

CHOICES

THE CENTER FOR ETHICS AND ADVOCACY IN HEALTHCARE

Fall / Winter 2004

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The Center Today: A Statement of Need



Sr. Peg McDonnell

Incredibly, it is documented that the United States is a third world country in the area of healthcare. In the midst of this reality the most frequently asked question about our work is: What do you do? In an attempt to answer this valid question we enclose: "Three Realms of Ethics" by Jack Glaser, Director of Ethics for the Sisters of St. Joseph of Health System and newly appointed Director of their Center for Healthcare Reform. Jack offers a "frame" within which to place the various areas of ethics needing attention. These areas are the institutional, the individual and the societal. (*If you are interested in seeing Jack's diagram, please contact The Center.*)

What, then, do we do? During this past year we have been engaged in the work of institutional ethics with Roy Smith, CSC, who is preparing to teach ethics to his Ghanaian brothers; with the Congregation of the Sisters of the Blessed Virgin Mary as they continue to deal with issues in their retirement facilities; and in teaching business ethics to Dominican students in their *Institute for Adult Learning*.

We have been involved in the work of individual ethics, helping people deal with serious healthcare ethics issues. We are the only ones doing this in the community. In this, The Center is unique. Sometimes the questions are easy, but the answers are hard. At other times it is hard to determine what the question is. Our Intake Sheet (*please see the link on the What We Do page of the website*) gives some indication of this difficulty. Health problems can involve an imbalance in relationships between the patient, systems, institutions, groups, or other individuals. In this, there may be inherent ethical issues needing to be named. Whatever, each experience of illness is unique and transforming. The transformation can be conscious when personal struggles are named. This is why we use this intake sheet. It helps us help others.

We gathered survey responses to determine community-based programming needs for 2005. People are interested in programs on decisionmaking, community healthcare, education about Alzheimer's, stem cell issues, hospice and home care. In spring 2005 we will continue with this part of the work.

We had a reception to honor the interns at the end of the summer program, and to honor the person and organization without whom the internship program would never happen: John Jones of the Glenview State Bank.

As we begin our tenth year in 2005 we ask once again for your continued financial support. A donation to The Center would help us to continue this work with people of all ages, cultures and income brackets. People should be defined not by a diagnosis or a code but as informed human beings. The continued existence of The Center is truly a tribute to donors, past and present. Do let us know if you need any more information.

Most gratefully,

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CHOICES

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JOHN JONES INTERNSHIP IN COMMUNITY HEALTHCARE ETHICS

The Uninsured

By Rachel Adamczyk

The numbers are staggering. In late August 2004, the US Census Bureau announced that 45 million Americans went without healthcare in 2003. How large is 45 million? 45 million uninsured Americans is nearly 12 million people more than the entire population of Canada, which is 32.3 million! That means that there are nearly 7,000 uninsured American patients for every Medicare inpatient hospital in the United States! While those numbers are overwhelming, it seems that they will only get worse. Healthcare costs are continuing to increase. Family premiums in employer-sponsored plans jumped 11.2 percent in 2004. These huge increases will likely affect small employers, and the negative effects are already substantial. According to the survey of 3,017 companies by the Kaiser Family Foundation and the Health Research and Educational Trust, there are at least 5 million fewer jobs providing health insurance in 2004 than there were in 2001.

What do all of these facts suggest? The state of healthcare is far from perfect in the United States, and although federal and local governments are working to alleviate the problems, many Americans are slipping through the cracks. These Americans come from all walks of life; the growing healthcare crisis in America is not limited to unemployed or destitute citizens. The crisis is affecting senior citizens, families who cannot afford high premiums, and self-employed or small business workers. No Americans, no matter what job or background they have, seem to be immune from rising healthcare costs.

Disease and death are the great levelers in our society. Unfortunately, no amount of money or job security can protect people from disease or accidents, and our society needs efficient healthcare now more than ever. Government alone cannot address this growing need for healthcare information and options. Grassroots organizations, like The Center for Ethics and Advocacy in Healthcare, are essential to help and educate those in need.

I interned at The Center for a second time this summer. Over the past two years, I experienced first-hand the need for healthcare assistance and education, even amongst the well-to-do suburban community that The Center often serves. The Center provides invaluable advice and information to those who call the office or read our website. The Center works to improve the healthcare situation in America by keeping abreast of the hot issues in Washington D.C. and communicating with local lawmakers. Most importantly, The Center acts as an intermediary between patients and families and their doctors, pharmacists, and healthcare institutions.

The Center has a complex record of pharmaceutical information, and can help people find medicines at a lower cost. The Center and its director, Sr. Peggy McDonnell, maintains connections within the North Shore community and around the country in order to help refer clients to the help they need and the coverage they deserve. *Continued on page 3*

TURN THE CROWD INTO A COMMUNITY: LIFT, HOPE, LEAD!

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The healthcare crisis in America is frightening. I believe, however, that grassroots organizations like The Center for Ethics and Advocacy in Healthcare play an integral role in helping to solve America's healthcare problems. I witnessed Sr. Peggy and the staff of The Center help many people while I worked there, and I am proud to have been a part of such a remarkable organization.

Rachel Adamczyk is a senior student at Northwestern University. She is experienced in conversational Italian. She writes of herself: "I would like to work for The Center because I want to learn more about ethics in healthcare. I have a special interest in advocacy for abused women and for the mentally and physically handicapped. My entire young life has been dedicated to advocacy; that is part of the reason why I want to become a lawyer. Rachel has been on the Executive Board of Special Olympics at Northwestern.

More Than Just a Part-Time Job

By Lauren Harlow

My experience at The Center began over a year ago when I was looking for a part-time job in the summer of 2003. I walked into the New Trier Township Employment Services Center, and almost instantly I had a job lined up. Little did I know that my effort to find a temporary, part-time summer job would turn into an experience that would open my eyes to reality, open my mind to thinking about new issues, and open my heart to new friends. While my special experiences at The Center are numerous, I would like to touch on a specific time in which The Center touched my life personally.

The Center has not only provided me with a knowledge base in healthcare ethics, but it has also provided constant support to me personally. Throughout my time at The Center, my family was confronted with many healthcare issues, issues that The Center deals with on a firsthand, day-to-day basis. I was fortunate to have The Center's resources, primarily Sister Peggy, at my disposal to help guide my family and me through difficult times.

Last spring, my 90-year-old, extremely independent, spunky grandmother became very ill. The reality hit our family that Grandma would no longer be able to live on her own and care for herself anymore. It was imperative that we find a home care agency that would provide around-the-clock care. Never having been faced with a situation like this, we did not know where to turn. The hospital only gave limited help and advice. We knew that we were going to have to interview agencies and ask pertinent questions about the providers of care. Not only did we need this for our family's comfort in knowing who would be caring for Grandma, but more importantly for Grandma's comfort and security with a stranger living in her home.

The Center has a wealth of resources on home care agencies. My mother talked with Sister Peggy about the situation and Sister Peggy was able to give us names of agencies that she thought would fit our family's need. It was comforting to be able to call the agency and have both background information on the company and also a recommended contact person. The Center and Sister Peggy have established relationships with the different area agencies.

Through Sister Peggy and The Center's help, my family was able to find caretakers from a recommended agency that everyone was comfortable with and who would be a good match for Grandma's needs. *Continued on page 4*

BUILDING A MORE MORAL HUMAN COMMUNITY

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I had been working at The Center for almost a year before the events with Grandma took place. It was not until that time did I appreciate and understand the true meaning of what The Center aims to accomplish. The Center offers incredible knowledge, advice, and recommendations for families struggling through the healthcare system. The community has a true gift at its fingertips.

Lauren started on staff with The Center in the summer of 2003, becoming an intern in the fall of 2003. Lauren took the lead in forming the summer 2004 internship program.

Summer Internship

By Zach Sufrin

The driving force animating The Center for Ethics and Advocacy in Healthcare is the belief that ethical considerations ought to be incorporated into the healthcare system as well as into everyday life. The physical organization that is The Center for Ethics and Advocacy in Healthcare is the bodily manifestation of these ideals. It serves to do more than perpetuate a notion. The mission of The Center has to do with transmitting a core belief in the value of ethical living, and to translate that belief into practice, particularly in the context of illness and perhaps even of death. To this end, my fellow interns and I were brought under the wing of The Center in order to learn about ethics in healthcare and about living the moral life. The case studies of local community members' affected by The Center, The Center's goals and aspirations, and tales of The Center's history are so compelling that my understanding of and attitudes toward healthcare ethics and ethical living in general have been dramatically enlarged, strengthened, refined.

The study and practice of ethics have always been important to me. Since my internship, however, I have become a much more ethical individual because my consciousness has been raised. I have become attuned to many of the previously unnoticed intricacies of ethical decisionmaking. I have also come to recognize the presence of ethical conflict where before I saw none. My life has been enriched, and I am grateful to The Center for the experience I was offered.

In the course of my internship, I represented The Center at the Systems in Action Conference sponsored by The Illinois Public Health Futures Institute. It was held in Peoria, Illinois in May. The subtitle of the conference was "Partnerships Improving Community Health", and its aim was to help agencies like The Center network so as to improve the health of the public throughout the state, to maximize access and to improve the quality of care for all.

To my surprise and dismay the word "ethics" did not appear anywhere in the vision or mission statements circulated at the conference. After my internship at The Center, I have to raise the question: How would the question of "Improving Community Health" have been different if the ethical dimensions had been raised? *Continued on page 5*

ACTIONS SPRING FROM READINESS FOR RESPONSIBILITY

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As part of our learning process this summer, Rachel and I also pursued a plan to return the generosity shown to us by Sister Peggy and The Center and to extend our learning a step further by teaching others. We designed and offered a workshop entitled “Making Ethical Decisions with Your Aging Parents.” The workshop aims at providing adult children with the tools needed to approach confidently difficult healthcare decisions with elderly parents. The workshop was a very important project for us and for The Center because it puts into practice the goals and beliefs held by The Center in a community-centric way, that is, by reaching out to as many individuals as possible. Thus this project continues The Center’s work both by extending education further into the community and by giving more community members knowledge of The Center’s work. The project draws attention to otherwise unnoticed ethical issues in healthcare and spreads information about the spectacular services offered by Sister Peggy and The Center.

Zach Sufrin is a senior student at Washington University, St. Louis. He is a Philosophy Major with an emphasis on social, political, and ethical theory. He wants to be more engaged in contemporary issues of politics and group conflict. He brought his superb skills in project management, research, critical thinking and leadership ability to the summer 2004 Internship Program. Zach is a “Renaissance man”, according to an “eye witness” We, his fellow workers, have “seen it, heard it, and we know it to be true!”

A View of the Internship from the Sidelines

By Michele Lanthier

I have been a part of and watched the interns over the last three Internship Programs and have been very impressed with their knowledge, dedication, and enthusiasm. They have ranged in age from 14 to 22, and they learned what it is like to work in an office and to be part of a team. As I watched them interact with each other and work on their projects, I realized that they were accomplishing more than just working through an assignment. I realized that the Internship Program is not only about completing an assignment. It has more to do with the interns’ interaction with one another and how they help and learn from each other. As in any working / life situation, there are no guarantees about the outcome, but much can be learned in the process of working together as a team, being open to learning, and appreciating the ability we have to adjust to new situations and not to criticize ourselves when things don’t turn out the way we expected.

It has been wonderful to see the interns pleased with what they accomplished during the program. When I see them returning to The Center and offering to help in any way that might be needed, or just to say hello, I know that they have enjoyed and benefited from their time in the program.

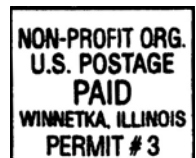
Michele Lanthier has been a Center staff person since January 2002.

We take this opportunity to recognize and thank the following individuals who have generously donated funds to The Center for Ethics and Advocacy in Healthcare. We ask your indulgence for any oversight and would appreciate being notified of the same. Certainly, without this donor support, The Center would not be able to continue. Donor support gives meaning to the communal dimension of the work.

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SUPPORTING THE CENTER

That part of the work which takes place in the community is largely unsupported. Any level of financial assistance to continue this work is greatly appreciated. The Center for Ethics and Advocacy in Healthcare is incorporated and is a 501c3, tax exempt and not-for-profit organization. All donations are tax-exempt as provided by law. Whether you have questions about programming or need assistance regarding fees for services or about membership, please give us a call. Please make checks payable to The Center for Ethics and Advocacy in Healthcare. There is a fee for our services. However, certain assistance with healthcare dilemmas is available at no charge to donors.



**THE CENTER FOR
ETHICS AND ADVOCACY
IN HEALTHCARE**
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ABOUT THE CENTER: AN OVERVIEW

VISION AND MISSION STATEMENT

“It is through the experience of others in situations of crisis, distress, vulnerability, weakness, and woundedness that the ultimate truth and meaning of every life is revealed.” (Michael Downey, *A Blessed Weakness*, Harper and Row, 1986)

VISION

The Center for Ethics and Advocacy in Health Care envisions a society that preserves and enhances personhood and human dignity in illness and dying.

MISSION

The Center for Ethics and Advocacy in Health Care, community-initiated and community-based, exists to help people make wise decisions as they move through our present healthcare institutions.

The Center effects a shift in decision making authority so that the individual becomes part of his or her own healthcare decisions. The Center works toward changing public policy in our country’s healthcare system and supports the extension of this work into the community through its programs.

IMPLEMENTATION

The Center for Ethics and Advocacy in Health Care’s method starts with the person and his or her own individual story:

- ✓ Recognizing that each one has a unique story;
- ✓ Encouraging each person to give caregivers access to that story;
- ✓ Identifying and protecting the values in each person’s life and decisions;
- ✓ Clarifying the moral conflicts inherent in life-and-death decisions;
- ✓ Gathering all pertinent information: personal, medical, social, psychological, and spiritual;
- ✓ Insuring that the patient, in concert with the family and care-giving community, makes the ultimate decision.

EDUCATION TAKES PLACE

- ✓ Around the living room and dining room tables, that is, at the table of life;
- ✓ In the home, the marketplace, the classroom: wherever ethical and healthcare decisions are made;
- ✓ With the staff of hospitals, long-term care facilities, and other healthcare institutions;
- ✓ At ethics committee meetings involving patients’ advocacy and the preservation of patients’ rights;
- ✓ In the cracks between healthcare institutions and the community.