Between Patient, Parent and Provider: The Ethics of Pediatric Decision-Making

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Outline

1. Differences Between Pediatric and Adult Decision-Making

2. Symposium and Consensus Standards

3. Framework for the Ethics of Pediatric Decision-Making

4. Six Principles

5. Case Application

What makes pediatric decision-making different?

Children not capacitated decision-makers

- We usually don't get consent directly from our patients.
- Because they likely never were capacitated decision-makers, we also don't strictly apply "known wishes" or "substituted judgment".

Parental authority for most decision-making

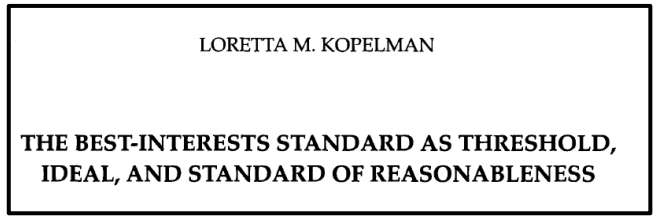
- The default decision-maker is parents.
- Patients don't usually get to appoint a decision-maker.

Children are vulnerable and dependent in ways that matter

- We worry about special things like: proper development, protection from abuse and neglect, the role of parents and families.

How should we make medical decisions for children?

Best Interest Standard?


LORETTA M. KOPELMAN

THE BEST-INTERESTS STANDARD AS THRESHOLD, IDEAL, AND STANDARD OF REASONABLENESS


The Best Interest Standard Is the Best We Have: Why the Harm Principle and Constrained Parental Autonomy Cannot Replace the Best Interest Standard in Pediatric Ethics

Johan C. Bester

Basic Interests Standard?


Better than Best (Interest Standard) in Pediatric Decision Making

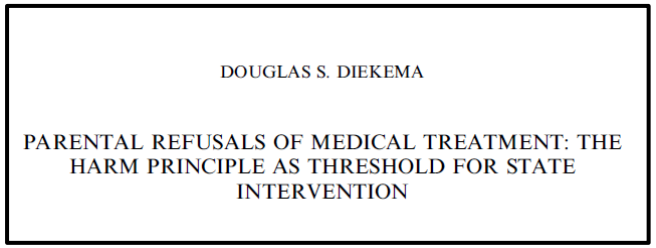
Lainie Friedman Ross


Theor Med Bioeth (2012) 33:179–198
DOI 10.1007/s11017-012-9219-z

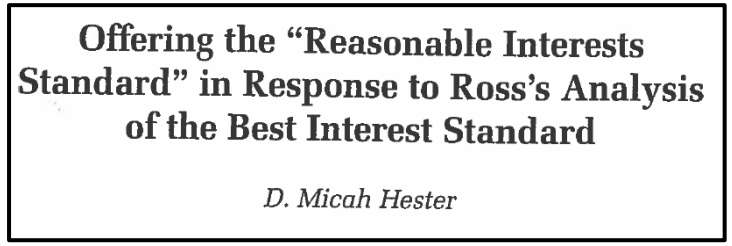
Deciding for a child: a comprehensive analysis of the best interest standard

Erica K. Salter

Something Else?


DOUGLAS S. DIEKEMA

PARENTAL REFUSALS OF MEDICAL TREATMENT: THE HARM PRINCIPLE AS THRESHOLD FOR STATE INTERVENTION


Offering the "Reasonable Interests Standard" in Response to Ross's Analysis of the Best Interest Standard

D. Micah Hester

How Much Do We Really Disagree?
“Best Interests and Beyond” Symposium

Standing L-R
Rosamond Rhodes
Lou Vinarcsik
Mark Navin
Armand Antommaria
Thad Pope
Mark Mercurio
Doug Diekema
Erin Paquette
Jeff Blustein

Sitting L-R
Johan Bester
Jay Malone
Lainie Ross
Erica Salter
Micah Hester
Ellen Clayton
Loretta Kopelman
Ana Iltis

Resulting Six “Consensus-Recommendations”

TABLE 1 Consensus Recommendations

Consensus Recommendations
1. Parents should be presumed to have wide, but not unlimited, discretion to make health care decisions for their children.
2. Parents should protect and promote the health interests of their child, while balancing practical constraints and/or other important obligations and interests.
3. A clinician's primary responsibility is to protect and promote their pediatric patients' health interests. Clinicians' recommendations should be informed by professional judgment and the best available evidence.
4. To respect children and promote their wellbeing, clinicians and parents should inform pediatric patients of salient information and invite their perspective to the degree that doing so is developmentally appropriate.
5. In addition to state mandated reporting requirements, clinicians should seek state intervention when all less-restrictive alternatives have been exhausted and a parental decision places the child at significant risk of serious imminent harm or fails to meet the child's basic interests.
6. Clinicians and parents should collaborate in a shared decision-making process to promote the child's interests.

Pediatric Decision Making: Consensus Recommendations

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1. Parents sh
2. Parents sh interests.
3. A clinician’s informed b
4. To respect perspectiv
5. In addition exhausted
6. Clinicians a

Take-Away: Rather than a single standard (e.g. the “Best Interests Standard”, a constellation of 6 interrelated principles that, taken together, describe the moral landscape governing medical decision making with and on behalf of children.

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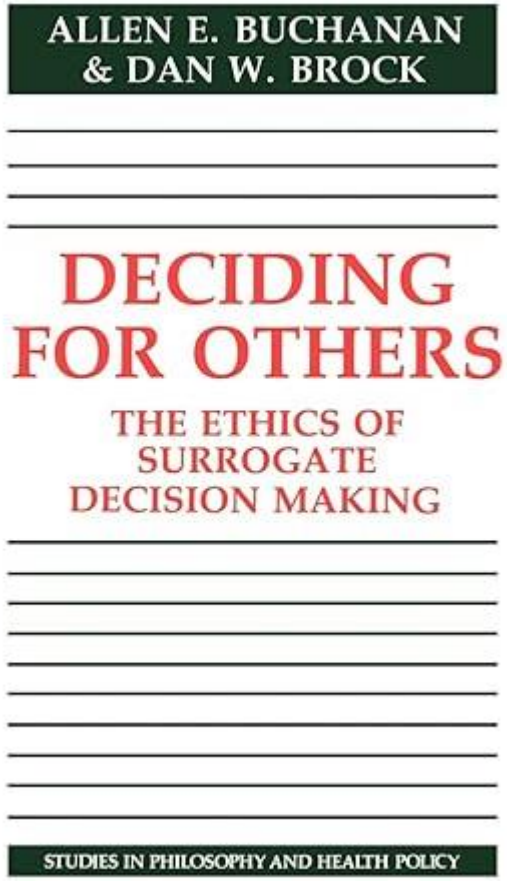
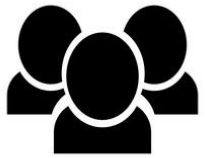
A Framework For Understanding the Ethics of Decision-Making



Underlying Values: What normative values underpin the framework?



Authority Principles: Who should have presumed authority to make decisions?

Guidance Principles: How should decision-makers go about making decisions?

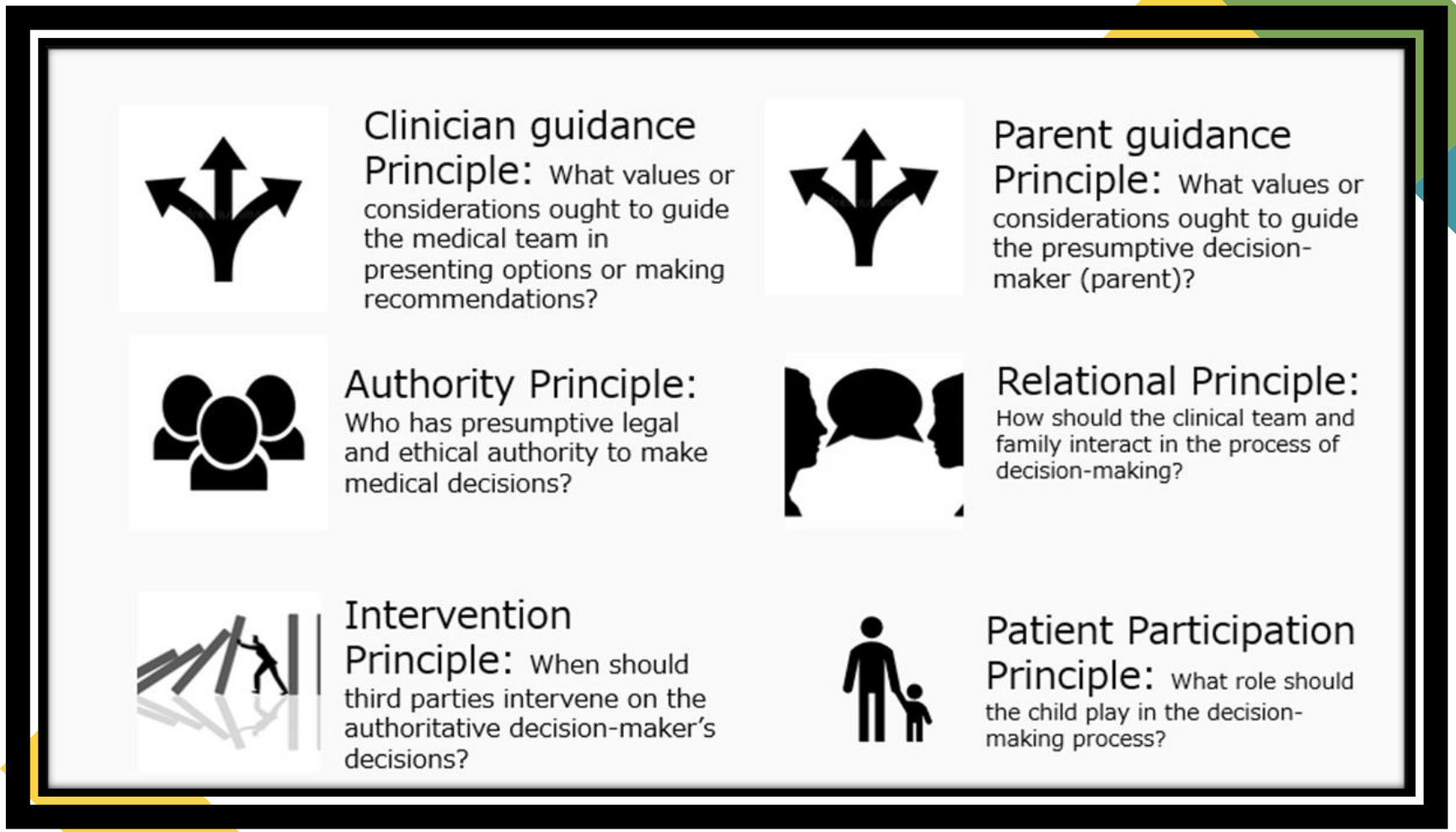
Intervention Principles: Under what conditions should third parties intervene on authoritative decision-maker's decisions?

Underlying Values

Adults	Children
Patient self-determination	Patient well-being
Patient well-being	Patient self-determination
	Parental/Family Interests

Buchanan and Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge.

Revisions and Additions



Hester, D.M. and Salter, E.K. 2022. "Reasonableness as a Relational Principle: An Integrated Framework for Pediatric Decision Making", *Journal of Pediatrics*, 251.

How to make a framework that is “child-centered”?

Discussion questions:

1. In your practice, what does child-centered decision-making look like in action vs. what it looks like on paper?
2. What might it look like to respect children (as children) and respect childhood, as a distinctive stage of life?
3. What are the biggest barriers to truly child-centered care in your setting?

Authority Principle: Why Parents?

"The liberty interest at issue in this case—the interest of parents in the care, custody, and control of their children—is perhaps the oldest of the fundamental liberty interests recognized by this Court… [I]t cannot now be doubted that the Due Process Clause of the Fourteenth Amendment protects the **fundamental right of parents to make decisions concerning the care, custody, and control of their children.**"

Justice Sandra Day O'Connor in Troxel v. Granville, (2000)

Authority Principle: Why Parents?

Parents generally:

1. Have privileged knowledge of their child, and thus, their interests.
2. Are motivated to advance their child's interests.
3. Know or can ascertain their child's perspectives.
4. Bear the responsibility for decisions made about their children.
5. Are best positioned to assess & negotiate inter-related family interests.

Parental Guidance Principle

What values or normative considerations ought to guide parents in making medical decisions for their children?

Best Interests of the Child (Buchanan and Brock)

+Parents should choose what will best serve the patient's interests, determining net benefits of each option and choosing that which will maximally promote the child's good.

Interests of the Child in the Context of the Family (Consensus Rec #2)

+Parents should protect and promote the interests of the child, while balancing practical constraints and/or other important obligations and interests.

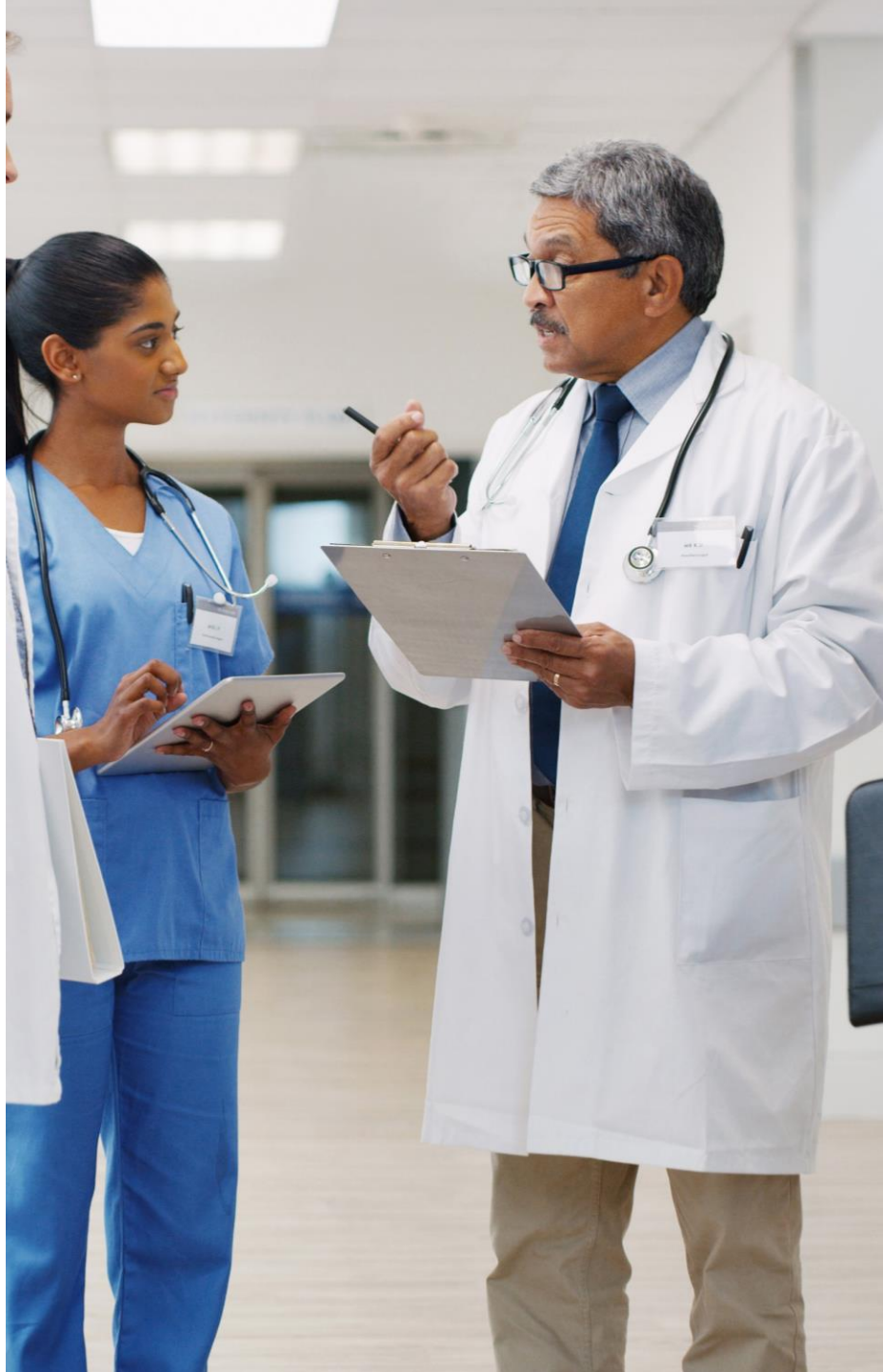
Clinician Guidance Principle

What values or normative considerations ought to guide clinicians' selection of treatment options and/or recommendations?

Medical Beneficence:

"A clinician's primary responsibility is to protect and promote their pediatric patients' health interests. Clinicians' recommendations should be informed by professional judgment and the best available evidence." (Salter et. al. 2023)

"As a guidance principle for pediatric clinicians, medical beneficence identifies a justified starting point for the clinical encounter: begin by ascertaining and recommending, as well as is possible, the option or range of options that best serves the patient's medical interests." (Hester and Salter, 2022).



Child Participation Principle

- More than mere “assent”.
- Engage directly with children, giving them multiple opportunities to express their fears, feelings, experiences and preferences.
- Given children multiple modalities to express themselves (not merely verbal/literal, but play, drawing, art and projective techniques).
- Keep parents involved, to promote a sense of emotional safety and security.
- Child’s perspectives should have some degree of evidentiary decisional impact.

Intervention Principle

Question: Does this parental decision rise to the level of justifying state involvement?

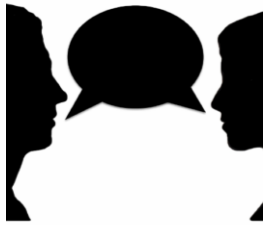
Goal: To determine whether coercive state force is justified in this case.

Does this parental refusal rise to the level of posing “significant risk of serious harm” to the child? (Diekema’s Harm Principle)

Table 1. Conditions for Justified State Interference with Parental Decision-making.

1	By refusing to consent are the parents placing their child at significant risk of serious harm?
2	Is the harm imminent, requiring immediate action to prevent it?
3	Is the intervention that has been refused necessary to prevent the serious harm?
4	Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?
5	Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?
6	Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
7	Can the state intervention be generalized to all other similar situations?
8	Would most parents agree that the state intervention was reasonable?

Diekema, D. 2004. "Parental refusals of medical treatment: the harm principle as threshold for state intervention." *Theor Med Bioeth* 25, no. 4 (2004): 243-264.

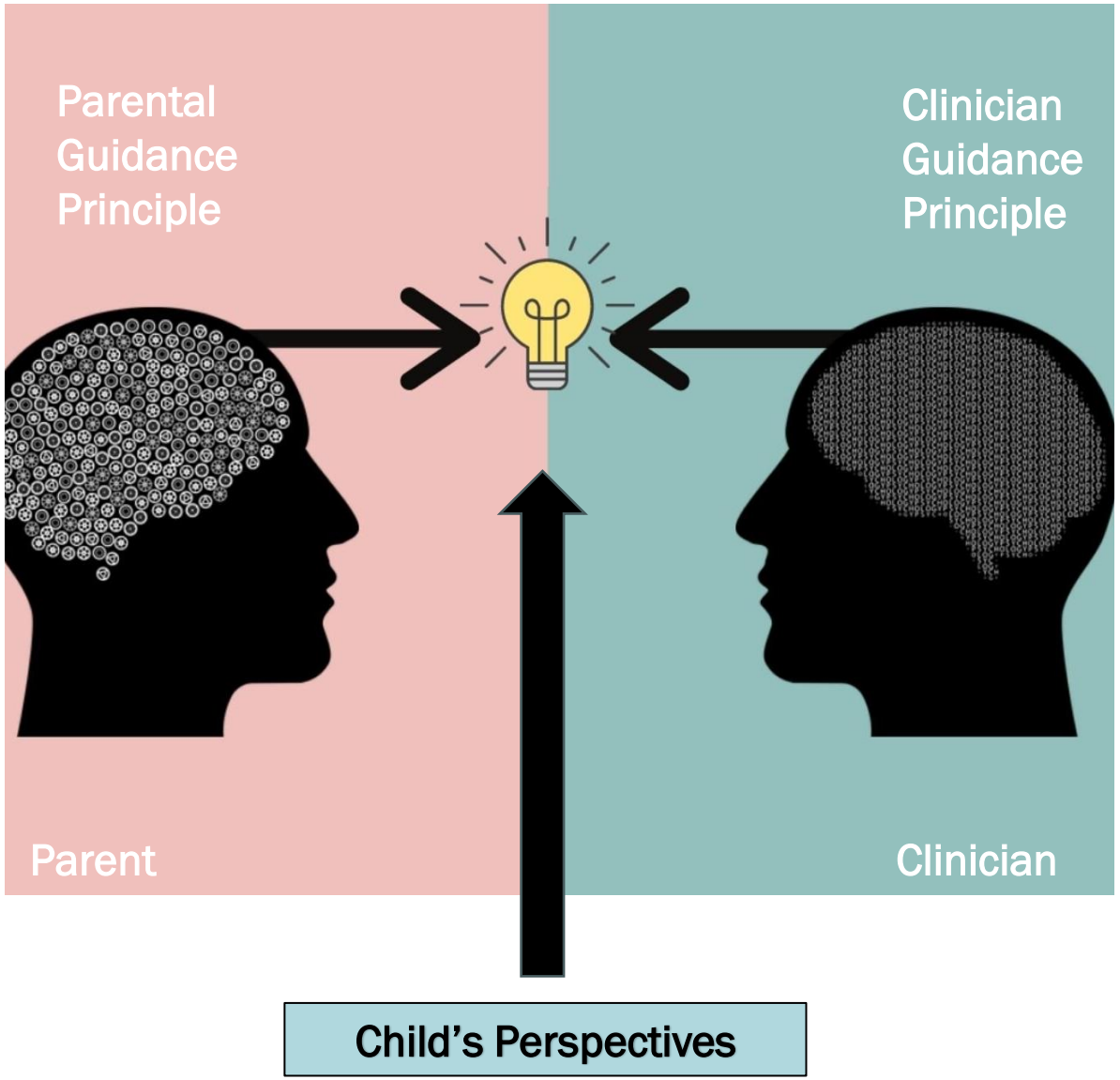


Relational Principle:

How should the clinical team and family interact in the process of shared decision-making?

Goals of the Clinical Team:

1. To develop a therapeutic alliance with parents.
2. To understand parental values, preferences and experiences.
3. To incorporate the perspectives of the child patient.
4. To decide how directive to be in the relationship.
5. To come to shared decisions about the child's care.



1. Authority
2. Parental Guidance
3. Clinician Guidance
4. Child Participation
5. Intervention
6. Relational

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Case Discussion: Jaylen

Jaylen is a 9-year-old with a two-year history of moderate-to-severe Crohn's disease. His disease has been inadequately controlled on conventional therapy, and his gastroenterologist, Dr. Osei, recommends initiating a biologic agent (infliximab). Jaylen's parents initially agree, but after researching online they have become concerned about the long-term risks of immunosuppression and have decided they would prefer to try an elimination diet protocol they found through a naturopathic practitioner — a protocol with no published efficacy evidence for Crohn's. Dr. Osei believes the diet protocol poses a real risk of disease progression, growth failure, and hospitalization, but acknowledges that Jaylen is not in immediate danger.

Jaylen's parents are warm, engaged, and clearly devoted to him. When Dr. Osei meets with the family together, Jaylen — who is talkative and bright — tells Dr. Osei that he hates his "stomach problems" and that they make it hard to play soccer with his friends. Despite Dr. Osei's recommendations, Jaylen's parents still feel that the diet is the right path forward. They say they're doing their own research and it's their job as parents to protect Jaylen from unnecessary risks.

Case Discussion Questions:

1. Are Jaylen's parents and Dr. Osei acting in accordance with their respective guidance principles?
2. Is the parental refusal of the recommended treatment harmful enough to cross the harm threshold (which would justify state intervention)?
3. How should Jaylen be engaged in this decision? What might it look like to give his perspectives some "evidentiary decisional impact"?
4. What should the next conversation with this family look like?

Why parents are NOT surrogates

	Surrogates (for adult patients)	Parents (of minor children)
The patient	Formerly capacitated	Never capacitated
The authoritative decision-maker	Named by the patient or chosen via default hierarchy	Parents
The decision-maker's role	To "stand in for" the patient, to extend patient autonomy	To promote the interests of the child
The guidance principle	Known wishes, substituted judgment (evidence of the patient's capacitated preferences), best interests standard	(Best) interests of the child in the context of the family
The intervention principle	Not following the autonomy-based guidance above	Significant risk of serious harm

Hester, D Micah et al. "Parents (of minors) are not surrogates: acknowledging (finally) the unique moral space of parents." *Theoretical medicine and bioethics* vol. 46,5 (2025): 419-432.

The Deficit Model of Childhood

Are children simply deficient adults?

Concerns with a Deficit Model of Childhood:

1. They prioritize the future adult over the present child.
2. They neglect the unique goods and goals of childhood.
3. They inappropriately import adult models into the space of childhood.

Saplings or Caterpillars?

What are the unique goods and goals of childhood? How do our healthcare practices and systems promote or inhibit those goods and goals?

Other Cases?
Questions?
Thank you!

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References

- Buchanan and Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge.
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- Troxel v. Granville, 530 U.S. 57 (2000).