

Rules Are Rules



What an ethicist does on
vacation

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The opinions in this presentation are those of the presenter and are not intended to represent the position of the Department of Veterans Affairs or the U.S. government.



Today's goals

- A brief review: where ethics began and some basic ethics frameworks
- Thirty years ago: what wasn't going on
- Today's new ethics: organizational ethics and consumerism
- What's on the horizon for biomedical ethics

I did not see this coming...




BUSINESS ETHICS = HONESTY, INTEGRITY AND QUALITY

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An ethics conflict...

- Two equally compelling choices
- Conflicts of interest are situational not based upon the state of mind of an individual.



A “good” ethicist...

- Should not choose for you... Or even make a strong suggestion.
- Should find what is at risk ethically?
- And for whom (the unheard voice)?



The Beginnings

- End of Life
- Beginning of Life
- Limited resources (who gets what)
- Technology affects all of the above
 - Ventilators (demand issue)
 - Solid Organs (supply issue)
 - Cost of Treatment (think drug costs)

How to sound like an ethicist:
mention *Dancing with Wolves* and *Avatar* in the
same sentence. And then, “slippery slope”

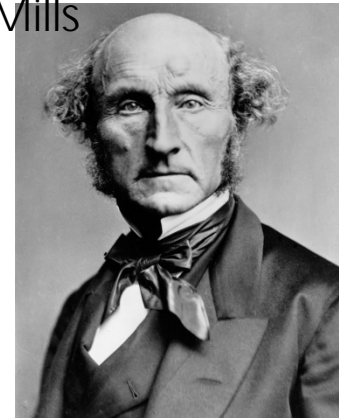
RULES

Deontological:
Kant



OUTCOMES

Utilitarianism:
Mills



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Not all that long ago...

Coined first by Potter in 1970 and again by Shriver, bioethics was described as “a new discipline that combines biological knowledge with a knowledge of human value systems”

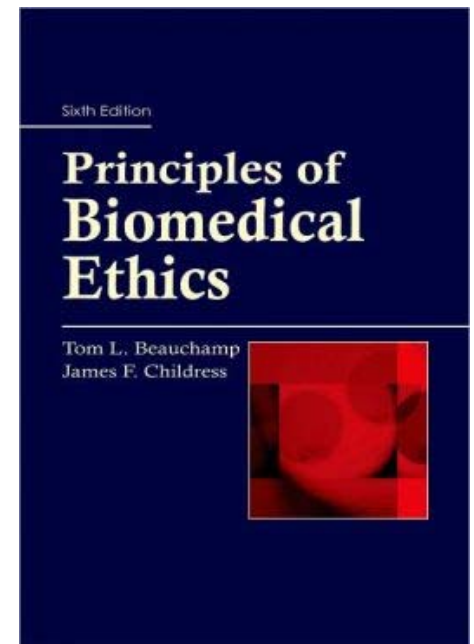
Thirty Years Ago: what wasn't

- Next to Nothing in the literature
 - And it was all on death and dying
- No Quinlan (intersection of technology and right to die and surrogacy)
- Dax and right to refuse TX (intersection of right to die and competency)
- Competency
- Surrogates



And then (in 1979)... Principlism!!

- Patient Autonomy
- Non Maleficence
- Beneficence
- Justice (so many versions!!)



Followed by: Communitarianism

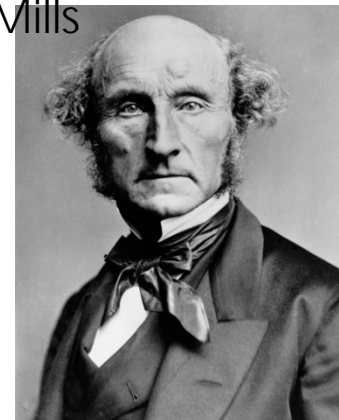
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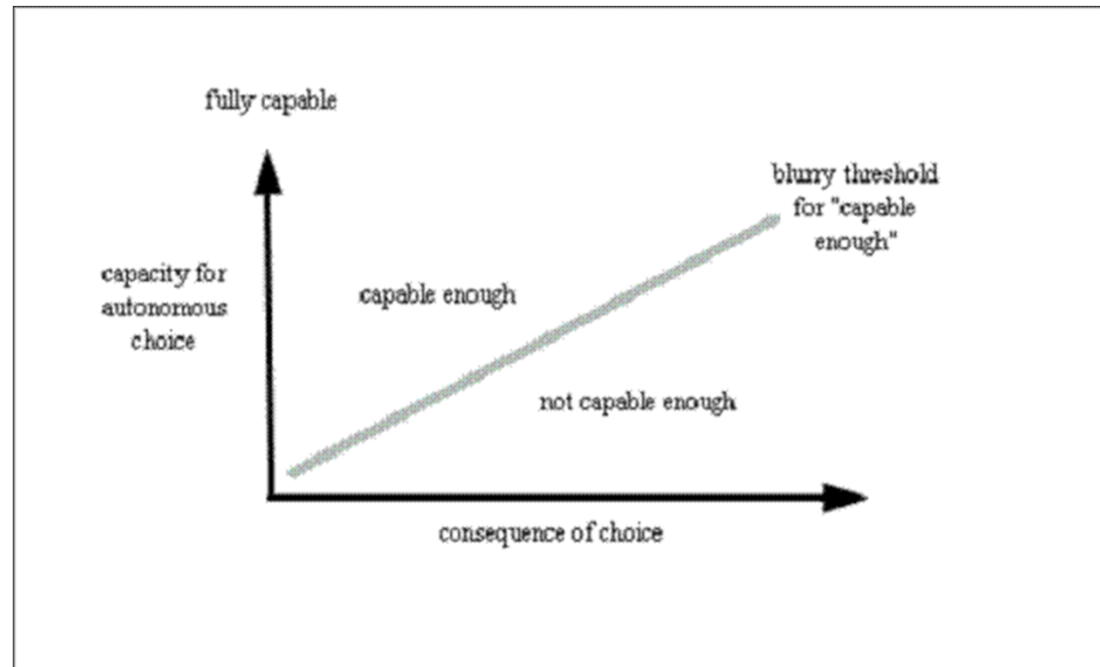
Utilitarianism:
Mills



A mandatory discussion regarding paternalism

- Blood and blood products
- Implied consent
- DNR
- Artificial Nutrition and Hydration

Competency or Capacity?



Surrogacy is state by state

- a) Health Care Agent
- b) Legal guardian or special guardian
- c) Next-of-kin
 - Relative
 - 18 years of age or older
 - In the following order of priority: spouse, child, parent, sibling, grandparent, grandchild
- d) Close friend

Please, please, please, if nothing else, get an advance directive



Just a bit more on surrogacy

- Best Interests standard
 - Substituted Judgement
 - Implied Consent
-
- Without consent of some type treatment is assault!!! (Cordozo in 1914)



Confidentiality

- Not so big an issue thirty years ago
- Stigmatization of some treatments and diagnosis
- HIV, BH, reproductive health, public health (vaccines), testing, and Tazazoff (duty to warn)
- HIPPA



And now...

- Patient centeredness
- IRBs and research
 - Research on children
 - Therapeutic misconception
 - Clinical studies in developing nations
 - Social science exceptions to informed consent

The evolution of patient centeredness



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Two early design themes: SepAration & Observation

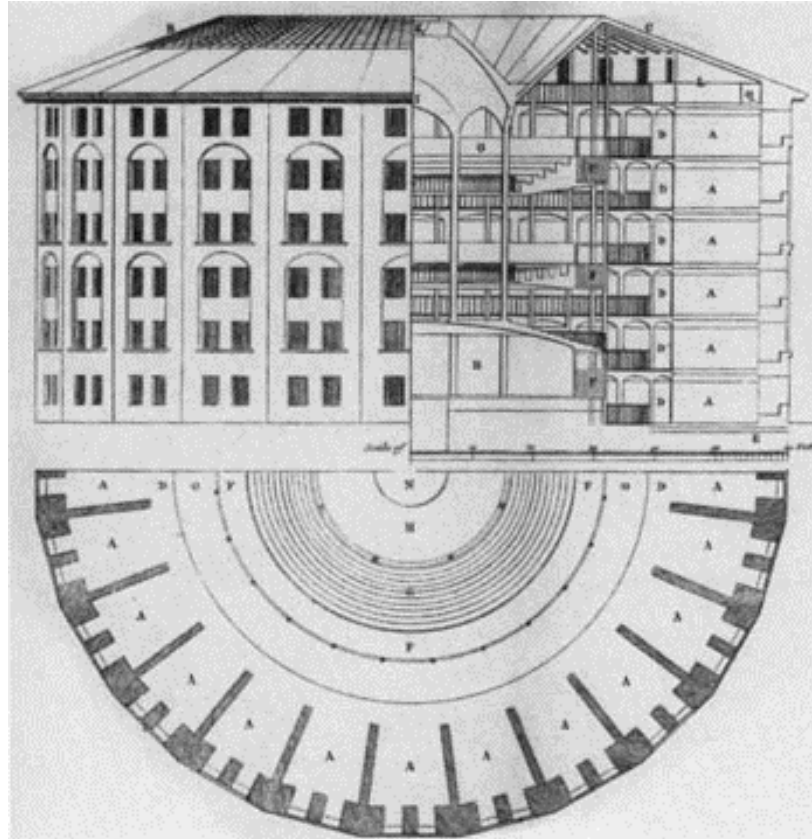


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The panopticon



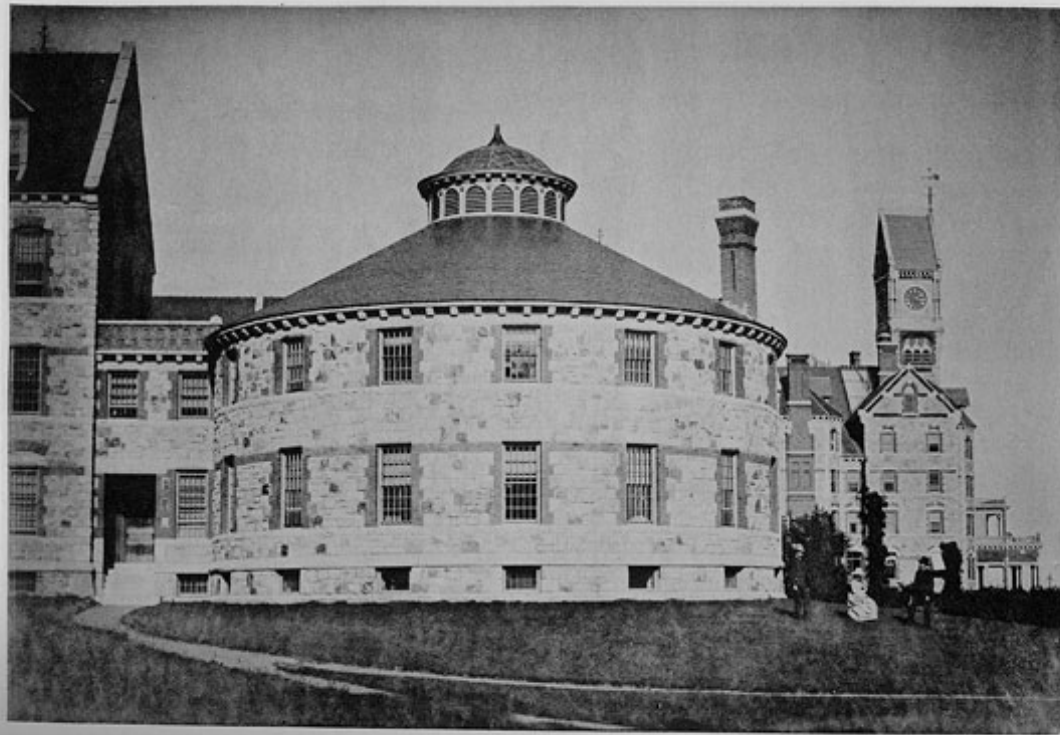
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Vienna's Narrenturm 1784



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A Panopticon design in Massachusetts



HOOPER HALL.

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Still in use to separate and observe



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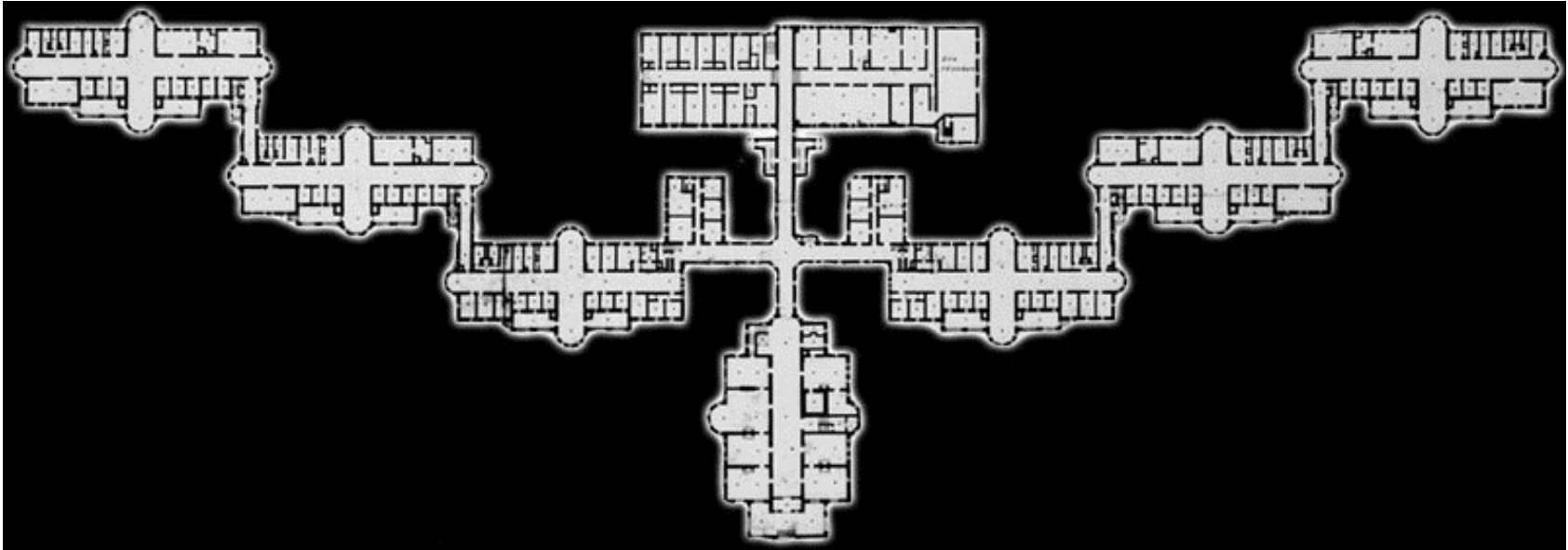
Instead of a warehouse,
A Place to treat...

“the building to can assist in the
cure”

– *G.T. Hine, 1901*

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Kirkbride: echelon style & a linear plan



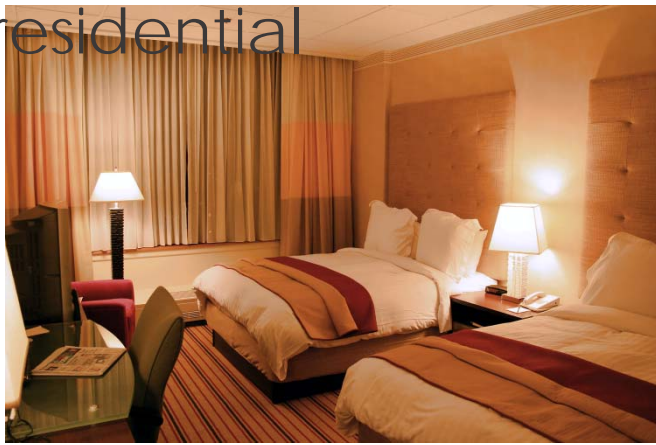
Evidenced based design is sometimes imperfect



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Occupancy can be misleading...

A locked BH unit may have been design to look residential



What to
do?

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Organizational Ethics: a departure from individual blame

- No escort tug
- No bow thruster
- Single screw
- Single boiler
- Not double hull
- Poor handling at slow speed



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Organizational ethics & mission

- A link between mission components and performance
- Framing and motivating the work of organizational members
- A knowledge structure that shapes how we think about the organization, how we connect our work to a shared sense of priorities

Ethical Consumerism

- Beyond green... **Corporate responsibility**
- “Our **business operations include everything** from how we move products to how our employees commute and how we operate our stores and facilities. Each of our **important stakeholders—our members, employees, vendor partners and nonprofit partners**—has expectations for how REI should prioritize its efforts in these areas. We prioritize by focusing on the things that matter most and have the greatest potential impact while **staying true to our values.**”

– from the REI website

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Ethical Consumerism



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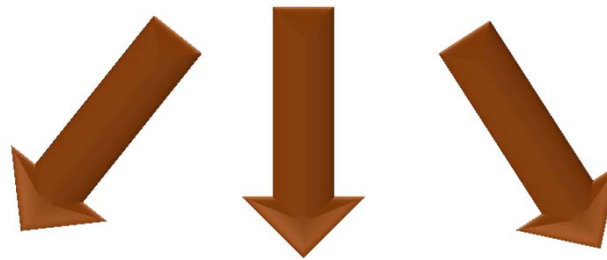


Just over the biomedical ethics Horizon

- Genetics: who owns my genes
- The ethics of big data
- Patient specific medical devices
- Personalized medicine
- Boutique medicine
- Medical tourism



Drivers in Ethics



**Past:
Disparity**

**“Social”
Solution**

**Present:
Access**

**“Organizational”
Solution**

**Future:
Personalized**

**“Technological”
Solution**

“Coming together is a beginning. Keeping together is progress. Working together is success.”

– *Henry Ford*



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