

# State Initiatives

## in End-of-Life Care

Issue 24, April 2005

Focus: Diversity and Discrimination

### Policies to Address Disparities in End-of-Life Care

*In this image, a caregiver from Zuni Home Health visits with a patient. Zuni Home Health provides culturally appropriate care to a Zuni, Navajo, and white population in New Mexico. Americans who are diverse in terms of their race, ethnicity, class, sexual orientation, disability, or geography often get less health care or substandard health care, and have worse health status than other Americans. They may be suspicious of mainstream medical care and find it hostile to their beliefs and needs. Policy changes that focus on ensuring access, mandating and funding training for caregivers, resolving legal issues related to treatment decisionmaking, and adequately reimbursing caregivers and institutions could help more Americans access adequate care at the end of life.*



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## Diversity and Discrimination: Gaps in Care and Policy

Americans from diverse populations are less likely to have access to medical services, may face discrimination, and may not be understood by care providers. Patients may be marginalized by race or ethnicity, sexual orientation, disability, income, or geography. Unfortunately, these Americans face barriers not only to general medical care but to adequate end-of-life care. They suffer needlessly at the end of life all too often.

There are three kinds of barriers to their care:

**Access.** People from diverse populations often lack access to medical care because they don't have insurance or the insurance they have requires high copayments and deductibles. In addition, there may not be primary care providers in their communities.

**Trust.** They may not trust the medical establishment, which has often ignored or dismissed them and, in the case of the U.S. Public Health Service study of syphilis in black males, abused their trust and ensured suffering and death.

**Training.** Medical care providers lack the training, knowledge, resources, and policy that would support them as they work with diverse populations.

It is not easy to address such profound difficulties in American society, since they permeate institutions and individuals and since many of the policy solutions will require additional funding. Nevertheless, the scale of human suffering is large and growing, as poverty and the number of uninsured people increase.

Policy changes that focus on ensuring access, mandating and funding training for caregivers, resolving legal issues related to treatment decisionmaking, and adequately reimbursing caregivers and institutions could help more Americans access adequate care at the end of life. ■

*"The entire history of health care in the United States has been shamefully blighted by a long series of racial inequalities. As a result, a legacy of distrust has been handed down from one generation to the next."*

## Remembering Marian Gray Secundy

This issue of *State Initiatives in End-of-Life Care* is dedicated to the memory of Marian Gray Secundy, PhD. A professor emeritus of bioethics at Howard University Medical School, Dr. Secundy worked her entire life to address racial injustice in the medical establishment. She devoted particular attention to ensuring that people of color could have access to adequate care at the end of life.

From 1999 until her death in 2002, she was the director of the new Tuskegee University National Center for Bioethics in Research and Health Care, formed two years after President Clinton apologized for the syphilis study conducted from



Marian Gray Secundy  
1938–2002

1932 to 1972 by the U.S. Public Health Service on African American men from Macon County, Alabama. Scientists studied the development and progression of syphilis in these men without telling them that they had the disease and without telling them that they could be treated and cured. "The entire history of health care in the United States has been shamefully blighted by a long series of racial inequalities," Dr. Secundy said. "As a result, a legacy of distrust has been handed down from one generation to the next."

Dr. Secundy served on the National Advisory Committee for Community-State Partnerships to Improve End-of-Life Care. She also played a very active role in the Initiative to Improve Palliative Care for African Americans, and she was responsible for securing funding for APPEAL: A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End. Her death was a loss to the community of those who work to improve end-of-life care for all Americans.

## Disparities in Care

The United States is becoming increasingly diverse. Hispanic and Asian populations, in particular, are growing at much faster rates than the population as a whole, according to 2003 statistics released by the U.S. Census Bureau. Of the total U.S. population, Hispanics now constitute 13.7 percent, African Americans constitute 13.3 percent, and Asians 5 percent. Yet ethnic and racial minorities represent only 5 to 7 percent of patients in hospice, according to at least one study. Minorities are not receiving a proportional amount of hospice care, but as it turns out, this is just part of a larger trend.

According to the Institute of Medicine (IOM) report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, racial and ethnic minorities tend to receive lower quality health care than whites do, even when they match insurance status, income, age, and severity of conditions. Minorities are less likely to receive routine medical procedures, are more likely to receive less desirable procedures (for example, limb

amputations for diabetes), and are less likely to receive life-prolonging treatments for HIV or cancer.

### Factors Leading to Disparities

Research shows that a range of factors keeps diverse populations from receiving adequate medical care.

### Unconscious Attitudes

According to the report, even medical providers who are consciously opposed to racist behavior may fall back on unconscious negative racial attitudes and stereotypes when diagnosing and treating patients, particularly given the time pressures and complexity of clinical settings.

### Less Comprehensive Insurance

In addition, people with lower socioeconomic status are more likely to be enrolled in affordable health plans that impose a larger financial burden on the patient by offering fewer resources along with higher copayments or deductibles. Patients may not be able to afford these expenses.

### Remote Treatment Sites

Even when they have the same level of insurance as whites, minorities are less likely to have access to primary care providers in their communities. Further, the move toward enrolling Medicaid patients in managed care, the IOM says, “may disrupt traditional community-based care and displace providers who are familiar with the language, culture, and values of ethnic minority communities.”

### Lack of Cultural Sensitivity

Patients and health care providers may be from other cultures and thus may have very different understandings of death, of what and how to communicate, of the meaning of pain, of the limitations of medical science, of the responsibilities of family, of the right to self-determination, and of the state’s role in helping individuals.

### History of Abuse

Minorities may mistrust medical providers because of a history of abuse and because care providers may make faulty assumptions and lack respect for cultural differences. For example, African American patients may suspect that the medical system doesn’t have their best interests in mind, and may therefore insist on ICU care and aggressive medical interventions at the end of life.

*Continues on page 4*



Photo: Susie Fitzhugh

*Experts say that racial and ethnic minorities tend to receive lower quality health care than whites do, even when they match insurance status, income, age, and severity of conditions.*

## Disparities in Care

*Continued from page 3*

### Language Barriers

Programs have little capacity to adequately translate documents, educational materials, and conversations between providers, patients, and families. In California, for example, providers may work with patients who speak only or mostly one of more than 200 languages. This lack of capacity to communicate may result in nonexpert translators giving a skewed version of the message or in family members—even young children—being inappropriately recruited to communicate on behalf of the medical system.

All of these factors prevent access to care, forestall real conversations about preferences, keep patients from receiving adequate care at the end of life, and cause real emotional distress for patients and families.

### New Policy Directions

Experts call for greater cultural competency and sensitivity about different cultures and acknowledgment of difference in policymaking. And they consistently point to the need for funding. Many programs struggle to provide adequate end-of-life care to

those who have access to medical services, feel comfortable receiving care, and have the resources needed to navigate the system. Programs tend to lack the resources that would allow them to overcome the many barriers that keep minorities from having adequate end-of-life care. So, while experts call for policy that would address these disparities, they also remind policymakers that implementation of such policy will require a significant and steady stream of financial resources from the states.

Policymakers who wish to address the barriers to adequate end-of-life care for minorities can mandate that care providers receive training in cultural competence, that hospitals have rooms large enough to accommodate families who wish to be involved in decision-making about a patient, and that hospices provide materials in the languages of those communities they serve. And, as the IOM report points out, the health care system at large needs more minority health care providers, especially since they are more likely to work in medically underserved communities.

### Abriendo Puertas: A Model of Service for Hispanic Communities

Hospice by the Sea (HBTS), in Boca Raton, Florida, is committed to providing staff with the training they need to provide culturally sensitive care to members of ethnic and racial groups that live in the region. They have developed Abriendo Puertas (Opening Doors), a model for culturally responsive end-of-life care for the Hispanic community. The program provides palliative care, bereavement counseling, and any other services families may need, such as organizing volunteers to bring food, helping families with long-distance and international communication, or even helping to send remains back to a home country. “Families are often fragmented, with some here and some in their home country,” says director Mari Chumaceiro. “Our program becomes a support system during a terrifying and lonely time. The families we work with are so grateful for our help.”

Abriendo Puertas uses a bilingual hospice team—nurses, physicians, social workers, volunteers, and spiritual counselors—to work with the patients and their families. It is important, Chumaceiro notes, that caregivers can speak English as well as Spanish: “While older members of the family may be comfortable in Spanish, the younger people may prefer English.



*An Abriendo Puertas staff member with a patient who is receiving care at home through a program that provides culturally responsive end-of-life care to the Hispanic community. Abriendo Puertas uses a bilingual hospice team that includes nurses, physicians, social workers, volunteers, and spiritual counselors to meet the needs of patients and their families.*

## Unequal Access to Pain Treatment

The team needs to be able to support the patient and the family and needs to be able to communicate easily with everyone. All of our materials are in both Spanish and English, too.” In Hispanic culture, discussing death is difficult, so the program offers support to Hispanic patients, families, and doctors, making it easier to broach the subject in a friendly and familiar atmosphere.

“Our program becomes a support system during a terrifying and lonely time. The families we work with are so grateful for our help.”

Mari Chumaceiro, director,  
Abriendo Puertas

HBTS is now starting a parallel program for African Americans, according to Neal Mize, a medical anthropologist who trains staff in cultural competence: “We are building on what we learned through Abriendo Puertas.” The spiritual life of African Americans is often rooted in the church, though it is a church with different traditions and structures from those that are central to the Hispanic community. A program serving African Americans has to take into account beliefs in miracles, prayer, and reliance on God, says Mize. It also has to address families’ suspicions that the medical system—including hospice—is indifferent or hostile to African Americans or that it will exploit them, he says. ■

For more information about the programs of Hospice by the Sea, visit [www.hospicebytheseafl.org](http://www.hospicebytheseafl.org).

According to the Institute of Medicine (IOM) report *Unequal Treatment*, minorities confront discrimination when seeking pain treatment. Other research also shows that racial, sexual, and class discrimination are profound barriers to pain management.

The IOM reports that minorities get less treatment and lower quality treatment than whites and are less likely to receive “even routine medical procedures.” A 2001 study found that male doctors prescribed twice the level of analgesic medication for white patients than for African Americans. Studies also suggest that poor people receive less pain treatment than the wealthy, that untreated pain levels are inversely proportional to income, and that women are less likely than men to be treated for pain.

Entire communities may not have access to necessary pain medication. For example, in a 2000 study of New York City’s boroughs, only 25 percent of pharmacies located in mostly non-white neighborhoods were found to stock adequate supplies of opioid medications; in white neighborhoods, just under three-quarters did. “The disparity that we observed between white and non-white neighborhoods was very disturbing,” says R. Sean Morrison, MD, Mount Sinai School of Medicine, the study’s lead author.

Previous studies have observed that African Americans or Latinos with cancer are at increased risk for not being prescribed pain medications. These studies, taken together with the New York pharmacy study, suggest a vicious cycle for minority patients with pain, states Morrison. “Physicians do not prescribe these medications and as a result, pharmacies in minority neighborhoods do not experience a demand for them. When

patients are prescribed opioids, their local pharmacies often do not carry them. The result is unnecessary suffering.”

Pharmacists told the researchers that just the threat of a DEA investigation was enough to prevent them from stocking Schedule II controlled substances. According to Susan Winckler of the American Pharmacists Association (APhA), in addition to worrying about the DEA, “there is a cost to having those medicines on the shelf. There is a cost to all that record-keeping.” Add to that the problem of poor patients on Medicaid, which pays a low rate and takes weeks or months to pay: “If patients can’t pay the pharmacist for the medications on the shelf, there are limits on what the pharmacist can do to help them,” Winckler says.

Winckler explains that the APhA works with pharmacists to teach them ways to meet the expectations of the DEA. They also help DEA agents understand that “just because the pharmacy is the highest dispenser of Schedule II narcotics in the county, that’s not necessarily a sign that there’s diversion.”

A 2001 study found that male doctors prescribed twice the level of analgesic medication for white patients than for African Americans.

# The Barriers of Poverty and Rural Isolation

For Americans of any race or ethnicity, life circumstances—such as poverty or rural isolation—can put people outside mainstream culture and medical care.

## Living and Dying in Poverty

According to the U.S. Census Bureau, in 2003 the number of Americans without health insurance grew to 16 percent (up from 14.2 percent in 2000). In addition, the number of Americans living in poverty increased to 12.5 percent (from 12.1 percent in 2002). Single-parent families were especially hard hit, with the poverty rate among households headed by a single woman reaching 28 percent, from 26.5 percent in 2002.

People with low incomes who are dying are subject to additional pressures that increase their suffering and keep them from getting adequate end-of-life care, according to Beverly Williams, PhD, University of Alabama at Birmingham Center for Aging. The demands of a poverty lifestyle may exclude low-income people from diagnosis and treatment and keep them from attending to their condition. They may see themselves as having no time to have surgery or be in the hospital. They may see themselves

**“Policymakers should understand that better end-of-life care will not be available to people in frontier rural areas until there is funding to pay for it.”**

Donna Bales, president and CEO, LIFE Project

as having no money for treatment and no options. “This is the other America,” Williams says. “They work long hours for low pay. They have no sick leave or insurance. They can’t leave the job to see a doctor or they will lose pay or even the job.”

Because of the stresses of living in poverty, diseases that affluent people typically experience late in life occur at midlife for the poor, Williams says, citing research. And since American culture tends to promote the idea that terminal illness is avoidable if people take good care of themselves, low-income people are often blamed (even by themselves) for becoming ill. Distressingly, the implications of serious illness and death have not only an emotional impact but often a devastating economic impact as well on the patient’s family. If a family lacks health or life insurance, a death can leave a family bereaved, without a source of income, and with huge expenses.

## A Program That Helps Patients Qualify for Hospice Care

The Balm of Gilead in Birmingham tries to address the needs of people who do not qualify for hospice care, typically because they lack homes or caregivers. While most of the patients they help are African American and urban, they also assist white and rural patients. The Balm works with patients to find a living situation, get them into hospice care, and help them manage pain and other symptoms. The program is currently moving from grant-based funding to hospital-based funding, a shift that has forced them to set aside some innovative practices, which points, again, to the need for consistent funding for programs that help underserved populations. The Balm was recently profiled in the *Journal of Palliative Medicine* (vol. 7, no. 3, 2004).

## Getting Care in Pioneer Rural Areas

In some states, there are counties that have only one or two thousand people spread out across a large area, called a “pioneer rural” area. Culturally, people living in pioneer rural areas tend to be strongly independent and dedicated to sustaining themselves. They may find it difficult to rely on people outside their immediate families, and with the increasing mobility of American life, their families may no longer live in the area. In addition, it is difficult for anyone who is sick to travel long distances for care.

Travel time for hospice workers is a big issue, since workers may only be able to see two patients in a day. Population-based formulas for calculating reimbursement don’t work for hospices in these areas. In very rural areas, a lone hospital gets a sole provider rate of reimbursement that covers actual costs of providing service. This means that rural people have access to acute care, but not necessarily hospice. Some experts have been arguing for sole provider status for hospices that access benefits administered through Medicare. This would mean that hospices would be reimbursed for the actual costs of providing care to patients living in extremely rural settings (including extensive travel time, for example), rather than being paid a per diem that is based on the costs of providing care in an urban environment.

According to Donna Bales, president and CEO of the LIFE Project, “Policymakers should understand that better end-of-life care will not be available to people in frontier rural areas until there is funding to pay for it.” ■

## Barriers for People with Disabilities

According to Census 2000, nearly one in five Americans over the age of five has at least one disability. Some disabilities leave a person incapable of informed judgment, while other disabilities affect only the body, not the individual's mind, will, or desire to live and die well. According to disability rights advocates, when individuals with disabilities are dying, they should have their pain and other symptoms managed, they and their families should be supported spiritually and socially, and their preferences and needs should be respected and fulfilled.

Hugh Gregory Gallagher, who died recently, was a dynamic force in the area of disability rights. According to Gallagher, "people in the mainstream disabilities community tend to be in denial about death because they have been so beaten up by the medical profession and by their own original trauma." American culture tends to devalue the lives of people with disabilities; the able-bodied (including health care providers) may refuse to acknowledge that people can live meaningful lives with chronic conditions and disabilities. People with disabilities cannot trust caregivers when they feel that they are seen as inconvenient or expendable, according to Gallagher and others.

Experts report that it is difficult to find health care facilities that can treat the acute health problems of people with disabilities while helping them manage their daily lives. This may result in people with disabilities going to hospitals with minor conditions and leaving with skin ulcers that can last for months, according to Lex Frieden, professor of physical medicine and rehabilitation at Baylor College of Medicine. Palliative care programs often excel at keeping people with disabilities comfortable.

Those who are disabled wards of the state face even more barriers to effective care when they are dying. Gary Stein, executive director, New Jersey Health Decisions, says that state policies can create barriers to getting palliative care for someone with a state guardian. New Jersey Health Decisions developed the Disability Ethics Network (DEN) using the model of hospital ethics committees to help people with disabilities (especially those in state-run developmental centers and community group facilities). DEN assembles an interdisciplinary team (social workers, physicians, nurses, advocates, and others) to analyze the medical, ethical, and legal issues relating to health care decisions for individual patients who are without decisionmaking capacity. The patient, caregivers, and guardians are heard and respected during the process.

DEN also offers training to social workers, medical care providers, and workers in the State Bureau of Guardianship Services. DEN has worked with the state to develop regulations that will provide for hospice and palliative care for people under guardianship who are expected to live less than a year.

The regulations are published in the New Jersey Administrative Code 10:48B. They took time and research to develop, notes Kim Friend, chief of the Bureau of Guardianship Services: "The process of learning what the community needed was good for us. It's worth the time it takes to develop a living, breathing policy that really meets individuals' needs. Because of this careful work, people are able to die with comfort and dignity." ■

## Policy Goals

### for People with Disabilities

**Experts argue that improved policy can support the rights of people with disabilities and ensure that they get adequate end-of-life care.**

#### Protect Rights

Observe and protect the rights and choices of people with disabilities and ensure that their lives are valued by the medical and legal communities and by the staff of public agencies.

#### Mandate and Help Fund Training

Ensure that training for physicians, other medical providers, and agency staff will prepare them to work effectively with people who are disabled and help them manage tasks of daily living. Facilities, equipment, and procedures may need to be adapted in order to accommodate patients.

#### Revise Reimbursement Policies

Revise Medicare reimbursement guidelines to allow doctors enough time to communicate with patients with disabilities and their families. Doctors need to know about patients' pain and other symptoms, their preferences, and their social contexts. This takes time that is too often not available because doctors are not adequately reimbursed for it.

#### Ensure Adequate Pain Management

Palliative care to control pain and other symptoms can help people with disabilities long before death, but policies restrict payment for hospice care to patients expected to die within six months, keeping patients with disabilities out of services that could improve their quality of life. Palliative care should be available to patients with disabilities sooner.

#### Tailor Policy to Support Real Needs

Determine policy governing the care of state wards by the needs of the individuals, not their status as wards. State policies can support effective end-of-life care for those who are wards of the state, including regulations for advanced directives where appropriate.

**Issues 12 and 13 of *State Initiatives in End-of-Life Care* provide detailed information on disability and guardianship issues.**

# End-of-Life Issues and the Gay Community

Gay people die of everything that kills heterosexuals, too: they die of heart disease, cancer, strokes, and any number of other diseases, traumas, or conditions. The gay community has developed some excellent end-of-life care programs for people with AIDS, but a gay person who is dying of some other disease or condition is likely not to find end-of-life care that supports his or her identity. In addition, say experts, as drug therapy for HIV has improved, even AIDS programs have de-emphasized their focus on end-of-life care.

Many gay people feel that they will not have anyone to take care of them if they need help. In fact, according to Reverend Ken South, Rainbow Aging Consultants, studies show that 80 percent of all care for frail elderly people is done by family, but 80 percent of gay people don't have family: they don't have children and may be estranged from their families of origin. So while gay siblings may be expected by other family members to take care of elderly parents because they don't have children, it is unclear who will take care of the gay siblings when they are elderly or dying. South explores these and other issues in the report *Outing Age*, available from the National Gay and Lesbian Task Force (visit [www.thetaskforce.org/reslibrary/list.cfm?pubTypeID=2](http://www.thetaskforce.org/reslibrary/list.cfm?pubTypeID=2) and click on the *Outing Age* download icon).

Because same-sex partnerships are less likely to be recognized by states, gay and lesbian couples often cannot access benefits automatically available to heterosexual married couples, including leave from work to care for an ill or dying partner, survivor benefits from private insurance or pensions, or income and asset protection for the partner of a nursing home resi-

dent. These differences create significant hardships at the end of life for gay and lesbian people.

While gay couples may plan for care at the end of life, their preferences and their partners may be ignored by family and the medical establishment. "Next of kin is a very powerful legal precedent," Ken South says. A few states, like West Virginia, have health care decision laws that embrace non-blood or marriage relations.

Some gay people may refuse home health care because they are afraid that the home health workers will harm them or treat them disrespectfully when they find out about their sexual orientation. In particular, older gay people may not feel comfortable coming out to their health care providers, making them feel like they are living inauthentically in their last days. A 1994 study by the Gay and Lesbian Medical Association found that 52 percent of gay doctors in the study saw colleagues deny or reduce care to patients based on their sexual orientation. Health care providers need training that will allow them to create an environment that supports all their patients.

"If you look at the continuum of care for someone who is gay, from diagnosis to death, at almost every moment, gay and lesbian issues have a presence, whether it has to do with health insurance, interactions with doctors and other providers, treatment, home care, hospice, relationships with family, final decisions, death, burial, or bereavement," says South. ■

## ➤ New Policy Brief Series Addresses the Nursing Shortage

### Information about the Series

"Diversity and Discrimination: Policies to Address Disparities in End-of-Life Care" is the 24th in a series of briefs profiling promising policies and practices in end-of-life care.

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