine and Bioethics* focused on health disparities, featuring scholars from around the nation.
- Presented at the International Academy of Law and Mental Health, pre-conference on health disparities. "Bioethics Unplugged: Social Determinants of Health in America," Montreal, Canada, July 2001
- Presented at numerous national bioethics conferences on health disparities, including the American Society for Bioethics and Humanities, October 2000, and University of Tennessee's "Bioethics: The Next Twenty Five Years," April 2000.

- Presented at the annual meeting of the Society for Pastoral Theology, conference on racism, workshop titled, “The Shadow Side of Organ Donation and Transplantation: African-American Disparities and Dilemmas,” Atlanta, GA, June 2004; for Mid-America Mensa, Shawnee, KS, Aug 2004; and at the annual conference of the Minority Donor Awareness Society, Kansas City, MO, Oct 2004
- Presented at the Last Miles on the Way Home conference in Atlanta, Georgia, February 2004.
- Published “Cultural Competency – the Caregiver Connection” by Jacqueline Voight in Bioethics Forum the Center’s scholarly magazine.

#### **Other**

- The Center participated as one of the first ten non-profit organizations in Project Equality. Board and staff were surveyed, diversity training was provided to the board and leadership team and a new board member was recruited from the Latino community.
- The Center devoted an issue of *State Initiatives to Improve End-of-Life Care* on diversity that was circulated to 28,000 policy makers.