

# ETHICS AND GENETIC COUNSELING



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# OBJECTIVES

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- Review basic terminology and concepts in ethics
- Outline principlist approach to ethics and prominent alternatives
- Discuss new genetic technologies and their impact on existing systems of ethics
- Case presentation (Erin Eichorn, MS, CGC)



# BASIC TERMINOLOGY

# Ethics

- Approach to examining and understanding the moral life
- Normative vs. non-normative ethics
  - ▣ Normative – what the norms *should* be
  - ▣ Non-normative – what the norms *are*

# Morality

- Norms about right and wrong human conduct
  - ▣ Includes ideal/virtuous/heroic behavior
- One may be morally but not legally obligated to perform an act
  - ▣ Disclosing genetic risk status to at-risk family members

# Principle

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- Basic generalization that is accepted as true
- Used as basis for further reflection on rules of morality

## Rule

- More restricted in scope and content
- Used to guide actions
- From the *principle* of autonomy stems the *rule* of respecting privacy

# Right

- Justified claim that one may make upon others
- Distinction between positive and negative rights
  - ▣ Positive – right to receive some good or service
    - Places obligation upon others TO ACT
  - ▣ Negative – right to be free from interference of others
    - Places obligation upon others TO REFRAIN from acting

# PRINCIPLIST APPROACH

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- Autonomy
- Non-maleficence
- Beneficence
- Justice

# Autonomy

- Self-rule that is free from limitations and in accordance with a self-chosen plan
  - ▣ Limitations include inadequate information
- Few, if any acts, are completely autonomous
  - ▣ Intimate relationships, lack of knowledge
  - ▣ Therefore, actions need only be **SUBSTANTIALLY** autonomous

# Non-maleficence vs. Beneficence

## Non-maleficence

- Obligation not to inflict harm on others
- Negative requirement to action

## Beneficence

- Contributing to another's welfare
  - ▣ Laudable but not morally obligatory
  - ▣ Rarely, if ever, are there legal sanctions
- Positive requirement to action

# Non-maleficence vs. Beneficence

- Impartial vs. “biased” principle
  - ▣ Obligation to act beneficently increases towards those with whom we have a close relationship
- Principle behind many public health programs
  - ▣ Vaccination programs – recognized harm to a few is justified by the benefit to the many
  - ▣ May opt out of vaccination but may not opt out of obeying the speed limit

# Justice

- Fair, equitable, and appropriate treatment in light of what is due or owed to persons
  - Distributive justice
  - Question: since we must discriminate under conditions of scarcity, on what grounds can we discriminate?
- Different theories of just discrimination
  - Equal shares, according to need/effort/merit, etc...

# Fair opportunity

- Social benefits should not be distributed according to *undeserved* advantages or disadvantages
  - ▣ Social benefits – goods or services that can be distributed
- Not responsible for our “lot” in the natural or social lotteries, therefore should not be held responsible for their consequences
  - ▣ Natural lottery – genetic properties (disease status, height, beauty, etc.)
  - ▣ Social lottery – social properties (being born into rich vs. poor family, married vs. single vs. separated parents, etc.)
- Advantages vs. disadvantages
  - ▣ Does not require that those with natural talents be handicapped
  - ▣ Makes distinction between treatment and enhancement

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# Prominent Alternatives

# Utilitarianism

- Fundamental goal: maximize the greatest good
- How do you define *maximize*?
  - ▣ On average? Individual? Societal?
- How do you define *good*?
  - ▣ Happiness? Wealth? Quality of life?
- Cost-benefit analysis
  - ▣ Individuals with certain genetic conditions “devalued” by having decreased life expectancy, quality of life

# Kantian theory

- Moral worth of action determined by moral worth of obligation upon which action is based
  - ▣ Ignores consequences, focus entirely upon motivation behind action
- Categorical imperative – moral rules must be able to be universally applied
  - ▣ Ignores individual desires or extenuating circumstances
- People should always be treated as ends in themselves and never *merely* as a means

# Liberalism

- Rights-based theory
- Moral behavior achieved by protecting basic liberties and rights so that individuals may pursue their own interests
  - ▣ Presupposes that the purpose of morality is to protect individual interests
  - ▣ Rights are not formally attached to any higher ideal or obligation so cannot answer the question, “I have the right to do X, but should I?”

# Ethic of care

- Emphasizes personal relationships and related traits (compassion, empathy, caring, etc.)
  - ▣ In direct contrast to previous language of ethics/rights/obligations
  - ▣ Intimate relationships are a necessary and inescapable aspect of humanity so should not be ignored in search of universal, impartial rules
- Foundation of NSGC Code of Ethics
  - ▣ Defines professional responsibilities according to relationships (GCs to themselves, to clients, to colleagues, and to society)



# Changing Technology, Changing Ethics

# Changing technology

- Increasing applicability
  - ▣ Karyotype → CGH → whole-genome sequencing
- Decreasing cost
- Decreasing risk
  - ▣ Amniocentesis → isolated cell-free fetal DNA
- Different approach
  - ▣ Panels, chips, arrays

# Informed consent

- Voluntary authorization for testing by patient after being informed of implications, limitations, risks, and benefits of testing
- As testing becomes more complicated and comprehensive, what happens to informed consent?
  - ▣ If we cannot adequately counsel for all conditions being tested, should we be testing for all of them?
  - ▣ Can you give meaningful informed consent to all the issues raised by genetic testing?

# Parental Autonomy

- Parental interests in autonomy, “good life” for their family not absolute
  - ▣ Balanced by health care professionals’ willingness to provide services
    - Termination for adult-onset conditions/sex, testing in minors
  - ▣ Limited by family resources, availability of testing
- As genetic testing becomes more available at earlier stages of pregnancy, how will the limits of parental autonomy change?
  - ▣ Who will set limits?
  - ▣ What should those limits be?

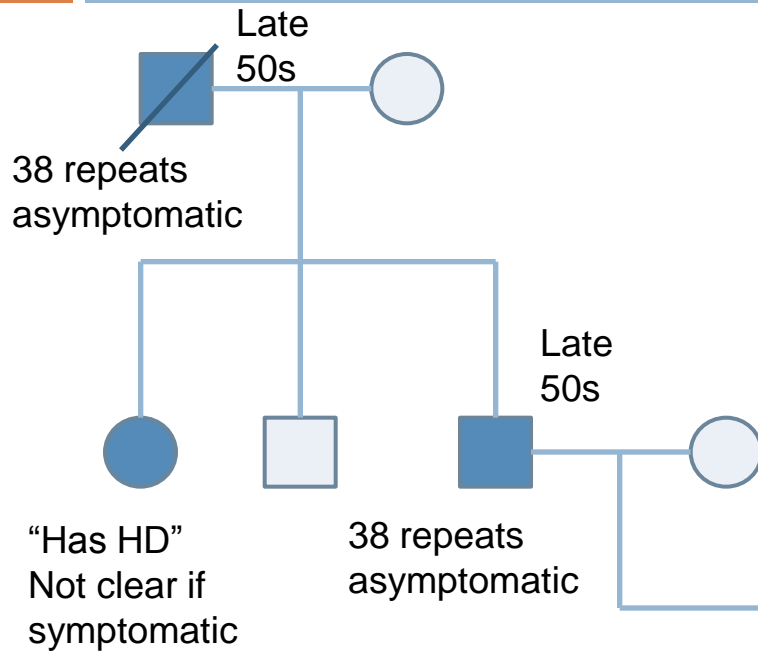
# Justice and Genetic Testing

- Advancing technology is shifting our understanding of what is just and what is fair
  - ▣ Things that are beyond our control (weather) are issues of fairness, not justice
- Can it be unjust to be born with a genetic condition?
  - ▣ Can parents then be held responsible for the outcomes?
    - Treatment vs. enhancement
    - Just distribution of limited resources
  - ▣ Changing public perception of genetic testing
    - 23andMe, Counsyl, Pathway Genomics

# References

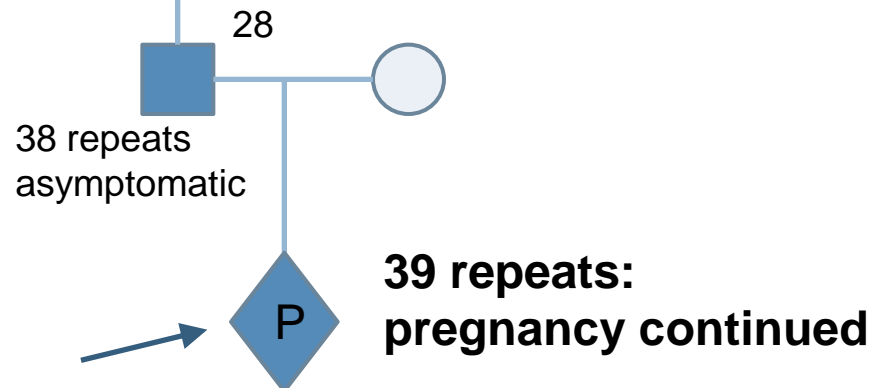
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# Case Presentation – Huntington’s Disease



- **Normal allele:** 26 or fewer CAG repeats
- **Intermediate alleles:** 27 to 35 CAG repeats
- **HD-causing alleles:** 36 or more CAG repeats
  - Reduced penetrance: 36-39 CAG repeats
  - Full penetrance: 40 or more CAG repeats

Decision: continue pregnancy if under 40 repeats



# Case presentation

## □ Issues raised

- **Autonomy:** parents vs. future child
- **Non-maleficence:** Is future child harmed by HD status being known by parents? Psychological trauma?
- **Beneficence:** Enabling parents the opportunity to decide whether to terminate or continue pregnancy.
- **Justice:** will child be treated fairly or discriminated on based on results?