



# Understanding Differences in Conflicts Surrounding the Medical Care of Children

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# Three Cases

- Mueller Case (Refused LP)
- Riley Rogers
- Abraham Cherrix



Observation #1

**Characterize things correctly**

# A Faulty Characterization

Autonomy

vs.

Beneficence

# Beneficence

- “To Do Good”
- Obligation to seek the good of others
  - Avoid inflicting harm
  - Prevent harm
  - Promote good

# Beneficence

Medicine is a form of applied beneficence

....so is parenting

# Beneficence and Decision-making: Different ways of Seeing

- Best Interests encompass spheres other than the medical: Total Well-being vs. Medical Well-being
- Trade-offs between competing medical goods: i.e. comfort vs. life extension vs. cure
- Balancing benefit and harms of a given therapy



Observation 2:  
We engage ethical issues and  
dilemmas at different levels

The level of engagement matters

# Levels of Engagement

1°	What should I do?	Agent/ Actor	Personal Ethics
2°	What should she do?	Counselor/ Educator	Ethics Consultation
3°	Will I tolerate her decision?	Judge	Criminal Law
4°	Should we make a rule?	Citizen/ Legislator	Public Policy

# Implications

- Tool of analysis may differ at different level of engagement
- Each level has a different set of constraints that may apply
- Conclusion at one level does not necessarily determine your conclusion at another level



## Observation #3

**“Best Interests” may not be the  
best standard for institutions**

# Parental Authority

- Moral, social, and legal grounding
- Consent vs. Assent
- Permission
- Limited by “best interests” of the child

# Limits of Parental Authority

- Best Interests of the Child
  - Reasonable Range
  - Not always separable from family interests
- Parental Incompetence
- Neglect or Abuse

# Purpose of a Standard for Surrogate Decision-making

- Provide Guidance to Decision-makers?
- Identify the limits of surrogate decision-makers?

# Best Interest Standard

- Origins in Family Law (adoption, custody, foster care)
- Subsequently has become the prevailing standard used to judge the adequacy of medical decision-making on behalf of children

# Best Interest Standard

- Brock/Buchanan: “Acting so as to promote maximally the good of the individual”
- Beauchamp/Childress: “...a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs”

# Difficult to Apply

- Often difficult to define the “best interest” of a child in the medical setting
- Inherently a question of values rather than an objectively measurable calculation
- Nature of interests complex
- Not clear the child’s best interest should be the sole consideration

# We don't expect it of parents

Parents frequently act in ways they know not to be optimal or best for their children:

- Education
- Safety
- Television
- Shopping
- Competing interests

# Society: A bit hypocritical?

- Education
- Health Care
- Minimum Wage
- Child Care
- Pollution and Housing
- Does it make sense for society to demand expensive interests in the “best interest” of the child when it would require bankrupting a family?

# The Courts

- Best Interests is frequently modified to become something else in its application
- Courts place a high burden on the state to prove the medical treatment is necessary before compelling treatment over parental objections
- Courts have been reluctant to require medical treatment over the objection of parents “except where immediate action is necessary or where the potential for harm is rather serious.” (Wing)

# Why does it matter?

Language is important. Moral understanding is metaphorical. By referring to best interests, health care providers are led to believe the standard is a different one than what we actually expect or use.



**In other words:**

We should be clear, say what we mean,  
and use a standard that makes sense.



# Observation #4

**The Harm Principle makes sense**

# The Harm Principle

“The only purpose for which power can rightfully be exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.”

--John Stuart Mill, *On Liberty*

# When can state action be justified?

- “Harm Principle”: State intervention (coercive) may be justified when the individual decision or action places others at substantial risk of serious harm.
- State action must be effective in preventing the harm.

No other options less intrusive to individual liberty are available

# Defining the Harm Threshold

- Ross' Model of Constrained Parental Autonomy:  
Deprivation of Basic Needs
- Feinberg: interference with the interests necessary for more ultimate goals like physical health and vigor, integrity and normal functioning or one's body, absence of absorbing pain and suffering or grotesque disfigurement, minimal intellectual acuity, and emotional stability.
- AAP: Substantial risk of serious harm

# Bottom Line when faced with Parental Refusal of Intervention

- Current Question: Is this intervention in the child's best interest?
- Proper Question: Does the decision made by the parents significantly increase the likelihood of serious harm as compared to proposed options?

# Conditions that justify state interference

- Parents action places the child at significant risk of harm that is serious and imminent
- Interference is necessary to prevent harm, likely to prevent harm (proven efficacy), and is not associated with similar risk of similarly serious harms (Proportionality)
- No less intrusive alternatives
- Test of Generalizability
- Test of Publicity (other would agree it is reasonable)

# Some Examples

- Refusal of Cancer Chemotherapy
- Refusal of Blood Transfusion
  - Jehovah's Witness vs. Scientist Parents
- Refusal of insulin in Type I Diabetes
- Refusal of routine childhood immunizations
  - Non-epidemic
  - Epidemic
- Donation of an Organ
  - Bone Marrow
  - Kidney

# The Institution's Obligation

- Absent state authority, the physician cannot treat or vaccinate without parental consent.
- State agencies should not be involved unless the parental decision places the child at substantial risk of serious harm (i.e. neglect)

Respectfully continue to work with the family



# Religious Objections to Care

Does it matter if the parental refusal  
is culturally or religiously based?



## Observation #5

**Adolescents should be treated with respect and taken seriously**

# Adolescents and Consent

- Conditional consent-emergencies
- Mature minor
  - Generally above 15
  - Understanding of nature, purpose, and consequences of proposed treatment
- Emancipated minors

# Children and Capacity

- Legal presumption of incompetence
- Developmental evidence
- Capacity is relative
  - Complexity of decision
  - Consequences of decision
  - Ability to understand and reason

# “Unreasonable” Parent Demands

Observation # 6: Should be carefully considered, treated respectfully, but need not always be complied with

# Suggestions

- Consider accommodating parents when...
  - Intervention will not harm the child
  - Intervention does not significantly harm others
  - Potential for benefit is possible, but not established
- Appropriate to limit interventions to those within the scope of the provider's practice/standard of care



## Observation #7 (the last!)

Procedural Justice is important. There needs to be a process for resolution of disagreement that is fair

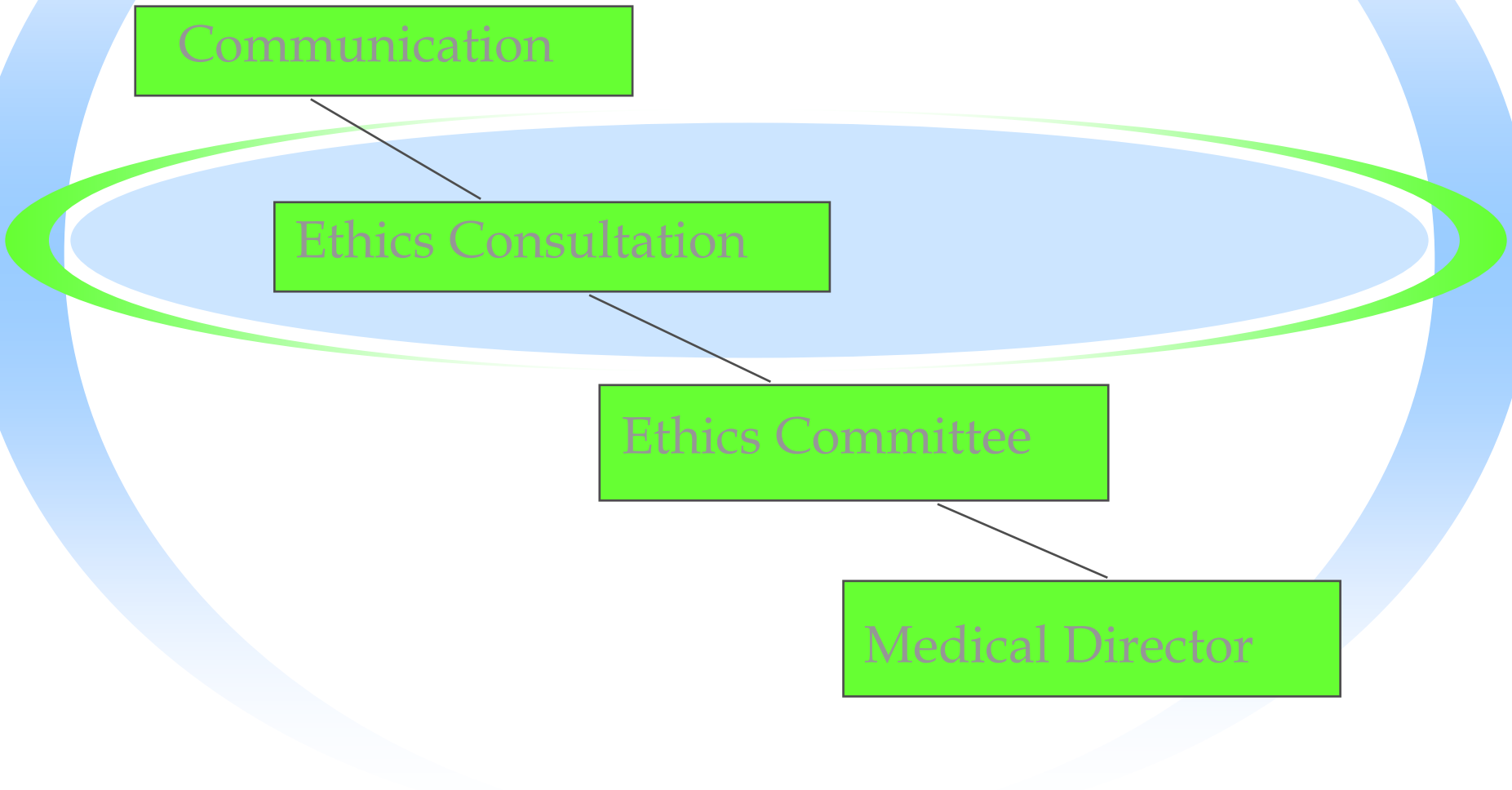
# CHRMCM Guidelines: Conflict Resolution

Communication

Ethics Consultation

Ethics Committee

Medical Director



# The Three Layers of Morality

- Character/Identity
- Vision
- Action/Response

# What is Ethics Consultation?

Ethics at its best is only bad poetry--  
that is, it seeks to help us see what  
we see every day but fail to see rightly...  
If ethicists had talent, they might be poets,  
but in the absence of talent, they try to  
make their clanking conceptual and  
discursive claims do the work of art.

--Stanley Hauerwas

# Moral Vision

“Moral differences are not just different choices given the same facts; they are differences of vision....moral views are less the product of reasoning and more the result of an image, a slogan, a metaphor.”

# Moral Vision

“...moral differences look less like differences of choice, given the same facts, and more like differences in vision...more like a total difference of *Gestalt*.”