MEDICALLY SHAPING CHILDREN

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OBJECTIVES OF SESSION

• To be able to construct/critique arguments about whether medically shaping children, at parental request, is ethically supportable
  – To place such requests in context
  – To apply ethical principles, modes of analysis, perspectives to such requests, using the Ashley case as an example
CONTEXT

- Medically sophisticated, "first world" country
- Economic, political, social realities
- Culture of individualism, "rights-based"
- 21st century; past history
- Western bioethics tradition
- Anglo-American legal system
CHILDREN ARE SHAPED
World Leading Center for Virtually 100% Guaranteed Gender Selection
MEDICAL SHAPING: WHAT IS IT?

• Goals
• Examples
  – Repair of cleft lip and palate
  – Surgery for ambiguous genitalia
  – Making boys taller or girls shorter
  – “Treating” deafness with cochlear implants
  – Managing behaviors through drugs
  – Ashley “treatment”
MEDICAL SHAPING AND ETHICS

• Decision-maker(s)
• Principles or rules, such as:
  – Value of human life
  – Human rights, interests
  – 4 principles of medical ethics
• Consequentialism, utilitarianism
• Modes of analysis & perspectives, such as:
  – Ethics of caring, feminist ethics, narrative ethics, virtue ethics
  – “Best interests” standard in pediatrics
ASHLEY: DIAGNOSIS

- Static encephalopathy
- Severe, permanent neurologic impairment
- Non-ambulatory, non-verbal, 3-6 month old cognitive capacity
- Ability to interact with family
- Normal life expectancy; life-long dependence
ASHLEY: PARENTS’ “DIAGNOSIS”

• Alive because of medical interventions
• Profoundly “unabled” and totally dependent
• Profoundly precious to her family
• QOL better with family than in institution
• Increased size is adverse to her best interests
• One of small category of “unabled” children (< 1%)
ASHLEY “TREATMENT”

- Growth attenuation: time-limited administration of high doses of estrogen
- Hysterectomy
- Surgical removal of breast buds
ASHLEY: DECISIONMAKER
ASHLEY: DIGNITY

“Ashley does not have the concept of dignity but she does have a very real experience with pain and discomfort. What is meaningful to her is to be as pain free and physically comfortable as possible . . . to be able to enjoy those things she can enjoy: being with family, hearing music, cuddling. Ashley shows enjoyment for being included in family activities. She kicks her legs and orchestrates her arms, she makes little happy sounds, her face radiates with smiles. We however care a great deal about our daughter's human dignity and feel that the treatment makes Ashley more dignified by providing her with a better quality of life.” (Ashley’s Dad)
ASHLEY: RIGHTS

- Sources of rights
- Significance of rights
- Rights vs. interests
ASHLEY: AUTONOMY

- Ashley herself
- Ashley’s family
ASHLEY: NON-MALEFICENCE, BENEFICENCE

- Do no harm: what is “harm” to Ashley?
- Beneficence: what is “good” to Ashley?
ASHLEY: JUSTICE
ASHLEY: CONSEQUENCES AND THE COMMON GOOD

- For Ashley and her family
- For children like Ashley
- For future “Ashley’s”
- For society
ASHLEY: MODES OF ANALYSIS, PERSPECTIVES
ASHLEY: THE “BEST INTERESTS” STANDARD IN PEDIATRICS

• What is in a child “best interests?”
  – Factors
  – Perspectives
• Critiques of BIS
• Alternatives to BIS
• BIS and Ashley
SELECTED REFERENCES: ASHLEY


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• Spriggs M. Ashley’s interests were not violated because she does not have the necessary interests. Am J Bioeth 10(1):52-54 (2010).
• Pilkington E. The Guardian, March 15, 2012. Interview with Ashley’s Dad; Website, pillow angel.
SELECTED REFERENCES: OTHER

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- Pistorius M.  *Ghost boy: the miraculous escape of a misdiagnosed boy trapped inside his own body.* Thomas Nelson, 2013.
- Films:  *A two year old goes to hospital, 1952; Babies, 2010; Dallas Buyers Club, 2013.*