Individualist Autonomy Models and Ableism

ETHICS: AUTONOMY AND HEALTH (SPRING 2014)
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For Your Consideration

- *House, M.D.*: "Three Stories" (S1E21)
  (28:55-34:14, 37:10-42:10)

- Do you think House is making a decision about his leg that ought to be respected? What are some problematic features of his decision?
- Has his proxy, Stacy, acted permissibly?
- How would you judge his doctor, Dr. Cuddy, in her decision to follow through with Stacy's "middle ground" solution?

Competing Models

Individualist

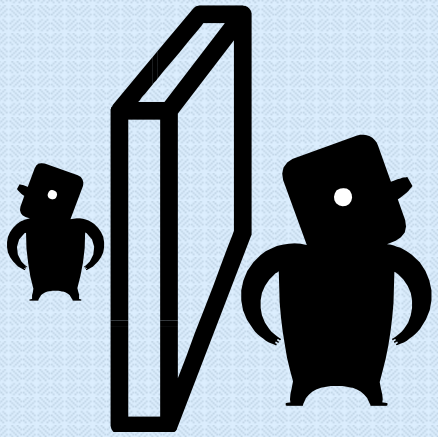
- Non-interference is best way to promote autonomy
- Maximize choice
- Inform, let patient decide → duties fully discharged
- Coercion concerns rooted in individual relationships
- Presume patient is free to choose according his/her own wishes

Relational

- Autonomous agency and sense of self are socially embedded
- Evaluate existing and absent choices based on context
- Informed consent is necessary, not sufficient
- Coercion can be structural, political, pervasive
- Freedom to choose can be undermined, distorted depending on context of choice

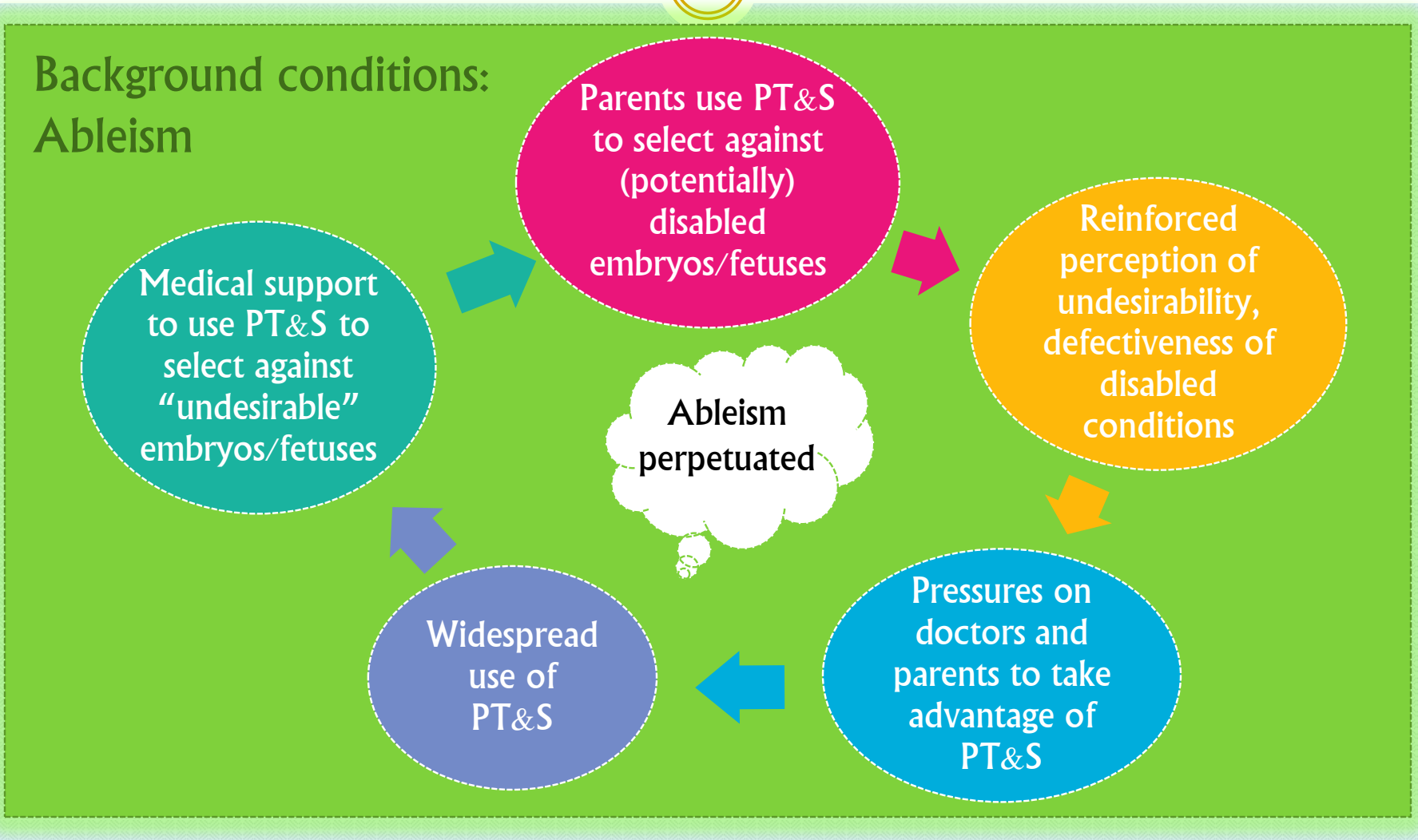
Epistemic Barrier

- **Epistemic barrier** between those who have never experienced disability and those who have/do
  - Insurmountable?
  - Methods for identifying and taking down this barrier?



- Barrier the **result of**
  - Marginalized status
  - Lack of a voice in decision-making (exclusion, disrespect)
  - Paternalistic attitudes ("pathetic, medical tragedies")
- Barrier **perpetuates**
  - Able-bodied, able-minded norms (power privilege)
  - False assumptions about quality of life, agency
  - Lack of accurate information about actual interests, needs

On Prenatal Testing & Screening (PT&S)



Different Questions to Ask

- Can parents autonomously consent to prenatal testing and screening (PT&S)? What are barriers to autonomous consent?
  - Moral differences in types of technology
- Do PT&S perpetuate ableism in families or the larger society?
- Should physicians recommend PT&S for all eligible patients?
  - What are physicians' moral obligations re: these current and future technologies?
- Even if taking advantage of PT&S is morally problematic, is it nonetheless morally permissible?
- Should PT&S be made available to as many prospective parents as possible?
  - What is the **moral justification** for it? What are the **moral costs**?

Ho's Conclusions

- Not suggesting we eliminate technologies, end-of-life options
- Not suggesting that autonomous decision-making is impossible in questions of disability
  - Identifying ways in which free, voluntary, informed consent can be tarnished, distorted, inauthentic, coerced
- "respect for autonomy should be about removal of [oppressive] social barriers or empowerment through social restructuring" (204)
  - Recognize how options are framed, interpreted, and communicated → effects on decision-making
  - More expansive notions of patient advocacy, respecting patient values

Group Discussions

- When it comes to offering prenatal/preimplantation testing and screening to prospective parents, what are some moral priorities?
  - What are some sources of moral conflict?
  - How should genetic counselors advise parents when there is a possibility of physical or intellectual disability?
- If a patient refuses life-sustaining care due to concerns about being a burden or being helpless as a disabled person, what are the moral obligations of the medical team?
  - What forms of paternalism may or may not be permissible?
- Do you agree with Ho that institutionalized policies and practices can coerce patient choice?