The CEP is an ethics education network which follows a cyclical, repeating three-year course. The first year of the CEP -- represented here by Beth Chaitin's article, "Same Scene, Different View" -- is devoted to laying a foundation in both the concepts and vocabulary of ethics for our members. This membership includes healthcare workers of all types, based in acute care hospitals, long-term care facilities, and rehabilitation institutions. Learning to incorporate an "ethics perspective" into their daily routines is a challenge. While many individuals have admitted this, Ms. Chaitin (who is also a graduate of Pitt's M.A. Program in Ethics) has articulated well what she went through during her first formal training in ethics. Alan Joyce's "Truly Useful Literature" article complements this observation with a view of Benjamin and Curtis' book on nursing ethics.

The second year of our basic curriculum is devoted to exploring the relationship between law and ethics. Issues in forgoing life-sustaining treatment, informed consent, privacy, and physician assisted suicide, previously examined through a philosophical "lens", are re-cast with a focus on legal roots and limitations. Last year, a consultation from one of our hospitals prompted a call to the University's Health Law Clinic; and as the feature article on "Sterilization and the Incapacitated Person" evidences, the collaboration was terrific! It brought expert legal counsel to the hospital's ethics committee, and also enabled the students to present their findings and learn a bit about "practical ethics!! and the law. Again, Alan's reviews of both The Surgical Solution and The Black Stork provide some historical reality checks to explain why PA law on sterilization is so strict. At the ethics committee meeting, I was struck by the contrast between the needs of the individual case and the fear of the "slippery slope" that legal counsel voiced. Both Pernick and Reilly have recorded historical chapters in our not-to-distant past to remind us that abuses can occur. Always trying to balance the abstract and the practical, this case posed new concerns for the CEP. It was a "test case" for the Consortium and the Health Law Clinic and there are several others in the works.

Finally, our third educational year is devoted to examining the interplay between ethics and the humanities. A topic clearly close to my heart, this year affords us the opportunity to bring some wonderful speakers to the CEP -- including scholars like Martin Pernick, and physicians like John Lantos (author of the new book Do We Still Need Doctors?) and Jack Coulehan (author of the poetry collections First Photographs From Heaven and The Knitted Glove). These speakers meet with our members and paint the richly textured portraits that place our immediate dilemmas in a "human perspective." Gene Hirsch, who has recently joined our faculty, adds to the newsletter with his article, "Why Poetry in Health Care?" At last year's retreat, Gene completed five poems and wrote "Physician" to capture one of our sessions. The review of The Tyranny of the Normal, provided by Alan Joyce, caps the "All CEP issue." Alan, a magna cum laude graduate of the University of Pittsburgh's English Literature program, has added his own unique analysis to this complex topic.

In closing, I admit that the break with tradition which I had first envisioned upon becoming guest editor has taken a bittersweet turn. Mark Kuczewski, my trusted colleague and Associate Director of the CEP, will serve his last day in that position on June 13th, 1997 -- so his usual editorial comments are replaced with a "farewell." Mark joined the program in 1993 as Community Ethicist, and after completing his Ph.D. and rebuilding his new home, put so many miles on his car traveling to hospitals in Western PA during that first year that he was rarely seen in the office. Since then, he has managed to be a visible presence in the office, on the road, and at national meetings. I am very proud of Mark. His contributions to the CEP, to the broader national ethics community, and his continuing creative approaches to philosophy and ethics are self-evident. I'll miss the day to day talks with my friend. He had a gentle way of making me "stop and smell the coffee" -- actually, he made the coffee every morning and mid-day! The very best to you. Maybe you'll guest-edit Community Ethics from the midwest?

Visit the CEP on the World Wide Web! http://www.pitt.edu/~caj3/CEP.html
Why Poetry in Health Care?

by Eugene Z. Hirsch, M.D.

When I was young, teachers approached poetry with trepidation. They certainly did not transmit an appreciation of its enormous power. So, my education consisted of reciting a few rhymes by rote. Only years later as a physician was I moved to explore poetry. I found I needed some means of recording spontaneous feelings, feelings about life experiences, in order to enable me to keep conscious contact with patients and with myself, and to monitor my progress in achieving humanism (at Western Reserve University, humanism was an important part of the medical curriculum which we "naive" students took quite seriously).

I suppose most poets write for more esoteric reasons. But, as a physician, I wanted to learn to come to terms with life without trying to control it - at least enough to resist losing my identity through the absorbing seduction of impersonal medical technology. Some physicians are fulfilled by centering their lives around tangible problems and systems rather than the intangible nuances which accompany long term interactions with people and their functioning. Indeed, in taking nebulous paths, I sometimes think I have failed in important aspects of medicine. With my limited ability to follow tangible guideposts in the rapid fire of clinical processing, I have gravitated toward patients with altered function and chronic medical problems rather than acute ones, keeping company with my geriatrician peers and with the imaginations of philosophers and English teachers. Indeed, I have wondered how it is that as humans we tend so well to fostering value-free hard science, yet seem so helpless in stimulating value-laden, humanistic progress in our affective and societal selves.

This is the setting in which I took refuge in poetry. Now, years later, past the myriad of clinical experiences that people and clinicians undergo, I sometimes review my poems (more than 400). I race myself through life and remember the meaningful encounters that have been so sad, happy - so incredulous, so fathomable. Most of these memories swim beneath the surface of events toward powerful forces that drive us to do and say the things we do. These forces swim in pools laced with complexities of paradox and unforewarned outcomes, riding waves in the human condition.

Early on, I felt a deep deficiency in trying to express such material in colloquial language or even prose. Fleeting feelings and images can be crafted only in spontaneous glimpses, in ways which help readers to expand their own experiences - in ways that can be studied and restudied in entirety in short spans of time when the need appears, helping to mold outlooks that will probably never be fully understood or understood differently with each passing. Yet, the search has seemed so necessary.

In reading and crafting poems I have had to learn not to judge them on comprehensibility and many times not to try to understand a poem at all. Life events are not always so easy to understand. Instead I have had to take the journey through which a poem or a nascent poem leads me in order to discover where I have arrived at the end. I have had to hone and compact language, sounds, and rhythm to derive the clearest, most focused, yet broadest stark images, to enlarge and compress time and motion and dimensions - to make contact with myself and the reader on some subliminal as well as literal levels - to fail, time and time again, falling short of my intentions, writing and rewriting poems, sometimes for years, each time rediscovering the power of contrast and repetition, of metaphor and the unspoken suggestion. These are all components of the human experience, not just poetics. Perhaps that is why a sense of poetry is so important for sensitive people to own.

The act of writing poetry or any brief, freely conceived piece, carries with it the potential to reformulate one's self. Each engagement, giving over to the images of a poem, reveals a new aspect of one's self, building a repertoire of facilities. Poems serve as moorings onto which we can string our dreams and keep them with us for our lifetime.

The symbolism in poetry frequently permits a universe of images to be expressed briefly and poignantly. For example, after I wrote the poem at left, I discovered the symbolism of the life cycle or a day's, or circadian cycle tersely put, so as not to impose words between the reader and the images - so as not to concentrate the reader on the words but to stimulate him with a few sounds and rhythms to roam within his own mind.

In this poem, a literal understanding is not important. Instead, deriving a feeling of beginning, transpiring, and retiring, is. If the sense of the poem touches you in any way, it has achieved its purpose. If it has not, but is reread at an appropriate later date and then touches you, it has also succeeded.

A second example is simply recording the ambiance of an event that has had a profound effect on me. This poem was written as I was touched by a talk given by Dr. Robert Arnold and his pa-
tient with HIV at last year's CEP retreat at Hidden Valley -- a talk which left the speakers and the audience in tears.

PHYSICIAN

You weep as you speak to your patient (souls joined in peril, sharing illness). Yet, you cannot suffer her pain nor die her death. Still, you anguish in her weakness, in the wasting substance of her body. And she, smiling without words, she will comfort you, gently taking your hand as you walk with her to the edge of life and bid her goodbye.

In this poem, I was merely a recorder. The emotion and the arresting images which flew throughout the room really belonged to Dr. Arnold and his patient as shared by those of us who attended. This poem was completed to themes in the Haydn Cello Concerto. It shall remain for me as true an emotional portrait as I think I could have ever felt. Indeed, once the poem was completed, it ceased to be mine. I felt as if I were as much a witness as might be anyone else who could share it. I was shaken by my own reaction. Again, my job here was not to be creative, only sensitive and faithful. For me, only a poem could preserve an event such as this.

Any who are familiar with the social messages spoken in the art of Francisco Goya will feel the wrenching and suffering of his subjects through his pen and brush. How could I share the impact of his images, which mean so much to me, within the scope of my familiar surroundings? (see "Fandango")

Finally, in the question of life and death, in a mysterious sense, who but the terminally unconscious patient can properly point his way? (see "Remembrance")

Through relating a bit of my own clinical and poetic thoughts and these poems, I hope to have made the point that poetry both captures life in words and is a part of life itself. Wherever patients and those who care come together to share, to preserve, to indulge in, and to study their common humanity, poetry becomes the universal language worthy of their striving to understand.

FANDANGO
(A Goya Collage)
(Acute Myocardial Infarct)

Here I lie, turning seconds into minutes into blazed hours. My donkey trample up and down my chest, trembling lips opened wide, teeth clenched in chatter, jowls round and plump, frathy face, a dripped blot of hairy ice in a white cone cap, with the chime of bells dangling from his mane.

He strums by crescent moon, stirring a babbled soup to feed my delusional quailing for Andalusian peasants, dismembered, slain to the songs of the mob and their wailing wives, to cymbal strophes of the donkey.

Parades of haunted rows of aged Jews, clothed in white, dunned and dragged through Madrid, through cobbled streets, chained to tinkles, little bells tied with bows and ribbons, praying for scaffolds, for steel blades, marching past my masked donkey, his galloping, chattered laugh, carved on the ladle of the taunting claque.

Faster and faster, al cante jondo, his cloven fingers twist into my chest, spilling his potion, burning my heart, exploding the walls of my room, to pour my fright over the floor and into the street below.

REMEMBERANCE

Your mind has died. It breathes no more. But your breast still heaves, then stops, then heaves, and your head still bobs with every sigh, and a faint rhythmic lift pulses from the torsion of your heart, through millions of rippling streams trickling through your limbs.

You do not move. Your shoes no longer cringe beneath the cuffs of your trouser-bags. Your hands wear only the horizons from whence they came. Your eyes, mosaic prisms, tarnish now, beneath their lids. Your leather skin grows limp.

Dear old man, you shall die again no more. The sidereal mill sounds a whistle for its change of shifts. The wind turns east and soot clears away into the mountains. Your masked friend gently waits to do as you wish, to carry you off on a midnight ride through the thicket to dead-land.

Community Ethics 4(2)
Several months ago Dr. Bob Arnold came to Shadyside Hospital to present a lecture on the topic of “The Licensure of Ethics Consultants.” In an effort to get us to think of the characteristics that define an ethics consultant he asked us, “How is an ethics consultant different from a social worker?” When he asked this question, I laughed to myself for this was not the first time I had heard this question.

Five years ago I began my practicum for the M.A. in Ethics program at the University of Pittsburgh. This was not a welcomed adventure. In fact, there was part of me that wondered what I could possibly learn from this experience. I had worked as a clinical social worker for years in various hospitals and I felt there was no difference between an ethics consultant and a social worker. After all, I was an effective listener and a good communicator. I was aware of the law as it relates to medical issues (or so I thought) and I had just completed numerous courses that discussed the role of philosophy and morality in the healthcare setting. I had served on both an ethics committee and an ethics consultation service and I was well aware of how many times I had assisted in end of life discussions with patients and families. Each time I thought about starting upon this required endeavor, I kept asking myself the following questions: Was I really going to see something in these settings that I had not seen a hundred times before? Why couldn’t I just go and do as I had done before and get credit for that experience? Why was this practicum so necessary? I soon found out the answers to all of these questions, and many more.

The first day of my internship I presented myself to the NICU at a local hospital where I once had been employed as a social worker. Some of the nurses remembered me and we quickly caught up on each others lives. It did not take long for them to ask me why I was there. When I answered, “I am getting a Masters Degree in ethics and this is part of my practicum,” everything changed. These women that I knew began telling me stories — familiar stories, with familiar themes — but for the first time I was uncertain of their meaning. The reason for my uncertainty was blatantly clear: I was totally unsure of my role as an ethics consultant. For years my role in the hospital setting included more tasks than I can list. Some of these tasks required every ounce of my intellect (negotiation with families or patients in crisis, the assessment of suicidal patients or the highly complex mediation requirements now in place with some managed care organizations), some required almost none of my intellect (ordering commode chairs or ambulances). All of these tasks were, however, familiar to me. But as I stood before these women, I was uncertain of what to do and uncertain of my role for the first time in a long while. This uncertainty filled me with fear, which was as real as the certainty I felt the day before when I was sure that I would learn nothing from this exercise. What was ironic was that the only thing I knew now was that I knew nothing.

Over the next week, these old friends sat me in a chair at the end of the NICU and began to bring people to talk to me. The people who came were residents, fellows, attendings and nurses. All of them were in pain and all wanted to relief themselves of their moral burden; as they did so, they seemed sure I would be the one to answer all of their previously unanswered questions. I felt like a priest in a drive-through confessional.

At first, I felt honored, but this lasted only a second before I reverted back to fear. What if I said something wrong? Finally, because I was so unsure, I fell back to what I knew: social work. They spoke to me of the death rate of low birth weight black infants, the plight of the single mother of a compromised infant, and the future of a child intubated at 26 weeks gestation. As I listened to their stories I began asking myself questions: Why do these things happen? What can be done to change these events?

During this time period I kept a journal that I submitted each week to my mentor, Rosa Lynn Pinkus. In this journal, I wrote of my feelings and discussed the moral outrage I felt because of the suffering of the patients, their parents, the doctors and the nurses. I wrote of a need for change and asked many questions based upon my desire for action. When I met with Dr. Pinkus the first time she asked me the question, “How is a social worker different from an ethicist?” I, of course, did not know how to answer this question; originally, I believed both to be the same. She helped by stating simply and without judgment, “When you sit and observe these stories and interactions, keep telling yourself that you are not there to reform or to change anything.”

During the next four weeks I did an internship with the paramedics out of Homewood. Upon my first night they provided me with a bullet-proof vest. I was sure it was a joke, they were sure it was not. I had worked in an ICU and in the emergency room so I was familiar with the sight of blood. I had gone to the operating room and had observed surgery so I had seen the human body open and exposed. I had interviewed psychotic patients and had been threatened, like all of my colleagues, so I thought I knew how to handle myself — but again, I was wrong. I had seen nothing that would prepare me for the sight of blood on the sidewalk. Blood had a different look and smell outside of the safety of the hospital. Blood shines under the street light like something in a surrealistic film and the smell is much more pungent when it is not surrounded by white sheets. In fact, everything changes when it occurs on the street or in the middle of someone’s living room. Control also feels very different outside the hospital. For example, on one call we went to an apartment where a drunken man was found unconscious by his girlfriend. When we arrived he was wide awake and cranky. He was belligerent and lunged toward me, the only person not in uniform. I got out of his way but I was not sure where the exits were. This experience gave me a new respect for the power of one human
over another, especially in their own environment. I slept poorly that night.

During these weeks I wrote in my journal and tried to put into perspective some aspects of what I had observed but again I frequently fell back upon the familiar: social work.

My final several weeks were spent in the emergency room of WPIC from six to midnight. I had seen plenty of crazy people in the emergency room over the years but usually it was during the day. I quickly learned that people are much more interesting at night. They also are more violent, more psychotic and use more chemical enhancement. Children are more out of control. The homeless are colder and more hungry and the schizophrenic patients have more visions.

It was during my last week at WPIC that I found myself observing for the first time. I saw the same things but I was seeing them from a different vantage point. Finally, I could watch the interactions and communications of others without needing to quickly identify why these actions were occurring or to interpret the meaning of the conversations, psychologically. More importantly, I had no need to design a plan for change. Because of this ability to observe clearly, I was able to identify ethical dilemmas more intellectually, less "encumbered."

Let me state clearly that I do not believe that my emotional responses or reactions had encumbered me; the ability to recognize and feel emotion is a highly desirable trait for all humans, even ethicists. My encumbrance was my past, my career. For years I had practiced one way. As a social worker intellectual observation meant disconnecting with the patient, which seemed to eliminate empathy. In my view, the interpretation of both my emotions and those of the patient was an essential aspect of the social worker's role. At the end of my ethics internship, I still observed and experienced emotions, but this did not guide my responses or result in a need to act. I was able to recognize dilemmas without being a part of the solution and I was able to respond to questions on various subjects without feeling a need to see if any of my advice was utilized.

So, Dr. Arnold and Dr. Pinkus, in answer to your question: An ethicist observes the actions, emotions and responses of others as they relate to a particular ethical dilemma. The ethicist provides insight and education, answers questions regarding the law and policy of the institution, and frequently discusses what morality and philosophy have taught us in regard to similar questions relating to human suffering. While the role of the social worker is to act toward a certain outcome, the ethicist does not always seek change. Change is occasionally the result of an interaction or the participation of an ethicist within a particular case but it is not always the necessary outcome. While social workers advocate for the rights of patients, ethicists identify the scope and nature by which these rights are exercised. Both roles serve a valuable and essential purpose within the hospital setting.

Even now as I reflect upon this question I can see that each role is an important aspect of me. However, because of this valuable experience, when I look at a problem I am able to see two views of the same scene: both of value, both different.

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**Thanks . . .
The Pleasure Has Been Mine**

by Mark Kuczewski, Ph.D.
Associate Director, Consortium Ethics Program

I will soon be leaving the CEP to join the faculty at the Center for the Study of Bioethics at the Medical College of Wisconsin in Milwaukee. For me and my family it is a time of great excitement, new opportunities, new hopes, and new beginnings. But, these changes also bring other thoughts and emotions with them. I am sad to be leaving a job that over the past four years has become a vocation. Each CEP member has been my educator. From your example, I have learned that a bioethics absorbed with abstract and exotic issues means little. Any bioethicist worth the name must be willing to be a part of a mutually respectful dialogue with clinicians and patients and their families about the challenges and stresses that are part of routine health-care delivery and financing. I thank you for the opportunity to work with you and to learn from you.

And, of course, there’s just the memories . . . my first presentation at a CEP member hospital (Sewickley Valley Hospital - I talked about informed consent - I think I still use some of the same jokes), the first issue of Community Ethics (remember the funny clip art?), the day a light bulb went off over our heads during an ethics committee meeting at Butler Memorial Hospital and “ethics week” was born, the retreats at Hidden Valley. But I’d better stop here before I . . .

I firmly believe the future of the CEP is bright. Its foundation is solid and the program continues to grow. The national search for my successor will provide the CEP with an assistant director whose energy and ideas will be a fresh source of growth for the program. I look forward to seeing the CEP’s continued success as a national leader among bioethics networks.

In closing, I’d also like to express my thanks to Jody Chidester and Alan Joyce who have made my day-to-day life pleasant and easy. Of course, I can’t really say enough to express my debt to my mentor and colleague Rosa Lynn Pinkus. It must suffice to say that the CEP couldn’t have better leadership. And, I look forward to continued collaboration with Rosa Lynn and the CEP across the miles. I still have a lot to learn. See you at the retreat at Hidden Valley - thanks for the invitation!
Sterilization of the Incapacitated Person: An Extreme and Difficult Option

by the University of Pittsburgh Health Law Clinic
Certified Legal Interns: Sarah Baker, Amy Buck, and John Renda
Supervising Attorneys: Karen Engro and Stella Smetanka, Assistant Clinical Professor of Law

Inquiry:

A nineteen-year-old mentally retarded individual is taken to her family physician by her mother. The mother requests that the physician coordinate plans for her daughter to be sterilized "so she can't have a baby." The mother reports that she has serious concerns that the daughter may engage in sex and then become pregnant. The nineteen-year-old, by virtue of the degree of her retardation, is not able to discuss her feelings regarding sterilization. She has not been adjudicated to be "incompetent" and no formal guardianship has been ordered. Does this individual's mother have the right to request and consent to such a procedure?

The Short Answer:

Yes -- provided that a court has declared the daughter incompetent, the mother to be the guardian of the daughter, and has specifically authorized the sterilization procedure at the exclusion of all other birth-control methods.

Analysis:

Competency

The mother of an adult, mentally retarded individual does have the right to request that her daughter be sterilized. However, the mother must be appointed as her daughter's guardian by a judge in the Court of Common Pleas. If, during this process, the daughter is found to have capacity to consent to sterilization on her own, the mother cannot consent to the surgery. In other words, if the daughter is of legal age she has a right to make her own health care decisions unless she has been declared incompetent by a court.

In such a situation the doctor should direct the mother to an attorney, since petitioning the court for guardianship is a legal matter. Because the doctor will play a large role in providing information to the court, a general overview of the procedure can be found at 20 Pa. C.S.A. §5501 et seq.

Guardianship

The first step is to file a petition asking the court to appoint a guardian for the mentally handicapped daughter. The petition should be filed in the Orphans' Court Division of the local Court of Common Pleas; the Orphans' Court deals with all guardianship petitions. Because the mother is asking a court to appoint a guardian for a specific task or purpose (the sterilization of her daughter) instead of for an indefinite period of time, a court would prefer granting a limited guardianship. After reviewing a number of considerations, including (1) the daughter's chances to become competent in the future, (2) whether birth control might suffice instead of sterilization, and (3) why sterilization is sought in the first place, the court decides whether to specifically empower the guardian to consent to sterilization in place of the incompetent daughter. The guardianship petition will in most cases be filed under seal because of concerns about the confidentiality of the family. After the petition is filed, the court will appoint an unrelated individual as the daughter's Guardian ad Litem (referred to hereinafter as "GAL") to protect the daughter's rights during the proceeding. This is done to erase the court's concern that the mother may be too emotionally involved in the situation. The court must be certain that the Guardian is acting in the represented daughter's best interests.

The GAL may consult with outsiders to gather information on the appropriateness of sterilization in the incompetent's life. This may bring publicity to the case, even though it is under seal. Many of the groups the GAL may consult are vehement in their opposition to the sterilization of the mentally handicapped and will battle to prevent the sterilization process. Any costs of the case will be the responsibility of the person seeking to be made the guardian — in this case it is the mother.
If the mother cannot afford to pay the court costs to be declared guardian, she can petition the court to allow her request to be heard *in forma pauperis*. A petition for leave to proceed *in forma pauperis* should be filed at the same time as the petition for guardianship, and requires that financial information, like income and debts, be spelled out. (The exact procedure for filing a petition for leave to proceed *in forma pauperis* is found in Pennsylvania Rules of Civil Procedure, Rule 240.) If the petition is granted, the filing costs will be waived; however, the law is unclear as to whether the costs of GALs or expert witnesses would be waived, since the statute only refers to costs or fees payable to the court, prothonotary or other public officials and employees.

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**Emergencies**

The court accepts requests for emergency guardianships, which it grants as quickly as possible, but it is unclear whether seeking the sterilization of an incompetent would qualify as an emergency. The issue to be resolved is whether the allegedly incapacitated person (the daughter) would suffer irreparable harm if the guardianship is not granted as soon as possible. Although an emergency guardianship is granted for 72 hours, it can be extended for up to 20 days. When this period expires, a petition for permanent guardianship must be made if the mother still desires the procedure for her daughter. See 20 Pa. C.S.A. § 5513 (1996).

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**Sterilization and Pennsylvania Law**

In order for the court to grant the power to consent to sterilization, several factors must be weighed. In the area of sterilization of incompetents, Pennsylvania law is articulated by the Superior Court in the case of *The Matter of Terwilliger*, 450 A.2d 1376 (Pa. Super 1982). The Superior Court expressed necessary prerequisites to authorizing sterilization: first, the court must find that the individual lacks the capacity to make a decision about sterilization and that their incapacity is not likely to change in the foreseeable future. Second, the court must find that the incompetent is capable of reproduction. If the court is able to make these findings, then the court must proceed to its ultimate determination, i.e., is sterilization in the incompetent’s best interest?

The *Terwilliger* court viewed the best interest determination as ultimately depending on a finding that sterilization is the only practicable means of contraception. The court must find that all less drastic contraceptive methods, including supervision, education and training, are unworkable. Detailed medical testimony must show that the sterilization procedure requested is the least significant intrusion necessary to protect the interests of the individual.

In *Terwilliger*, the court provided the following nonexclusive list of “guidelines” to assist Pennsylvania trial courts in arriving at a decision on whether sterilization is in an incompetent person’s best interests: (These guidelines were adopted from the decision of the Supreme Court of New Jersey in *In re Grady*, 426 A.2d 467 (1981), and modified.)

A) the possibility that the incompetent person will experience trauma or psychological damage if she becomes pregnant or gives birth, and, conversely, the possibility of trauma or psychological damage from the sterilization operation.

B) the likelihood that the individual will voluntarily engage in sexual activity or be exposed to situations where sexual intercourse is imposed upon her.

C) the inability of the incompetent person to understand reproduction or contraception and the likely permanence of that inability.

D) the ability of the incompetent person to care for a child, or the possibility that the incompetent may at some future date be able to marry and, with a spouse, care for a child.

E) evidence that scientific or medical advances may occur within the foreseeable future which will make possible either improvement of the individual’s condition or alternative and less drastic sterilization procedures.

F) a demonstration that the proponents of sterilization are seeking it in good faith and that their primary concern is for the best interests of the incompetent person rather than their own or the public’s convenience.

Despite the apparent specificity of these guidelines, the *Terwilliger* court allowed trial courts latitude in making the ultimate determination of an incompetent’s best interests. The Superior Court in *Terwilliger* expressly stated that the list was not exhaustive, and that as each new case varies, the weight to be accorded to each factor would vary appropriately as well.

**Case #1: "Terwilliger"**

In the case of *Terwilliger*, Mildred Terwilliger was the alleged incapacitated person. Her father testified that his daughter was 25 years old and had attended “special schooling.” Nevertheless, she could neither read nor write. Her father also testified that because of her mental deficiency, she had been exploited. Ms. Terwilliger gave birth to an illegitimate child in December of 1980, and then continued to be the object of “designing men.” Such conduct persisted for “a period of over maybe two years.” As far as the care and feeding of the infant was concerned, Mr. and Mrs. Terwilliger had taken it upon themselves to care for the child since Ms. Terwilliger assumed no maternal duties.

The *Terwilliger*’s family physician testified that, in his opinion, Ms. Terwilliger was retarded. He based his opinion on the knowledge that Mildred had attended special education classes and that she was not able to keep pace with the normal education process. Additionally, the doctor noted that he had observed that Ms. Terwilliger could not write her own name, or add two and two.
On cross examination, the physician admitted that the birth control pill would be an effective alternative to sterilization. He did, however, admit that the feasibility of such an approach should be discounted since he doubted that Ms. Terwilliger could "count her pills," which would constantly force her parents to have to monitor her intake in an atmosphere of "the hecticness and all the friction that is prone to be in the Terwilliger household, or lack of a household." Later on in the questioning the doctor dismissed the practicability of any alternative form of birth control. It is important to note that in 1982, at the time of the Terwilliger hearing, hormonal treatments, like Depo-Provera, were not considered when factoring in alternative forms of birth control which is a requirement when establishing whether or not sterilization is the only practicable means of contraception.

Other witnesses included the visiting nurse who made conclusory statements as to Ms. Terwilliger's lack of maternal instincts. The nurse based her observation on the fact that Ms. Terwilliger was absent from the home whenever she was there, twice a week, to supervise the baby's care. Additionally, the town police chief testified that he had observed Ms. Terwilliger walking the streets of the community in early morning hours. In addition, he testified that citizens had informed him that they had been propositioned by Ms. Terwilliger and, based on this information, he stated that he felt it was possible that Ms. Terwilliger could be sexually abused by several men in the community.

Ms. Terwilliger was the last witness to testify at the hearing and stated that she did not want any more children because her father told her to have "no more." In addition, test results from the Clarion Intermediate Unit were admitted into evidence, which indicated that Ms. Terwilliger's I.Q. was 33.

The court ultimately decided that the evidence and testimony procured during the hearing were not clear or convincing enough to establish that sterilization was in Ms. Terwilliger's best interests. The court remanded Ms. Terwilliger's case to the trial court in order to develop a more comprehensive and detailed record on all the relevant issues.

**Case #2: "C.W."**

Twelve years later, the Superior Court was faced with a similar case of *Estate of C.W.*, 640 A.2d 427 (Pa.Super 1994). Relying on the standards set forth in *Terwilliger*, the *C.W.* court determined that there was clear and convincing evidence to establish that sterilization would be in the patient/incompetent's best interests. The court remanded Ms. Terwilliger's case to the trial court in order to develop a more comprehensive and detailed record on all the relevant issues.

**Physicians and Guardianship**

The doctor's role in the guardianship proceeding is to provide facts and expert testimony. The doctor should be prepared to testify (to a reasonable degree of medical certainty) to what option is in the best interests of the incompetent person. The proposed guardian will have to prove that sterilization is in the best interest of the incompetent person, and that other alternatives are not reasonable. Sterilization as the incompetent person's best option must be proved by clear and convincing evidence, which is the heaviest burden of proof in civil court proceedings. The court considers a wide variety of contraceptive methods, including supervision, barrier methods, hormonal treatments, and the birth control pill before considering the appropriateness of sterilization. Convenience alone will never meet this standard.

The best plan of action is to discuss all available methods of birth control with the mother and the daughter, and work through the advantages and disadvantages of each. The court is looking for the least restrictive method of birth control, and if a doctor plans on testifying, he or she will need to be able to say why all other available methods are unsuitable. Supervision is viewed by courts as less restrictive than physically invasive methods, even though it may infringe on the person's privacy far more than any other method.
Sterilization has a history of abuse in the United States. Probably the most famous case demonstrative of sterilization abuse is *Buck v. Bell*, 274 U.S. 200 (1927). In this case Carrie Buck was committed to a state institution for epileptics where her mother Emma was also a patient. Given an I.Q. test upon admission, Carrie was deemed to have the mental age of nine years. Her mother’s I.Q. test placed Emma Buck’s mental age at slightly under eight years. Furthermore, Carrie’s seven-month-old baby was said to have “a look” that was “not quite normal.” [Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Penguin Books, 1985)]

Medical experts supplied the court with depositions claiming that Carrie’s alleged “feeblemindedness” was “unquestionably hereditary.” They never examined Carrie, her mother, or her daughter in person. One of the experts noted that Carrie’s family belonged to a class of people that “modern science and beneficent social legislation is obligated to eradicate for the greater good of the White Civilization.” [Dana Atwell and Irene Paige, *Eugenic Sterilization* (New York: Case Memorial Foundation, 1958)]

In *Buck*, the Supreme Court allowed the state of Virginia to sterilize Carrie Buck under a program providing for the involuntary sterilization of a “probable potential parent of socially inadequate offspring.” Writing for the Court, Justice Holmes stated:

“Carrie Buck is a feeble-minded white woman who was committed to the State Colony. […] She is a daughter of a feeble-minded mother in the same institution and the mother of an illegitimate feeble-minded child. […] We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. […] Three generations of imbeciles are enough.”

Strangely enough, Carrie’s sister Doris was also sterilized under the same law. Doris, however, was told that the operation was to remove her appendix. Doris and her husband tried to start a family for years and checked with specialists and hospitals before finally finding a reference to her operation in Carrie’s medical records.

It wasn’t until 1942 that the Supreme Court heard the case of *Skinner v. Oklahoma*, 316 U.S. 535 (1942), recognizing procreation as a fundamental right. The *Skinner* court held that the “power to sterilize, if exercised, may have subtle, far-reaching and devastating effects.”

Coupled with the Court’s recognition of an individual’s right to make autonomous decisions regarding reproduction and the fact that an individual’s incompetence does not diminish her fundamental rights, careful procedures surround the sterilization of a mentally handicapped individual.

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**Conclusion**

In the end, it is important to note that the courts have a duty to recognize the past abuses of sterilization when dealing with those deemed incompetent in our society. A situation such as the case of the 19 year-old whose mother seeks her sterilization will produce someone who will act as “judge” with abilities to make choices for another human being. Usually when a person undergoes such a procedure, she is the “judge” for such a procedure. However, in this case, someone must substitute his or her judgment for the incompetent’s. Cognizant of past abuses, Pennsylvania chooses to have all such cases come before the court so that the court can be assured that the rights of the incompetent are represented and protected.

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**About the Health Law Clinic**

The Health Law Clinic of the University of Pittsburgh School of Law is an intensive client-centered trial skills experience for law students in their last year of legal education. Under the supervision of their attorney professors, the "certified legal interns" grapple with health-related legal problems of low income clients. While most of these problems involve appeals from denials of health care benefits, the clinic is grateful for the opportunity to explore the law and policy surrounding bioethical issues also.
Truly Useful Literature

by Alan Joyce

In this edition of TUL, as always, we offer up some suggestions for further reading on each of this issue's topics — from some particular challenges in clinical ethics, to the history and legality of involuntary sterilization, to the interplay of literature and medicine. In keeping with the "All CEP" theme, there are a couple of other points worthy of mention: first, Consortium members should note that Martin Pernick, author of The Black Stork, will be speaking at the Advanced CEP class on May 19th; in addition, many readers may be interested to know that the book The Tyranny of the Normal contains several additional poems by Eugene Hirsch (including "He", reprinted on page 11) as well as a contribution by long-time CEP faculty member Jack Coulchlan.

Drs. Coulchlan and Hirsch will also run a poetry workshop at this year's CEP retreat. But now, on with the literature!

The Health Law Clinic's "Historical Overview" of involuntary sterilization touches on some episodes which are placed into context and covered at greater length in Philip Reilly's The Surgical Solution: A History of Involuntary Sterilization in the United States. Reilly has a particular interest in legal issues, and as a result the book may be of most interest to those who share this focus. The Surgical Solution is largely a chronology of organizations, legislation, and statistics, beginning with the scientific and social origins of the eugenics movement and combing through the history of sterilization from the late 19th century to today. Along the way, Reilly does link sterilization laws and practices to the parallel evolution of social and scientific understandings of the heritability of "undesirable" individual traits — but the book clearly seems to focus on the "what" and "when" of involuntary sterilization, rather than the challenging "whys."

An excellent companion to Reilly's book, then, is Martin Pernick's The Black Stork: Eugenics and the Death of "Defective" Babies in American Medicine and Motion Pictures Since 1915. Pernick describes how medicine, media, and eugenics intersected in the person of Harry Heiselden — a physician who became a "star" of the eugenics movement through several well-publicized medical cases and his starring role in the feature film and "eugenic melodrama," The Black Stork. With the film at the heart of the book, Pernick pursues a web of connected developments and controversies early in the twentieth century: dramatic increases in the medical profession's power; the new-found ability of propagandistic films like The Black Stork to focus and direct public debate; concerns about the proper role of medicine in eugenic "race improvements" and other social issues; early debates about euthanasia and the withholding of medical care; and the legacy of modern, "progressive" views and the widespread belief that science could provide objective answers to social and ethical questions (see last issue's TUL for related problems in the brain-death debate).

Most of this book focuses on a narrow time period in the history of eugenics (the 1910s and 20s), but Pernick brilliantly weaves together these disparate themes of medicine, politics, propaganda, art, and censorship. The book is split into two parts which deal in turn with the medical aspects and the film representations of eugenics; but as Pernick notes in the introduction, a reader who chooses to read only one part would miss an important point: "that medicine and the media evolved together in the context of a common culture."

Also of timely interest is the close of the book and Pernick's account of public debate about these issues in the latter half of the twentieth century. He examines the political and media mechanisms that have permitted (or forced?) this debate to disappear from the public forum and to return occasionally in the guise of "new" technology-oriented debates that carry little historical resonance. In a time when the media may be a more pervasive influence on individuals than ever before, when some of the most popular television shows and movies are "hospital dramas," and when issues in human genetics are being touted as "brand-new" problems for medicine, this book provides some important insights and historical context for current dilemmas.

A recent anthology entitled The Tyranny of the Normal (Carol Donley and Sheryl Buckley, eds.) brings a different mix of art and analysis into the dialogue. The collection kicks off with a recap of the Greek legend of Procrustes, a robber who forced his victims to fit the length of an iron bed by either stretching them or chopping off their legs. This myth stands as a unifying metaphor for this collection — the forcing of individuals or groups to meet an arbitrary or subjective standard.

This ties in well with the issues raised by the previously mentioned books — though of course the eugenics movement is only one high-profile, dramatic example in the long history of social and individual responses to "abnormality." The editors of this volume have taken care to select literary works that deal with a variety of stigmatized afflictions, and a number of ways to unravel the psychology of abnormality. Present here are selections addressing "normal" people's reactions to those who appear strange or grotesque (Raymond Carver's "Fat"), more metaphorical works in which personal, universal feelings of otherness take physical manifestations (Kafka's "A Hunger Artist"), attempts to get inside the mind of those perceived as "abnormal" (Dallas Denny's "Just Another Year in Chronie IA") and satirical looks at larger-scale, societal reactions to disability and deformity (Kurt Vonnegut's "Harrison Bergeron"). [Note: for additional pointers to medicine- and medical ethics-related topics in literature, see Joanne Troutman & Carol Pollard's Literature and Medicine: An Annotated Bibliography.]

Also included are selected essays and articles from healthcare providers, addressing a range of topics: the history of deformity in literature and the reciprocal use of literature in medical responses to deformity (the interestingly-named "Quasimodo Complex"); the difficulties that follow on from the setting of
cultural “norms”; and challenges in establishing empathy in the healthcare setting. These are all useful, but the real worth of the collection probably lies in the literary selections, which engage the reader in these dialogues in ways that no “scientific” article could – and which go a long way towards promoting and understanding the elusive “humanism” that Eugene Hirsch mentions in this issue of Community Ethics.

Concerns with empathy and humanism also seem to be at stake in Beth Chaitin’s article, embedded in the challenge of resolving her dual roles of ethicist and social worker. Martin Benjamin and Joy Curtis address similar concerns in their book Ethics in Nursing – and although it focuses on nurses, these essays, cases, and commentaries should be of interest to anyone in healthcare who wants to understand the complexities of ethical decisionmaking in the context of specific job- and institution-related duties. Benjamin and Curtis identify some of the expected qualities and duties of nurses and analyze the ways in which these may help or hinder nurses in ethical decisionmaking. Among these are a variety of emotional, professional, and political issues, such as doctor-nurse relationships, conflicts among nursing staff, protective or parentalistic feelings towards patients, and nurses’ responsibilities towards their institutions and their profession.

Chaitin notes that she felt “encumbered” by her past, having approached medical decision making in only one way throughout her career. In a way, Benjamin and Curtis provide an explicit method for nurses (and with a little generalization, a blueprint for other professionals) to identify the aspects of their profession which influence them to view dilemmas in a particular way, and thus to approach decision making from an empathic but more fully informed and far-seeing point of view.

True objectivity may be an impossible dream, as Pernick’s book cautions. But the balancing act described in this newsletter and in these books – the combination of professional awareness and lessons learned from history and literature – may be one of the best alternatives for anyone involved in ethical decisionmaking.

**Bibliographical Information:**


Carol Donley and Sheryl Buckley (eds.) *The Tyranny of the Normal: An Anthology.* The Kent State University Press, 1996.


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**He**

by Eugene Hirsch

He was sitting, feet dangling from the side of his bed, faced by a tray of food on a stand. He slowly took bits of beans, each load, a basket of gravel, each sip of juice, a pilgrimage to the shrine for holy water, each taste of bread, his very last. His black hands were like prunes, the jagged purple marks under his skin betraying the grape sludge flowing through his veins. His head, so recently plush, held only a few thin hairs. His face and eyes were yellow-gaunt. A gown hung over his shoulders as over a hanger in a closet with no clothes beneath. He looked up when I came in with his daughter and his new grandson. The sight almost scared his cancer away, as he smiled so wide, this warrior, this young man whom we had sent to war so few years ago, whom no one now would touch.

Originally appeared in *The Tyranny of the Normal.* Reprinted with permission of the author.

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**Congratulations!**

Jody Chidester, Administrative Assistant to the Consortium Ethics Program, was recently awarded the 1997 CME Staff Recognition Award by the University of Pittsburgh’s Center for Continuing Education in the Health Sciences. The award was established to recognize those who consistently exceed the continuing education compliance standards.

As the CEP has grown, so has our yearly schedule of accredited classes and outreach programs (over 75 are currently listed for the 1996-97 program year). Jody has put in an incredible amount of work "behind the scenes" to make sure that the accreditation process and all other aspects of our educational programs run smoothly. We applaud her efforts and offer our sincere thanks.
Consortium Ethics Program
1997 Annual Retreat
September 19-21

Upcoming Events

Local

**CEP Basic Classes**

**June 9, 1997**
9:00 a.m. - 12:00 p.m.
Confidentiality and Truth-telling: People Say the Darndest Things
Beth Chaitin, BS, MSW, MA
(Shadyside Hospital)
Mary Therese Connors, RN, MA
(Duquesne University / St. Francis Health System)

**CEP Advanced Classes**

**May 19, 1997**
1:00 p.m. - 5:00 p.m.
The Changing Meanings of Death: From the Fear of Premature Burial to the Debate Over Brain-Death
Martin Pernick, Ph.D.
Professor of History,
University of Michigan

**June 9, 1997**
1:00 p.m. - 5:00 p.m.
Ethical Issues in Pediatric Care
Joel Frader, M.D.
Associate Professor, Pediatrics
Associate Professor, Anesthesiology & Critical Care Medicine
University of Pittsburgh

Basic Series

- "Organizational Ethics"
  Andrew Thurman, J.D., M.P.H.

- "Historical Perspectives: What Has History To Do With Ethics?"
  Rosa Lynn Pinkus, Ph.D.

- "Ways of Thinking: Psychology & Moral Development"
  Jyotsna Vasudev, Ph.D.

- "Philosophy and Moral Development: The General and the Particular"
  Mark Kuczewski, Ph.D.

- "Physician Assisted Suicide"
  David Kelly, Ph.D.

- "A Narrative Based Approach to Medical Ethics"
  Martin Kohn, Ph.D.

- "Fortitude and Frankenstein: Reader's Theater"
  (Performance & Discussion)
  Jack Coulehan, M.D.

Advanced Series

- "Private Talk and the Moral Life: From Self-Interlocutor to Dramaturge"
  Martin Kohn, Ph.D.

- "A Death In The Family"
  Bob Arnold, M.D. (and guests)

- "Talking About Advance Directives" (role plays)
  Bob Arnold, M.D.

- "Medicine and Metaphor"
  Jack Coulehan, MD and Eugene Hirsch, MD

- "Informed Consent: Does It Take A Village?"
  Mark Kuczewski, Ph.D.

- "Respecting both Adolescent Patients and Their Families"
  William Aiken, Ph.D.

- "Organizational Ethics"
  Andy Thurman, J.D., M.P.H.

- "Cross Cultural Ethics"
  Jyotsna Vasudev, Ph.D.
June 22-26, 1997

MIDWEST INTENSIVE BIOETHICS COURSE (MiBC)

Sheraton Metlrodome, Minneapolis, MN. A joint project of the Bioethics Centers of the University of Minnesota, University of Wisconsin, and the Medical College of Wisconsin, the MiBC provides a unique opportunity to gain a deeper understanding of current issues in bioethics and various methods of approaching them. Nationally and internationally recognized faculty include: Mila Aroskar, R.N., Ed.D.; Dianne Bartels, R.N., M.A.; Muriel Beben, Ph.D.; Alan Buchanan, Ph.D.; Alta Charo, J.D.; Ronald Cranford, M.D.; Patricia Cristan, Ph.D., R.N.; Arthur Derse, M.D., J.D.; Kathy Faber-Langendoen, M.D.; Jeffrey Kahn, Ph.D., M.P.H.; Rosalie Kane, D.S.W.; David Mayo, Ph.D.; Steven Miles, M.D.; Robyn Shapiro, J.D.; and Susan Wolf, J.D. Residential tuition is $1,200. Non-residential tuition is $950. For information contact: Center for Bioethics, University of Minnesota, 2221 University Avenue SE, Suite 110, Minneapolis, MN 55414. Phone: 612-626-9756, Fax 612-626-9786, or E-mail: holmb006@maroon.tc.umn.edu.


CASE NARRATIVE AND THE CONSTRUCTION OF OBJECTIVITY

Sponsored by the Medical Ethics and Humanities Program, Northwestern University Medical School, Chicago, IL. This interactive program will address topics including the use of narrative reasoning, case genres, the representation of fact in medicine and bioethics, the place of the patient’s narrative in medical and bioethics cases, “real” cases and the question of authenticity, whether some medical case histories are more ethical than others, and whether the medium of representation affects response. Faculty include Kathryn Montgomery Hunter, Ph.D., Todd Chambers, Ph.D., William Donnelly, M.D., and Suzanne Poirier, Ph.D. CME credits available. Tuition is $600; some meals included; reasonable hotel rates available. Application deadline is May 10, 1997. For more information contact Joan Broholm, Phone: (312) 503-7962; E-mail: <j-broholm@nwu.edu>, or send CV and a letter indicating your interest and lodging needs to Kathryn Montgomery Hunter, Ph.D., Director, Medical Ethics and Humanities Program (M-105), Northwestern University Medical School, 303 East Chicago Avenue, Chicago, IL, 60611; E-mail: <k-hunter@nwu.edu>.

August 4-8, 1997

SUMMER SEMINAR IN HEALTHCARE ETHICS

Sponsored by the Department of Medical History & Ethics, School of Medicine, University of Washington. To be held in Seattle, WA. Directed to physicians, nurses, social workers, chaplains, teachers, and others involved in the care of patients or the education of providers, this annual Summer Seminar provides an intensive introduction to the concepts, methods, and literature of healthcare ethics. Albert Jonsen, Ph.D., will lead the Seminar, and Linda Emanuel, M.D., Vice President for Medical Ethics at the American Medical Association, and Ezekiel Emanuel, M.D., Ph.D., of Harvard University, will be the guest faculty. The University of Washington School of Medicine designates this course for approximately 30 hours of Category 1 of the Physician’s Recognition Award of the American Medical Association. For further information contact: Marilyn J. Barnard, Program Coordinator; Medical History & Ethics; Box 357120; School of Medicine; University of Washington; Seattle, WA 98195-7120; Phone: (206) 616-1864; FAX: (206) 685-7515, or E-mail: mbarnard@u.washington.edu.

November 5-9, 1997

Visions for Ethics & Humanities in a Changing Healthcare Environment

The Joint Meeting of the American Association of Bioethics, the Society for Bioethics Consultation, and the Society for Health and Human Values

Baltimore Marriott Inner Harbor; Baltimore, Maryland. This meeting is meant to provoke reflection on both the perils and the possibilities inherent in the rapid changes now taking place in the American healthcare system, and to some extent in healthcare systems throughout the world. Sessions will fall under three main themes: Institutional Change, Science/Technological Change, and Social/Cultural Change. For more information write to: 1997 Joint Meeting, 6728 Old McLean Village Drive, McLean, VA 22101. Phone: (703) 556-9222. email: shhv@aol.com.

April 17-18, 1998

Whose Ethics? Which Medicine? The Tacit and Explicit Development of a Medical Ethic

The Spring Meeting of the Society for Health and Human Values

Co-sponsored by the Consortium Ethics Program and the Dale Ethics Center of Youngstown State University. This meeting will examine the assumption that there is a single field of bioethics and medical humanities that shares principles, a vocabulary, and methods. In order to see if this is the case, clinicians, social scientists, and scholars from the humanities will team up to examine the development of clinical ethics in a variety of specialties and subspecialties. The conference will provide a forum for those engaged in these reflective assessments to examine the ways in which various approaches to bioethics determine our conception of medicine and its ethical issues. Why have some voices emerged louder than others? Is a “new” common voice achievable? A call for submissions will be mailed out in the coming months; Community Ethics will carry further announcements as the conference takes shape. To be added to the mailing list for the meeting, contact the CEP at: 3708 5th Avenue, Suite 300, Pittsburgh, PA, 15213; Phone: 412-647-5834; Fax: 412-647-5877; Email: caj3+@pitt.edu.