

Pediatric Decision Making: Ross, Rawls, and Getting Children and Families Right

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In a democratic society, then, it is recognized that each citizen is responsible for his interpretation of the principles of justice and for his conduct in light of them.

—John Rawls, *A Theory of Justice*

ABSTRACT

What process ought to guide decision making for pediatric patients? The prevailing view is that decision making should be informed and guided by the best interest of the child. A widely discussed structural model proposed by Buchanan and Brock focuses on parents as surrogate decision makers and examines best interests as guiding and/or intervention principles. Working from two recent articles by Ross on “constrained parental autonomy” in pediatric decision making (which is grounded in the Buchanan and Brock model), I discuss (supportively) features of Ross’s effort *vis-a-vis* the best interest standard. I argue that any pediatric decision-making model that brackets or formally limits an engagement with the child patient assumes too much. Further, any model that under appreciates the place of parents and their autonomy, and the dynamic parent-child relationship, misses an opportunity to broaden the clinical encounter by considering questions of justice for the child (Rawls) and within a family (Ross). In this context, I focus on the child’s

emerging and ongoing emotional and intellectual development and autonomy—their capabilities and identifying primary goods.

Most, if not all, of the day-to-day healthcare decisions that many parents will make for their children are routine. They align with standards of care. On other occasions, parents and/or care-providers are considering what ought to be done among the many the things that can be done. In these instances, what process ought to guide decision making?

In the prevailing view, decision making for children in healthcare is informed and guided by the question, “What is the best interest of the child?” Yet there is disagreement about whether this question is sufficient, who it addresses, and what counts as an answer. Is it directed to, or intended to be used by, parents who must make medical decisions for their child—as a guidance principle? Or is the question, and the parents’ reply, a guide for physicians to use in considering whether and when to challenge parental autonomy—as an intervention principle?

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Or, can the question function both ways? And, in each instance, what are the limitations?

I take as a point of departure several questions that were suggested by my reading of two articles by Lainie Friedman Ross in this issue of *The Journal of Clinical Ethics* on “constrained parental autonomy” and the prevailing “best interest” standard of pediatric decision making, relating, broadly, to considerations of justice for the child and within the family, the prioritization of rights in association, and the identification of children’s primary goods and needs: the necessary conditions, the facilitating environment, for a child to flourish.¹

My effort is also to contextualize this clinical encounter in a way that prioritizes and hopefully further illuminates the relationship parents have with their child, as well as their child’s relationship with them, in the immediate clinical context and together with careproviders.

CONSTRAINED PARENTAL AUTONOMY

Broadly, the challenge is to illuminate the procedure and the practice of medical decision making in pediatrics. The framework of shared decision making in play in the physician-patient relationship between adults can only take us so far when used as a guide to the physician-patient-parent relationship in pediatrics, but it offers a convenient and grounded first step.

The principles and framework for decision making with adults, and in surrogate decision making, as proposed by Buchanan and Brock,² and taken onboard by Ross,³ focus on the ethical values of respect for individual self-determination and concern for individual well-being. To be clear, the prioritization of and focus on these two ethical values is a methodological or procedural decision—an ethical standpoint assumed by physicians toward all patients,⁴ but prior to engaging any one patient. While it is likely that there are objective grounds for these two principles upon which all physicians and patients may initially agree, the concepts are interpretively broad enough to accommodate physicians’ aspirations (professional responsibilities) for care and patients’ self-regarding interests (autonomy). This is not to suggest that one term or the other is the outpost of either physicians or patients. The concepts are bidirectional but not interchangeable. Their compatibility rests on reading them as mutually supportive, within a relationship. But this is not the

only reading. When operationalized, these principles may or may not be aligned. Off the cuff, it is not difficult to imagine a situation in which the hard edge of self-determination, a respect for the dignity and autonomy of a patient’s choice, is in conflict with a physician’s concern, more subjectively, for the patient’s well-being. In short, at critical moments it is likely, if not expected, that these values must be reconciled. But how? And by whom? Since physicians assume these two principle ethical values prior to an engagement with any patient, it seems that the first reconciliation or reevaluation must begin within the physicians’ standpoint. The patient may simply be thinking about, or perhaps insisting on, her or his right to self-determination. My point is that the two ingredients that are mixed together to make the foundation of shared decision making can be antagonistic. I don’t want to push this example too far, as there are mechanisms for negotiation and regulation within a robust physician-patient relationship with adults, as patients can refuse treatment, and there are limits to what they can demand by virtue of their autonomy. However, it seems reasonable to imagine how the tension in this antagonism may become more apparent and pronounced in pediatric decision making, as appeals to concern can—consciously and unconsciously—overlap self-determination. And this is so for both physicians and for parents—they are both striving to represent the interests of the child. In these instances, when children cannot speak for themselves (and I will argue that the default must always be toward robust inclusiveness, for this child’s direct participation: autonomy always has significance to and for children), whose authority is controlling? Who first defines the best or the good enough for the child? More importantly, who gets to decide what is done—or refused? And, whose justification will stand? Then, the question: “How can the power of reason be made into a social power?”⁵

Here, likely amidst competing claims and principled tensions, I side with Ross in favor of “constrained parental autonomy.”⁶ The parents’ standpoint should be, at minimum, and *prima facie*, the default position. This said, justice requires that there must be limits to the parents’ determination and control over their child’s life. Although I offer a few observations on this point, a comprehensive defense of the features and boundaries of such limits or constraints is beyond the scope of this article.

Focusing our attention on shared decision making, we return to a question of method or procedure. Throughout the articles considered here, the model, following Buchanan and Brock, focuses on the parents as surrogate decision makers for their child.⁷ The assumption, a stipulation, is that a child is incapable of making these decisions. The child's participation is bracketed. A child is, as it were, a silent subject—talked about but not talked with. While this move is defensible, providing we know that a child is incapable of participating, a more detailed engagement with the boundaries of capacity would illuminate and help us to understand and evaluate both the process and the implementation of shared decision making generally, “constrained parental autonomy,” the “best interest standard,” and basic interests. As we noted above, procedurally, any model of shared decision making for the physician-parent-patient frame must default whenever possible to including children, whenever and however possible, following their emotional and intellectual capacity.

Ross is right to point to the limitations of “best interest” as an “aspirational guidance principle.”⁸ It is idealized and presumptive. Here language can be bewitching. After any pronouncement of “best interest” we can always ask, ironically: “But is this best?” In the high-stakes context of deciding with or for children, we—all participants—are likely further challenged and compromised both emotionally and rationally. As such, as Ross suggests, parents should not be “required to consider what is medically best nor what is best, all things considered.”⁹ And even if it were possible to reach some accommodation of what was best in some modalities, in other areas the standard simply “does not accommodate the diversity of values that exist between and within families.”¹⁰

In a broader ordinary conversation—or perhaps as a heuristic—it seems natural if not unsurprising that the question of a child's “best interest” might occur to parents, as would a consideration of harm. In high-stakes decision making for their child, we can expect that parents are uncertain, if not afraid, and sometimes overwhelmed, and struggle to make sense of their thoughts and feelings, to fulfill their responsibility to a child they love and to their family.¹¹ For others, “to extol parents to give reasons”¹² is to risk alienating parents and further burdening them. The question of “best interest,” once asked, becomes controlling. There is an implicit

presumption of power in asking this question of another. Even if we imagine that parents did provide reasons, what then? Shall we assume that the questioner has the right answer—a better answer—to which the parents' answer will be tested? When a decision must be made, an action taken or declined, we might also imagine second- or third-party challenges on what's best. Here again the legitimacy of an intervention must be questioned and clarified. We must similarly understand and describe when parental autonomy should be constrained. Following Ross, “since we cannot agree upon what we think is best . . . we should not consider intervention if parents make good enough decisions; but only if parents fail to respect the child's basic needs and interests.”¹³ Yet, it seems that this response must similarly avoid the failure of the “what we think best” standard: that we may not be able to agree on a just balancing of parental, family, and child rights when rights and interests might be in tension. Another challenge for decision making is that although parents may care deeply for their child, they may not be up to the task; they may be unable or unwilling to manage what parental autonomy, constrained as it is, demands. There should be a procedural accommodation for these parents that preserves their dignity and respects what they can do, and does not cause them to feel as if they have failed their child.¹⁴ In other cases, hopefully rare, it may be that parents' decisions are irrational and injurious to their children, where the parent-child relationship—and the family relationship—is fractured, and intervention is a moral necessity.¹⁵ In every case, a challenge to decisions made from within the parent-child relationship carries a significant risk. In otherwise healthy relationships, a simple challenge by careproviders may work contrary to the child's and the parents' interest by undermining or destabilizing the confidence and the trust they have in one another. Children might wonder if—and why—their parents fell short of protecting them; children may also feel the need to take sides to protect their parents—especially if a careprovider's view prevails.

SOME FURTHER THOUGHTS ON SHARED DECISION MAKING

We—typical parents and careproviders alike—want nothing more for our children than to preserve for them an open horizon. When we

imagine getting anything right, it must be in what we imagine for our children. The aspirational nature of the endeavor, our parenting and care, is reflected in how our life project is commonly described: we are raising *our* children. And the “right of parents to control the upbringing of their child as they see fit” is well recognized in law.¹⁶ Although the U.S. Supreme Court determined in *Meyer v. Nebraska* that parents have authority over their children, this authority is not without limit; it is, arguably, bounded by a consideration of a child’s interests and needs. But what are children’s interests, and what do they need? These are questions that every parent or guardian—and every careprovider who invokes “the best interest standard”—must engage. As Burt argues, “the way we think of children and their needs determines the sort of authority we think it is appropriate to exercise over them.”¹⁷ A similar view is supported by Brighthouse and Swift, who write, “parents’ rights over their children are justified by appeal to children’s rather than parents’ interests.”¹⁸

Arguably, parents have the responsibility to serve the interests of their child.¹⁹ Even as children are dependent upon their parents in a variety of ways, interpersonally and socially, and they are at different times and ways incapable of providing for and sustaining themselves, children enjoy basic rights as persons. Put simply, children have a voice. Following Rawls, “I have said that the minimum requirements defining moral personality refer to a capacity and not to the realization of it. A being that has this capacity, whether or not it is yet developed, is to receive the full protection of the principles of justice.”²⁰ The act of sorting out rights and responsibilities, prioritizing some and making others subordinate, is part and parcel of family dynamics, negotiations within a family, and within any healthy relationship. Yet, the Supreme Court opinion in *Meyer v. Nebraska* provides but a modest foundation, if that, to understand the boundaries and limits of parental authority and control.²¹ As Nussbaum observes, “social contract theorists have typically treated the family domain as off-limits to political justice.”²² She notes Rawls’s “tortuous engagement with this question” and argues that “the family should be treated as a sphere that is precious but not ‘private.’”²³

Looked at from another perspective, from what we will describe as parents’ best intentions, children both contain and suffer their parent’s

projections and defenses. Similarly, children are both the beneficiaries and the unwitting inheritors of their parents’ attention. In part, children cannot avoid making sense of their lives through understanding their parents’ projects for, and attitudes about, them: their relationship together. In several essential ways, it is a relationship unlike any other. Family members are intimately and epistemologically bound to one another—the family is the world.

Following Brighthouse and Swift, “the family is justified because it produces certain goods that would otherwise not be available. . . .”²⁴ Further, they write, “when we think about parents’ rights to shape values, we mainly have in mind the need to protect and respect the separateness of their children. The problem is to work out what kinds of value-shaping activities, and interactions with their children, parents may claim as rights. . . .”²⁵ However, they recognize, similarly to Ross, that “it is not plausible to expect parents always and single-mindedly to pursue their child’s best interests. Adults who parent will also have lives of their own to lead—they will have rights and duties that have nothing to do with the fact that they are parents—and it is quite appropriate for them sometimes to weigh their other interests, and their duties to others, against those of their children.”²⁶

Tacking for a moment, there are vexing questions of the legitimacy (and boundaries) of “engagement”—from suggestive nudges to force—within the family, in interpersonal relationships, by the state, or in shared decision making—to promote the “interests” of children, citizens, or patients. If “health careproviders should consider what is medically best,”²⁷ these recommendations may be proposed to be value neutral only within a very narrow, if not artificial, context. I will not argue the point here, but simply suggest that all “engagement” with patients, or interpersonally, has a normative component, intentional or unconscious—it is unavoidable.

We are challenged to understand and be clear about children’s fundamental interests and needs, their developing capacity, and the boundaries of their agency in exercising or claiming these interests. Broadly, as we know, this capability can be seen to follow a child’s age. But this is a limited generalization. Diagnostic and treatment discussions ought to be transparent and inclusive, following an assessment of the child’s capabilities, which should be individually assessed in every instance. As with adults,

a course of action, doing this rather than that, is arrived at “with the patient,” not “done to the patient.”

Such engagement should begin by talking meaningfully together with a child—anything less is an infringement of duty owed to the child. More complexly, we also need to understand how our hopes and expectations influence, sometimes unconsciously, our view of other’s interests—especially a child’s—and how we can get his or her interests wrong. To this point, I recall an anecdote from the psychoanalytic literature, describing an account offered by the mother or governess of several children. “I gave everything to these children,” she said. The psychoanalyst observed, “You could see this in the horror in the children’s eyes.”

What about children’s competence? As Brighthouse and Swift point out, “some sociologists question our ordinary assessments of children’s competence in making and acting on judgments for themselves about particular issues.”²⁸ On this point, they cite Priscilla Alderson’s work on children’s consent to surgery. Alderson, in her own work and citing the testimony of surgeons, “claims that children are frequently better decision makers than adults.”²⁹ As expected, an authentic assessment is dependent upon the right conversation and asking the right questions. Then, if children “ask an appropriate question leading on from the information, I think you can assume that they are able to communicate something they’ve taken in, and understood and can deal with.”³⁰ While I agree with the direction of this effort, assessing what a child understands and “can deal with” is always nuanced, and may be a highly charged endeavor. Done well, it will require time—and a particular set of skills.³¹

Certainly, we want children to become autonomous and self-directed adults. We want them to feel safe and to feel accepted and loved. We try to avoid situations where they are overwhelmed. We want them to flourish, to have the opportunity to develop their capabilities and talents: to become who they are.³² It is the responsibility of parents to provide for their child’s emotional and moral development; to provide a facilitating environment—an intimate and trusting relationship within which this maturation can occur: where a child can flourish.

However, as noted earlier, this relationship is not solely for the benefit of the child. Parents too have an opportunity to grow in new and unimagined ways through this bond. Good

parenting—as in every dynamic relationship, but more so here, given the parents’ responsibilities to and for their child—requires circumspection and self-reflection and, at its best, a recognition of, and resonance with, their child.

JUSTICE IN THE FAMILY?

In his account of the sequence of moral development, the “morality of authority,” Rawls writes, “I shall assume that the basic structure of a well-ordered society includes the family in some form, and therefore that children are at first subject to the legitimate authority of their parents.”³³ Interestingly, Rawls adds, “in the broader inquiry the institution of the family might be questioned, and other arrangements might indeed prove to be preferable.” Rawls’s suppositions on the capacity of children are constrained. He writes, “it is characteristic of the child’s situation that he is not in a position to assess the validity of the precepts and injunctions addressed to him by those in authority, in this case his parents. Indeed, the child lacks the concept of justification altogether, this being acquired much later. Therefore he cannot with reason doubt the propriety of parental injunctions.”³⁴ Rawls’s use of “the child” throughout this section of *A Theory of Justice* is as a blanket term, without differentiation, and spanning an unspecified time. Rawls’s sketch of a child’s moral development unfolds in a series of matter-of-fact highlights: He notes parents “first loving their children so that the child comes to love them in return.”³⁵ He writes, “Their love is displayed by their taking pleasure in his presence and supporting his sense of competence and self-esteem,”³⁶ and that their “supporting his sense of confidence and self-esteem . . . [is necessary] to affirm his sense of the worth of his own person.”³⁷

A significant limitation in Rawls’s discussion is that there is no explicit recognition or engagement of a child’s threshold and trajectory toward increasing independence. Instead, Rawls limits his engagement within a state of childhood dependence. He writes, “The child’s morality of authority is primitive because for the most part it consists of a collection of precepts, and he cannot comprehend the larger scheme of right and justice within which the rules addressed to him are justified.”³⁸ Again, there is a practical weakness here. Rawls is silent about when—and by what measure—children might

come to exercise their basic rights, or outside of their reliance on their parents, participate in or benefit from a discussion of their transition, at whatever pace. Rawls avers, laconically, that “the child’s morality of authority is temporary.”³⁹ Interestingly, Rawls writes at length to favor or to default to a child’s duty to obey. Indeed, Rawls writes, “The prized virtues are obedience, humility, and fidelity to authoritative persons; the leading vices are disobedience, self-will, and temerity.”⁴⁰ He continues, “We are to do what is expected without questioning, for not so to act expresses doubt and distrust, and a certain arrogance and tendency to suspicion.” This tone having been set, the save for Rawls is theoretical: “Clearly the morality of authority must be subordinate to the principles of right and justice which alone can determine when these extreme requirements, or analogous constraints, are justified.”⁴¹

Rawls may have provided a well-ordered account of key features in the parent-child relationship, and the operation of authority within the family, but it seems without question to be limited by its assumption of the child and childhood as static, the child as spoken about, rather than spoken with. What’s missing is recognition of the lived life of a child, in which personal development occurs, an account that contemplates a child’s emergent and ongoing emotional development. In *Political Liberalism*, Rawls recognizes one aspect of this earlier deficiency when he writes about matters that *A Theory of Justice* leaves aside: “Other major matters are omitted, for example, the justice of and in the family, though I do assume that in some form the family is just.”⁴²

Finally, if constrained parental autonomy is to successfully serve as a guidance principle and an intervention principle, and it is grounded on promoting and protecting a child’s primary good and needs, principles that Ross takes from Rawls, the next move for Ross is to identify and elaborate on just what these primary goods and needs are, and in what ranking (providing, with apologies, she has not done so elsewhere). This will require bridging theoretical and practical concerns, as Nussbaum has done, for example, in her ongoing development of capabilities.

Nussbaum writes, “For Rawls the theory of primary goods is closely linked to a Kantian conception of the person: primary goods are introduced as goods that people characterized by the two moral powers [moral and prudential

rationality] would want in order to pursue their life plans.” “The capabilities are not understood as instrumental to a life with human dignity: they are understood, instead, as ways of realizing a life with human dignity, in the different areas of life with which human beings typically engage.”⁴³

Imagining a way forward in theory and practice in pediatric decision making, a move furthering constrained parental autonomy and a preoccupation with the maturation and emotional needs of the child, I offer observations by D.W. Winnicott that may be touchstones for both parents and careproviders alike. Winnicott writes, “We discuss providing for the child—and for the child in the adult. The mature adult is in fact taking part in the providing. In other words, childhood is a progression from dependence to independence.” “We need to examine the changing needs of the child as dependence changes to independence.” “Providing for the child is therefore a matter of providing the environment that facilitates individual mental health and emotional development.”⁴⁴ The mother (and father) Winnicott writes, “knows about the infant’s needs *through her identification with the infant*.” As for careproviders, “we do have to organize ourselves so that in every case there is someone who has the time and inclination to know what the child needs.”⁴⁵

The conversation continues.

EPIGRAPH

J. Rawls, *A Theory of Justice* (Boston, Mass.: Belknap, Harvard University Press, 1999), 342.

NOTES

1. L.F. Ross, “Better than Best (Interest Standard) in Pediatric Decision Making,” in this issue of *The Journal of Clinical Ethics*, volume 30, number 3, Fall 2019; L.F. Ross, “In Further Defense of ‘Better than Best (Interest),’” in this issue of *The Journal of Clinical Ethics*, volume 30, number 3, Fall 2019.

2. A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1989).

3. Ross, “In Further Defense of ‘Better than Best,’” see note 1 above.

4. The use of the term *patients* includes surrogate decision makers.

5. On this question, see “Seminar with Bernard Williams,” *Ethical Perspectives* 6 (1999): 3-44, 252-3. Making this process more complex, as Ross notes—

with Freud—we are not always rational creatures. Ross, “In Further Defense,” see note 1 above. Both Rawls and Jürgen Habermas have, throughout their works, examined the principles of, and mechanism for, an engagement in reflective conversation with the presumption of certain minimum capacities and initial attitudes by all participants.

6. Ross, “Better than Best,” see note 1 above.

7. Buchanan and Brock, *Deciding for Others*, see note 2 above.

8. Ross, “In Further Defense of ‘Better than Best,’” see note 1 above.

9. Ibid.

10. Ibid.

11. A conversation for another time is the difference here between parents’ “responsibility” for their child and their “love” for their child.

12. Ross, “In Further Defense of ‘Better than Best,’” see note 1 above.

13. Ibid.

14. A. Gawande, “Annals of Medicine: Whose Body Is It, Anyway?” *New Yorker*, 4 October 1999. Atul Gawande writes that when he must make a medical decision for his daughter, he is unable to do so, and defers to her attending.

15. T. Westover, *Educated: A Memoir* (New York: Random House, 2018).

16. *Meyer v. Nebraska*, 262 U.S. 390 (1923).

17. S. Burt, “The Proper Scope of Parental Authority: Why We Don’t Owe Children ‘An Open Future,’” *Nomos* 44 (2003): 242-7.

18. H. Brighouse and A. Swift, *Family Values: The Ethics of Parent-Child Relationships* (Princeton, N.J.: Princeton University Press, 2014), 18.

19. J. Raz, *The Morality of Freedom* (Oxford, U.K.: Oxford University Press, 1996), 19.

20. J. Rawls, *A Theory of Justice* ((Boston, Mass.: Belknap, Harvard University Press, 1999), 342.

21. *Meyer v. Nebraska*, see note 16 above.

22. M.C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Cambridge, Mass.: Harvard University Press, 2007), 321.

23. Ibid.

24. Brighouse and Swift, *Family Values*, see note 18 above.

25. Ibid.

26. Ibid.

27. Ross, “In Further Defense of ‘Better than Best,’” see note 1 above.

28. Brighouse and Swift, *Family Values*, see note 18 above.

29. P. Alderson, *Choosing for Children: Parents’ Consent for Children* (Oxford, U.K.: Oxford University Press, 1990).

30. Ibid.

31. For an interesting engagement of questions for and against paternalism, as well as “children’s liberation” and the social construction of expected roles of children and adults, see Brighouse and Smith, *Family Values*, see note 18 above, chapter 3.

32. Pindar, “The Second Olympian Ode,” *The Olympian and Pythian Odes of Pindar*, ed. and trans. W.H. Race (Cambridge, Mass.: Harvard University Press, 1997). D. W. Winnicott argues that a child has an “inherited potential,” a “true self,” to be nurtured and respected, “a personal psychic reality and a personal body-scheme.” D.W. Winnicott, *The Maturation Process and the Facilitating Environment: Studies in the Theory of Emotional Development* (Madison, Wisc.: International Universities Press, 1965), p. 47.

33. Rawls, *A Theory of Justice*, see note 20 above, p. 405.

34. Ibid.

35. Ibid.

36. Ibid., 406.

37. Ibid.

38. Ibid., 408.

39. Ibid., 409.

40. Ibid., 408.

41. Ibid., 409.

42. J. Rawls, *Political Liberalism*, exp. (New York: Columbia University Press, 2005), xxix.

43. Nussbaum, *Frontiers*, see note 19 above, p. 161. For a fuller discussion of capabilities, see *ibid.*, pp. 155-223; and M.C. Nussbaum, *Women and Human Development: The Capabilities Approach* (New York, Cambridge University Press, 2012).

44. D.W. Winnicott, “Providing for the Child in Health and in Crisis,” in *The Maturation Process and the Facilitating Environment: Studies in the Theory of Emotional Development* (Madison, Wisc.: International Universities Press, 1965), 65-7.

45. Italics in the original. Winnicott’s summary adds:

I have attempted to relate the needs of children to those of babies, and to relate what we provide in child care to that which is provided naturally by parents (that is, unless they are too ill to respond to the call of parenthood). We need not think then of being too clever, or even of knowing all the complex theory of the emotional development of the individual. Rather, we need to give opportunity for the right kind of people to get to know the children themselves and so feel their needs. One could use the word “love” here, at risk of sounding sentimental.

D.W. Winnicott, “The Theory of the Parent-Infant Relationship,” in *The Maturation Process and the Facilitating Environment*, see note 44 above, p. 45.