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# THE ROLE OF ETHICS IN MEDICAL DECISION-MAKING

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# WHAT IS ETHICS?

## *HOW DO WE DISTINGUISH IT FROM OTHER DISCIPLINES*

| | |
|---|---|
| **Ethics:** | • Addresses question of morality -what is right thing to do? what ought we to do? |
| **Law:** | • Codifies those actions society deems right or wrong and has system of courts and jurisdictions to enforce and penalize |
| **Medicine:** | • Provides diagnosis, prognosis and treatment options based upon scientific research and evidence-based medical practice |

ATLANTIC HEALTH SYSTEM

- **What is the Role of Ethics in Health Care?**
  - **Ethics Committees: *Quinlan case* (1976) - hospitals, nursing homes, health care agencies. Role: (1) Education, (2) Policy and (3) Consultation**
  - **Ethics Consultation: Bedside, Individuals/families/providers**
  - **Role of ethical input in Covid-19 planning:**
    - **Allocation of scarce resources protocol; DNR policies, Visitor restrictions, triage of patients; system level priorities; protection of vulnerable populations; protection of medical providers**

# WHAT DO WE LOOK AT?

- ***Ethics analysis***
- ***Competing incentives***


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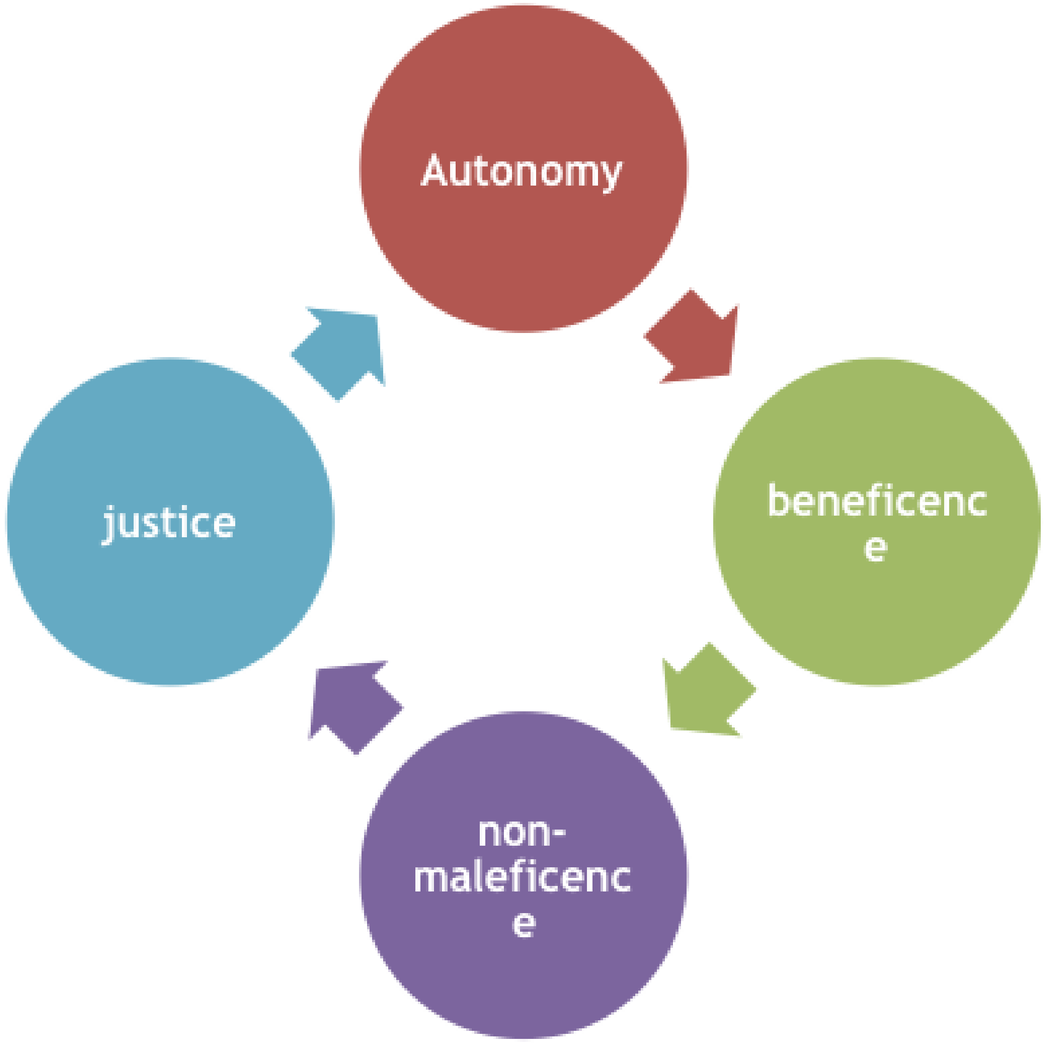
# Basic Cornerstone Principles

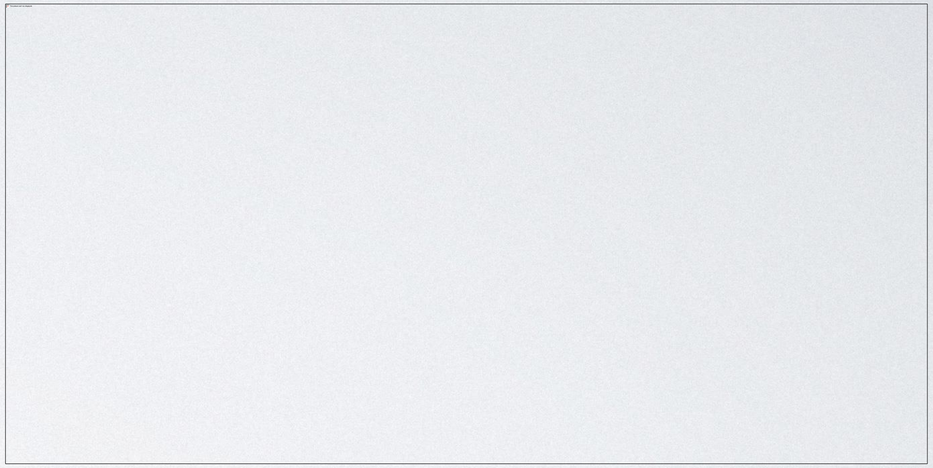
***Reference: Principles of Biomedical Ethics, by Beauchamp & Childress***




ATLANTIC HEALTH SYSTEM

# WHY IS ETHICS SO IMPORTANT IN HEALTH CARE TO THE I/DD AND DEMENTIA POPULATIONS?

- **Vulnerabilities:**
  - Decisional capacity
  - Understanding choices
  - Judgmental views of others about “quality of life”
  - Underlying chronic conditions - shorter life “expectancy”
  - Decisions of “others” (family, guardians, unrepresented)
  - Lack of advance care planning discussions and documents to protect preferences/values



Who will decide for her?

# How do ethics consultants help in ordinary times?

- Consultation with patients and families struggling with decisions
- Consultation with legal guardians prior to medical decisions (mandated in some states)
- Education for caregivers/guardians about medical choices, prognosis, expectations (CPR), options, benefits and burdens/risks
- Resource for medical providers about policy, patients' rights, laws
- Facilitate advance care planning for I/DD and dementia patients and caregivers

# ETHICAL FRAMEWORK

## *ORDINARY TIMES VS PANDEMIC CRISIS*

***Principle:  All persons are treated as equal on the basis of their humanity alone***

*In Ordinary Times:*

Respect for individual autonomy and self-determination
Decisions made by patient/surrogate/physician in keeping with the patient's preferences and best interests
Patient/Surrogate/Physician - Shared decision-making

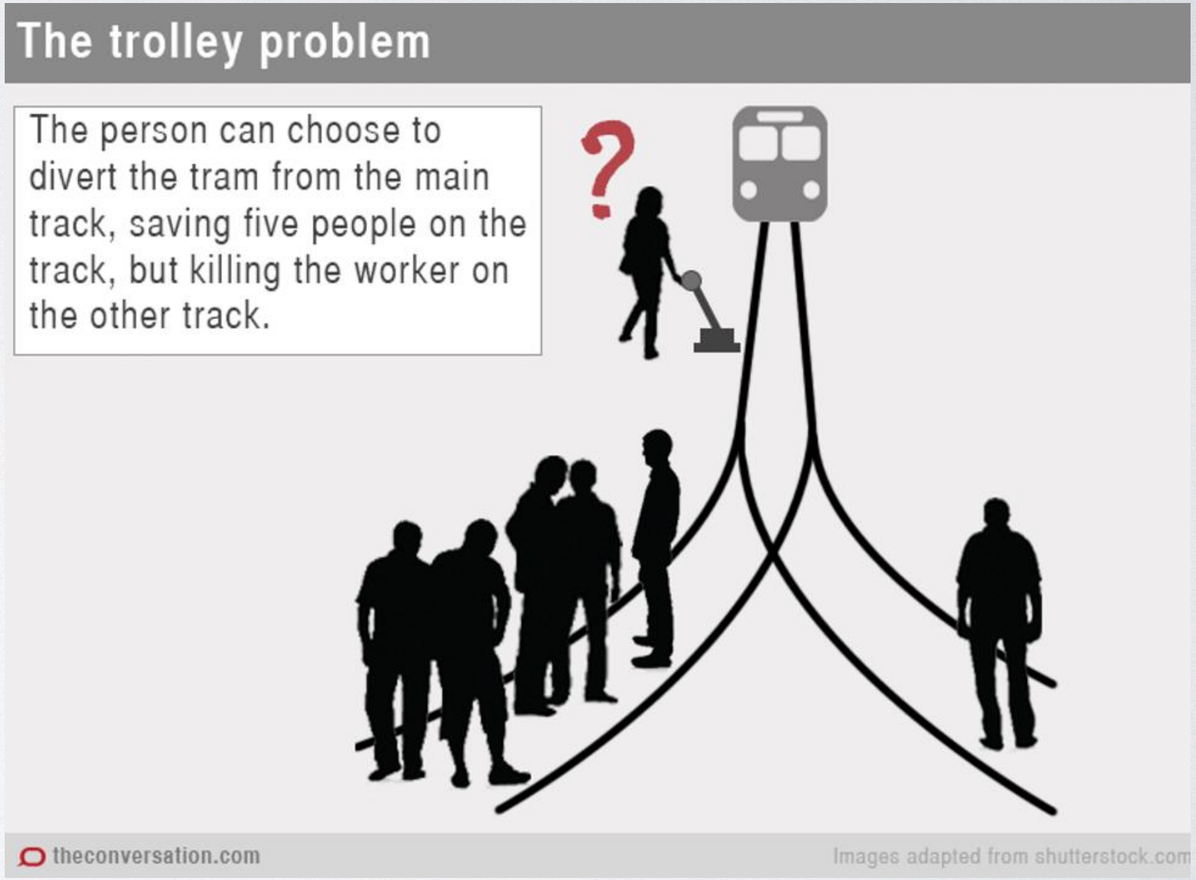
*In Pandemic:*

Utilitarian Model:  ""Greatest good for the greatest number" - Respect for the Common Good, not just the sum of the individual good….  an integral sense of the common good

**"The good of the whole partly determines each individual's good"**

# The Trolley Car Example of Utilitarian Model of Ethics….

- What would you do?

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# THE ROLE OF ETHICS IN A PANDEMIC

# ROLE OF ETHICS IN PANDEMIC

- **Preparation**:
  - Critical role of ***ethics consultants*** to be on Triage Allocation Planning Teams
  - Recognition of "**exclusion criteria**" and "**co-morbidities**" unfair as absolute barriers; rather than methods to "prioritize" **all** patients based on ***objective medical criteria*** that does ***not discriminate*** against those with disabilities
  - Adoption of protocol with **ethical structure/principles** that have pro-active protections for the disabled and other vulnerable populations

# What should an Allocation Protocol Look Like?

Process/Protocols for allocation of scarce resources must be:

- Reasonable
- Objective
- Transparent
- Applicable to *all patients*

# WHAT DOES THAT TRIAGE PROTOCOL LOOK LIKE?

## SAVING LIVES AND SAVING LIFE-YEARS ENSURING MEANINGFUL ACCESS FOR ALL PATIENTS

- **Protocols *only enacted* when State/Regional authority declares State of Medical Emergency *and* facility calls for Crisis Standard of Care (not enough ICU beds, ventilators for number of patients needing them)**
- **Individualized patient assessments based on objective medical knowledge (SOFA scores)**
- **Patients more likely to survive with ICU care prioritized over those less likely to survive with ICU care**
- **Patient with severe limited life expectancy (even if they survive the acute illness) given lower priority over those with greater life expectancy - no examples listed of conditions that limit life expectancy - such lists run risk of becoming “blanket” judgments**
- **Absence of rigid categorical “exclusion criteria”**

## ETHICAL ISSUES FOR I/DD AND DEMENTIA WE FOUND DURING…

The Covid-19 Cloud

- **Sense of urgency to “triage” prematurely (ED/ICU)**
- **“life expectancy” “life years” assessment - sometimes biased judgment**
- **Staff and home care providers expected to shelter in place if Covid + (no PPE)**
- **Lack of staff to accommodate increased needs (cancelled day programs, activities)**
- **Behavioral difficulties (difficult to isolate residents, wear masks, - keep safe)**
- **Lack of testing for asymptomatic infection (staff and residents);**
- **Visitation policies for hospitalized patients; (family, support person)**
- **Dying alone - grief, bereavement services, funerals, staff impact - complicated grief**

# WHAT IS NEXT?

- **Review State/Hospital allocation protocols**
- **Community grass roots efforts to increase PPE and awareness of needs in group homes, nursing homes and congregant living**
- **Examine State/Hospital visitation policies for hospitals (NJ - example)**
- **Prepare for expanded facility options for separation of Covid + patients**
- **Work with State & Guardian services to expedite decision-making process**
- **Recognition and value of staff in congregant homes and home settings**

# WHAT MORE CAN WE DO?

- ***Review the data*** (what happened; to whom; where; mortality rates; infection rates) - how can we do it better?  how can we be ***better prepared***?

- ***Stories and experiences*** from caregivers and patients

- Increase conversations about "**what if**"…. ***advance care planning*** - for all of "us".  (POLST.org) ("Life Story" by Teepa Snow)

- Build community awareness and collaboration - lessons from Covid-19

# RESOURCES

- "Hospitalized Patients & Designated Support Staff Policy Statement", Committee on Public Policy and Advocacy. April 2020. AADMDCONFERENCE.com. AADMD.org
- "Confronting Disability Discrimination During the Pandemic" by Katie Savin and Laura Guidry-Grimes, www.thehastingscenter.org, April 2, 2020.
- "Evaluation Framework for Crisis Standard of Care Plans" by Ari Ne'eman, an Sam Bagenstos. April 8, 2020.
- POLST.org, "Guide for I/DD individuals"
- EndofLifeWA.org (dementia advance directive)
- ***The Art of Dying Well*** by Katy Butler

# *THANK YOU!!*