Adolescent Medical Decisionmaking Rights: Reconciling Medicine and Law

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Dennis Lindberg came into his aunt’s care when he was in the 4th grade because his parents struggled with drug addiction and could not provide for him. At thirteen, he was baptized in his aunt’s faith as a Jehovah’s Witness. Just days after he turned fourteen, on November 6, he was diagnosed with acute lymphoblastic leukemia.

The prognosis was that Dennis had a 75% chance of cure with standard oncology treatment. Consistent with the requirements of his new faith, however, Dennis told his doctors, “I do not want to be treated if the requirement is that I would have to take a blood transfusion.” His aunt, whose custodial rights seem not to have included medical decisionmaking, was adamant that “[t]his is Dennis’s decision.”

The hospital social worker assigned to Dennis’s case assured his aunt that “having just turned 14, [he] could be considered mature enough to make his own decisions.” But hospital psychologists declined to evaluate Dennis’s maturity because they did “not have the tools for such an assessment.” Established hospital policy described the failure to provide a minor with necessary, life-saving care as medical neglect. Hospital ethicists advised that Dennis’s autonomy interests were outweighed by the benefits associated with treatment. And, standard oncology practice norms are that doctors should push back against minors’ lifesaving treatment refusals. Still, Dennis’s doctor agreed with his social worker and aunt, saying, “We owe respect to a 14-year-old [.]” In this view, he was supported by colleagues on staff and by hospital counsel.

A county judge got the case only at the eleventh hour, on an emergency motion filed by Dennis’s parents and Child Protective Services for a declaration of dependency and to compel the necessary transfusion. Although Dennis was degrading rapidly, his doctor testified that if a transfusion were ordered that day, Dennis still had a 70% chance of survival. The judge had no background in the applicable law and no time to research the issues; nevertheless, he denied the motion concluding, “It is time to do what Dennis has decided.” “Seven hours later, at 6 p.m., on Nov. 28, Dennis died.”

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1Isolde Raftery, When a 14-Year-Old Chooses to Die Because of Religion, Can Anyone Stop Him?, KUOW, (Nov. 4, 2015, 3:08 PM), https://www.kuow.org/stories/when-14-year-old-chooses-die-because-religion-can-anyone-stop-him [https://perma.cc/KWL4-L7SJ]. Some also come from our interviews, the medical record, and the transcript of the legal proceedings, all of which are in our files.
I. INTRODUCTION

Dennis Lindberg’s case is unusual in some respects, but surprisingly not as to the most provocative point that for some in the medical community, when children turn 14 or are perceived to be mature, they may be respected as autonomous decisionmakers whose voice either supersedes or is respected alongside that of the adults—including parents and doctors—who are otherwise responsible for their care.² Isolde Raftery, the principal reporter on the Lindberg story, has observed that the doctrine that allowed the result in Dennis’s case “has expanded” beyond religiously-motivated requests, to cover a broad range of important medical decisions, including “to allow trans teens to take hormones and girls to get abortions without telling their parents.”³ Some of this is consistent with law in a few jurisdictions which establishes “maturity” or a certain age as the basis for medical decisionmaking rights. Mostly, though, this trend on the ground flies in the face of well-established law on the books—including the constitutional law of parental rights and the web of related state family, torts, contracts, and maltreatment law that reflect the widely and deeply-held norm that parents speak for their minor children.

This Article describes this formal law and the contrary trend and makes recommendations for reforming both law and medicine accordingly.⁴ While there is a lot of writing in the medical and bioethics literatures on decisionmaking in pediatric settings,⁵ and a few articles in the legal literature on aspects and applications of the mature minor rule,⁶ this Article looks at the combined literatures thoroughly to examine adolescent medical decisionmaking rights in general medical settings. Specifically, it describes and compares formal decisionmaking law to everyday practice in this area, and attempts to sort out the implications of the existing dichotomy for both professions, including for their practical and aspirational norms. Finally, it is the first in the legal literature to introduce Dennis Lindberg’s extraordinary case, which we feature as an illustration of adults abdicating their traditional legal responsibilities to children, but which raises numerous, important legal and political questions that call for additional attention and perspectives.

Part II describes the “law on the books,” including the federal constitutional law rule that parents make their children’s medical decisions and its public health and

²Id.

³Id. Adolescent girls already have a constitutional right to bypass their parents if this is necessary to obtain an abortion; however, this bypass right generally involves judicial intervention, i.e., the medical decisionmaking stick is transferred from parents to the state which is represented by another adult who may then authorize the abortion itself or else the girl to make her own decision. See discussion infra Part II.C (summarizing the doctrine). Dennis Lindberg’s case is analyzed in additional detail throughout this Article.

⁴This Article follows from a shorter, differently-directed piece we wrote and published in the medical literature entitled The Legal Authority of Mature Minors to Consent to General Medical Decisions. Doriane L. Coleman & Phillip M. Rosoff, The Legal Authority of Mature Minors to Consent to General Medical Decisions, 131 PEDIATRICS 786 (2013). See infra notes 94-96 and accompanying text describing our different objectives for that piece.


individual health and status exceptions. It then focuses on the individual health exception that is the mature minor rule. The genesis of the mature minor rule in the United States Supreme Court’s adolescent reproductive autonomy cases and its alternative sources in the common law of responsibility for torts and crimes are discussed in this context. This part concludes with an up-to-date survey of the jurisdictions that have adopted and retained the mature minor rule in some form. The survey shows that as of 2021, it arguably exists in only ten jurisdictions, and there is no apparent trend toward further adoptions.

Part III provides a window into the “law on the ground” and the apparent trend in that context of allowing adolescents important decisionmaking rights. Our goal was to understand the sources and contours of this phenomenon, not its breadth or pervasiveness; thus, based on a literature review, interviews, and an evaluation of changing guidance from the American Academy of Pediatrics (“AAP”), our research and analysis indicate that adolescent medical decisionmaking rights tend to arise as a result of three different, often overlapping phenomena: (1) mistakes and nullifications of law, (2) patient non-adherence, and (3) evolving medical culture, including evolving medical ethics norms and the development of shared decisionmaking models. It is especially significant that adolescents have been afforded de facto medical decisionmaking rights in life and death situations where their voice is least likely to be legally relevant. Further, these rights are afforded in circumstances and ways that suggest medicine’s complicated relationship with the law’s fiduciary model of parental authority.

Part IV returns to Dennis Lindberg’s case, detailing how these three phenomena—mistakes and nullifications of law, concerns about patient non-adherence, and evolving medical culture—operated to afford Dennis decisionmaking rights he did not have in formal law at the same time they deprived him and his parents of explicit legal protections. Our legal analysis of his case complements existing work in the medical and bioethics literatures and in the popular press. Part V uses the analyses in Parts III and IV to develop recommendations for medicine and law. We suggest that the medical community develop a better understanding of the outer bounds of its decisionmaking authority as well as of the merits of maintaining institutional rules that curtail the discretion of individual physicians and provider groups to operate outside the boundaries of widely-held medical and social norms. And we suggest that law needs to do more to translate and disseminate its inflexible rules for those in medicine who are governed by their terms, including to distinguish law from medical ethics, as well as to notice and process the implicit critique from medicine about how formal law conceives of and treats adolescent patients. Because this critique is consistent with developments and commitments in related areas, it suggests the kind of normative shift that can be a foundation for law reform.

The Article concludes with reflections on how these recommendations might guide the development of a new model for adolescent medical decisionmaking that reconciles the law and the norms that animate its terms with medicine’s particular professional and ethical commitments to patient care. As Isolde Raftery noted, the phenomena that drove the result in the Lindberg case have had effects well beyond his particular

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7 See infra note 133 (further detailing our objectives and the remaining, unanswered questions).
factors, to include adolescents in a range of circumstances not formally covered by law. From adolescents seeking vaccinations against viral diseases to teens needing reproductive health care to trans youth seeking gender affirming care, these circumstances should be brought into the light and regulated on the books so that adolescents are afforded both medical decisionmaking rights and protections consistent with their evolving capacities.

II. THE LAW ON THE BOOKS

The “law on the books” refers to formal law as it is found in federal and state constitutional, statutory, and regulatory law, as well as in the decisions of the state and federal courts. The scope, details, and limits of adolescent medical decisionmaking rights are the negative of their parents’ medical decisionmaking rights, which are found in federal constitutional law and in state common and statutory law. Focusing on its application to medical decisionmaking, this Part of the Article first describes the constitutional doctrine of parental autonomy and the web of state law that both reflects and is reflected in that doctrine. It then summarizes the standard public and individual health exceptions before turning to a close examination of the mature minor rule. Our principal goal is to make clear that the applicable law is not only to be found in state cases and statutes, but also in federal law through which state law must be read; and to provide the reader with the details of that integrated legal scheme.

A. Parental Rights

It is long and well established in federal constitutional law that among the bundle of sticks that make up parental rights is the right of a parent to make their child’s medical decisions; this right supersedes rights and interests others may assert, including those of the child. Notably, in law a “child” is any person who has not reached the age of legal majority—this includes adolescents. The relevant line is between minors and adults. To the extent that parental rights are limited, it is only by constitutionally valid exceptions.

This law, also known as the doctrine of parental autonomy, is grounded in the First and Fourteenth Amendments, including in the Speech, Religion, Association, and Due Process Clauses. It recognizes that parents have the right to raise their children as they see fit, including to make important decisions for them until they reach the age of majority. In addition to medical decisions, the doctrine of parental autonomy also affords parents plenary rights related to children’s education, religion, and other associations. As the Court explained in *Prince v. Massachusetts*, “[it] is cardinal with us that the custody, care, and...
nurture of the child reside first with the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder."

We are mostly familiar with the practical implications of this doctrine when parents make important decisions about their children’s lives, for example, choosing: where their children will go to school, whether they will be homeschooled, whether they will be raised with a particular religion, and who they will spend time with. But the decisionmaking right also includes the minutiae: whether children have access to the internet or play football, and so on. While the children themselves as well as outsiders may judge these choices, they are within the parental prerogative. The doctrine is rationalized in three ways, as follows.

First, the law holds that children, including adolescents, are not competent decisionmakers. They are held to lack the combination of cognitive capacity and life experience necessary to exercise sound or wise judgment. In law, cognitive capacity (in the sense of neural processing power) is an insufficient basis upon which to rest decisionmaking authority. Adolescence is generally viewed as a period of growth and development, during which the child is preparing for the age of majority—they are adults-in-training. Once they reach the age of majority, unless there is reason to believe that a particular individual lacks capacity to the point where they should be declared incompetent, the presumption shifts and the law holds that individuals have the capacity and life experience they lacked in childhood. While the age of majority—almost always eighteen—is acknowledged to be an arbitrary line as to any given individual, it is respected for practical reasons. It is the point at which the law formally recognizes that the child has matured sufficiently enough to can move into their parents’ shoes and become a rights holder themselves, including an autonomous decisionmaker. Whatever informal arrangements parents and children may make beforehand or afterward, the formal handoff of physical custody and decisionmaking rights is at that age.

Second, before children reach the age of majority, the law holds that parents are their children’s best proxy decisionmakers, or their “first best caretakers,” because, among the adults and institutions that might be designated as proxies, parents are most likely to act in their best interests. This is because they are most likely among this broader group to love their children, to be focused on their survival and success, and to know the facts necessary to make good decisions.

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14Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (describing the broad range of parental decisionmaking rights including about religion); see also, e.g., Meyer v. Nebraska, 262 U.S. 390, 400-01 (1923) (holding that the state may not override a parentally chosen private school curriculum); Parham v. J.R., 442 U.S. 584, 604 (1979) (finding that parents generally are presumed to have plenary power over medical decisions for their minor children); Troxel v. Granville, 530 U.S. 57, 57 (2000) (holding that the state cannot force nonparental visitation right over the objections of a child’s custodial parent).

15See, e.g., Ginsberg v. New York, 390 U.S. 629, 635-37 (1968) (discussing the evolving capacities of the child and their relevance to legal decisionmaking authority in the context of a case about access to pornography). The law’s longstanding sense of adolescent decisionmaking capacity is complemented by the results of research in the neurological and social sciences. See, e.g., Grace Icenogle, et al., Adolescents’ Cognitive Capacity Reaches Adult Levels Prior to Their Psychosocial Maturity: Evidence for a "Maturity Map" in a Multinational, Cross-sectional Sample, 43 L. & Hum. Behav. 69, 79 (2019); Petronella Grootens-Wiegers, et al., Medical Decision-making in Children and Adolescents: Developmental and Neuroscientific Aspects, 17 BMC Pediatrics 1, 6-7 (2017).

16Elizabeth S. Scott, The Legal Construction of Adolescence, 29 Hofstra L. Rev. 547, 587 (2000) (discussing the line-drawing issue in the context of an analysis of juvenile justice issues); see also Stanford v. Kentucky, 492 U.S. 361, 396 (1989) (Brennan, J., dissenting) (recognizing that “age 18 is a necessarily arbitrary social choice as a point at which to acknowledge a person’s maturity and responsibility”).

17Coleman et al., Where and How to Draw the Line Between Reasonable Corporal Punishment and Abuse, supra note 11, at 111.

18Parham, 442 U.S. at 602.
These two rationales are best articulated in the medical setting in the Court’s 1979 decision in *Parham v. J.R.*:

The law’s concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience, and capacity for judgment required for making life’s difficult decisions. More important, historically it has recognized that natural bonds of affection lead parents to act in the best interests of their children…. Most children, even in adolescence, simply are not able to make sound judgments concerning many decisions, including their need for medical care or treatment. Parents can and must make those judgments…. The fact that a child may balk at hospitalization or complain about a parental refusal to provide cosmetic surgery does not diminish the parents’ authority to decide what is best for the child.19

Notably, when the law speaks of “best interests” in this context, it does not mean that parents must select the “best” option from an outsider’s perspective focusing only on the child herself.20 Indeed, the law expressly rejects the notion that parents should have their proxy decisionmaking rights revoked or replaced on the basis that someone else would make a different or objectively better decision.21 Rather “best interests” simply means falling within the broad range of reasonable parenting allowed in a diverse society.22

Third, so long as parental choices fall within this broad range,23 parental rights are justified on a rights and responsibilities model: rights are granted to parents in exchange for the responsibility the law imposes on them to provide for their children’s necessities. As the Pennsylvania Supreme Court explained in its 2000 decision in *Commonwealth v. Nixon*, in which it specifically rejected a parent’s claim that their sixteen-year-old was mature enough to exercise the autonomous choice to forego medical treatment,

> by mandating primary responsibility for the child’s wellbeing upon the parents, the legislature has not only acted toward fulfilling its role as *pares patriae*, but also has recognized that parents have a duty to provide for their children which accompanies the right to raise children with minimal state encroachment.24

Citing the Court’s decision in *Prince*, the *Nixon* court emphasized that this rights and responsibilities model reflects an exchange between the child’s sovereign “parent”

19Id. at 602-04.
21Reno v. Flores, 507 U.S. 292, 304 (1993) (“So long as certain minimum requirements of child care are met, the interests of the child may be subordinated to the interests of other children, or indeed even to the interests of the parents … themselves.”).
23The caveat is “so long as parental rights fall within this broad range.” No constitutional right is absolute and parental autonomy is no exception. *Parham*, 442 U.S. at 604.
24*Commonwealth v. Nixon*, 761 A.2d 1151, 1153 (Pa. 2000). The Pennsylvania Supreme Court also noted that “[b]y placing an affirmative duty upon parents and guardians, the legislature has acted to partially fulfill the Commonwealth’s duty to care for those individuals who for one reason or another are legally incapacitated. This duty to care for those who are legally incapacitated arose under the sovereign’s duty of *pares patriae*, and following independence was assumed by individual states.” *Id.*
(the government) and natural parent (the legal caretaker) that does not permit the handoff of responsibility, even to an older child. This responsibility is held in partnership between parents and the state. The responsibility extends until children reach the age of majority—again, regardless of any individual child’s capacities and experience. As a result, so too do parental rights.

The doctrine of parental autonomy is the law of the land not only because the Supremacy Clause establishes this as a formal matter, but also—as Commonwealth v. Nixon suggests—because its underlying commitments pervade related areas of both federal and state law. This includes the clauses of the federal Constitution discussed above as well as state family, tort, contract, and maltreatment law. The story in this area is normally one of alignment because there is broad and deep societal commitment to the doctrine across the political spectrum. As the Alabama Supreme Court explained in a 1990 decision involving a 17-year-old girl,

[in such matters as deciding on the need for surgical or hospital treatment, the wishes of young children are not consulted, nor their consent asked when they are old enough to give expression thereto. The will of the parents is controlling, except in those extreme instances where the state takes over to rescue the child from parental neglect or to save its life. Similarly, the right to grant or refuse a medical examination of a child belongs not to the child but to the parents.]

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25 Id.; see also Ginsberg v. New York, 390 U.S. 629, 639 (1968) (“[C]onstitutional interpretation has consistently recognized that the parents’ claim to authority in their own household to direct the rearing of their children is basic in the structure of our society.”); Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (“It is cardinal with us that the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder.”); Pierce v. Soc’y of Sisters, 268 U.S. 510, 535 (1925) (“The child is not the mere creature of the State; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations.”).

26 Coleman, Testing the Boundaries of Family Privacy, supra note 10, at 1294 (“Within this scheme, the state and its twin parents patriae and police power roles is viewed mostly as a ‘junior partner,’ assisting the parent to raise her child up to be a healthy and responsible member of society, but also as a last check on the parent who might violate her fiduciary obligations by causing harm to the child that transgresses the boundaries of family privacy.”).

27 It remains an abiding interest that parents are endowed with such power over the fates of their children. This interest appears to stem from the distinction between rights and capacities, and the assumption that the latter properly informs the former. See Hugh LaFollette, Licensing Parents, 9 PHIL. & PUB. AFFS. 182, 186-88 (1980); Philip M. Rosoff, Licensing Surrogate Decision-Makers, 29 HEALTHCARE ETHICS COMM. F. 145, 150-51 (2017).

28 Directly conflicting law may exist on the books and be used by unsuspecting or strategic actors so that it effectively develops a life of its own, but if it is subject to challenge it will be preempted. U.S. CONST. art. VI.

29 The anti-vaccination and home schooling movements, which are populated by parents of different parties and ideological persuasions, are illustrative of the largely apolitical nature of this commitment. See, e.g., Charles McCoy, Anti-Vaccination Beliefs Don’t Follow the Usual Political Polarization, CONVERSATION (Aug. 23, 2017, 8:34 PM), https://theconversation.com/anti-vaccination-beliefs-dont-follow-the-usual-political-polarization-81001; Kerry McDonald, The Rise of Homeschooling was Broad and Bipartisan, FOUNDRY FOR ECON. EDUC. (Apr. 25, 2017), https://fee.org/articles/the-rise-of-homeschooling-was-broad-and-bipartisan; Isolde Raftery, Seattle Schools with the Most Unvaccinated Students are in Wealthier Neighborhoods, KUOW (Oct. 13, 2014, 7:39 AM), https://kuow.org/stories/seattle-schools-most-unvaccinated-students-are-wealthier-neighborhoods; Eula Biss, On Immunity: An Inoculation (2014); Coleman & Rosoff, supra note 4, at 788-89; Karen Houppert, Who’s Afraid of Gardasil?, NATION (March 8, 2007), https://www.thenation.com/article/archive/whos-afraid-gardasil/; R.J.D. v. Vaughan Clinic, 572 So. 2d 1225, 1227-28 (Ala. 1990) (emphasis omitted). As we note above the line and at note 29 immediately above, the fact that this decision is out of the Alabama Supreme Court should not be mistaken as any indication that parental rights are the particular province of conservatives. Conservatives, libertarians, liberals, and progressives—basically most parents in this society—feel strongly about protecting their autonomy.
Thus, family law conceives of parental custody using some version of the bundle of sticks metaphor from property law, and rests those sticks with the child’s parents; if the parents split, the law parses custodial rights between parents according to the child’s best interests.31 “Best interests” in this context is sometimes characterized as the least detrimental alternative with some decisions going to the mother (e.g., choice of religious upbringing), others to the father (e.g., choice of education), and those capable of being jointly administered to both (e.g., physical custody and medical decisionmaking).32 A parent who violates the terms and extent of their allocated rights is subject to sanctions.33

Tort law generally declines to define reasonable parenting,34 and it describes any harmful or offensive touching of a child that hasn’t been authorized by a parent or guardian as a battery.35 As is the case with adults, an unauthorized medical touching in particular is considered offensive in law even if it is the standard of care.36 Absent an established exception, therefore, a doctor who touches a child without lawful parental consent may be liable in battery.

Traditional contract law, though in flux, generally does not recognize deals made by children as legally binding.37 Further, such deals are binding on their parents and guardians only if they are for necessities the latter would not otherwise have supplied themselves.38 As a result, services to a child that are not requested or ratified by a parent may go unremunerated.39

Maltreatment law defines neglect as the failure to provide adequately for the child’s necessaries, including necessary medical care; and it defines abuse as any unnecessary physical intrusion that risks or causes important harm.40 However state law reads or is interpreted on the ground, this definition is federally prescribed.41 Consistent with the constitutional standard, mere adequacy is all that is required—it is presumed that state intervention in the family is not in the child’s best interests unless the child is at risk of
serious harm. While this adequacy rule is generous to parents and thus protective of their rights, it is also undoubtedly a limitation designed to set the outer boundaries of reasonable parenting—again, no constitutional right is absolute. Finally, children are children in maltreatment law until they reach the age of majority because the law recognizes their vulnerability; they cannot waive their interests in this protection or absolve adults of abuse or neglect.

Taken together, these different branches of state law create a comprehensive web of protections for parental decisionmaking rights, including medical decisionmaking rights. This web also defines the outermost boundaries of parental decisionmaking authority. Importantly, unlike federal constitutional law whose protections may only apply to state action, federal and state statutory and regulatory law applies to—and as against—both governmental and private actors, including the children themselves. Thus, public hospitals and their physicians are bound by both federal and state law; and private hospitals and physicians may be conditionally bound by federal law (e.g., if this is a condition of federal funding), and are always bound by applicable state law. As always, where federal law is inconsistent with state law, the former prevails.

B. General Exceptions to Parental Medical Decisionmaking Rights

No constitutional right is absolute. We live in a legal and political culture that is characterized by a system of ordered liberty. Thus, like all other constitutional rights, parental rights are subject to regulation and exceptions. Parents may lose or have their medical decisionmaking authority curtailed in a number of circumstances that have either already met or presumably would pass constitutional muster.

Aside from custody and maltreatment law which shift decisionmaking authority among adults, there are a number of exceptions which shift decisionmaking authority from parents to their children. The latter fall into two categories:

The first is a set of public health exceptions. Generally statutory and thus broadly applicable, these exceptions are grounded in society’s compelling interest in ensuring that children are treated for infectious diseases and conditions that affect the general welfare. Depending on the jurisdiction, they may include provisions for children to seek and obtain treatment on their own for drug and alcohol addiction, sexually transmitted infections, and mental health. Exceptions in this category are sometimes conditioned on a child’s age,
but consistent with their basis in protecting the public rather than individual health, they mostly apply unconditionally.50

The second is a set of individual health and status exceptions. Both statutory and common law based, so their applicability is variable, these are motivated by society’s compelling interest in assuring that minors who are on their own or whose parents are unavailable or unwilling to consent to necessary care are still able to be treated.51 Depending on the jurisdiction, they may include minors who seek emergency care, are emancipated, or who seek pregnancy-related care.52 Although this is not always the case, consistent with their terms, exceptions in this category are most likely to be conditioned on a child’s age, cognitive capacity, or maturity.53

C. The Mature Minor Rule

The mature minor rule is categorized as an individual health and status exception. In modern law, the notion that mature minors either take or share their parents’ medical decisionmaking rights generally derives from the Court’s adolescent reproductive autonomy decisions.54 These decisions establish that pregnant minors who want an abortion, do not want to involve their parents, and can prove their maturity to an alternate (to their parents) adult decisionmaker must be allowed to make the decision themselves.55

The factors typically considered by courts as indicia of maturity are consistent with the law’s focus on the combination of cognitive capacity and life experience. Thus, they typically include “age, level of education, success in school, engagement in work or other extracurricular activities, disciplinary issues, and future plans.”56 Case outcomes are consistent with the law’s general sense that even older adolescents may lack the necessary combination of cognitive capacity and life experience, as courts often find against minors who seek declarations of maturity.57 Abortion is legally available to immature pregnant
minors, but it requires either the involvement of their parents or an alternate adult proxy (e.g., a judge) who can evaluate whether the procedure is in the minor’s best interests.58

The prevailing rationale for the reproductive autonomy cases is that the decision whether to conceive and bring a child to term is so uniquely impacting and so time sensitive that it is sui generis among medical treatment decisions, thus justifying a departure from the parental decisionmaking right described in Parham.59 As the Court explained in Bellotti v. Baird,

[t]he abortion decision differs in important ways from other decisions that may be made during minority…. There are few situations in which denying a minor the right to make an important decision will have consequences so grave and indelible…. Although … deference to parents may be permissible with respect to other choices facing a minor, the unique nature and consequences of abortion make it inappropriate ’to give a third party an absolute, and possibly arbitrary, veto over the decision of the physician and his patient to terminate the patient’s pregnancy, regardless of the reason for withholding the consent."60

Consistent with this rationale and with the doctrine of parental rights generally, in the scheme of federal law, adolescent reproductive autonomy, which also includes the right to obtain contraceptives,61 is the only application of the mature minor exception. In other words, to date, the parental right to make children’s medical decisions, affirmed in Parham, remains complete except as to contraception and abortion.

Nevertheless, some states have taken the position that the concept underlying the reproductive autonomy cases may apply more broadly to cover other instances where individual minors can demonstrate maturity to a relevant third-party adult. They argue that if the Court allows adolescents to prove their maturity on a case-by-case basis for reproductive decisionmaking, other adolescents should be able to do the same in general medical settings where the decision is equally or even less important.62 The constitutionality of such a general extension has not been tested. However, given the strength of parental rights, their basis in more than children’s immaturity, and the particularity with which the reproductive autonomy exception was developed, especially its sui generis characterization,63 it is difficult to imagine that it would be sustained.


58Bellotti, 443 U.S. at 643-44.

59Parham and Bellotti were both decided in 1979, Parham on June 20, and Bellotti on July 2. Bellotti, 443 U.S. at 622; Parham v J.R., 442 U.S. 584, 584 (1979).

60Bellotti, 443 U.S. at 642-43.


62See, e.g., Illinois v. E.G. (In re E.G.), 549 N.E.2d 322, 324, 326-327 (Ill. 1989) (deciding that a “mature 17-year-old” had a right to refuse medical treatment such as a blood transfusion even though it would likely result in death).

63The Court’s adolescent reproductive autonomy cases emphasize the uniqueness of the abortion decision in the life of the pregnant adolescent in terms that make clear its intent closely to circumscribe the doctrine; that Bellotti and Parham were issued just days apart so that they can be read in tandem makes this especially clear. See supra note 59 (setting out the Parham and Bellotti decision dates); Hodgson v. Minnesota, 497 U.S. 417 (1990).
It is probably because of this, and an aversion to the abortion exception in particular, that some states have sought to avoid the bright line rule that is the age of majority on alternative common law grounds—for example, by analogy to the Rule of Sevens. This legal state of affairs is particularly likely to be the strategy in more conservative political cultures. Where it still exists, the Rule of Sevens provides that children between the ages of seven and fourteen are presumed to be incapable of legal responsibility for their torts and crimes, but that children between the ages of fourteen and twenty-one (the old age of majority) are presumed to be capable of such responsibility. Both presumptions are rebuttable by evidence that a particular child either has or lacks relevant capacity. Like the standard for maturity, the evidence required in this context goes to the child’s age, intelligence, and experience.

Although the rationales underlying the treatment of minors who commit torts and crimes are not the same as those supporting adolescent medical decisionmaking rights, the Rule of Sevens has a general appeal. In replacing the bright line age of majority rule with three lines (seven, fourteen, and eighteen or twenty-one), the rule retains the efficiencies inherent in clear lines but reduces the arbitrariness inherent in any single cutoff. Moreover, because the lines are rebuttable presumptions rather than categorical, they provide flexibility when individualized assessments of capacity suggest their inapplicability to a particular child.

As of the date of this writing, only ten states have adopted some version of the mature minor exception to the general requirement of parental consent: Alabama, Arkansas, Illinois, Idaho, Kansas, Montana, Oregon, South Carolina, Tennessee, and West Virginia.

Two states condition the minor’s decisionmaking rights on the capacity for informed consent: Arkansas and Idaho. This requires establishing that the patient understands the risks and benefits of proposed treatment and voluntarily accepts or refuses the same. These states do not require a separate finding of maturity, although a version of the notion is embedded at least in the “understanding (or “knowing”)” prong of the informed consent standard.

Four states condition the minor’s rights on the capacity for informed consent and maturity: Illinois, Tennessee, West Virginia, and Kansas. This requires establishing

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64 See, e.g., Cardwell v. Bechtol, 724 S.W.2d 739, 749 (Tenn. 1987) (affirming the Rule of Sevens).
65 Id.
66 See infra note 76 (explaining our decision not to include Pennsylvania on this list); supra note 51 (explaining the different ways the individual status exceptions including the mature minor rule might be sorted).
70 See supra note 35 and accompanying text.
71 In re E.G., 549 N.E.2d at 327-28.
72 Cardwell, 724 S.W.2d at 748; Tenn. Att’y Gen., Opinion Letter No. 03-087, Medical Treatment of Certain Prisoners in County Facilities (July 10, 2003).
both that the patient understands the risks and benefits of proposed treatment and voluntarily accepts or refuses the same, and that they satisfy the state’s indicia of maturity. In other words, cognitive capacity alone is insufficient, life experience and the resulting capacity for sound judgment are also required.\(^{75}\)

Four more states use age and/or schooling as a proxy for capacity and maturity:\(^{76}\) Alabama (14),\(^{77}\) Oregon (15),\(^{78}\) South Carolina (16),\(^{79}\) and Montana (high school graduate).\(^{80}\) These are objective criteria that do not require providers to exercise any judgment themselves about their patient’s maturity or cognitive capacity.

Importantly, where it exists in one of these permutations, the mature minor rule does not appear to be useful to ratify a minor’s treatment refusals in circumstances where the treatment is necessary to avoid serious bodily harm or death. That is, despite one widely distributed decision out of Illinois, In re E.G.,\(^{81}\) the rule appears to have developed primarily to allow physicians lawfully to treat older minors who, for various reasons, seek treatment on their own. The law’s commitment to assuring all children receive necessary treatment, which describes the failure to do so as medical neglect, is generally unaffected by the mature minor rule.\(^{82}\)

Consistent with the legal and political strength of the general rule that parents make their children’s medical decisions, this line-up has remained the same for years.\(^{83}\) There is no modern or recent trend suggesting that more states are inclined to adopt some form of a mature minor exception. Thus, in 40 out of 50 jurisdictions, while there may be other grounds permitting children and their physicians to proceed...
without parental consent, there is no mature minor exception outside of the abortion context.\textsuperscript{84}

Some practitioners and commentators have doubted this point, suggesting that the mature minor rule may exist in a jurisdiction in which it has not yet been discussed.\textsuperscript{85} If this is a description of the law on the books, they misunderstand that law. As we explain above, the default in every jurisdiction is that parents have the right to make their children’s medical decisions.\textsuperscript{86} Therefore, it is unlawful to treat a child in the absence of parental authority unless an established exception transfers that authority to someone else. No discussion means that there is no established exception. This is why, for example, the federal government had to require that states develop express exemptions to child neglect law in order to authorize religiously-motivated parents to refuse to consent to certain medical treatments.\textsuperscript{87}

Creating a new exception is always a possibility through the courts or the legislature, and scholars periodically argue for new adoptions of expanded versions of the mature minor rule in particular.\textsuperscript{88} Currently, this is especially prevalent among those who are interested in increasing access to medicine for trans youth with dissenting parents.\textsuperscript{89} But unless and until this effort is successful, those who operate as though an exception exists do so in derogation of formal law.\textsuperscript{90}

Finally, as already noted, public hospitals are state actors and so are bound to the higher authority of the U.S. Constitution, even in jurisdictions with a state law-based mature minor rule.\textsuperscript{91} That authority makes clear that fit parents have medical decision-making rights through the period of their children’s minority, with the exception of the abortion decision which may be made by a mature minor once their maturity is properly established.\textsuperscript{92} Fitness is a legal standard, not a personal point of view. The mature minor doctrine in constitutional law is not broader than this: There is no Rule of Sevens and so fourteen is not a magic age; and there is no exception for minors who can meet the informed consent standard.

\textsuperscript{84}See supra note 66, and accompanying text.

\textsuperscript{85}We first discussed this point in our 2013 article in Pediatrics. See Coleman & Rosoff, supra note 4 at 787 (focusing on medical commentators). In conducting our research for this article, we encountered additional examples of this phenomenon, which we discuss further below.

\textsuperscript{86}See supra Part II.A (summarizing the combination of federal constitutional and state common and statutory law that establishes this default).

\textsuperscript{87}See Coleman, Religiously-Motivated Medical Neglect, supra note 41, at 378.


\textsuperscript{90}See, e.g., Cardwell v. Bechtol, 724 S.W.2d 739 (Tenn. 1987).

\textsuperscript{91}Parents of emancipated adolescents are not considered parents in law, i.e., emancipation exists as a doctrine in part to dissociate parents from their original bundle of rights. This includes their medical decision-making rights. As a result, a medical provider faced with an emancipated minor is free to proceed on the basis of the minor’s consent. The California emancipation scheme is illustrative. \textit{Emancipation, CAL. CTS.}, https://www.courts.ca.gov/selfhelp-emancipation.htm?rdeLocaleAttr=en [https://perma.cc/N295-B759] (last visited Nov. 14, 2021).
III. THE LAW ON THE GROUND

The “law on the ground” refers to the rules that operate in fact, whether they are consistent with formal law or not.93 We first distinguished the law on the books from the law on the ground in an article titled The Legal Authority of Mature Minors to Consent to General Medical Treatment.94 The article began from the premise that because some in the medical community misunderstood the contours and applicability of the mature minor doctrine, a thorough survey and explanation of the law across the jurisdictions would be helpful.95

During the peer review process, one reviewer insisted that we had “raised a ‘strawman argument’ [because] there is no practicing pediatrician holding [the] belief”96 that mature minors have the right to make general medical decisions.96 We agreed that no practicing pediatrician should hold this belief outside of those few states that have some form of a mature minor rule. But he was wrong about his colleagues and thus about adolescent medical decisionmaking rights. Indeed, our motivation for writing in 2013, and again today, is that we continue to encounter important examples to the contrary.

Our focus in that first piece was to make this point and to correct the persistent misunderstanding of formal law by accurately describing it. We have two goals here: First, we aim to provide a description of the etiology, history, and resilience of the misunderstanding. Second, we explore the nature and scope of the de facto rights that flow to adolescents as a result.

A. THE HISTORY OF ADOLESCENT MEDICAL DECISIONMAKING RIGHTS

The history of adolescents’ de facto medical decisionmaking rights reflects the evolving relationships between physician and patient autonomy, and between medical ethics and law. Our current sense of the nature and extent of those rights is bound up in this history, even as important recent touchpoints also exist. Over time, it is likely that adolescents have had medical decisionmaking rights whenever non-parental adults in a position to facilitate them have allowed their exercise and parents have lacked the will or the cultural capital necessary to enforce their own.

Thus, through the early to mid-1900s, providers of medical services exercised their autonomy in making medical decisions for their patients, including for their pediatric patients. In an informal precursor to the “shared decisionmaking” models that proliferate in this period, they likely did so with variable respect for their patients’ wishes.97 Physician
“autonomy” has been recharacterized as “paternalism” and mostly rejected on that basis, but the right of doctors to practice in a way that respects their professional priors remains salient in significant aspects of the law.\footnote{For example, medical malpractice law and the law of informed consent, including of the associated right to refuse lifesaving medical treatment, all continue to involve the balancing of patients’ autonomy interests against physicians’ professional and ethical norms, as well as their practical concerns.} Formal law in this same period had staked out a strong claim to parental autonomy\footnote{See supra Part II.A.} and against medical paternalism;\footnote{See Schoenedorff v. Society of New York Hospital, 105 N.E. 92 (1914) (requiring consent for medical procedures); Bonner v. Moran, 126 F.2d 121, 122-23 (D.C. Cir. 1941) (discussing that parental consent is required for a doctor’s operation on a child); Salgo v. Leland Stanford University Hospital, 317 P.2d 170 (Cal. Dist. Ct. App. 1957) (requiring informed consent for medical procedures).} on the ground, however, as we have just noted, parental rights were more theoretical than real for parents who lack the will or capital to intervene.

Beginning in the period following World War II, the bioethics and medical ethics movements sought to turn the promises embedded in this formal law into real patient rights. Specifically, paternalistic exercises of physician autonomy were strongly discouraged in favor of patient autonomy; proxy consent was required when patients were unavailable or incompetent; patients were discouraged from appointing their physicians as proxies; and parents were understood to stand in the shoes of their children through the period of their minority.\footnote{While formally regarded as separate domains, clinical care and clinical research have served as the overlapping bases for the evolution of the role of the patient (or authorized surrogate) in medical decision making. The revelations of the Nuremburg war crimes trials, and particularly the gruesome and horrifying disclosure of the activities of the Nazi doctors’ “experiments” with prisoners in concentration camps demonstrated a renewed need for further empowering the patient (or research subject) in the physician/researcher-patient/subject relationship dyad. See Robert Jay Lifton, THE NAZI DOCTORS: MEDICAL KILLING AND THE PSYCHOLOGY OF GENOCIDE 4, 269 (Basic Books 2000) (1986). While the role of informed consent was at least legally animated by the Salgo case, the effect of Nuremberg and the resulting ethics codes (and the related Universal Declaration of Human Rights in 1947) on and progress in the conduct of human clinical research was relatively modest until the exposure of the Tuskegee syphilis study and its systematic and institutionalized deprivation of basic human rights that was not substantively different from concentration camp experimentation. See Susan M. Reverby, EXAMINING TUSKEGEE: THE INFAMOUS SYPHILIS STUDY AND ITS LEGACY 192, 193 (Waldo E. Martin Jr. & Patricia Sullivan eds., Univ. of N.C. Press 2009). The publication of the Belmont Report with its recommendations and outline of the core tenets of what have effectively become the basis for a praxis of Western biomedical ethics, especially in the United States and Canada, have driven the outlines of the conversation ever since. Nat’l Comm’n for the Prot. of Hum. Subjects of Biomedical & Behav. Resch., THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (1978). Thus, while they are nominally separate fields with different regulatory structures, clinical care and clinical research both use similar structural frameworks of informed consent and decision making by autonomous patients. These include the now canonical four ethical principles that govern both research and practice: autonomy, beneficence, nonmaleficence, and justice. Tom L. Beauchamp & James F. Childress, PRINCIPLES OF BIOMEDICAL ETHICS (Oxford Univ. Press 7th ed. 2013) (1979).} Whether physicians adhered to these norms to avoid liability, because they embraced them in substance, or both, the effect was more consistent alignment of ethics and law.

In pediatrics and adolescent medicine, this alignment, to the extent it held, was complicated from the beginning of the Civil Rights Era as a result of challenges by scholars and advocates to the concept of “childhood” as a monolithic period from birth to eighteen during which everyone is an “infant” and thus an “incompetent” in the eyes of the law.\footnote{See Neil Postman, THE DISAPPEARANCE OF CHILDHOOD 143-45 (Delacorte Press 1982) (on childhood as a social construct); see generally Scott, supra note 16 (on adolescence as a legal construct).} The project to re-imagine “adolescence” as a separate legal category sought to eliminate, or at least reduce, the instances of de jure discrimination against adolescents that could not be justified on the basis of real differences.\footnote{Franklin E. Zimring, THE CHANGING LEGAL WORLD OF ADOLESCENCE 26-28, 99-101 (1982).} Scholars and advocates sought rights, not
just interests, for adolescents, and they imagined that these rights could be enforced as against adults, including their parents. The notion that parents stand in their children’s shoes for medical decisionmaking purposes might have been in line with then-progressive views about patient (versus physician) autonomy, but it was not in line with this new progressive view that the law should reflect only children’s evolving capacities and not also parents’ political rights.

Adolescents in the United States did obtain some constitutional and state law rights in the process, but aside from those described in Part II above, none reduced the plenary authority of parents to stand in their children’s shoes for purposes of general medical decisionmaking. Indeed, the Court’s 1979 decision in *Parham v. J.R.*, expressly confirming this plenary authority, even as against adolescents, was confirmed just days before the Court’s decision in *Belotti v. Baird*, which announced adolescent reproductive autonomy as its still singular constitutional exception. Notably, this legal status quo is unaffected by the United Nations Convention on the Rights of the Child (CRC), which says that children acquire rights incrementally and based on their “evolving capacities.” The United States has not implemented the CRC because the Convention rejects the American model of parental rights and adolescent legal (in)capacity.

Pediatric ethicists nevertheless continued to pursue their civil rights agenda, in which “evolving capacities” was very much the guiding theme. In the 1980s and 1990s, this effort was designed to push law to reflect their ethics rather than the other way around; if this could not be done on the books, advocates would make it happen on the ground. We believe this was accomplished by either conscious or mistaken blindness to Court doctrine, by the suggestion that physicians ought not be concerned about the prospect of tort liability, and by an abiding but incorrect sense that the CRC’s evolving capacities standard was somehow actually prevailing law. We have identified two particularly important touchpoints in this context.

The first was the publication of Angela Roddey Holder’s book *Legal Issues in Pediatrics and Adolescent Medicine* in 1985. At the time, Holder was counsel for medico-legal affairs at the Yale School of Medicine and a well-respected pediatric bioethicist. Her book is presented as a treatise on the formal law, but in some respects, it is more accurately characterized as a reflection on what physicians might get away with on the ground—in other words, as the perspective of an advocate for a certain kind of progressive physician. Thus, Holder’s discussion of the mature minor rule is misleading from the start, as she writes, “[t]here are no reported decisions within the past twenty-five years in which a parent recovered damages, even in the absence of a minor treatment statute, for treatment of a child over the age of fifteen.

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104 See infra notes 113-18 and accompanying text (giving the example of the AAP’s own analysis); supra notes 88-89 and accompanying text (giving examples of scholars who have argued for an extension of the mature minor rule).
105 See cases cited supra note 59.
without parental consent. This is known as the ‘mature minor rule.’” She goes on to note that courts are least likely to hold physicians liable for treating adolescents without their parents’ consent when the minor was “near majority” and needed care that was “less than ‘major’ or ‘serious.’” As we explain below, Holder’s discussion was widely read and cited in both the bioethics community and the medical profession.

The second was the publication ten years later, in 1995, of the AAP Committee on Bioethics statement on Informed Consent, Parental Permission, and Assent in Pediatric Practice (“1995 AAP Statement”). Consistent with the deeply held view of its developer William G. Bartholeme that “children are in the process of becoming … intelligent, observant, capable, and responsible persons” who deserve our utmost respect,” the statement takes the general position that “[p]atients should participate in decision-making commensurate with their development; they should provide assent to care whenever reasonable.” In general, it envisions a consultative process much like the shared decisionmaking models au courant in this period that involve the patient, physician, and parents. Throughout the statement, the details about the role and authority of parents and children are imagined very differently from, and sometimes are flatly inconsistent with, formal law. Most importantly, it either misunderstands or rejects the rule that parents are their children’s medical proxies, concluding that

100 Holder, supra note 108, at 133. This is misleading because very few cases result in reported decisions, especially if they are resolved in the trial courts; and easy battery claims are unlikely even to make it to court because a provider’s insurance company is likely to write a check to resolve them short of litigation. The fact that Holder did not find reported decisions is therefore not an indication of how cases actually proceeded. Moreover, to the extent that parents are unlikely to litigate because they lack the necessary financial and cultural capital, Holder’s sense of physician’s power is premised on a willingness to ignore formal law and that different distributive injustice.

101 Id. at 134. We do not dispute this point, as it is consistent with the reported cases. However, their outcomes are primarily explained on different grounds, i.e., these are exactly the kinds of cases where parents are least likely to seek to vindicate their rights and, even if they do, where courts are least likely to bother to write opinions. Her conclusion is also flawed. She writes that, “[i]f a teenager comes to a physician with a cold, it may be perfectly reasonable to provide care without notifying the parents, but no surgeon, presumably, would consider operating on that same teenager for a brain tumor without discussing it with [them].” Id. at 135. This distinction is irrelevant as a matter of most formal law. Whether a parent has the motivation, time, and money to pursue a claim in the former instance is, again, an entirely different matter, as is how irritated a judge would be to get a claim like this. In other words, Holder’s advice is about what physicians might get away with rather than what the law actually says.

102 As of November 16, 2021, Google Scholar provides a cite count of 218 for Holder’s book, but as we explain below, it appears that the pick-up by the AAP and its citation in the organization’s journal Pediatrics amplified its influence. See e.g., Garry S. Sigman & Carolyn O’Connor, Exploration for Physicians of the Mature Minor Doctrine, 119 J. Pediatrics 520, 520 (1991) (citing Holder for the proposition that “the ‘mature minor doctrine’ is often applicable and provides a legal basis for adolescents to give informed consent if they are capable of doing so.”). Id. at 521-22 (suggesting that “state courts have made the mature minor doctrine a recognized exception to the parental consent rule”). Interestingly, the authors thank “Tomas Silber for review of the manuscript and suggestions.” Id. at 525. As we indicate at note 96, Silber was the reviewer on our Pediatrics piece who insisted that no practicing physician believes that mature minors have the right to make general medical decisions.


104 Id. at 314.

105 We discuss these models in more depth in Part III.B.3 infra.

106 See 1995 AAP Statement, supra note 113, at 314-15 (incorrectly describing and complicating the law’s premise that parents stand in their children’s shoes and are their formal proxies for all purposes relevant to the informed consent process); id. at 315 (“Thus, ‘proxy consent’ poses serious problems for pediatric health care providers. Such providers have legal and ethical duties to their child patients to render competent medical care based on what the patient needs, not what someone else expresses. Although impasses regarding the interests of minors and the expressed wishes of their parents or guardians are rare, the pediatrician’s responsibilities to his or her patient exist independent of parental desires or proxy consent.”); id. at 316 (“As children develop, they should gradually become the primary guardians of personal health and the primary partners in medical decision-making, assuming responsibility from their parents.”); id. (“Social forces tend to concentrate authority for health care decisions in the hands of physicians and parents and this tendency diminishes the moral status of children. Thus, those who care for children need to provide for measures to solicit assent and to attend to possible abuses of ‘raw’ power over children when ethical conflicts occur. This is particularly important regarding the initiation,
“[i]n situations involving adolescents and young adults, the Academy encourages physicians to obtain the informed consent of the patient ... Such patients frequently have decision-making capacity and the legal authority to accept or reject interventions, and, in that event, no additional requirement to obtain parental permission exists.”117 Notably, the statement cites Holder for support, as well as others who themselves cited Holder:118

According to pediatrician and bioethicist Douglas Diekema, the effect was as at least some advocates intended: the conflation of ethics and law, but this time in the direction ethics was taking rather than as law dictated.119 Likely because some of the same advocates were involved, this conflation was facilitated by the federal government which had begun in some instances to require those engaged in pediatric research, including researchers in dual clinical-research settings, to obtain “assent” from children who were deemed capable of providing it.120 Although the government itself did not draw the line at the age of fourteen, some bioethicists did and their arguments appear to have been persuasive enough to set research practice standards.121 In the course of our investigation, we learned that at least some medical schools may have collapsed their lesson on the federal assent and state law consent requirements into a single slide that featured age fourteen and failed to distinguish between the two concepts.122 Again according to

withholding, or withdrawing of life-sustaining treatment.”); id. at 317 (While recognizing patients’ decision-making capacity, “the Academy encourages parental involvement ... as appropriate.”).

117 Id. at 316-17 (“Ethical and legal factors ... suggest that the physician involve parents after appropriate discussion with the adolescent elicits his or her permission to do so.”).

118 See id. at 315 n.11; Sigman & O’Connor, supra note 112, at 520-21 (citing HOLDER, supra note 108, at 133).

119 Interview with Douglas S. Diekema, Professor, Univ. of Wash. Sch. Of Medicine, [hereinafter Diekema Interview] (on file with authors). Diekema’s original work on the Lindberg matter, his close association with the institutions at issue, including as they dealt with the case, and his deep historical knowledge of the field, including of the politics of the field, made him an important interview subject. Among other things, he was very helpful in the development of our understanding of how the multidisciplinary team at Seattle Children’s – and some other medical professionals – came sincerely to believe that fourteen-year-olds are legally capable of consenting, and of withholding consent, to general and life-saving treatment.

120 The assent requirement attaches except where “the intervention or procedure involved in the research holds out a prospect of direct benefit that is important to the health or well-being of the children and is available only in the context of the research.” 45 C.F.R. § 46.408(a) (2020). See also Coleman, The Legal Ethics of Pediatric Research, supra note 11, at 539 nn. 84-86 and accompanying text (discussing this rule).


122 Whether this in fact has been the case or not, physicians whose work bridges clinical and research settings may be unclear about our definitions of assent and consent and how they differ. The National Institutes of Health (NIH) define assent as “a child’s affirmative agreement to participate in research.” 45 C.F.R. § 46.402 (b) (2020). Specifically, the Department of Health and Human Services (HHS) explains that:

[Assent] means the child must actively show his or her willingness to participate in the research, rather than just complying with directions to participate and not resisting in any way. When judging whether children are capable of assent, the Institutional Review Board (IRB) is charged with taking into account the ages, maturity, and psychological state of the children involved. The IRB has the discretion to judge children’s capacity to assent for all of the children to be involved in a proposed research activity, or on an individual basis. The IRB should take into account the nature of the proposed research activity and the ages, maturity, and psychological state of the children involved when reviewing the proposed assent procedure and the form and content of the information conveyed to the prospective subjects. For research activities involving adolescents whose capacity to understand resembles that of adults, the assent procedure should likewise include information similar to what would be provided for informed consent by adults or for parental permission.

Off. for Hum. Rsch. Prot., Research with Children FAQs, U.S. DEPT. OF HEALTH & HUM. SERVS., https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/children-research/index.html [https://perma.cc/H999-BDGD] (last visited Nov. 13, 2021). This is not the case with clinical practice in which assent may be ethically desired but is not mandatory to initiate diagnosis and treatment. For the minority of states that have
Diekema, this may have influenced the view of at least some in the medical community that fourteen in particular has special legal significance as the age at which adolescents become formal or informal participants in medical decisionmaking, either together with or in lieu of their parents.

Regardless of how it developed, this view has been remarkably resilient. The best example is from the AAP itself, which affirmed its 1995 position most recently in 2016, three years after it published our corrective survey of the law in Pediatrics. This time without any citation or legal support, even to Holder, its 2016 statement announces (incorrectly) that “most states” give mature minors general medical decisionmaking rights. This marks a shift from its more nuanced, but still erroneous, earlier claim that “many states give decision-making authority (without the need for parental involvement) to some minors who are otherwise emancipated but who have decision-making capacity (‘mature minors’).”

In addition to and perhaps because of the AAP’s repeated error or advocacy, related work—including both academic and instructional literature—often reflects the same mistaken assumptions. Thus, since 2013, we have continued to find medical and legal publications providing both qualified and unqualified advice that adolescents or mature minors—whether they are adolescents or not—have the legal right to make general medical decisions. For example, borrowing from the terms of the mature minor doctrine in other states—but notably not in Ohio law—an Ohio law firm’s website explains that

[a] “mature minor” is someone over the age of fifteen who can show a health care provider that he or she has enough maturity and understanding to make medical care and treatment decisions without parental consent. On a case-by-case basis, a provider must use the same criteria that would be used to determine if an adult is capable of making medical decisions. If the minor is found capable of consenting, a provider must give the minor the same informed consent an adult would receive.

mature minor exceptions to the parental consent requirement, the minor is giving consent according to state tort law’s informed consent standard, not assent according to the federal government’s standards for research. See supra Part II.C (discussing the legal standard). Diekema Interview, supra note 119.

See Coleman & Rosoff, supra note 4, at 789-92. Am. Acad. of Pediatrics, Comm. on Bioethics, Policy Statement: Informed Consent in Decision-Making in Pediatric Practice, 138 Pediatrics 1, 4 (2016) [hereinafter 2016 AAP Statement]. The full sentence in the 2016 AAP Statement is that “[m]ost states have mature-minor statutes in which the minor’s age, overall maturity, cognitive abilities, and social situation as well as the gravity of the medical situation are considered in a judicial determination, finding that an otherwise legally incompetent minor is sufficiently mature to make a legally binding decision and provide his or her own consent for medical care.” Id. We don’t know how the authors of the 2016 AAP Statement arrived at this conclusion or why it was not sourced. It is possible that they assumed the conclusion to be so well-established that it was not in need of support.

1995 AAP Statement, supra note 113 at 316. In support of this last proposition, the Statement quotes a 1991 article which is itself wrong on the law, in part because that article’s scaffolding was also wrong or at least misleading. Id. at 316 n.18 (quoting Sigman & O’Connor, supra note 112). As we explain above, the latter derive much of their analysis from their reading of Holder’s book Legal Issues in Pediatrics and Adolescent Medicine. Sigman & O’Connor, supra note 112, at 520.

Laura F. Fryan, When Can Minors Consent, BOURSE McDOWELL (Dec. 14, 2015), https://www.bourse.com/when-can-minors-consent [https://perma.cc/J4Y3-XN7R]. Fryan follows this with the qualification that “[t]here is little case law in Ohio and other states regarding the mature minor doctrine.” However, the impression she leaves is that the rule applies (including in Ohio) so long as the maturity test is met. See also Phillip T. Glyptis, Most Minors Need Parental Consent for Medical Treatment, OHIO STATE BAR ASS’N (Apr. 15, 2016), https://www.ohiobar.org/public-resources/commonly-asked-law-questions-results/healthcare/most-minors-need-parental-consent-for-medical-treatment/ [https://perma.cc/PVV7-R9ZH] (noting, in the same language as Fryan, that while Ohio law requires “people under age 18 (minors) [to] have the consent of a parent or guardian before receiving medical care … there are several exceptions to this general rule” including “‘mature minors’ [who] can
And in March 2018, THE AMERICAN JOURNAL OF BIOETHICS published an article by Aleksandra E. Olszewski and Sara F. Goldkind entitled The Default Position: Optimizing Pediatric Participation in Medical Decisionmaking, in which the authors describe patients who are seven and fifteen as sufficiently mature enough to be included in the medical decisionmaking process, specifically as agents distinct from their parents.128 Olszewski and Goldkind were focused on finding ways to include children not to exclude parents from the medical decisionmaking process; still, for the law, which treats fit parents as “one” with their children, this notion – of children as agents distinct from their parents – is provocative.129 Their characterization of the children’s maturity and the physician’s proper role in relation to children and their parents was immediately challenged by others in their field, but it was nevertheless important as instruction regarding how some pediatricians think and practice and also about what ideas an influential publication is willing to distribute.130

Given this messaging, it should not be surprising that the belief that adolescents have general medical decisionmaking rights is also reflected in practice. Aside from the patients Olszewski and Goldkind described in their article,131 the best-known example of this belief is probably Dennis Lindberg, who is featured in our Introductory illustration.132 We discuss Dennis’s case in additional detail in Part IV below. The point here is simply that this misunderstanding is not merely academic. It has important real-world consequences.

B. THE CIRCUMSTANCES IN WHICH MINORS HAVE DE FACTO MEDICAL DECISIONMAKING RIGHTS

Physicians are generally well-versed in the rule that parents stand in their children’s shoes for purposes of medical decisionmaking. As a result, from routine procedures like vaccinations to serious surgical interventions, when parents have the will and the capital – economic or cultural – to insist on exercising their proxy, the nature and scope of parental autonomy in this area is consistent with formal law. When this is not the case, as we detail below, our research and analysis suggest that adolescents have de facto decisionmaking rights in three different, sometimes overlapping circumstances: when the adult actors make mistakes about or choose to nullify the formal law, when the adolescent patients are nonadherent with their clinical protocols, and when medical culture diverges from formal law.133

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128 Olszewski & Goldkind, supra note 5.
129 We pick up on their idea in the final part of this Article as we discuss the lessons the law might take from medicine, see discussion infra Part V.
130 In particular, the description of a seven-year-old as mature for decisionmaking purposes was clearly a leap for many pediatric ethicists who thereafter suggested that the authors went too far in that case. See, e.g., Maya Sabatello et al., Pediatric Participation in Medical Decision Making: Optimized or Personalized?, 18 AM. J. BIOETHICS 1 (2018) (responding to Olszewski and Goldkind).
131 See Olszewski & Goldkind, supra note 5.
132 See supra note 1.
133 As we note in the Introduction and in Coleman & Rosoff, supra note 4 and accompanying text, because this is a cross-disciplinary paper in a cross-disciplinary publication, we want to be clear that in this context – which is a legal analysis – we use the word “research” in its legal not its scientific sense. That is, consistent with standard practice in law, we searched for, read, and evaluated the cases and articles on point. Although some lawyers and legal scholars conduct empirical research, we did not attempt a full forensic review of the literature across the disciplines in which the mature minor rule is discussed, nor did we attempt a thorough...
1. Mistakes and Nullifications of Law

Mistakes and nullifications of formal law, specifically about the scope of parental rights and the mature minor rule, provide an important basis for adolescent decisionmaking authority. They typically involve errors and nullifications relating to federal supremacy or federalism and to either poor or overly-aggressive—beyond creative—lawyering. They are made by both medical and legal professionals, although the former tend to make them more than the latter simply by virtue of their different training. Over time, where these mistakes are not corrected, they may become part of practitioner and institutional policy, and, as Dennis Lindberg’s case suggests, they may even become part of the informal law of a locality.

Supremacy errors and nullifications occur when the relevant adult actors do not know or understand the applicability, preemptive status, and effect of federal law in general, and when they do not know or ignore applicable federal law. As we explain in Part II, the Court has held that parents stand in their children’s shoes for purposes of general medical decisionmaking. Parents are not entitled to make “martyrs” of their children, but otherwise, as long as their decisions are at least adequate, they are presumed to be in the child’s best medical interests. It is irrelevant that the child herself and her physician may disagree. The only exception recognized by the Court is for decisions relating to reproductive care. Others that are on the books in state law that we believe would survive constitutional scrutiny include the established public health exceptions and the individual health and status exceptions. The mature minor rule is not one of those exceptions, and it would be difficult to argue that Parham and Belotti decided and read together do not mean what they say, i.e., that parental authority in this sphere is plenary with the narrow exception of reproductive matters. State law that provides to the contrary is likely preempted by this doctrine. To the extent a hospital or physician is subject to its terms because they are public institutions or employees, focusing on avoiding eventual tort liability misses this point.

Nevertheless, our research suggests that adult actors on the ground often do not know about or else choose to ignore applicable federal law. As a result, they operate

accounting of the practice settings in which it has been adopted. As a result, we cannot answer one of the questions that logically follows from our disagreement with Tom Silber, i.e., how prevalent is the misunderstanding. Because our objective is to understand and describe the circumstances in which de facto decisionmaking rights emerge and exist, and because the examples we examine provide a rich sense of the nature of the phenomenon as well as something of its scope and effects, we leave the prevalence question for others to resolve.

Unlike the mature minor rule, these exceptions are typically grounded in the states’ police power and parens patriae authorities. See supra Part II.B.

In our view, under the applicable constitutional standard, it would be difficult for a state to support the argument that it has an important or compelling interest in providing mature adolescents with general medical decisionmaking rights that trump those of their parents; nor could it successfully defend the claim that, for example, using the age of fourteen as the line of maturity, and for the transfer of medical decisionmaking authority from parents to children, is an appropriately narrow way to tailor its infringement of parents’ otherwise plenary rights. To the extent that some states have some form of a mature minor rule, it is probably in derogation of this standard. Because of this, we wonder how often the rule is actually employed other than to protect the state law right of physicians to be paid for medically necessary services they provided to adolescents based only on their consent.

See Parts III and IV (discussing this phenomenon in general and in the context of the Lindberg case in particular). Physicians and bioethicists are certainly familiar with Prince v. Massachusetts, 321 U.S. 158, 170 (1944) (“Parents may be free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”). Parham v. J.R. and Bellotti v. Baird may not be so well known, at least not by name, and thus, the former’s breadth and the latter’s limitations aren’t readily available to inform non-law-trained adults’ sense of adolescent decisionmaking authority. Or, if they have had occasion to review or to be instructed on these, they may have been told or decided that they are not specifically on point. For example,
without the guidance it provides and the requirements it imposes. These go not only to the specifics of decisionmaking authority but also to the framework for understanding related state law. For example, silence on the subject of the mature minor rule in a particular jurisdiction could be misunderstood as permission to proceed as though it existed if one were unaware or else dismissive of applicable federal law. Similarly, inattention to federal law allows adult actors erroneously to think that if a mature minor rule exists for abortion, it also exists for other medical decisions.

Federalism errors and nullifications occur when adult actors mistakenly assume that the law of one state is applicable in another. One state’s law may be influential in a different state that is developing its own policy, but no law is binding precedent unless it is within the jurisdiction. Federalism errors and nullifications also occur when adult actors choose intentionally to ignore this fact about law. Our research suggests that in addition to the state-specific mature minor statutes, two state cases have been principally misused in this respect: Cardwell v. Bechtol out of the Supreme Court of Tennessee137 and In re E.G. out of the Supreme Court of Illinois.138 Cardwell held that the common law “rule of sevens” applies beyond children’s responsibility for torts and crimes also to afford minors from the age of fourteen a rebuttable presumption of capacity to make medical decisions.139 In re E.G. held that a seventeen-year-old Jehovah’s Witness could refuse a lifesaving blood transfusion.140 Neither is law outside of their own jurisdiction. Nevertheless, both are frequently cited in medical and bioethics materials as support for a broader application of the mature minor rule.141

while the Court in Parham initially speaks to parents’ decisionmaking authority most broadly, on the facts it applies this doctrine to the institutionalization of children with mental health issues. Similarly, in Bellotti the Court applies the mature minor rule to the abortion context without discussing its applicability (or not) in other circumstances. These applications allow for the argument that the Court might not view parental autonomy so broadly in the context of physical health or when institutionalization is not in issue; and that it might not restrict the mature minor rule to the abortion setting. See infra Part IV for interviews with individuals involved in the Dennis Lindberg case (on file with authors). It is consistent with good lawyering practice to distinguish cases on factual grounds; indeed, law students are specifically trained in this skill. However, the merits of particular distinctions depend on the strength and breadth of the legal rule in question, and as we describe in Part II.A, this legal rule is especially broad, deep, and resilient. Parental rights are limited only by the states’ police power (general health and welfare) and parens patriae (state as parent) authorities, neither of which provide the government with the power to redistribute parental rights to children as a general matter. Successful state interventions thus tend to be on very specific, often startlingly serious facts. See, e.g., State v. Baxter, 141 P.3d 92, 99 (Wash. Ct. App. 2006) (setting out the rule that “the State may interfere with the parents’ rights to raise their children only where it ‘seeks to prevent harm or a risk of harm to the child’” and applying it to permit prosecution of a parent who tried personally to circumcise his child). American law’s aversion to such redistribution is the principal reason for the United States’ refusal to implement the United Nations Convention on the Rights of the Child. Its embedded notion that children have “rights” as against their parents and the state that grow to be plenary consistent with their “evolving capacities” – as opposed to “interests” that parents and the state see to consistent with their rights and authorities – has not been politically viable in this country. See Coleman & Rosoff, supra note 4.

137Cardwell v. Bechtol, 724 S.W.2d 739 (Tenn. 1987).
139Cardwell, 724 S.W.2d at 749.
140In re E.G., at 327-28.
141See, e.g., S.Y. Tan, Consent and the Mature Minor, MDedge (Feb. 3, 2015), https://www.mdedge.com/internalmedicine/article/96890/practice-management/consent-and-mature-minor/page/0/1 [https://perma.cc/53XJ-74E6] (suggesting that “court decisions favoring the minor abound” and referring to both Cardwell and In re E.G. in the process); The Adolescent Alone: Decision Making in Health Care in the United States 86 (Jeffrey Blustein, Carol Levine, & Nancy Neveloff Dubler, eds., 1999) (citing both of these cases as well as Bellotti for the proposition that “some minors have the capacity to give – or to withhold – informed consent for medical care”).
It is difficult to know whether Cardwell influenced the view that fourteen-year-olds have consent authority or whether it is found and used instrumentally as support for a pre-existing position to the same effect. It is our sense from the overall project that both are probably true. Regardless, when it is used outside of Tennessee as more than evidence of the law in Tennessee—for example as it appears to have been by the AAP and by legal and medical actors in Seattle around the time of Dennis Lindberg’s case—it is at least a federalism error.

Reading errors and nullifications occur when those who interpret formal law do so either with insufficient training or carelessly. They also occur when attorneys push their otherwise appropriate lawyering role beyond reasonable bounds to reach a desired result. There is a difference between arguing from precedent and mischaracterizing precedent. The former is a litigation skill. The latter is malpractice, but it can still be found where no one challenges the overreach.

2. Clinical Non-Adherence

Clinical non-adherence, sometimes described as non-compliance, is the most commonplace and best understood of the three circumstances in which children, especially adolescents, are afforded the de facto right to make medical decisions. Non-adherence occurs when the patient resists or neglects their prescribed treatment regime, generally of their own accord. Non-adherence sometimes presents as affirmative choice and action and thus as a paradigm instance of autonomous decisionmaking. But it is also often characterized by knowing or merely negligent omissions. We include all forms of non-adherence as examples of decisionmaking here because these same behaviors are well-studied and generally regarded as exercises of autonomy by individuals with capacity.

We also include them because, when adolescents’ choices and behaviors are not countered by their parents or treatment team, they effectively preempt or replace the adults’ decisions. If it is the latter, the adolescents’ decisions become the adults’ decisions, either by default or because the adults ultimately come to embrace them.

142 See generally supra Part III.A and infra Parts III.B and IV.
143 As we have already noted, lawyers do sometimes encourage courts to consider amending local law based on what other states have done, but this is different from taking action in one state based on the law of another. See supra note 136 and accompanying text.
144 This is to be distinguished from non-adherence due to the primary actions of the parents, guardians or adult caregivers on behalf of the minor child.
146 Signe Hanghøj & Kirsten A. Boisen, Self-Reported Barriers to Medication Adherence Among Chronically Ill Adolescents: A Systematic Review, 54 J. of Adolescent Health 121 (2014).
147 Diagnostic and therapeutic non-adherence is a complex topic and vexing for both patients and healthcare providers. The causes are multifactorial. See Pablo A. Herrera, Laura Moncada, & Denise Defey, Understanding Non-Adherence From the Inside: Hypertensive Patients’ Motivations for Adhering and Not Adhering, 27 Qualitative Health Rsch. 1023 (2017); Caroline Hayard et al., Intentional Nonadherence as a Means to Exert Control, 27 Qualitative Health Rsch. 1215 (2017); Meredith K. D. Hawking et al., Adherence and the Moral Construction of the Self: A Narrative Analysis of Anticoagulant Medication, 30 Qualitative Health Rsch. 2316 (2020). Non-adherence amongst adolescents is a particularly challenging problem especially for those children with chronic medical conditions and reflects their growing autonomy and wish to exert control over their lives. See Michael O. Killian et al., Psychosocial Predictors of Medication Non-Adherence in Pediatric Organ Transplantation: A Systematic Review, 22 Pediatric Transplantation e13188 (2018); Meghan E. McGrady & Ahna L.H. Pai, A Systematic Review of Rates, Outcomes, and Predictors of Medication Non-Adherence Among Adolescents with Cancer, 8 J. Adolescent & Young Adult Oncology 485 (2019).
148 This and the following observations are based on Dr. Rosoff’s longtime clinical experience.
Although younger children may sometimes resist when their parents or physicians seek to treat them—struggling against shots and IV lines or refusing to swallow medication are common examples—they can generally be convinced to comply. Where this approach is unsuccessful adults tend not to hesitate to use force and physical restraints to ensure necessary care. In contrast, adolescents are known affirmatively to resist prescribed treatment in circumstances where the adults are unable or unwilling to use force and restraints to ensure compliance. For example, they may not want to submit to prescribed diagnostics or therapy or to take prescribed medication because they do not like the real or perceived side effects. Medications for attention deficit and hyperactivity disorder (ADD/ADHD) and oncology treatments are common examples here.149 Adolescents may resist adult authority in these and related contexts as a way of expressing their evolving personhood and autonomy, which is consistent with normal adolescent development.150 They may also be motivated by sincerely-held religious beliefs or treatment fatigue.151 Although the patient’s motivation matters—treatment fatigue is more likely than perceived social stigma to sway adults—unless they are forced to do so by institutional authorities, the adults involved are unlikely to “tie down” a resistant patient. This is especially likely to be the response if the patient’s condition is chronic or long-term and thus would necessitate multiple such interventions. It appears also to be the likely response where, regardless of his age, the patient presents as physically strong and mature.152 In these situations, adolescents are, in effect, in the shoes of adults who refuse to consent to necessary care; their assertion of autonomy is likely to be discouraged but ultimately respected.

Younger children are not generally given the opportunity to neglect their treatment regime, but as with resistance, older children and adolescents are differently situated. By choice or by necessity, adolescents are often in partnership with adults regarding their care. For example, especially as they get older, adolescents are often principally responsible for receiving and taking prescribed medications, attending and engaging with therapy sessions, and foregoing contraindications. This is the case even as adolescents are developmentally prone to mental states, perspectives, and behaviors that suggest they may not be good partners in the treatment effort. Willfully, knowingly, or merely negligently, they are a patient sub-population that is known to skip doses; to minimize the significance of essential details; and to find it difficult to resist peer-related opportunities that are


150 Joseph R. Rausch et al., Changes in Treatment Adherence and Glycemic Control During the Transition to Adolescence in Type 1 Diabetes, 35 DIABETES CARE 1219, 1223 (2012).


detrimental to their general welfare. However these acts and omissions are motivated, they often run counter to the treatment plan.

3. Medical Culture

Finally, minors have de facto medical decisionmaking rights when medical culture regarding those rights diverges from formal law. While most medical providers follow the law if they know it – even when they disagree with its terms – some are willing to diverge where their own norms and priors are to the contrary. As Angela Holder noticed many years ago, few parents actually pursue battery or constitutional rights claims in this setting: as a result, violating formal law is often not a high-risk proposition and medical providers seem to know this. Two related medical norms are likely to be particularly at issue in this context.

The first is respect for patient autonomy. As applied to pediatric patients, and consistent with the clinical standard of care which takes child development into account, autonomy is gained either incrementally, consistent with normal development, or as of a set age – for example, fourteen – as capacity for informed consent solidifies. Thus, medical professionals working with adolescents may see the cognitively capable child as a person in their own right who is not necessarily well-represented by their parents or guardians. The concept of the child and the parent-child relationship reflected in Parham v. J.R. is foreign in this setting, both in its view that all children under the age of majority are legally immature medical decisionmakers who lack legally cognizable autonomy, and in its presumption that parental decisions are in their children’s best interests even when they do not reflect objectively acceptable views about those interests. If the child can understand the nature of the treatment including its risks and benefits, is capable of participating in treatment discussions, and is not under apparent duress, their autonomy should be respected, again even as against their parents. Respect for autonomy is not absolute, of course. In clinical practice, including in clinical ethics deliberations, autonomy is almost always balanced against beneficence. This is perhaps particularly true in pediatrics where, at the end of the day, adults do get to decide whether they listen to the child. Still, respect patient autonomy stands as an important medical norm, perhaps especially in research hospitals where the practice of satisfying the federal government’s assent rules for pediatric research may come to be the de facto governing standard in purely clinical contexts.

153Koster et al., supra note 152, at 833.
154Holder indicated only that she could not find many judicial decisions on point. Given her legal training, we assume she knew that this meant that few claims were brought and pursued to a decision; and that judges in the cases that were brought and pursued didn’t write opinions. See supra notes 108 and 109 and accompanying text.
155See, e.g., Interview with Jeff Sconyers [hereinafter Sconyers Interview] (on file with authors).
156See supra Part II.C. In those few states with mature minor rules, this approach merges with legally-based autonomy. Id. (describing these state laws).
157See supra notes 20-22 and accompanying text (discussing best interests in medicine and law).
158The AAP, which has adopted fourteen as the age at which pediatricians should begin to respect the child’s autonomy, and pediatricians Aleksandra E. Oliszewski and Sara F. Goldkind, who have, in their work, taken the position that children as young as seven may be proper subjects of respect as decisionmakers separate from their parents, are illustrative. See 1995 AAP Statement, supra note 113, at 317, and Oliszewski & Goldkind, supra note 5, at 4, 8, and accompanying text (discussing these approaches).
159See, e.g., infra notes 174-75 and accompanying text (providing as an illustration the ethics consult in the Lindberg case).
160See supra notes 113-26 and accompanying text (discussing the AAP’s conflation of the two standards); infra Part IV (illustrating the operation of this conflation in practice in the Lindberg case).
The second is the modern preference for shared decisionmaking. This model comes in various forms but the general principle is that decisions about treatment courses are not made by physicians alone (either as fiduciaries or as paternalistic actors) or by patients alone (as entirely autonomous consumers of medical services), but rather through a collaborative process that respects and engages both the physician’s experience, expertise, judgment, and ethics, and the patient’s knowledge, requirements, and goals. As applied in the pediatric setting, consistent with pediatric patient autonomy norms, the shared decisionmaking model often seeks to include the child “at the table” alongside the relevant adults, especially as she matures and her capacities evolve. Depending on the circumstances and how it is applied, this model can run counter to the law’s concept of the parent and child as one, with the parent speaking for the child. Even if it represents an outlier version, the shared decisionmaking model described by Olszewski and Goldkind is illustrative of this disconnect as it sees even a young child who expresses mature tendencies as a patient to be consulted separately from their parents. In this respect, their version of the model is also consistent with the way the medical team operated in Dennis Lindberg’s case, which we discuss next.

IV. THE DENNIS LINDBERG CASE

Dennis Lindberg died on Wednesday, November 28, 2007, of complications from cancer. Specifically, he succumbed to complications from acute lymphoblastic leukemia. But in our opinion, he also died because his aunt, who was his caregiver at the time, had encouraged his very recent religious conversion and, throughout the period of his hospitalization, continued actively to insist that he not be transfused with human blood products. His parents, who were apparently methamphetamine users and lived in a


162 See supra Part II.A.

163 See Olszewski & Goldkind, supra note 5 and accompanying text (summarizing their version of the shared decisionmaking model).

164 The details described in this paragraph are based in the medical record, in the reporting of Isolde Raftery, and in our interviews with Jeff Sconyers and Doug Diekema, all of which are in our files. See also supra note 1 and accompanying text (providing additional details in the introductory illustration). Dennis’s specific diagnosis was acute lymphoblastic leukemia (ALL).

165 Id.

166 The causal claims throughout this section are all opinions, and all our own, based on our analysis of the factors that together combined to take Dennis from the day he was admitted to the hospital (November 6), to the moment of his death (on November 28). It is our opinion that the facts and factors we describe in this section were necessary together to take us to November 23. This includes Dennis’s aunt. From what we can tell from the records, her insistence from the day of Dennis’s admittance to the day of his death appears to have been uncompromising: along with Dennis’s cancer, this is the vein that runs all the way through the story. Thus, at least beginning at intake and in the following few days, if not already beforehand, it appears that she worked with the social worker assigned to Dennis’s case in an effort to establish both that he was mature enough to make his own decisions and that, regardless of how his disease progressed, they would not be wanting blood products. On the day that the hospital indicated that it could no longer omit blood products from his treatment regime, she wrote what was essentially a lay brief arguing against its right to proceed and picking apart its ethics consult. It also appears that she arranged for a lawyer for Dennis, who faxed a letter to the hospital indicating that Dennis had the maturity “of a 24 year old” and suggesting that it would be battery to proceed with treatment without his consent. In the final days before his death, when Dennis himself apparently lost lucidity, she – along with Dennis’s doctor – were the lead witnesses against CPS and his parents, insisting that he be permitted to die. Medical record and hearing transcripts (on file with authors).
different state, lacked the financial and cultural capital effectively to assert their rights when they were finally alerted to his situation and tried to intervene.167

The political and medical cultures of the place in which he ended up also, in our opinion, contributed to Dennis’s death. Unlike Idaho, where Dennis had previously lived with his parents, Seattle is a multicultural city where tolerance of religious and cultural differences runs especially deep, including within the medical community and the local division of Child Protective Services (CPS).168 This culture of tolerance apparently joined with the medical team’s professionally engrained respect for adolescent medical decision-making to create a particularly deferential environment in which a medically sophisticated guardian, her apparently convincing ward, and their faith-based entourage together managed to be atypically persuasive.169 The hospital’s interest in not being involved in litigation with the family may also have been a factor.170

167Isolde Raftery writes,

[A]t 13, Dennis was baptized. The same day, he signed what Witnesses call a “blood card,” saying he would refuse blood. Around this time, [his aunt became his “law custodian”]. His parents said they believed it was a temporary arrangement so that Dennis could cross the nearby border to Canada for a religious convention.

Six months later, Dennis found himself out of breath playing football. His doctor ordered tests and within a day sent him [and his aunt] to Seattle Children’s Hospital.

Raftery, supra note 1. The full record, including further reporting by Raftery, Dennis’s medical record, and the transcript of the court proceedings, suggests that Dennis’s parents probably retained their parental rights, including their medical decisionmaking rights, and thus may have been improperly dismissed once they intervened to force what would probably have been a lifesaving blood transfusion. His aunt told the court Dennis had provided her with a durable power of attorney six months before (presumably when he was 13) that included medical decisionmaking rights, but this would not have conveyed lawful authority. Shelter care hearing transcript (on file with authors). And so, it appears that all she had was a court order, dated January 2007, giving her the incomplete status of a “law custodian,” which the court and CPS indicated did not come with medical decisionmaking rights. See Final hearing transcript at 5 (on file with authors) (a “law guardian” doesn’t have medical decisionmaking rights); Preliminary hearing transcript at 14 (on file with authors) (“their [parents]’ rights are not terminated”).

168The details described in this paragraph are from our interview with Jeff Sconyers, supra note 156, and from the medical record. See also Doriane L.Coleman, *The Seattle Compromise: Multicultural Sensitivity and Americanization*, 47 DUKE L.J. 717, 743 (1998) (describing the decision of a different Seattle hospital to help a group of Somali refugee mothers who sought to avoid the traditional circumcision of their young daughters by the performance instead of a symbolic circumcision).

169Isolde Raftery’s notes indicate that Dennis’s aunt was studying to become a nurse at the time and was familiar with medicine and hospital protocols. Both the hospital record and Raftery’s reporting, indicate that Dennis could be convincing. Raftery explained to us that because of his difficult childhood, Dennis was used to having to negotiate with adults to get what he needed. His oncologist’s notes and the ethics consult are not detailed, but both suggest that the physicians involved believed that Dennis was speaking for himself when he told them that he wanted to live but did not want blood products. The hospital record, also on file with authors, indicates that Dennis’s aunt and/or other Witnesses were almost always in his room, and that his aunt sought to prevent his medical team from discussing treatment with him in her absence.

170Our sources did not emphasize this point, i.e., their focus in recounting the decisionmaking at the time was on the staff’s respect for Dennis’s voice, on their treating physicians, and on their collaborative process. Still, standard institutional averseness to litigation should not be discounted, and there is evidence that this was in play in the decisionmaking in Dennis’s case. Written hospital policy in effect when Dennis was admitted put the onus on patients who would refuse the standard of care to petition a court for an override. See Hospital Policy document [hereinafter Policy] (on file with authors). In general, the Policy made clear that the hospital’s formal position was that parental failure to accept the standard of care in an emergency is medical neglect. In the run-of-the-mill case, it probably ensured that the hospital only had to go to court if a patient felt so strongly that they choose themselves to initiate that process. However, the lawyer who was retained for Dennis about ten days before he died disputed its lawfulness and suggested that it would be battery to treat him in the absence of an emergency or his formal consent. Letter from Gaylen Payne to Hospital Risk Manager, (Nov. 19, 2007) (on file with authors). Given this threat of a tort action, doing nothing, i.e., offering the family the option of palliative care instead of the standard of care, was another way out of litigation at that point, but only so long as doing this could not itself
The claims throughout were that it was Dennis’s own decision to forgo standard oncology treatment and that this decision had to be respected because he was fourteen and thus presumptively mature.171 But the hospital never undertook a formal or independent evaluation of his maturity—when asked for this evaluation by CPS, consistent with what that agency believed to be the legal requirement in the state of Washington, the hospital’s psychology department indicated it did “not have the tools for such an assessment.”172 The hospital did put Dennis’s decision through a version of a shared decisionmaking process which included an ethics consultation on November 13,173 followed by a conference on November 21 – seven days before he died – at which his treatment team, the ethicist(s) involved in the consult, and hospital counsel together discussed his case and ultimately determined both to respect Dennis’s decision and, relatedly, not to characterize the situation as medical neglect.174 Additional factors cited for the decisionmaking team’s conclusions were that Dennis was adult-sized despite having just turned fourteen and that his doctor worried that Dennis might have to be physically restrained if transfusions were ordered over his objections.175 In other words, respect for children’s evolving capacities and fealty to a shared decisionmaking model reflecting a local culture of tolerance

be characterized as medical neglect. Ultimately, it was this concern, i.e., that foregoing the standard of care could be characterized as medical neglect by the hospital, that landed the parties in court. Sconyers Interview, supra note 155. This brought the hospital full circle, back to its Policy that describes the failure to treat as medical neglect, and to its ethicists who, consistent with the Policy, suggested the same. See Policy and Report of Ethics Consult (on file with authors).

171 This claim was made by Dennis’s aunt, the hospital social worker assigned to his case, the lawyer someone retained to write a letter to the hospital threatening litigation, and ultimately by his attending physician.

172 Medical Record (on file with authors); see also Interview by Isolde Raftery with Douglas Diekema [hereinafter Raftery-Diekema Interview] (on file with authors) (“You have a child who has been taken out of the custody of his parents, he’s completely dependent on his aunt, and bearing in mind that many of these emotional decisions are driven by social survival, … of course he’s going to make a decision that maintains his standing with his aunt and his church…. His brain is looking at, ’What do I need to do to survive?’ His social standing is tied up with pleasing his aunt and pleasing his church—two major sources of support.”). Despite Dennis’s oncologist’s insistence that he was respecting Dennis’s view, his notes suggest he may not have been so sure. See Progress Note (Nov. 19, 2007) (on file with authors) (“Dennis continues to prefer lying flat in bed, but is able to sit up briefly…. He has developed extreme anemia due to family refusal of blood products…. I explained that [without blood products] cardiac collapse is imminent…. Dennis’s aunt reiterated her lack of consent for blood transfusion and Dennis appears to support this approach, although Dennis spoke less than his aunt at the meeting”). The oncologist’s notes also indicate that he was aware that Dennis’s young age was an issue. Progress Note (Nov. 20, 2007) (on file with author) (“Based on my conversations with Dennis, he appears to understand the implications of his treatment choice despite his age.”).

173 Medical Record: Including Report of Ethics Consult (Nov. 13, 2007) (on file with authors) (finding that “although it may be arguable that Dennis is able to act autonomously at his age, we felt, given the consequences of his refusal, our ability to assess his competence through a limited number of conversations, and a perceived acquiescence with receiving blood products, given the dire scenario presented to him—we felt it is appropriate to give him blood products in that scenario and communicated to the family their need to obtain a court order if the family plans to refuse blood products”).

174 Interviews with Jeff Sconyers and Douglas S. Diekema (on file with authors). This two-step process reflected the approach Dennis’s aunt had taken all along. As she expressed to the hospital social worker assigned to their case, she needed to be sure that Dennis would be treated as an autonomous decisionmaker so that she could not be charged with medical neglect. As early as the first few days following his admittance, to these ends she insisted that Dennis be formally evaluated to establish his maturity. Wilkinson Case Report, (on file with authors). Once she realized this would or could not be done, she fixed on the assurances the hospital social worker apparently gave her that he would be treated as mature simply by virtue of the fact that he was 14. These assurances, together with unchecked allegations about what others at the hospital told her about how Dennis was “mature for his age,” became the foundation for the final decision in his case. It is noteworthy, however, that CPS and the court also asked for an independent evaluation of his maturity. But when CPS tried to meet with Dennis for this purpose, its caseworker was refused access on the ground that he had “taken a turn for the worse.” An independent evaluation is standard protocol in cases involving maturity claims in the abortion context.

175 Preliminary Hearing and Final Hearing transcripts at 7-8 and 5-6. But see Raftery’s case notes at 5 (on file with authors), including notes from the Raftery-Diekema Interview, in which Diekema explained that
apparently combined with the prospect of patient non-adherence to yield a result out of the hospital to allow Dennis to die. Ultimately fatal in our opinion, however, were the numerous errors and nullifications of formal law that ensured the usual legal safeguards did not operate in Dennis’s case. Consistent with formal hospital policy, which was in this case abandoned by its keepers, those safeguards provide that medical decisions are made by parents or legal guardians until children reach the age of majority, not by the children themselves. If those adults are unavailable or refuse to consent to necessary, lifesaving care, the decision is taken from them and consent is provided by an alternate guardian who will make the consent decision in their place. Life and ensuring children make it to the age of majority are the overriding goals. In no circumstances does formal law permit a team of responsible adults to stand by and watch a child degrade over the course of a month in a hospital bed when the standard of care would almost certainly have saved his life.

“Yes” is the right answer to Isolde Raftery’s original question, “When a 14-year-old chooses to die because of religion, can anyone stop him?”

We begin the legal piece of this story where we first took it up, as part of our 2013 fifty state survey of the law on the right of adolescents to make general medical decisions. In that context, we established which states have mature minor rules and what they look like. Washington did not come up in this survey as a mature minor state. That is, there is no statute, regulation, or case that provides that it is. Our assessment was and remains consistent with other fifty state surveys on the same issue. It is our opinion that no lawyer applying standard legal research methodologies would identify Washington as a mature minor state.

Nevertheless, following the publication of the results of our survey, we learned from a hospital social worker at our home institution that colleagues in Seattle had been instructed that, in Washington, mature minors are entitled to make their own general decisions.

I proposed a very unpopular solution to Dennis’s case…. I would have brought the blood into his room, and I would have hung it, and I would have hooked it up. And if he had allowed me to do that, I would have just done it. I would have told him that I’m sorry, and I would have apologized to him and I would have told him that I know this disrespects what you want but I can’t let you die… that’s how you test someone’s convictions. Someone like Dennis telling you that this is unacceptable because he’s a Jehovah’s Witness, and he knows he has to say that. Or does he really believe it? … There’s a lot of heterogeneity in that community in terms of their belief systems, whether it’s OK to get blood if it’s forced on you, whether it’s not … we have had parents of babies we have forced transfusions on, … they cannot give you permission to do it. Their worst nightmare is that you won’t transfuse their baby… who know? Maybe Dennis was in that situation. I don’t know how you know that unless you push it.

176Policy, supra note 170 (providing a protocol for minors consistent with these safeguards). Hospital counsel indicated to us that, other than Dennis, in the years he had been at the hospital they had only had to use the Policy in the case of younger minors; and so the issue presented to them by Dennis and his family, and by the lawyer retained for Dennis, was whether the policy was also applicable to an older minor. It was in answering this question that, in our opinion, informal law came to play its dispositive role.

177Raftery, supra note 1.

178Coleman & Rosoff, supra note 4, at 789-91.

179Id.; see also supra Part II.C (providing the updated survey we did in connection with our research on this Article).

180Coleman & Rosoff, supra note 4, at 789-91

181See also Sconyers Interview, supra note 155 (concurring in our opinion in this respect and indicating his view that the flyer we describe immediately below, published at the time by Washington Legal Help and others, was “wrong”).
medical decisions. We tracked this view to a flyer entitled Providing Health Care to Minors under Washington Law: A summary of health care services that can be provided to minors without parental consent.182 The flyer includes a table that lists eleven different scenarios in which “unemancipated minors” may seek medical attention in the absence of their parents.183 Beside each scenario, the table indicates whether parental consent is or isn’t required; and then it provides the legal basis or support, generally a statutory provision, for this indication. We were able to locate two older iterations of the flyer.184 Beside the scenario “non-emergency medical services,” both assert that the mature minor rule is applicable in Washington. The earlier flyer, dated March 28, 2006, doesn’t include legal support for this proposition; indeed, it is the only one of the eleven scenarios for which this is the case.185 The later iteration of the flyer, dated November 5, 2007, fills that void with a citation to a 1967 decision out of the Washington Supreme Court, Smith v. Seibly.186 We do not know whether the absence of this citation in the earlier version was inadvertent or intentional, but it is noteworthy that the void was filled just three days after Dennis was admitted to the hospital when his aunt was pressing, through the social worker assigned to his case, to secure Dennis’s authority to make his own decisions.187

In any event, the problem is that Seibly is not on point and does not support the proposition that unemancipated mature minors can make their own general medical decisions. In fact, the case does not discuss the mature minor rule at all. It is a standard emancipation case, affirming that an eighteen-year-old married man and father of one, who lives apart from his parents, works outside of the home, and supports himself and his family financially, is entitled to make his own medical decisions.188 As both iterations of the flyer otherwise make clear, emancipation is a non-controversial, well-established basis,
separate from the mature minor rule, for granting medical decisionmaking authority to adolescents who meet these independence criteria.\textsuperscript{189}

We assume that those who developed the flyer understood that emancipation and the mature minor rule are separate legal bases for adolescent medical decisionmaking because they introduce their table with the note that it is designed to provide information about the circumstances in which “a single \textit{unemancipated} minor can receive treatment without parental consent;” and they go on to distinguish the legal rights of emancipated and unemancipated minors.\textsuperscript{190} We also assume that those who developed the flyer knew that \textit{Seibly} was an emancipation decision because they used its language, verbatim, to explain how a practitioner can determine whether a minor is “mature,” even though the case itself uses this same language to explain how a trier of fact can determine whether a minor is emancipated.\textsuperscript{191} It is our opinion that citing to \textit{Seibly} as support for the mature minor rule was one of three things: sloppy lawyering, overzealous advocacy amounting to overreach, or an outright (albeit disguised) nullification of law.\textsuperscript{192}

Regardless, because this move was apparently not checked at its origins and the flyer was widely distributed, especially within the hospital social work community, many people in Seattle and beyond came to believe that Washington is a mature minor state.\textsuperscript{193} As of this writing, the error either remains to be, or has only recently been, cured. For example, Wikipedia cites \textit{Seibly} and the 2007 version of the flyer (updated in 2015) as support for its generic description of the mature minor rule.\textsuperscript{194} The University of Washington continues to publish the 2006 version.\textsuperscript{195} One of the nonprofit organizations that has long been associated with the document continues to distribute a 2017 version.\textsuperscript{196} Most notably, until at least 2020, the King County (Seattle) government distributed a derivative work titled “The Mature Minor Rule” which provided that the rule was “created” by \textit{Seibly} but that its “age guideline is not as restrictive as it was when [it] was developed” in that case.\textsuperscript{197} Without providing any additional legal support for this move away from its

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\item \textsuperscript{189}Indeed, \textit{Seibly} is recognized as a case that “helped to define the scope of the emancipated minor.” See, e.g., Arshagouni, supra note 6, at 335. See also id. at 334-340 (setting out emancipation separate from the mature minor doctrine as two different exceptions to the rule that children are not legally competent medical decisionmakers).
\item \textsuperscript{190}See sources cited supra note 183 and accompanying text (“A legally emancipated minor or a minor married to either an adult or an emancipated minor is treated as an adult.”)
\item \textsuperscript{191}Compare \textit{Seibly}, 431 P.2d at 723 (“A married minor, 18 years of age, who has successfully completed high school and is the head of his own family, who earns his own living and maintains his own home, is emancipated for the purpose of giving valid consent to surgery if a full disclosure of the ramifications, implications, and probable consequences of the surgery has been made by the doctor in terms which are fully comprehensible to the minor. Thus, age, intelligence, maturity, training, experience, economic independence or lack thereof, general conduct as an adult and freedom from the control of parents are all factors to be considered in such a case.”), with 2006 Flyer and 2007 Flyer (“In determining whether the patient is a mature minor, providers will evaluate the minor’s age, intelligence, maturity, training, experience, economic independence or lack thereof, general conduct as an adult and freedom from the control of parents.”).
\item \textsuperscript{192}During the course of our research, we sought to untangle the story of how \textit{Seibly} came to be used as support for the mature minor rule. To this end, we reached out to the lawyers at Washington Legal Help and Columbia Legal Services, but we were unable ultimately to communicate with them. We have not sought to do more than this.
\item \textsuperscript{193}Sconyers Interview, supra note 155.
\item \textsuperscript{195}See sources cited supra note 183.
\item \textsuperscript{197}As of the time we drafted this section of our paper in 2020, this document “lived” within the Seattle & King County’s “Public Health Centers and other office locations” site, although we originally found it on the
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terms, the County advised that “[t]reating both 13 and 14 year olds as Mature Minors when they demonstrate key qualities of the Mature Minor is reasonable. Treating youth who are 12 and under is up to the provider's best judgment.”198 The document then returned to Seibly, listing the additional criteria the court set out for determinations of emancipation, cementing what appeared to be an approximately sixteen-years-long effort to have that case stand for a proposition that was foreign both to its facts and to the controlling doctrine.199

Given this, it is not surprising that our sources referred to the flyer as authority for the further proposition that Dennis had legal decisionmaking authority specifically because he was fourteen. Although neither the flyer nor Seibly translates “mature” as fourteen, the move to that specific age as a proxy for maturity can be traced to the multiple manifestations of this effort, which were only reinforced by the related messages from the AAP and some of the medical literature on assent and consent.200

As Isolde Raftery’s reporting makes clear, reliance on this age proxy was critical to the outcome in Dennis’s case.201 From the day he was admitted to the day he died, no other determination of maturity was ever attempted by the medical or legal decisionmakers involved in his case.202 Not the one derived from Seibly and listed on all versions of the flyer. Not the one state—including the State of Washington—use in the abortion context. And not any from medicine itself.

Consistent with this state of the record, Dennis’s attending oncologist testified at the emergency hearing the day before Dennis died:

[I] met with all of my senior colleagues on Wednesday night[.] … [W]e acknowledge[d] that even though someone [is] not an adult at about the age of 14[,] assuming normal cognition and no coercion[,] … we owe respect to a 14 year old[.] … That applies to research studies and to general care. Even thought [sic] we disagree with the decision [to forego standard treatment], 70 percent … is a good chance and a blood transfusion is an easy thing to do[.][w]e feel strongly with the rest of the group that a 14 year [sic] old [who is] able to clearly articulate and explain why … that we owe respect to.203

It is noteworthy that in his testimony, Dennis’s oncologist did not argue that Dennis was mature. Rather, the transcript suggests that he was proceeding on the view that at fourteen, a typical patient has the cognitive capacity to satisfy medicine’s informed consent/assent standard, as well as on the basis of his related concerns about the physical issues associated with regularly transfusing a noncompliant patient.204 His case notes are consistent, indicating that he focused on ensuring that Dennis was lucid and understood the implications of both treatment and treatment refusal.205

Hospital counsel took the position that his role was to be an advocate for the doctors on staff, and his view was that the law could be read to allow him to defend their...
decision to respect Dennis.\textsuperscript{206} To support this reading, counsel cited the flyer and related assent rules pegged to the age of fourteen, as well as his sense that the local division of CPS would not intervene in the case because their decisions were in line with Seattle’s culture of tolerance for cultural and religious diversity.\textsuperscript{207} Assuming the flyer was accurate, the mature minor rule would negate any eventual medical malpractice claim because Dennis had provided informed consent. And because both Dennis and his aunt agreed that he should refuse treatment, until his parents were notified of his condition just days before his death, there was no sign that anyone would be interested in filing such a claim. Indeed, the risk of tort liability seemed to run in precisely the opposite direction, as the lawyer someone hired for Dennis in the week before his death had written to the hospital to say that treating him would put the hospital at risk of a battery claim.\textsuperscript{208} Finally, non-intervention by CPS would signal that the relevant experts in maltreatment law did not see the failure to treat as actionable medical neglect. That Dennis’s parents were not consulted had no bearing because his aunt had represented herself as his legal guardian.

Counsel’s analysis exemplified practical, on-the-ground lawyering. That the matter was resolved in the hospital’s favor, at least in terms of the formal law, suggests that he did his job. He may have taken a risk that some others would have avoided, but there is no reason to believe it was anything but consistent with his client’s interests. That his “higher ups” had him place a courtesy call to CPS following their team meeting on Wednesday, the 21\textsuperscript{st}, provided the hospital with effective cover.\textsuperscript{209}

In any event, it appears from the record that hospital counsel correctly perceived that CPS was not inclined to characterize Dennis’s situation as medical neglect; or that CPS did not understand at the time of the call that Dennis’s situation was as dire as it was; or, because the next day happened to be Thanksgiving, that further work on the matter was simply put off by CPS until the following week.\textsuperscript{210} Regardless, it was not until right after the long holiday weekend—on Monday, November 26, when CPS’s investigator sought to interview Dennis in person—that CPS learned that he was no longer lucid and likely just days from death.\textsuperscript{211} The hospital staff who spoke with the case worker indicated that they were surprised Dennis had made it through the weekend.\textsuperscript{212} Regardless of the reasons for CPS’s nonaction on November 21, once it understood the critical nature of Dennis’s situation, CPS connected with his parents, flew them to Seattle, and filed an emergency petition for a dependency declaration, a pick-up order, and an order compelling a transfusion.\textsuperscript{213}

The following morning, on Tuesday, November 27, a local magistrate judge heard from Dennis’s father (who testified that he wanted Dennis to have the transfusion); Dennis’s teacher (who testified that he was anxious to please his aunt); Dennis’s aunt (who testified that he was anxious to please his aunt); Dennis’s aunt (who...
testified that he was committed to his faith and should not be transfused); and Dennis’s social worker and doctor (who testified that he was capable of making the decision himself, that we owe respect to a fourteen year old, and that if transfusions were ordered, an order also needed to be entered to permit the hospital to restrain him in the event he resisted treatment). Lawyers were appointed for Dennis’ parents and the matter was transferred to the county judge assigned to hear cases that day, who said that he would render a decision the next morning. According to Isolde Raftery’s reporting, that afternoon and evening, the judge—who had not had occasion to try related matters and was not familiar with the applicable law—sought to read and learn as much as he could, and then he went to bed.

The next morning, on Wednesday, November 28, the judge read this decision from the bench:

I think it is time to do what Dennis has decided, to place this in God’s hands. I find nothing to justify my finding that Dennis is either abused nor neglected or that he has not adequately been cared for. This is a very personal decision, which Dennis has made. Dennis has the capacity to make it.

Dennis died at six o’clock that night. A little over a month later, on January 7, 2008, CPS formally closed its investigation. A note in the file concludes, “There were not any abuse or neglect issues as the aunt took the child to the doctor and obtained treatment for the child. This is a case where the child chose his fate.”

V. INDICATIONS FOR MEDICINE AND LAW

Parts II and III of this Article provide descriptive accounts of the law on adolescent medical decisionmaking rights as it exists on the books and as it stands on the ground. Part IV provides an analysis of the Lindberg case with a focus on how the disjunction between these two expressions of the law affected the decisions that ultimately contributed to Dennis’ death. Apart from its standalone value, for purposes of this Article this analysis illustrates the risks that arise when institutional boundaries, authority, and standards are unclear or ignored, or when decisionmaking is poorly guided and thus ad hoc. This final section is prescriptive; it suggests reforms for medicine and for law that derive from the analysis of current practices.

Although it is commonplace to say that patients have decisional autonomy, it has long been the case that medical decisionmaking is a dynamic, interactive process that also involves physicians exercising their autonomy and, where necessary and appropriate, ethical and judicial players exercising theirs. Each of these players brings different disciplinary competencies, authority, and normative priors to bear on medical decisionmaking. Their interactions impart lessons about the strengths and weaknesses of their respective approaches but also about the problems that arise out of the intersections themselves. Our normative claims are that these lessons should be the basis for reform of applicable

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214 Hearing transcripts (on file with authors).
215 Hearing transcripts and case filings (on file with authors).
216 Interview with Isolde Raftery (on file with authors).
217 Transcript of Record at 13-14.
218 Id.
219 Case notes entered by Cindy Palmer (Jan. 7, 2008) (on file with authors).
220 Id.
standards and practices in both medicine and law and that with respect to adolescent medical decisionmaking in particular, consistent with both medical and legal standards, those reforms should privilege (1) the standardization of process to avoid ad hoc decisionmaking; (2) the inclusion of the minor’s voice in that process according to an “adults in training” or “guided or supported decisionmaking” model that has them practicing and gaining independence incrementally and graduating to full autonomy by the age of majority; and (3) the preservation of physical life and other generally-agreed upon essential systems.

A. **Indications for Medicine**

Medicine’s institutional competence and authority extend to the evolution and establishment of medical standards of care as well as to the medical ethics process and standards that attach within that sub-discipline. Importantly, both medicine and medical ethics exist, evolve, and operate beside but separate from related law.221 In the development of medical standards of care and of the medical ethics process and standards, medicine is guided by physical facts such as the state of the physical body and the physical implications of particular treatment, but it is also guided by norms including a fealty to science, healing, and patient autonomy. The societal boundaries of medicine’s institutional competence and authority are set by law which itself has the institutional authority to check “out of bounds” moves and decisions. At least hospital counsel, if not also the risk department and the managers of physician practice groups, may act as intermediaries between medicine and law in this regard.

Medicine’s approach to adolescent medical decisionmaking is varied. In some contexts, physicians and their institutions hold firm to the view—which is wholly consistent with formal law—that the adolescent patient’s voice is important but ultimately channeled and checked by their adult proxy, generally their parent. In others, physicians seek to establish and treat that voice as distinct from that of their proxy, and also as more broadly preemptive. The latter approach is informed by the fiduciary nature of the doctor-patient relationship and by the knowledge that, although the adolescent brain is still evolving toward complete capacity, it generally reaches the specific capacity to meet the informed consent standard by early-to-mid adolescence.222

The decision to treat the minor’s voice as distinct from that of their proxy and as preemptive in circumstances where they have the specific capacity to meet the informed consent standard represents an institutional strength but also a weakness.

It is a strength because it focuses on respect for the individual based on their factual (rather than political) capacities in a context in which that focus is perhaps uniquely warranted, *i.e.*, in matters related to the individual’s bodily wellbeing. Especially as the child becomes an adolescent and forms a sense of themselves as physically and psychologically distinct from their parents, respecting their physical integrity sometimes requires respecting their contributions to medical decisionmaking, if not their decisions themselves. Whether the medical issue is big and important or small and relatively insignificant, it is constructive that medicine sees, responds to, and respects the child as an individual in

221Those rules are sometimes the same because the two influence each other, but as the voluminous ethics literature demonstrates, ethics and law are often differently inspired and thus sometimes generate different results. Indeed, our review of the ethics literature as it relates to this Article suggests that ethics and law may operate in distinct silos. The answer to the question, “What does medicine and medical ethics say and how do they get there?” can be different from the answer to the question “What does law say and how does it get there?”

222See supra notes 156-61 and accompanying text (discussing the informed consent process and adolescent consent capacity).
their own right. In contrast, ignoring the child as to matters pertaining to their own body can be deeply destructive of their wellbeing and developing personhood. Medicine is arguably better than law on this point because it is flexible in circumstances where law, which is focused on parental rights, sometimes results in a trap from which children cannot escape even after they have reached the age of majority.

Establishing and treating the adolescent’s voice as distinct and preemptive is a weakness in that adolescent decisionmaking capacities remain incomplete, i.e., their higher cortical functions beyond the capacity for informed consent are merely developing, not developed; we know from common experience and empirical evidence that even cognitively capable teenagers sometimes make very bad decisions. Most of us would not wish to be forever bound to choices we made in that formative period in our lives, and if we were later told that this had happened out of respect for our emerging autonomy, we might wonder about the judgment of the adults in the room. This approach is also a weakness because it collides with strong social norms about parents as children’s first and best caretakers in the transition to adulthood and about the responsibility of adults to protect and preserve children’s lives and options during the period of their minority. Finally, because adolescent medical decisionmaking rights are generally dependent on the inclinations of particular physicians acting in particular circumstances, they are neither systematically and transparently regulated to ensure that they are in fact protective (and not damaging), nor consistently available to ensure that similarly situated individuals—including children and their parents—are treated equally. The effect is that adolescents and their parents who lack financial and cultural capital are disparately impacted.

To address these weaknesses, medicine needs to develop a better understanding of the inflexible rules from law not only so that the players know what is in and out of bounds for liability purposes, but also—and for us mainly—because those rules express valuable norms about the care and lives of minors, and about non-discrimination. (As things stand, because those rules are often bent and broken, including by institutional actors who should know better, it appears that they are flexible when they are not.) Medicine needs to incorporate these inflexible rules within its structures and understand that they are valuable beyond their liability implications. We should train medical professionals and their support staff consistently, for example, by ensuring that from medical and professional school onward, they understand that assent is different from consent; that with some jurisdictional exceptions that are not broadly applicable, minors do not have general medical decisionmaking rights, and even where they do, their authority generally extends only to physically beneficial treatment not to treatment refusals; and that failing to provide a minor with available, lifesaving medical attention is generally considered medical neglect. Finally, incorporating the inflexible rules from law also requires the adoption of systems to curtail the discretion of individual physicians and provider groups to act sub rosa on an ad hoc basis. Arbitrary, even if well-intentioned, exercises of power should be restricted because they tend to jeopardize individual and societal welfare.

At the same time, to the extent the law’s rules are not inflexible—where there is room either to push back on the law or to work creatively but still legitimately within its boundaries—medicine should seek to influence that development. It is already doing this

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223It is important here to note the difference between personalized medicine within bounds, and sub rosa, ad hoc exercises of power. The former contemplates the lawful practice of medicine where the latter involves intentional or negligent violations of legal rules and norms. It is the lawful practice of medicine, for example, to personalize a treatment plan for a Jehovah’s Witness child that avoids blood products until these are necessary to avoid serious degradation and death. It is a violation of legal rules and norms about medical neglect to continue this approach once it is clear they are necessary.
indirectly when it includes the adolescent’s voice in medical decisionmaking informally, and negotiates with dissenting parents consistent with its own norms. There is nothing in law that prevents a physician or practice group in non-emergency settings from resolving the terms of engagement with their patients’ proxies in a way that incorporates fiduciary principles and an evolving respect for the child’s autonomy so long as that proxy remains the ultimate decisionmaker once the doctor-patient relationship is established. However, the development of formal law codifying this informal practice would express important commitments beyond medicine and secure benefits for adolescents more systematically. Parental rights in this country are deeply embedded in the law, which is reflected in, among other things, our rejection of the United Nations Convention on the Rights of the Child. Nevertheless, laws that are pegged to its evolving capacities standard already exist. Potentially useful examples include adolescent reproductive autonomy law, the assent rules that apply to pediatric research, and graduated licensure for adolescent drivers. Medicine should teach law how it might formally include the adolescent’s voice in general medical decisionmaking consistent with the approaches taken in these related areas.

B. Proposals for Law

Law’s institutional competence and authority extends to the codification and expression of broadly held social norms and the development of specific standards for itself and others, including standards that circumscribe the boundaries of other institutional authority. In the development of the specific standards that govern medical decisionmaking, the law is guided by a combination of norms, including those about the importance of process and the rule of law, individual autonomy, the preservation of life, reasonable care, and nondiscrimination. These norms are similar to but, as we have shown throughout this Article, also distinct from those that govern medicine’s approach to decisionmaking.

As we describe in Part II, the law’s approach to adolescent medical decisionmaking is relatively simple: except in specifically delineated circumstances – denominated exceptions to the general rule – legal autonomy is not attained until the age of majority. Until then, general medical decisionmaking rights formally belong to the minor’s parents or guardians. As a doctrinal matter, that authority is based in a combination of fiduciary and property-like principles, although the former are likely to be preferred in the modern context. Consistent with these principles and the law’s fealty to life, parent proxies have almost plenary authority, i.e., their decisionmaking rights are checked only in circumstances where their exercise would result in serious harm to their charge. Within this rubric, withholding necessary medical treatment is legally denominated medical neglect. An important – if not the most important – objective is to get the child physically to adulthood when they can decide for themselves.

Locating general medical decisionmaking authority in the child’s adult proxies to the age of majority is both a strength and a weakness of the law. It is a strength in that even older, cognitively capable adolescents lack the experience and maturity necessary to make consistently good decisions, and so it is in their interests – and in society’s interests – that they are represented by designated adult proxies who have rights and responsibilities that are themselves consistent with fiduciary principles. Although it is often considered beneficial in different circumstances to afford children the leeway to make and to learn from bad decisions, and to experience failure in the process, this is unlikely to be true in most medical settings where bad or failed decisions can have existential implications. (As with our now typical approach to graduated licensure in the context of driving, in the medical setting, it is understood that unguided
discretion and absolute autonomy are likely to have societally unacceptable effects.) The law’s selection of the child’s parent as their default first-best caretaker is generally held to be the likeliest to yield individually-sound, protective decisions. Finally, the fact that all children have a designated default caretaker assures – at least theoretically – that no child is subject to arbitrary treatment in this setting.

The law’s approach is problematic principally because its bright line rules do not recognize the fact that capacity for good decisionmaking develops incrementally along with individuality and personhood over the course of the child’s minority, and there are significant costs associated with policies that ignore their voice. It is also problematic because, in intact families, the law’s fiduciary standard tends not to place much value on children’s psychological (as opposed to their physical) wellbeing. Finally, children are subject to arbitrary treatment notwithstanding best caretaker theory because either they do not have an active parent, or their parent lacks the financial and cultural capital required effectively to exercise their rights and responsibilities.

The implicit critique from medicine centers on the first and second of these three weaknesses. Because medicine is driven by science, including by an understanding of the inextricable physical relationship (rather than theoretical dichotomy) between the mind and the body, its sense of its fiduciary obligations to pediatric patients encompasses both, or at least it sees them as an integrated system. In turn, this means that medicine tends to see and place value on the child’s real or actual capacities and even on their early efforts to exercise decisional autonomy. Medicine’s approach to these issues is increasingly consistent with the broader society’s evolving concept of the child as an individual in their own right, and of related, also evolving social norms about our responsibilities to children.

Law should partner with medicine on the development of formal rules (not only practice standards) that reflect these norms. Shared decisionmaking models that contemplate the inclusion of the minor’s voice in an advisory or educational capacity in the process leading up to the decision should be within constitutional bounds because parents would retain final decisionmaking rights. The extra procedure involved in their exercise would be consistent with the fact that parental rights exist in part to ensure that a committed adult is tending not only to the child’s physical welfare but also to their successful march toward adulthood and full citizenship. The latter undoubtedly includes the development of their adult decisionmaking capacities. In their participatory aspects, shared decisionmaking models support parents by fulfilling that educational function. Parents would retain the right to reject such models, but if they were part of the deal that established the doctor-patient relationship at the outset, so long as the situation was not emergent, they would be enforceable. Like the rules that are part of a parent’s contract with a private school – for example, for a particular curriculum or disciplinary process – they would be lawful delegations of parental rights.

Regardless, the law needs to do more to translate and disseminate its inflexible rules. It is deeply problematic that so much informal law contradicts rather than fills interstices in the law is deeply problematic. This is especially so as it concerns law that protects children’s lives and against ad hoc, discriminatory treatment of those who lack the financial and cultural capital necessary to secure their rights and interests. We hope that this Article will do some of that work, but the development of learning modules designed specifically for medicine – including for medical schools, hospital counsel, and continuing medical education – would be worthwhile. Those who work with the law could also use some version of the same. This includes judges, lawyers, child protective services, and hospital social workers. Certainly, no child should suffer serious harm because there is a dearth of clear and correct knowledge about the law’s requirements for their protection.
VI. CONCLUSION

The question whether adolescents have and should have general medical decisionmaking rights is understudied, important, and perennially topical. Whether adolescent girls have and should have the right to make their own abortion decision is most frequently discussed in this context, but there are other recurring situations that raise these same questions. One is whether religiously motivated treatment refusals by adolescents should be honored. And, increasingly, another is whether trans teens can and should be able to direct their own medical treatment, including as it concerns the use of puberty blockers, gender affirming hormones, and surgery; the latter is especially difficult in this period, because many trans teens are struggling with dissenting parents, and while the medical standard of care is established, it is still relatively new and so questions about its long term implications remain to be answered. A variety of more mundane but still important situations involving treatment choices that could be made by adolescents comprise the bulk of the cases that arise on the ground.

Resting decisionmaking authority in adolescents in general medical settings is a complicated business. On the one hand, we know that by mid-adolescence at least, but certainly before the age of majority, teenagers have the cognitive capacity for rational decisionmaking, including for satisfying medicine’s traditional informed consent standard. The latter requires that medical decisions be made voluntarily, with at least a basic understanding of the physical risks and benefits of the treatment choice. On the other hand, we know that even bright, disciplined teenagers often make very poor decisions because they lack the life experience necessary for making better ones, and their full neurological capacity—especially their executive functions—are still in development. The dilemma is ultimately whether and how to respect their existing capacities as well as their individuation—their emerging autonomy and personhood—while also remaining appropriately protective given the stakes.

Formal law remains clear: the carefully delineated exceptions to the traditional rule that parents make their children’s medical decisions through the period of their minority do not include general medical decisionmaking. Most states have not adopted the mature minor rule in any form, and other exceptions—like the right to get treatment for sexually transmitted infections—are designed exclusively to address very particular public health concerns. Because this legal state of affairs is the result of a strong, fiduciary-driven constitutional doctrine of parental rights and a set of state laws that reinforces its terms, adolescent decisionmaking rights exist mostly informally.

That informal law appears to be robust. Although this is not the case everywhere, as we describe in this Article deviations do not appear to be anomalies; indeed, in some places they are apparently routine. In part, this is because the relevant players do not know or choose to ignore (to nullify) formal law. But it is also because, for many adults, it is both intuitive and a moral imperative to treat even the minor patient as an individual in their own right, perhaps especially as it concerns their body, in circumstances where the child seems to be able to express an intelligent, deep-seeded sense of their separate (from her parents) needs and values. The law’s concept of the child as one with their parents and as categorically incapable to the arbitrary age of majority, even if this is ultimately a fiduciary design, sits uncomfortably with how the law should be, at least in individual cases.

In this Article, we argue that informal law is problematic, but formal law should take lessons from the resistance to its terms and use them to guide the development of better doctrine. Because informal law operates sub rosa and in an ad hoc fashion, it risks unacceptable harm to individuals and discrimination against those who lack the financial or cultural capital to protect their rights and interests. These risks must be addressed
including through educational initiatives that ensure that the law is known and understood. At the same time, the imperatives that drive deviations, especially medicine’s respect for the child and their emerging autonomy and personhood, should inform the law’s fiduciary model. To the extent that parental rights are inflexible because they are constitutionally fixed, they will continue to provide the frame within which such legal innovation takes place. But because these rights are rationalized on the basis of society’s interests in the survival and healthy development of children, and because parents partner with their communities in that childrearing venture, there is room for medical and medical ethics norms to influence the sub-constitutional law that rests within that framework.