

## Whose Body Is It Anyway - An Updated Model of Healthcare Decision-Making Rights for Adolescents

Kimberly M. Mutcherson

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# WHOSE BODY IS IT ANYWAY? AN UPDATED MODEL OF HEALTHCARE DECISION- MAKING RIGHTS FOR ADOLESCENTS

*Kimberly M. Mutcherson*<sup>†</sup>

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## INTRODUCTION

*“It is important that we allow children to exercise self-determination in treatment situations whenever their capacities, the circumstances, and the law allow it. But it is just as important that we not burden them with decisions that may have far-reaching implications for their lives in those cases in which they do not appear to have the capacity to address the decisions meaningfully.”<sup>1</sup>*

In a winter 2004 edition of the New York Times Sunday magazine, “The Ethicist,” Randy Cohen, responded to a letter written by a medical student on a pediatrics rotation.<sup>2</sup> The letter writer expressed dismay that after diagnosing an eleven-year-old boy with leukemia, the patient’s parents refused to reveal the child’s diagnosis to the child.<sup>3</sup> The impression left by the letter was that the healthcare providers acted in accordance with the wishes of the parents and withheld information about diagnosis from their patient who would continue to receive outpatient treatment at the healthcare facility. The letter writer queried whether the child had a “right to know his diagnosis.”<sup>4</sup> In his response, Cohen recognized that the law supported the parents and not the healthcare provider in these circumstances and also acknowledged a child’s ethical, if not legal, entitlement to be treated in accordance with his emerging cognitive capacity. Cohen wrote, “if the parents remain obdurate [after attempts by the healthcare provider and others to get them to reveal the diagnosis to the child], the doctor should do what’s best for the patient.”<sup>5</sup>

Though it is not exactly clear what Cohen imagined would happen if the healthcare providers acted on their ethical obligation to do what was best for the patient, even in the face of parental conflicts, the fact that the question was asked highlights ongoing conflicts in the law’s handling of young people accessing healthcare. The law’s treatment of minors in the healthcare context has been scattered and contradictory,

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<sup>1</sup> Thomas Grisso & Linda Vierling, *Minors’ Consent to Treatment: A Developmental Perspective*, 9 PROF. PSYCHOL. 412, 425 (Aug. 1978).

<sup>2</sup> Randy Cohen, *The Ethicist, No Kid Gloves*, N.Y. TIMES, Feb. 22, 2004, (Magazine), at 17.

<sup>3</sup> *Id.*

<sup>4</sup> *Id.*

<sup>5</sup> *Id.*

reflecting the pull of competing forces including concern for the welfare of inexperienced young people, respect for a parent's fundamental right to the care and custody of a child, fear of the spread of communicable diseases by young people who avoid healthcare, and preservation of the state's role in protecting vulnerable populations.<sup>6</sup> In the healthcare context, the law has traditionally erred on the side of protecting young people from themselves and from those who would do them harm by withholding certain rights from adolescents and vesting most decision-making authority in parents or other guardians. For the most part, with important exceptions, people under the age of eighteen may not make binding decisions about their own medical care.

The law as it pertains to adolescents and healthcare reflects the dilemma of a nation that is at once afraid of and afraid for its young people. A collective sense of adolescents as incapable and incompetent regularly clashes with a begrudging acknowledgment that young people can and do engage in decidedly unchild-like activities and then face consequences that require adult-like decision-making with or without the guidance of trusted adults. The law's role, then, is to determine the best way to ensure that young people get the support that they need and want in order to make individualized decisions about their own best interest.

This article queries whether the law inappropriately deprives adolescents of the right to participate in and potentially direct their own healthcare.<sup>7</sup> I argue that the broad withholding of healthcare decision-making rights from adolescents is morally unfounded and practically unnecessary and that the age marker dividing childhood from adulthood for purposes of healthcare decision-making has been set too high. Evidence of adolescent cognitive abilities requires a re-imagining of the appropriate balance between over and under protection of young people in the law. In choos-

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<sup>6</sup> U.S. CONG., OFFICE OF TECH. ASSESSMENT, *Adolescent Health-Volume III: Cross-Cutting Issues in the Delivery of Health and Related Services, Consent and Confidentiality in Adolescent Health Care Decisionmaking* OTA-H-467 123 (Washington, D.C.: U.S. Government Printing Office, June 1991), available at <http://www.wws.princeton.edu/cgi-bin/byteserv.prl/~ota/disk1/1991/9104/910406.PDF>.

<sup>7</sup> Limiting the discussion in this article to the context of healthcare is not meant to suggest that the ideas shared here could not be equally applied to the other contexts in which the law treats young people in a paternalistic fashion, sometimes to their benefit and at other times to their detriment. Instead, I limit my focus for reasons both pragmatic and personal. First, healthcare is a uniquely personal and critical domain in which the stakes can be extremely high, making it a highly charged and important topic of debate. Second, healthcare is an arena in which the dilemmas confronting adolescents and adults are often identical. This provides a good base from which to compare the consequences of treating one group differently than another. Third, a body of research and scholarly comment contending with some of the questions with which I grapple here already exists, allowing for arguments grounded in both theory and practice. Fourth, by limiting the discussion to healthcare, the proposal focuses on a deliberate and thoughtful expansion of the law rather than a wholesale shift in all contexts. Ultimately, the idea of shifting the law to recognize the lived experiences of adolescents is a worthwhile project to pursue in many other arenas.

ing the chronological age marker of eighteen, the law denies rights to fourteen to seventeen-year-old adolescents who are generally capable of exercising such rights in a thoughtful fashion.

Though chronological age is an imprecise measure that does not do justice to the intricacies and variations of individual cognitive development, this article does not dispute the reality that chronological age is a useful and pragmatically necessary tool for determining a baseline presumption of competence for purposes of healthcare decision-making. However, it is appropriate and ultimately beneficial to a variety of parties to lower the age at which the law extends the right to make autonomous healthcare decisions to young people facing a variety of healthcare dilemmas. A reduction in the age of consent for healthcare decision-making from eighteen to fourteen in most circumstances will promote the development of adolescent autonomy by protecting minor's inherent right to know about their own health status and share in decision-making about their own healthcare in consultation with a parent or other trusted adult and healthcare providers. In a shared decision-making model as envisioned in this article, most healthcare decisions would require the consent of both patient and parent, rather than just parental consent, with some necessary exceptions for particularly difficult circumstances in which sole decision-making by the young person or parent would be most appropriate. Such a change may improve the actual physical health of young people by encouraging access to care and providing the psychological benefits that come from wielding some measure of power over one's own healthcare.

Part I provides an overview of the existing healthcare-related legal landscape for young people, including state statutes that provide limited rights to healthcare decision-making in a small universe of cases. This part describes the ways in which the law reinforces outdated notions of broad adolescent incompetence while also carving out limited spaces in which adolescents may engage in autonomous decision-making.

Part II discusses the limitations of the current system of state laws and suggests what might be gained from more comprehensive thinking about and legislating for adolescents. This part details the ways in which the lack of a legally enforceable right to consent to healthcare ignores the realities of family life, leads to a lack of family communication in some circumstances, and discourages the creation of optimal healthcare provider-patient relationships, all of which compromises the quality of care provided to adolescent patients. The current system has its advantages for young people, but the system's flaws outweigh its strengths.

Part III proposes a shift in the existing hodgepodge of laws providing limited healthcare decision-making power for adolescents. I articulate explicit and implicit goals of healthcare emancipation statutes and

offer a proposal for better achieving both types of goals that rests upon a model of shared healthcare decision-making powers for parents and adolescents. I suggest that an appropriate response to the shifting parameters of adolescence and adulthood and the increasing scientific evidence of the fluidity of these categories is a reduction in the age of consent for healthcare decision-making to fourteen from the usual eighteen, thus allowing young people to share decision-making power with their parents or other adult caretakers in most circumstances. I envision a regime in which the baseline assumption is that parents and adolescents between the ages of fourteen and seventeen share decision-making responsibility for most healthcare decisions. This regime is premised upon the idea that adolescents have the right to know about their own healthcare status and have the capacity to meaningfully participate in decisions about their own healthcare even in the face of parental conflicts.

Part IV discusses the relationship between the shared decision-making model and the constitutionally protected parental right to care and custody that has traditionally extended to allowing parents to make largely unfettered healthcare decisions for minor children.

#### I. THE LAW OF HEALTHCARE DECISION-MAKING FOR ADOLESCENTS: CRITIQUING THE STATUS QUO

*When discussing any legal system, we must remember that the law is more than just a set of rules, procedures and prohibitions. Law itself is rhetoric and the vision by which community and culture are established, maintained, and transformed.*<sup>8</sup>

The law has evolved as lawmakers attempt to regulate adolescence in a way that both respects and protects young people while granting appropriate deference to the desire of parents to play a primary role in determining the fate of their children. The law has progressed from treating all children as the property of their fathers, to allowing adolescents to pursue adult activities, to pursuing protectionist policies that downplay adolescent autonomy, to the current incarnation that blends policies in order to balance between extremes. This section explores the current terrain in which decisions about healthcare for adolescents get made, details two purposes behind healthcare consent laws for adolescents, and discusses how these purposes are and are not achieved.

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<sup>8</sup> Joan M. Smith, *A Child-Centered Jurisprudence: Reconciling the Rights of Children and Parents Within the Family*, in CHILDREN AS EQUALS: EXPLORING THE RIGHTS OF THE CHILD 146 (Kathleen Alaimo & Brian Klug eds., 2002) (citation omitted).

## A. THE LEGAL LANDSCAPE AND ITS ORIGINS

For many years, with some exceptions, the law has defined adulthood based on chronological age with adults generally being those who have celebrated their eighteenth birthday.<sup>9</sup> Before reaching this point, one is first a child and then ultimately reaches adolescence loosely defined by Black's Law Dictionary as "that age which follows puberty and precedes the age of majority."<sup>10</sup> In a similarly cryptic fashion, Webster's dictionary describes adolescence as "the time of life between puberty and maturity; youth."<sup>11</sup> Adolescence, then, is less of place of being as it is a place of being in-between.<sup>12</sup>

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<sup>9</sup> Obviously, there are other significant ages, both before and after eighteen, at which young people become privy to various adult privileges. For instance, the legal drinking age in the states is twenty-one. See, e.g., ALA. CODE § 28-1-5 (2003); ARIZ. REV. STAT. § 4-101 (2004); COLO. REV. STAT. § 12-47-901 (2003); FLA. STAT. § 562.11 (2003). Young people may obtain a driver's license, with some restrictions, upon their sixteenth birthday in most states. See, e.g., ALASKA STAT. § 28.15.055 (Michie 2003); MD. CODE ANN., TRANSP. I § 16-103 (2001); MICH. COMP. LAWS ANN. § 257.308 (West 2001); S.D. CODIFIED LAWS § 32-12-6 (Michie 2003). Other states issue unrestricted licenses to those sixteen or older, see, e.g., MONT. CODE ANN. § 61-5-105; N.D. CENT. CODE § 39-06-03 (1997), or those older than seventeen, see, e.g., COLO. REV. STAT. § 42-2-105.5 (2003); IDAHO CODE § 49-303 (Michie 2003). In the criminal context, most states have statutes which allow for the transfer of juvenile court cases to criminal courts or that allow a juvenile to be sentenced to an adult correctional facility. See, e.g., Patrick Griffin, *Trying and Sentencing Juveniles as Adults: An Analysis of State Transfer and Blended Sentencing Laws*, (October 2003), available at <http://www.ncjj.org>. A small minority of states allows a minor to consent to marriage, without parental permission, before the age of eighteen. See, e.g., OR. REV. STAT. § 106.010 (2003) (young person age seventeen or older may consent to marriage); see also GA. CODE ANN. § 19-3-2 (2004) (young person age sixteen or older may consent to marriage); MICH. COMP. LAWS 551.51 (young person age sixteen or older may consent to marriage); see also S.C. CODE ANN. § 20-1-100 (Law Co-op. 2003) (young person age sixteen or older may consent to marriage); see also ALA. CODE § 30-1-4 (2003) (young person age fourteen or older may consent to marriage). Some states draw a gender distinction in their marriage consent laws setting different ages for men and women. See, e.g., DEL. CODE ANN. tit. 13, § 123 (setting a marriage age of consent at eighteen for men and sixteen for women); see also MISS. CODE ANN. § 93-1-5 (2003) (setting a marriage age of consent at seventeen for men and fifteen for women). Adolescents and even younger children have been tried or sentenced as adults for particularly egregious crimes such as murder. See, e.g., Glenda Cooper, *Florida Teen Gets 28 Years in Teacher's Shooting Death*, WASH. POST, Jul. 28, 2001, at A03 (describing the twenty-eight year sentence given to fourteen-year-old Nathaniel Brazill after his conviction for second-degree murder and the automatic life sentence given to Lionel Tate after his conviction for first-degree murder for a crime committed when he was twelve years old). For purposes of this article, however, it is appropriate to speak of eighteen as an age with specific implications because that is the age in the states at which a person can make broad healthcare decisions without the knowledge or consent of a parent or other caretaker.

<sup>10</sup> BLACK'S LAW DICTIONARY 49 (6th ed. 1990).

<sup>11</sup> WEBSTER'S NEW WORLD DICTIONARY & THESAURUS 9 (1996).

<sup>12</sup> Adolescence did not come to be a distinct time of life warranting research and discussion until the late nineteenth and early twentieth century. NANCY LESKO, ACT YOUR AGE 110-11 (2001). At this point, the understanding of adolescence as a state of transition became quite entrenched. Nancy Lesko explains the ways in which the rhetorical power of the language used to describe adolescence highlights this state of limbo. She writes:

For most adolescents, in most circumstances, this period of being in between leaves them stranded in the midst of a legal system in which “even older children are permitted to decide very little for themselves.”<sup>13</sup> As one author explains:

While adolescent minors have more legal authority than they used to have, for the most part they still must follow the direction of their parents with regard to the central features of teenage life — residence, association, and conduct. Within the family, an uncomplicated legal regime still applies, with occasional exceptions, to minors of all ages. Parents control and provide care for their children; children obey parental direction. In these respects, the legal status of adolescents differs little from that of all other children. Everyone under eighteen, now the common age of majority, is lumped together as minors or, adding insult to incapacity, “infants.” Their distinguishing legal characteristic is the inability to make decisions on their own behalves. Minors are “a group of individuals with few responsibilities, many restrictions, and a complex legal status that maintains a dependency on adults for privilege and access to resources.”<sup>14</sup>

The law is not an insulated institution and it inevitably reflects the confusion and contradictions of the larger society. Given its amorphous status as a sort of purgatory prior to achieving adulthood, the law has struggled to establish a means of regulating the lives of young people that rejects inflexible presumptions of both childhood dependence and adult independence. As the culture shifts, lawmakers re-draw the lines of adolescence and respond to debate about the borders of adulthood.

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Teenagers are “at the threshold” and in “transition to adulthood.” These phrases suggest an evolutionary arrival in an enlightened state after a lengthy period of backwardness. These phrases also participate in an “ideology of emergence,” which is a belief that teenagers are naturally emerging and outside of social influences. They are autonomous beings who get dropped down into various social and historical contexts. “Coming of age” makes adolescence into a powerful and uncontrollable force, like the arrival of spring that swells tree buds. Finally, “coming of age” and “at the threshold” are also homilistic. These terms appear to give adolescence importance but really confer greater authority on the author of the homily. Scientists and educators who proclaim the potentials and problems of the not-yet-of-age are positionally superiors. In one or two simple and repetitious phrases we can understand the workings of evolutionary progress, science, and religion.

*Id.* at 3.

<sup>13</sup> Carol Sanger and Eleanor Willemsen, *Minor Changes: Emancipating Children in Modern Times*, 25 U. MICH J.L. REFORM 239, 244 (Winter 1992).

<sup>14</sup> *Id.* at 244 (citation omitted).



During the colonial period, all children were the property of their fathers and had no true legally cognizable rights.<sup>15</sup> Over time, in part perhaps because of a dearth of legal regulation, young people enjoyed a certain degree of autonomy and were thought of as more akin to adults than children.<sup>16</sup> By the early twentieth century, the law had shifted to lumping adolescents in with children who were decisionally incapable and in need of significant protection.<sup>17</sup> As the decades progressed, there came to be a more middle-ground approach in which some areas were more regulated than others and in which various cultural shifts preceded shifts in the legal line between immature adolescents and mature adults.

A remarkable example of the pliability of the categories of adult and adolescent occurred in 1971. During that year, in the midst of the turmoil of student protests, the war in Vietnam, changes in the educational opportunities available and pursued by young people, and questions being asked about the appropriateness of sending young people to die in wars when they were unable to vote,<sup>18</sup> Congress passed and the states

<sup>15</sup> James Morrissey writes:

Codified law in early colonial America encompassed a "parental sovereign" approach insofar as children were concerned. Derived from seventeenth and eighteenth-century English law, statutes defining intrafamily relationships tended to recapitulate prevailing European social structures, which were aristocratic and hierarchical in form. Children had no constitutional or protective rights of their own, and parents had almost absolute autonomy in respect to their minor offspring and hence almost complete control.

JAMES MORRISSEY ET AL., CONSENT AND CONFIDENTIALITY IN THE HEALTH CARE OF CHILDREN AND ADOLESCENTS 2 (1986).

<sup>16</sup> As Heather Prescott explains:

[T]he experiences of premodern youth were substantially different from those of modern adolescents: although the former certainly had an ambiguous social status that encompassed parts of both childhood and adulthood, early modern youth also enjoyed a greater flexibility of roles and larger degree of autonomy from adult supervision than do modern adolescents. Rather than being a "psychosocial moratorium" from adulthood, childhood and youth were seen as periods of gradual introduction to adult roles and responsibilities.

HEATHER MUNRO PRESCOTT, A DOCTOR OF THEIR OWN 15 (1998) (citation omitted).

<sup>17</sup> Roger Levesque states:

In the first half of the Twentieth Century another truly fundamental change in the image of childhood occurred, which was the "invention" of adolescence. Its invention resulted from the same forces behind the progressive, child-saving efforts. That is, child-saving efforts contributed to adolescence being viewed not as a period close to adulthood but rather as a part of childhood. As a result of extending children's attributes to the post-pubescent period, laws governing infants were applied to adolescents. This marked a notable change since adolescents had heretofore enjoyed much more personal freedom. That is, adolescents, in essence, became children under parental control and choice, and subject to adults' paternal attention.

Roger Levesque, *The Internationalization of Children's Human Rights: Too Radical for American Adolescents*, 9 CONN. J. INT'L L. 237, 247-48 (1994) (citations omitted).

<sup>18</sup> See, e.g., *Lowering the Voting Age to 18: Hearings Before the Subcomm. on Constitutional Amendments of the S. Comm. on the Judiciary*, 91st Cong. 15 (1970) (statement of Theodore E. Sorenson, Formerly Special Counsel to President Kennedy) ("To [eighteen to

quickly ratified the Twenty-Sixth Amendment allowing those eighteen and older to vote in all Federal elections.<sup>19</sup> Suddenly, eighteen, rather than twenty-one, marked a young person as mature enough to cast a ballot for a candidate of her choice illustrating the fluidity of the categories of adult and child and the dance between law and culture.<sup>20</sup>

Present day, the law continues to lay claim to a compromise approach with concerns about the immaturity and recklessness of young people giving way to recognition that some life circumstances are of such weight and significance that young people faced with these peculiarly adult circumstances should be accorded adult rights with which to deal with the personal crisis.

The jumbled approach to doling out decision-making power to adolescents is powerfully illustrated by reviewing the wealth of state statutes regulating adolescent access to various types of healthcare with or without parental approval. For the most part, barring a statute such as those described in the paragraphs that follow, parents and caretakers are the only parties legally allowed to provide consent to healthcare for a person under the age of eighteen.<sup>21</sup>

In forty-eight states and the District of Columbia, the age of majority, meaning the age at which a minor becomes an adult and inherits many of the privileges and perils that come with that status, is eighteen.<sup>22</sup> Until this age, in the context of healthcare, state laws rest on a presumption that minors are incompetent and lack the ability to make cogent, mature, and binding decisions about their own well being.<sup>23</sup> One com-

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twenty-one-year-old soldiers,] the debate over Vietnamization, reescalation, and negotiation is not just a matter of party politics or abstract foreign policy – it is literally a matter of life or death. Yet they have no voice whatever in the process which determines whether they live or die.”).

<sup>19</sup> U.S. CONST. amend XXVI.

<sup>20</sup> Interestingly, though they have come to possess great cultural significance, the early origins of twenty-one and eighteen as markers of adulthood were based, at least in part, on a young man’s ability to carry weapons and bear armor and not an assessment of cognitive capacity. Lois A. Weithorn, *Involving Children in Decisions Affecting Their Own Welfare*, in CHILDREN’S COMPETENCE TO CONSENT 239 (Gary B. Melton et al., eds., 1983) (“Yet, the ages of 18 and 21 delineating majority are arbitrary and stem from currently irrelevant historical concerns such as sufficient physical strength to bear heavy armor.”).

<sup>21</sup> Walter J. Wadlington, *Consent to Medical Care for Minors*, in CHILDREN’S COMPETENCE TO CONSENT, *supra* note 20, at 59-60.

<sup>22</sup> See, e.g., ALASKA STAT. § 25.20.010 (Michie 2002); ARIZ. REV. STAT. ANN. § 1-215 (West 2002); CAL. FAM. CODE § 25.1 (2002), HA. REV. STAT. ANN. § 577-1 (Michie 2002); D.C. CODE § 46-101 (2001); FLA. STAT. ANN. § 743.07 (2003); LA. CIV. CODE § 29; M.C.L.S. § 722.4. Some exceptions to the general rule of eighteen as the age of majority are Alabama and Nebraska where the age of majority is nineteen. ALA. CODE § 26-1-1 (2002); NEB. STAT. § 43-2101 (2002). In Mississippi the age of consent for medical purposes is eighteen though the general age of majority is twenty-one. WEST’S A.M.C. §§ 41-41-3, 41-41-51.

<sup>23</sup> The following indicates this presumption:

One rationale [for requiring parental consent to healthcare for minors] is that minors lack the capacity to make their own health care decisions and need to be protected

mentator summarized the law as it relates to adolescent decision-making as follows:

Legal treatment of adolescent autonomy for medical decision-making is based on a presumption of decisional incapacity. Specifically, minors . . . are presumed incapable of medical decision-making. The law's presumption of decisional incapacity for adolescent patients stems from a paternalistic paradigm in existence since the turn of the twentieth-century. . . . Underlying this paternalistic approach to adolescence is the idea that juveniles lack decisional capability and hence responsibility and accountability attendant for their acts . . . .<sup>24</sup>

The rule of parental consent is not solely based upon fears of adolescent incompetence. Other rationales for the rule include "the state's interest and families' interest in encouraging family involvement in minors' lives and health care providers' interest in being able to receive compensation for the services they provide to minors."<sup>25</sup>

The idea of competence to make medical decisions is a legal construct requiring individualized, rather than global, assessments based on the capacity of a given patient at a given point in medical treatment.<sup>26</sup> For purposes of healthcare decision-making, competence essentially refers to a patient's ability to provide informed consent, meaning consent that is offered "voluntarily, knowingly, and intelligently."<sup>27</sup> Rather than determining competence, healthcare providers have a responsibility for evaluating a patient's decision-making capacity prior to obtaining valid informed consent.<sup>28</sup>

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from their own improvident decisionmaking. The legal presumption that minors are incompetent rests at least in part on an assumption of courts and legislators that minors as a class lack the requisite capacity to make health care decisions for themselves.

U.S. CONG., OFFICE OF TECH. ASSESSMENT, *supra* note 6.

<sup>24</sup> Rhonda Gay Hartman, *Adolescent Decisional Autonomy for Medical Care: Healthcare Provider Perceptions and Practices*, 8 U. CHI. L. SCH. ROUNDTABLE 87, 91 (2001).

<sup>25</sup> OFFICE OF TECH. ASSESSMENT, *supra* note 6, at 123.

<sup>26</sup> *Id.* Courts charged with determining the competence of patients making seemingly irrational choices about life-saving treatment often turn to the testimony of mental health experts to evaluate a patient's ability to consent or refuse to consent to treatment. *See, e.g., In re Quackenbush*, 156 N.J. Super. 282 (1978) (based on a short meeting with the court and the testimony of two psychiatrists, judge found a medical "conscientious objector" competent to refuse amputation of his gangrenous legs in spite of impending death).

<sup>27</sup> Preston A. Britner et al., *Psychology and the Law: Evaluating Juveniles' Competence to Make Abortion Decisions: How Social Science Can Inform the Law*, 5 U. CHI. L. SCH. ROUNDTABLE 35, 40 (1998) (footnotes omitted).

<sup>28</sup> A competence evaluation and a determination of decision-making capacity are not one and the same. A healthcare provider who determines decision-making capacity makes a clinical determination rather than a determination on competence, which is a legal construct.

Issues of decision-making capacity and legal competence become more complicated and charged when a young person is involved. The issues are complex because the young patient is not legally required or allowed to provide consent to care even if he is capable, willing, and eager to give that consent or, in some circumstances, withhold consent. Parents possess a Constitutionally protected role, subsumed within the broad parental right to care and custody of a child, that includes making decisions for minor children on a wide range of issues including where they will live, what school they will attend, and what healthcare they will receive.<sup>29</sup> As explained by the United States Supreme Court:

Our jurisprudence historically has reflected Western civilization concepts of the family as a unit with broad parental authority over minor children. Our cases have consistently followed that course; our constitutional system long ago rejected any notion that a child is “the mere creature of the State” and, on the contrary, asserted that parents generally “have the right, coupled with the high duty, to recognize and prepare [their children] for additional obligations.” Surely, this includes a “high duty” to recognize symptoms of illness and to seek and follow medical advice. 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.<sup>30</sup>

Despite multiple cases throughout the decades that have directly or indirectly posed challenges to parental authority, the Supreme Court has held to its respect for the primacy of the parent.<sup>31</sup> While the Court continues to re-shape the contours of parental rights as family structures

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John D. Lantos & Steven H. Miles, *Autonomy in Adolescent Medicine*, 10 J. ADOL. HEALTH CARE 460, 462 (Nov. 1989).

<sup>29</sup> *Parham v. JR.*, 442 U.S. 584, 602 (1979); *see also* *Wisconsin v. Yoder*, 406 U.S. 205 (1972); *Prince v. Massachusetts*, 321 U.S. 158 (1944); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Meyer v. Nebraska*, 262 U.S. 390 (1923).

<sup>30</sup> *Parham*, 442 U.S. at 602 (1979) (citing *Pierce*, 268 U.S. at 535).

<sup>31</sup> *See, e.g.*, *Troxel v. Granville*, 530 U.S. 57 (2000) (declaring unconstitutional a child visitation statute that gave courts broad discretion to award visitation with any party over the objection of the fit custodial parent); *Hodgson v. Minnesota*, 497 U.S. 417 (1990) (declaring unconstitutional a two parent notice requirement for those under 18 seeking an abortion); *Parham*, 442 U.S. at 584 (involving a parent’s ability to “voluntarily” commit a minor to a psychiatric facility); *Carey v. Population Services International*, 431 U.S. 678 (1977) (involving a state’s ability to regulate minors’ access to contraception).

change and challenges to parental authority come from various corners,<sup>32</sup> the basic premise that parents are, in the first instance, the most appropriate party to engage in decision-making on behalf of all minor children remains at the core of family law jurisprudence.<sup>33</sup> As such, when a minor is in need of healthcare, it is the parent, not the patient, who must be informed and give consent for most procedures.<sup>34</sup>

Given the overarching legal paradigm when it comes to parents and children, it is not surprising that the vast majority of young people who receive healthcare during their adolescence cannot consent to that care but must have a parent or guardian make final decisions about diagnosis and treatment.<sup>35</sup> During minority, parents have not only a right, but also a statutory responsibility to seek medical care for their children.<sup>36</sup> In extreme cases, a parent may face criminal sanctions for dereliction of his duty to provide healthcare to a child.<sup>37</sup> Where the parent or guardian is

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<sup>32</sup> See, e.g., *Parham*, 442 U.S. at 584 (involving appropriate procedures for involuntary commitment of young people based on consent of their parents).

<sup>33</sup> See, e.g., *Troxel*, 530 U.S. at 66. ("In light of . . . extensive precedent, it cannot now be doubted that the Due Process Clause of the Fourteenth Amendment protects the fundamental right of parents to make decisions concerning the care, custody, and control of their children.").

<sup>34</sup> As Wadlington explains:

If it is to be binding, consent to medical treatment must be obtained from a person who has legal capacity to give it. . . . Until a child reaches the legal age of majority, is emancipated generally or is specifically empowered by legislative or judicial action to consent to medical treatment, the child's parent or guardian usually has legal capacity to give or withhold consent to treatment. If consent is withheld arbitrarily, contrary to the needs of the child, a course of action may be available against the parent under the abuse and neglect statutes; courts generally are empowered either through such laws or under the broad scope of *parens patriae* jurisdiction to appoint a guardian for the purpose of consenting to treatment of an incompetent. But without consent from some competent person or agency, a physician who renders treatment not falling within the exception of the emergency doctrine risks a legal action.

Wadlington, *Consent to Medical Care for Minors*, in Melton, *supra* note 21, at 59-60.

<sup>35</sup> Heather Boonstra & Elizabeth Nash, *Minors and the Right to Consent to Healthcare*, THE GUTTMACHER REPORT ON PUBLIC POLICY, Aug. 2000, at 4.

<sup>36</sup> See, e.g., ALA. CODE § 12-15-1 (2004) (defining a dependent child as one "[w]hose parent, parents, guardian, or other custodian neglects or refuses. . . to provide or allow medical, surgical, or other care necessary for the child's health or well-being); ALASKA STAT. § 47.10.014 (Michie 2004) ("[T]he court may find neglect of a child if the parent, guardian, or custodian fails to provide the child with . . . medical attention. . . though financially able to do so or offered financial or other reasonable means to do so."); CAL. WEL. & INST. CODE § 300 (2004) (dependent child is one who "has suffered, or there is a substantial risk that the child will suffer, serious physical harm or illness, as a result of . . . the willful or negligent failure of the parent or guardian to provide the child with . . . medical treatment. . .").

<sup>37</sup> See, e.g., *Ex parte Lucas*, 792 So.2d 1169 (Ala. 2000) (involving mother indicted for capital murder based on a failure to provide life-saving medical services for her child); *Everley v. State*, 784 So.2d 963 (Fla. 1999) (involving mother convicted of felony child abuse for failure to seek out medical care for child with pneumonia who died); *Woods v. State*, 724 So.2d 40 (Ala. Crim. App. 1997) (upholding criminal conviction for father who failed to get medical treatment for child with second-degree burns).

so deficient in caretaking duties that he risks the health and safety of the young person, the state may seek a finding that the child has been neglected and may invoke its *parens patriae* power through which decision-making for the child will shift, not to the affected young person, but to the state.<sup>38</sup> Therefore, in general, a young person cannot seek a vaccination, attend an annual physical, have a cavity filled, or ask for an eye exam without the knowledge or consent of an adult caretaker. Even the most innocuous provision of care generally cannot legally take place without consultation and consent from parents or caretakers.

While the baseline rule is that a healthcare provider can only provide care to an adolescent with the consent of a parent or guardian, states have carved out a limited number of exceptions to the rule. Pregnancy is one area in which the emergent needs of an adolescent trump concern about parental rights and adolescent incompetence. Recognizing the serious issues inherent in a decision to carry a pregnancy to term and become a mother and the reluctance of some young women to talk about these issues with parents, laws in twenty-eight states and the District of Columbia confer limited adult status on pregnant young women. In these states, a healthcare provider treating a pregnant adolescent who wishes to carry her child to term is legally bound to provide prenatal care to that young woman as though she has obtained the age of majority.<sup>39</sup> Further, for the most part, the treating healthcare provider has no legal obligation

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<sup>38</sup> See, e.g., *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991) (involving state seeking a finding of neglect against Christian Scientist parents who refused consent for chemotherapy for a child with cancer); *In re Philip B.*, 156 Cal.Rptr. 48 (1979) (involving state seeking a finding of dependency where parents refused to consent to heart surgery for their child afflicted with Down's Syndrome); *In re Helen Vasko*, 238 A.D. 128 (N.Y. 1933) (involving state seeking a finding of neglect where parents refused consent to eye surgery for their two-year-old daughter).

<sup>39</sup> ALA. CODE § 22-8-6 (2004); ALASKA STAT. § 25.20.025 (Michie 2003); ARK. CODE ANN. § 20-9-602 (2003); CAL. FAM. CODE § 6925 (West 2004); HAW. REV. STAT. ANN. §§ 577A-2, 577A-3 (Michie 2002) (allowing for disclosure to parents at the discretion of the healthcare provider); IDAHO CODE § 39-4302 (Michie 2004); 325 ILL. COMP. STAT. ANN. 10/1 (West 2002); COLO. REV. STAT. § 13-22-105 (2004); D.C. MUN. REG. § 600.7 (2004); FLA. STAT. ANN. § 743.065 (West 2004); KAN. STAT. ANN. § 38-123 (2003); KY. REV. STAT. ANN. § 214.185 (Banks-Baldwin 2004); MD. CODE ANN., HEALTH-GEN. I § 20-102 (2004); MASS. GEN. LAWS ANN. ch. 111, § 121A (2004); MICH. COMP. LAWS ANN. § 333.9132(1) (West 2001); MINN. STAT. ANN. § 144.343 (West 2004); MISS. CODE ANN. § 41-41-3 (2004); MO. REV. STAT. § 431.061(4) (2004); MONT. CODE ANN. § 41-1-402 (2003); N.J. REV. STAT. 9:17A-1 (2002); N.M. STAT. ANN. §§ 24-1-13, 24-1-13.1 (Michie 2004); N.Y. PUB. HEALTH LAW § 2405 (McKinney 2003); N.C. GEN. STAT. § 90-21.5 (2004); OKLA. STAT. ANN. tit. 63, § 2602 (2004) (healthcare provider may disclose to parents at her discretion); 35 PA. CONS. STAT. §§ 521.13, 10103 (2003); TENN. CODE ANN. § 63-6-229 (2004); TEX. FAM. CODE ANN. § 32.003 (2002); VT. STAT. ANN. tit. 33, § 1101 (2004); VA. CODE ANN. § 54.1-1969(E)(2) (Michie 2002).

and, in some cases, no statutory right to report the pregnancy to the patient's parent or guardian.<sup>40</sup>

For young women who do not wish to carry a pregnancy to term, states may regulate access to abortion, though there are limits on how restrictive the state may be.<sup>41</sup> More than half of the states require a young woman to notify a parent before getting an abortion,<sup>42</sup> though the Court has required that these statutes provide a young woman with the option of seeking a judicial bypass of the parental notification requirement.<sup>43</sup>

Pregnancy is only one criterion for conferring limited healthcare decision-making rights on minors. In all states and the District of Columbia, minors who have a sexually transmitted infection ("STI"), specifically including human immunodeficiency virus ("HIV") in some states and not in others, may consent to STI related treatment.<sup>44</sup> Adoles-

<sup>40</sup> See, e.g., COLO. REV. STAT. § 13-22-105; D.C. MUN. REG. § 600.7; FLA. STAT. ANN. § 743.065; KY. REV. STAT. ANN. § 214.185; MO. REV. STAT. § 431.061(4); N.Y. PUB. HEALTH LAW § 2405; TEX. FAM. CODE ANN. § 32.003.

<sup>41</sup> See, e.g., *Belotti v. Baird*, 443 U.S. 622 (1979) (declaring unconstitutional a Massachusetts parental consent statute without an adequate judicial bypass provision); *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52 (1976) (declaring unconstitutional a Missouri parental consent requirement).

<sup>42</sup> PLANNED PARENTHOOD, *Fact Sheet Teenagers, Abortion, and Government Intrusion Laws*, available at <http://www.plannedparenthood.org/library/ABORTION/laws.html> (stating that thirty-four states have laws mandating the involvement of at least one parent in abortion decision-making unless a woman obtains judicial approval for the procedure).

<sup>43</sup> *Ohio v. Akron Center for Reproductive Health*, 497 U.S. 502, 510 (1990); *Hodgson v. Minnesota*, 648 F. Supp. 756, 763-64 (1990).

<sup>44</sup> ALA. CODE § 22-8-6; ALASKA STAT. § 25.20.025; ARIZ. REV. STAT. ANN. § 44-132.01; ARK. CODE ANN. § 20-16-508 (healthcare provider may disclose information over the objection of the patient); CAL. FAM. CODE § 6926(a); CAL. HEALTH & SAFETY CODE § 121010; CONN. GEN. STAT. § 39a-592 (requires parental consent unless healthcare provider believes that parental involvement would result in non-treatment or if minor request that parents not be informed); DEL. CODE ANN. tit. 16 § 710; D.C. MUN. REGS. § 600.7, D.C. CODE ANN. § 7-1605 (allows for testing for HIV and healthcare provider may inform parents at her discretion); FLA. STAT. ANN. § 384.30; GA. CODE ANN. § 31-17-7(a) (healthcare provider may disclose to parents at her discretion); HAW. REV. STAT. ANN. §§ 577A-2, 577A-3 (healthcare provider may disclose at her discretion); IDAHO CODE §§ 39-4302, 39-4303; 410 ILL. COMP. STAT. ANN. 210/4 (West 2002); COLO. REV. STAT. § 25-4-402(4); IND. CODE ANN. § 16-36-1-3 (Michie 2002); IOWA CODE ANN. §§ 139A.35 (2002) (allows for disclosure of HIV test results to parents); KAN. STAT. ANN. § 65-2892; KY. REV. STAT. ANN. § 214.185; LA. CIV. CODE ANN. § 40:1095 *et. seq.*; ME. REV. STAT. ANN. tit. 22 § 1501 *et. seq.*; MD. CODE ANN. HEALTH-GEN. I § 20-102; MASS. GEN. LAW ANN., ch. 111 § 117, MICH. COMP. LAWS ANN. § 333.5127; MINN. STAT. ANN. § 144,343; MISS. CODE ANN. § 41-41-13; MO. REV. STAT. § 431.061(4); MONT. CODE ANN. § 41-1-402; NEB. REV. STAT. § 71-504; NEV. REV. STAT. § 129.060; N.H. REV. STAT. ANN. § 141-C:18.(II) (2002) (minor must be fourteen or older); N.J. REV. STAT. 9:17A-4 (healthcare provider may disclose at her discretion); N.M. STAT. ANN. § 24-1-9; N.Y. PUB. HEALTH LAW § 2305; N.C. GEN. STAT. § 90-21.5; N.D. CENT. CODE § 14-10-17; OHIO REV. CODE ANN. § 3701.24.2; OKLA. STAT. ANN. tit. 63, § 2602 (healthcare provider may disclose at her discretion); OR. REV. STAT. § 109.610 (2001); 35 PA. CONS. STAT. § 10103 (2002); R.I. GEN. LAWS § 23-8-1.1(2001); S.C. CODE ANN. §§ 20-7-280, 290 (minor must be 16 or older); S.D. CODIFIED LAWS § 34-23-17; TENN. CODE

cents in forty-three states and the District of Columbia may make decisions related to care for drug or alcohol dependency, generally without the knowledge or consent of a parent or guardian.<sup>45</sup> Adolescents in need of mental health services may seek those services without the knowledge or consent of their parents in twenty-two states and the District of Columbia.<sup>46</sup> Several states also have statutes providing that minors may

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ANN. § 63-6-229; TEX. FAM. CODE § 32.003; UTAH CODE ANN. § 26-6-18; VT. STAT. ANN. tit. 18, § 4226 (healthcare provider must notify parent if condition requires immediate hospitalization); VA. CODE ANN. § 54.1-2969(E)(1) (healthcare provider may release test results to parent or guardian at her discretion); WASH. REV. CODE § 70.24.110 (minor must be fourteen or older); W. VA. CODE §§ 16-4-10, 16-3C-2; WIS. STAT. § 252.11; WYO. STAT. ANN. § 35-4-131.

<sup>45</sup> ALA. CODE § 22-8-6; ARIZ. REV. STAT. ANN. § 36-2024 (1986) (providing that a minor or her parent may apply for treatment for alcohol dependency); ARK. CODE ANN. § 20-9-602; CAL. FAM. CODE § 6929 (providing that a minor twelve years or older may consent to services, provided that the healthcare provider includes parents in treatment plan, unless such involvement would be detrimental to the child); COLO. REV. STAT. § 25-1-308; CONN. GEN. STAT. ANN. § 17a-682; DEL. CODE ANN. tit. 16, § 2210 (providing that a minor twelve or older may consent); D.C. MUN. REG. § 600.7; FLA. STAT. ANN. §§ 394.499-94.4995; GA. CODE ANN. § 37-7-8; HAW. REV. STAT. ANN. § 577-26; IDAHO CODE § 39-307; 410 ILL. COMP. STAT. ANN. 210/4 (West 2002); IOWA CODE ANN. § 125.33 (West 1997); KAN. STAT. ANN. § 65-2892a; KY. REV. STAT. ANN. § 214.185; LA. REV. STAT. ANN. § 40:1095; ME. REV. STAT. ANN. tit. 22, §§ 1501, 1502-A (West 1995); MD. CODE ANN. HEALTH-GEN. I § 20-102; MASS. GEN. LAWS ANN. ch. 112, § 12E (West 2004); MICH. COMP. LAWS ANN. § 333.6121; MINN. STAT. ANN. § 144.343; MISS. CODE ANN. § 41-41-14 (providing that minor must be fifteen or older); MO. REV. STAT. § 431.061(4); MONT. CODE ANN. § 41-1-402; NEV. REV. STAT. § 129.050 (requiring healthcare provider to "make every reasonable effort to report the fact of treatment to the parent"); N.H. REV. STAT. ANN. § 318-B:12-a (requiring minor to be twelve years or older); N.J. STAT. ANN. § 9:17A-4 (providing that healthcare provider may inform parents at her discretion); N.Y. MENTAL HYG. LAW § 22.11 (McKinney 1999); N.C. GEN. STAT. § 90-21.5; N.D. CENT. CODE § 14-10-17; OH. REV. CODE ANN. § 3719.012; OKLA. STAT. ANN. tit. 63, § 2602 (providing that a healthcare provider may inform parents at its discretion); OR. REV. STAT. § 109.675 (providing that minor must be fourteen or older and healthcare provider must involve the parents); 71 PA. CONS. STAT. ANN. § 1690.112 (providing that healthcare provider may notify parents at her discretion); R.I. GEN. LAWS § 14-5-3, 14-5-4 (requiring parental consent unless it will negatively impact treatment); S.C. CODE ANN. §§ 20-7-280, 20-7-290 (providing that minor must be sixteen or older); S.D. CODIFIED LAWS § 34-20A-50; TENN. CODE § 63-6-229; TEX. FAM. CODE § 32.003; VT. STAT. ANN. tit. 18 § 4226 (requiring a healthcare provider to notify parent if condition requires immediate hospitalization); VA. CODE ANN. § 54.1-2969(E)(3); WASH. REV. CODE ANN. §§ 70.86A.235, 13.32A.030 (providing that minor must be thirteen or older and parents may be notified with consent of minor or if healthcare provider deems it necessary); WIS. STAT. ANN. § 51.47 (providing that minor must be twelve or older).

<sup>46</sup> ALA. CODE § 22-8-6; ARK. CODE ANN. § 20-9-602; CAL. FAM. CODE § 6924(b) (providing that minor twelve years or older may consent but healthcare provider must notify parents unless to do so would be detrimental); GA. CODE ANN. § 37-3-20(a); IDAHO CODE § 39-4302; 405 ILL. COMP. STAT. ANN. 5/3-501 (West 2002); COLO. REV. STAT. § 27-10-103; CONN. GEN. STAT. ANN. § 17a-682; D.C. MUN. REG. § 600.7; FLA. STAT. ANN. § 394.459; KY. REV. STAT. ANN. § 214.185; MD. CODE ANN., HEALTH-GEN. I § 20-102; MICH. COMP. LAWS ANN. § 330.1707(1) (must be fourteen or older); N.H. REV. STAT. ANN. § 135-C:12 (2004) (providing that minor may only consent to treatment in a state-run facility); N.M. ADMIN. CODE § 7.20.11.7 (minor must be fourteen or older); N.C. GEN. STAT. § 32A-32; OHIO REV. CODE ANN. § 5122.04 (minor must be fourteen or older); OR. REV. STAT. §§ 109.675(2),



make their own healthcare decisions when faced with an emergency.<sup>47</sup> A small number of states allow minors who have been sexually assaulted to consent to care related to the assault.<sup>48</sup>

The law of emancipation is another area in which the law manipulates the boundary between adolescence and adulthood. Statutory emancipation is a mechanism by which a small sub-class of adolescents seeks legal relief from the disability of their minority.<sup>49</sup> Through this process, “minors attain legal adulthood before reaching the age of majority,”<sup>50</sup> thereby assuming the power to: sign binding contracts, own property, keep their earnings, and disobey their parents. Although under eighteen, they are “considered as being over the age of majority” in most of their dealings with parents and third parties. Thus, while emancipated minors can sign contracts and stay out late, their adult status also means that their parents are no longer responsible for the minors’ support.<sup>51</sup>

A young person can obtain statutory emancipation in at least two ways, either through a court order or automatically pursuant to a statute. A minor can seek a court order of emancipation when she is living independently, thereby evidencing the capacity to function without parental resources, monetary and otherwise.<sup>52</sup> Statutes contemplate that minors who seek a court order of emancipation will establish a level of maturity that justifies their overnight transformation into legal adults although it is not clear that this showing is always made or required by decision-makers.<sup>53</sup>

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109.680 (minor must be fourteen or older); PA. STAT. § 7201 (2002) (minor must be fourteen or older and healthcare provider must notify parents); TENN. CODE ANN. § 63-6-229; TEX. FAM. CODE ANN. § 32.003; VA. CODE ANN. § 54.1-2969(E)(4) (Michie 2004); WASH. REV. CODE ANN. § 71.34.030 (minor must be thirteen or older).

<sup>47</sup> ALA. CODE § 22-8-3; ARIZ. REV. STAT. ANN. §§ 36-2271, 44-132; 405 ILL. COMP. STAT. ANN. 5/3-504; 410 ILL. COMP. STAT. ANN. 210/3; DEL. CODE ANN. tit. 13, § 707; KAN. STAT. ANN. § 65-2891; MISS. CODE ANN. § 41-41-7; MO. REV. STAT. § 431.061; MONT. CODE ANN. § 41-1-402; NEV. REV. STAT. § 129.040; N.H. REV. STAT. ANN. § 135:21-b; N.D. CENT. CODE § 14-10-17.1; OKLA. STAT. ANN. tit. 63 § 2602; S.D. CODIFIED LAWS ANN. § 20-9-4.2 (specifically does not apply to elective abortion, sterilization, or birth control).

<sup>48</sup> 410 ILL. COMP. STAT. ANN 70/5; ME. REV. STAT. ANN. tit. 22 §§ 1501, 1507; MD. CODE ANN., HEALTH-GEN. I § 20-102; N.J. STAT. ANN. § 9:17A-4.

<sup>49</sup> Sanger & Willemsen, *supra* note 13, at 240.

<sup>50</sup> *Id.*

<sup>51</sup> *Id.* at 240-41.

<sup>52</sup> *See, e.g.*, ALA. CODE §§ 26-13-1, 26-13-2, 26-13-4, 26-13-6 (providing that a minor may be emancipated with leave of the court); CAL. FAM. CODE § 7002; 750 ILL. COMP. STAT. ANN. 30/3-1, 30/3-2, 30/4, 30/5 (providing that a minor may be emancipated with leave of the court); MINN. STAT. ANN. § 144.341 (allowing emancipation for minors who are living independently); R.I. GEN. LAWS § 14-1-59.1 (2003) (providing that a minor may be emancipated with leave of the court).

<sup>53</sup> In a small study of emancipation petitions filed and approved over a two-year period in a California county, the authors recount rapid hearing procedures that lacked rigor and during which judges often failed to conduct a more than cursory review of the petitioner’s

Second, other minors are emancipated by statute based on status, rather than any requirement of establishing maturity and independence through a court proceeding.<sup>54</sup> In twenty-four states, certain categories of minors, typically those who are married, pregnant, parents, or in the armed services, are considered emancipated based on that status alone and may make independent decisions about general medical services.<sup>55</sup> Oddly enough, in some states, a young woman may be able to make healthcare decisions for her child that she could not make for herself without parental approval.

Emancipation provides a young person with broad, though not total, relief from the disabilities of age. For instance, the California statute grants adult-status to minors only in the following areas:

consenting to medical care; entering contracts; suing and being sued; ending parental support; controlling earnings; establishing a residence; dealing in real property; obtaining a work permit; ending parental vicarious liability; enrolling in school; owning stock; buying insurance; making a will or an estate plan; creating or revoking a trust; and authorizing other probate and estate-related activities.<sup>56</sup>

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satisfaction of the statutory requirements of independent living, financial responsibility, and voluntariness. Sanger & Willemssen, *supra* note 13, at 284-89.

<sup>54</sup> See, e.g., ALA. CODE § 22-8-4 (2002) (providing that minor must be fourteen or older and must be a high school graduate, married or pregnant); ALASKA REV. STAT. § 25.20.025; ARK. CODE ANN. § 20-9-602; CAL. FAM. CODE §§ 6911, 6922 (providing that minor must be living apart from parents and must manage his or her own financial affairs); FLA. STAT. ANN. §§ 743.064 & 743.0645; IDAHO CODE §§ 39-4302, 39-4303; 410 ILL. COMP. STAT. ANN. 210/1 (West 2002) (providing that minor must be married, a parent themselves, or have parental consent); IND. CODE ANN. § 16-36-1-3(a) (Michie 2002) (providing that minor must be emancipated, married, divorced, in the military, authorized by statute, or fourteen or older and living away from parents); KAN. STAT. ANN. § 38-123b (requiring minor to be sixteen or older); KY. REV. STAT. ANN. § 214.185; MD. CODE ANN., HEALTH-GEN. I § 20-102; MISS. CODE ANN. § 41-41-3 (providing that minor must have intelligence to understand procedure and its consequences); MONT. CODE ANN. § 41-1-402 (providing that minor must be married, pregnant, a high school graduate, emancipated, living apart from parents, and financially self-supporting if the health care is for minor's child); NEV. REV. STAT. § 129.030 (providing that minor must be living apart from parents for four months, married or been married, a mother, in danger of a serious health hazard, or able to understand the nature, purpose, and need for medical care and voluntarily request the care); N.J. REV. STAT. 9:17A-4 (providing that a healthcare provider may inform parents at its discretion); OR. REV. STAT. § 109.640 (providing that minor must be fifteen or older and the healthcare provider must involve the parents); 28 PA. CODE § 27.97; R.I. GEN. LAWS § 23-4.6-1 (providing that minor must be sixteen or older, married, or a parent); S.C. CODE ANN. § 20-7-280; TENN. CODE § 63-6-229; VA. CODE ANN. § 54.1-2969(A)-(B) (requiring a court order); WYO. STAT. § 14-1-101(b) (providing that minor must be legally married, on active duty in the military, treatment need must be urgent, and parents or guardian cannot be located, or minor must be living apart from parents and managing her own affairs).

<sup>55</sup> See *id.*

<sup>56</sup> Sanger & Willemssen, *supra* note 13, at 259 (citing CAL. CIV. CODE §§ 63, 63.1, & 63.2).

Therefore, for the purpose of legally buying or consuming alcohol or obtaining a driver's license, emancipation based on status or court order may not confer adult status on an emancipated minor.<sup>57</sup> However, an emancipated minor, whether emancipated by court order or by statute, is freed from an obligation to confer with parents or seek their consent on healthcare choices and bears financial responsibility for those choices.

In addition to or in place of statutes, some state courts invoke the common law mature minor doctrine to evaluate a minor's right to make healthcare decisions. The mature minor doctrine provides a seldom-used mechanism for circumventing the need for parental consent when a court determines that a young person is capable of making a healthcare decision with which his parents, healthcare provider, or the state may not agree.<sup>58</sup> The mature minor doctrine "holds that if a minor is of sufficient intelligence and maturity to understand and appreciate both the benefits and risks of the proposed medical or surgical treatment, then the minor may consent to that treatment without parental consent, other issues . . . not withstanding."<sup>59</sup> Importantly, adolescents adjudicated to be mature minors

differ from emancipated minors in that they are living at home, are not contributing to room and board, or are not parents themselves, married, or members of the armed forces; they are the most typical adolescents. The basis of their authority to consent derives from the developmental maturation of cognition, not from life-style status, as for emancipated minors, or age, as for those who have achieved majority.<sup>60</sup>

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<sup>57</sup> See *id.* at 259-59.

<sup>58</sup> The Illinois Supreme Court confronted the issue of mature minors when a seventeen-year-old Jehovah's Witness stricken with leukemia refused blood transfusions that were a necessary component of treatment for her terminal illness. *In re E.G.*, 549 N.E.2d 322, 325 (Ill. 1989). In finding that a young woman only six months shy of her eighteenth birthday and who the record indicated was quite mature could refuse life-saving treatment, the court wrote "[a]lthough the age of majority in Illinois is 18, that age is not an impenetrable barrier that magically precludes a minor from possessing and exercising certain rights normally associated with adulthood." *Id.* Similarly, the Tennessee Supreme Court adopted a mature minor exception as part of the state's common law where a seventeen-year-old woman consented to care by an osteopath that resulted in injuries to her back. See *Cardwell v. Bechtol*, 724 S.W.2d 739 (Tenn. 1987). The court wrote, "[w]e hold that the mature minor exception is part of the common law of Tennessee. Its application is a question of fact for the jury to determine whether the minor has the capacity to consent to and appreciate the nature, the risks, and the consequences of the medical treatment involved." *Id.* at 749; see also *In re Swan*, 569 A.2d 1202 (Me. 1990) (allowing parents to effectuate the desire of a seventeen-year-old in a persistent vegetative state to end artificial nutrition).

<sup>59</sup> MORRISSEY ET AL., *supra* note 15, at 43.

<sup>60</sup> *Id.*

Application of the mature minor doctrine does not depend on the nature of the young person's ailment<sup>61</sup> though some opine that it would not be applied to "non-beneficial care, including tissue donation, particularly when complex issues and significant risks are involved which could be difficult for any patient to appreciate."<sup>62</sup> Furthermore, application of the doctrine does not require that the young person has reached any specific age though it is generally applicable to older adolescents.<sup>63</sup> Significantly, the application of the mature minor doctrine, in allowing for individualized assessment of a young person's decision-making capacity, is based "on a rejection of the presumption of minors' incompetency and the underlying assumption that minors as a class lack decisionmaking capacity."<sup>64</sup>

Based on current law, while most adolescents seeking care from a healthcare provider will need to do so with the consent and knowledge of their parents, certain limited categories of young people—generally those who have or suspect that they have an STI, are pregnant, need drug or alcohol treatment, mental healthcare services or who have been emancipated by court order or statute—may seek healthcare on the same basis as adults. One commentator has decried the inadequacy of this "patchwork quilt of rights and limitations" creating an incongruous situation in which "[a] teenage mother must give consent before her baby may be treated, but, by and large, is not permitted to consent to her own health care. An adolescent boy can be tested and treated for HIV without parental involvement, but his parents must consent to setting his broken leg."<sup>65</sup>

#### B. UNDERSTANDING THE EXCEPTIONS TO THE RULE

The statutes and doctrines creating a web of exceptions to the idea of broad adolescent decisional incompetence in the context of healthcare further at least two categories of goals: one practical and the other ethical. The practical goal is a public health one that seeks to stem the spread of communicable diseases, decrease rates of untreated drug or alcohol addiction, and allow access to other stigmatized treatment such as pregnancy related care for a young woman by encouraging young people to access care in circumstances that might lead to a failure to receive care if parents had to be informed.<sup>66</sup> As the overwhelming number of

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<sup>61</sup> *Id.*

<sup>62</sup> *Id.*

<sup>63</sup> *Id.*

<sup>64</sup> OFFICE OF TECH. ASSESSMENT, *supra* note 6, at 127.

<sup>65</sup> Michelle Oberman, *Minor Rights and Wrongs*, 24 J. L. MED. & ETHICS 127, 127 (1996).

<sup>66</sup> Jennifer Rosato, *Let's Get Real: Quilting a Principled Approach to Adolescent Empowerment in Health Care Decision-Making*, 51 DEPAUL L. REV. 769, 778 (2002) ("[T]he

jurisdictions legislating on the issue of STIs indicates, fear of driving potentially infectious, sexually active young people away from care that could be curative helped push many legislators to pass laws giving minors significant freedom in deciding the course of their STI-related health care.<sup>67</sup>

One commentator rationalized the existence of healthcare emancipation statutes as “reflect[ing] a public consensus that ensuring minors’ access to the given treatment outweighs parental interests in controlling the care a child receives. The focus of such exceptions rests not on an assessment of maturity, but on a calculus that grants minors autonomy only when the treatment is relatively low-risk, and when denying access may cause the minor (or the public at large) to suffer permanent harm.”<sup>68</sup>

In addition to personal risk, there are larger societal consequences to which these healthcare emancipation statutes respond. Substance abuse has a significant societal cost in the form of crime, incarceration, loss of productive citizens, and the need for healthcare and rehabilitation.<sup>69</sup> By making sure that young people have access to confidential care, society protects its interest in the health of its citizens and its financial interest in the public health. Similarly, teenage pregnancy and STI transmission have an identifiable and quantifiable societal cost, both financial and otherwise, as young women with, at best, only high school educations and largely limited resources give birth to children whom they will struggle to support. At the same time, young people with STIs burden the public health system when disease spreads unchecked ultimately causing unrec-

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basic rationale of [status based exceptions to the rule of parental consent] is that the cost of a minor failing to seek treatment is greater than the state’s desire to involve parents in their child’s health care decision-making.”); Tomas J. Silber, *Ethical Considerations in Caring for Adolescents*, 10 PEDIATRIC ANNALS 408, 409 (1981) (“[M]any adolescents who need access to medical care in order to better protect their health would never consult a doctor if they knew he would require parental consent prior to treatment.”).

<sup>67</sup> Michelle Oberman explains the advent of statutes allowing minors to consent to STI related care as follows:

During [the 1960s], growing evidence suggested that sexual activity among teenagers was relatively commonplace, and that, because they could not consent to care on their own, teenagers’ health status was in jeopardy. Specifically, it became increasingly evident that an epidemic of sexually transmitted diseases was spreading among unemancipated teenagers. This public health concern, coupled with a fear that teens would not seek treatment for these communicable conditions if their parents had to be notified of—let alone give consent for—such treatment, led states to pass “minor treatment statutes.”

Oberman, *supra* note 65, at 130.

<sup>68</sup> *Id.* at 131.

<sup>69</sup> One source indicates that wide-ranging societal costs of substance abuse explaining that “untreated substance abuse increases the cost of every state’s criminal justice system; Medicaid; child welfare; juvenile justice; and mental health systems, totaling \$77.9 billion dollars in 1998.” HAZELDEN FOUNDATION, *Social and Criminal Impact* (Sept. 1998), available at [http://www.hazelden.org/servlet/hazelden/cms/ptt/hazl\\_7](http://www.hazelden.org/servlet/hazelden/cms/ptt/hazl_7) (citing CASA Study).

essary outbreaks and epidemics, creating a larger pool of individuals in need of treatment.<sup>70</sup> Thus, society has already made determinations that young people should be granted a right to autonomous decision-making where the failure to make a decision may have serious societal consequences. In contrast, where the benefit is a more individual one, the law has been slower to respond to the needs of young people.

The end result is that many healthcare emancipation statutes best serve a practical purpose that reflects not an assessment of maturity, but a need to protect minors from the adverse consequences of their own fear, unfounded or not, of parental repercussions.<sup>71</sup> Importantly, these statutes are not steeped in particular beliefs about adolescent capacity for decision-making.

Advocates who, during the height of the sexual revolution of the 1960s, pushed for the passage of statutes that provided limited consent rights to adolescents seeking care for STIs,

avoided using terminology that condoned sexual freedom among teenagers. Instead, the legislation was framed in terms of a “least harm” perspective, which justified removing parental consent barriers because doing so would protect young people from the consequences of their sexual behavior. The more fundamental issue of whether young people in general, and young women in particular, had the right to make reproductive decisions independently of their parents was carefully avoided, possibly because advocates feared that using a “reproductive rights” argument would make their cause even more controversial than it already was. For example, statues permitting minors to obtain treatment for sexually transmitted diseases without parental consent were aimed at preserving the public health and protecting the minor from the health risks associated with sexual intercourse, not at increasing the minor’s self-determination.<sup>72</sup>

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<sup>70</sup> A report from the Alan Guttmacher Institute estimates that “the total estimated cost of the nine million cases that occurred among fifteen to twenty-four year-olds in 2000 is \$6.5 billion.” Harrell W. Chesson, et al., *The Estimated Direct Cost of Sexually Transmitted Disease Among American Youth 2000*, 36 PERSP. ON SEXUAL AND REPROD. HEALTH, 11, 15 (2004). While rates of teenage pregnancy have been in a steady decline, those young women who do experience pregnancy are more likely to drop out of high school and live in poverty, and their offspring will often experience various “health and developmental problems.” PLANNED PARENTHOOD, *Fact Sheet-Reducing Teen Pregnancy-Pregnancy & Childbearing Among U.S. Teens* (December 1999), available at [http://www.plannedparenthood.org/library/TEEN-PREGNANCY/teenpreg\\_fact.html](http://www.plannedparenthood.org/library/TEEN-PREGNANCY/teenpreg_fact.html).

<sup>71</sup> Oberman, *supra* note 65, at 131.

<sup>72</sup> PRESCOTT, *supra* note 16, at 157.

Though the rhetoric behind these statutes gave little credence to the idea of adolescent self-determination, it is clear that advocates for young people, particularly as they pursued cases in the courts, recognized the benefit of framing their positions in terms of adolescent rights. For instance, in *Carey v. Population Services International*, decided in 1977, the Supreme Court, while admitting reluctance to “define ‘the totality of the relationship of the juvenile and the state,’”<sup>73</sup> described adolescents as important rights-bearers, reiterating earlier contentions that “[m]inors, as well as adults, are protected by the Constitution and possess constitutional rights.”<sup>74</sup> While the case struck down a New York statute restricting access to contraceptives to those under sixteen, the Court specifically declined to speak to the question of what level of Constitutional protection for private and consensual sexual conduct existed for adolescents or adults.<sup>75</sup> Even in making these judgments, the Court did not focus on the issue of adolescent capacity for thoughtful decision-making to ground its determination that young people should have access to contraceptives.

The preceding discussion should not diminish the importance of the public health purpose that appears to have been a motivating force behind some adolescent healthcare emancipation statutes. However, in an ever-evolving world, it is wise to reflect on what other loftier and perhaps more intangible ethical goals, not explicitly a part of earlier campaigns, might be served in the present. While it may not have been prudent to speak in terms of adolescent capacity or autonomy during previous eras, there is value in re-evaluating the underlying premises of such laws, explicit and implicit, and ascertaining whether an evolving world and expanding knowledge can breathe new life into old statutes. In that vein, it is prudent to speak to the importance of autonomy and respect for decision-making capacity as a cornerstone principle of the provision of healthcare for young and old.

Part of the ethical analysis of how healthcare is provided focuses on the extent to which a patient’s autonomy is protected and respected.<sup>76</sup> Applying an autonomy analysis to the healthcare provided to an adolescent who cannot consent to her own care, one must “reject[ ] the formulation that the adolescent is being protected [and i]nstead . . . view[ ] the insistence on parental consent as a denial of the adolescent’s rights as a person, separate from his parents.”<sup>77</sup>

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<sup>73</sup> *Carey*, 431 U.S. 678, 692 (1977) (citing *In re Gault*, 387 U.S. 1 13 (1967)).

<sup>74</sup> *Id.* at 692 (citing *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52, 74 (1976)).

<sup>75</sup> *Id.* at 695.

<sup>76</sup> Silber, *supra* note 66, at 409.

<sup>77</sup> *Id.*

The personal autonomy at issue in this context refers to “[t]he realm of inviolable sanctuary most of us sense in our own beings.”<sup>78</sup> Personal autonomy, as manifested in the healthcare context by requiring informed consent, is widely understood to be of enormous value and benefit to individuals. As one philosopher has noted, “Whatever else we mean by autonomy . . . it must be a good and admirable thing to have, not only in itself but for its fruits—responsibility, self esteem, and personal dignity. Autonomy so conceived is not merely a ‘condition,’ but a condition to which we aspire as an ideal.”<sup>79</sup>

While debates have raged in philosophy and law about the meaning or usefulness of autonomy, particularly when the concept is subjected to critique based on gender or age,<sup>80</sup> for purposes of this article, I assume that autonomy is overall a good thing and that it embraces the notion that “[t]he autonomous person, as the saying goes, is ‘his own man’ or ‘her own woman.’ He/she doesn’t ‘belong’ to anyone else, either as property or as possession. Anyone who would deal in her affairs must come to terms with *her*, or her agent. It will not do to negotiate only with her parents or her boss, and she has no ‘keeper.’”<sup>81</sup>

This is not to say, however, that an autonomous individual is without connection, community, or allegiance. As recognized by many feminist theorists, one of the myths of autonomy is the insistence by some that dependence is the antithesis of an autonomous existence.<sup>82</sup> Martha Fineman explains:

[A]utonomy is often presented as a state of being that is attainable by all. It is also perceived as an individually (and autonomously) developed characteristic that ulti-

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<sup>78</sup> See Joel Feinberg, *Autonomy*, in *THE INNER CITADEL—ESSAYS ON INDIVIDUAL AUTONOMY* 27 (John Christman ed., 1989).

<sup>79</sup> *Id.* at 31.

<sup>80</sup> See MARILYN FRIEDMAN, *Autonomy and Its Discontents*, in *AUTONOMY, GENDER, POLITICS* 30-55 (2003) (describing and responding to various criticisms of autonomy); see generally *RELATIONAL AUTONOMY* (Catriona Mackenzie and Natalie Stoljar eds., 2000) (collection of feminist essays critiquing traditional notions of autonomy and embracing the notion of relational autonomy).

<sup>81</sup> Feinberg, *supra* note 78, at 31.

<sup>82</sup> MARTHA FINEMAN, *THE AUTONOMY MYTH* (2004). One advocate for children explains:

Dependency should not be a reason to be deprived of choice and respect. An important contribution of feminist moral theory has been to question the firmly embedded assumption that moral agency and citizenship rights require a person to be independent, totally autonomous. Feminists, such as Carol Gilligan in *In A Different Voice* and Marilyn Friedman, have questioned this deeply held assumption. It is, they argue, derived from a specifically male experience of social relations which values competition and solitary achievement. It is inappropriately individualistic. Dependence is a basic human condition. We have all been dependent and many of us have passed through phases of dependency or will do so.

MICHAEL FREEMAN, *THE MORAL STATUS OF CHILDREN* 73 (1997).



mately reflects the worth (or lack thereof) of the person. In this simplistic version of autonomy, the realities of . . . dependency are absent. In fact, the world that this vision of autonomy imagines is a world that can only be populated by adults, and then only by those adults possessing sufficient capabilities and competencies to make it possible that their only demand of government (aside from the provision of security and courts of law) be for rules that guarantee their right to be left alone to realize the gains and glory their individual talents may bring. . . . [S]uch a vision is a chimera, and [ ] this version of autonomy is both undesirable and unattainable on an individual level, and therefore, destructive from a policy perspective. We all experience dependency, and we are all subsidized during our lives (although unequally and inequitably so).<sup>83</sup>

As used in this article, autonomy does not demand a rugged or radical individualism in which people are outside of communities, but instead embraces individuals who make decisions with the support of and in conjunction with the communities, large and small, to which they belong. As philosopher Joel Feinberg elucidates:

[I]f we so desire, we can minimize our commitments and thus achieve a greater amount of de facto moral independence. We may, if we wish, go through life unmarried, or forgo having children, or near neighbors. We may make as few promises as possible to others, incur no debts, join no partnerships. The picture that emerges from all of this is that of an uncommitted person, maximally independent of the demands of others. Yet it is hard to imagine such a person with the moral virtues that thrive on involvement—compassion, loyalty, cooperativeness, engagement, trust. If we think of autonomy as the name of a condition which is itself admirable, a kind of ideal condition, then the uncommitted person is subject to demerits on this score. He is clearly no paragon.<sup>84</sup>

Few well-functioning human beings can, or would wish, to claim a completely independent existence. We live in various webs of interde-

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<sup>83</sup> FINEMAN, *supra* note 82, at 272-273.

<sup>84</sup> Feinberg, *supra* note 78, at 38 (internal citation omitted).

pendence formed by families, friendships, employment, and citizenship in various communities and countries.<sup>85</sup> Feinberg explains,

There is a danger in discussing, in the abstract, the ideal qualities of a human being. Our very way of posing the question can lead us to forget the most significant truth about ourselves, that we are social animals. No individual person selects “autonomously” his own genetic inheritance or early upbringing. No individual person selects his country, his language, his social community and traditions. No individual invents afresh his tools, his technology, his public institutions and procedures. And yet to *be* a human being is to be part of a community, to speak a language, to take one’s place in an already functioning group way of life. We come into awareness of ourselves as part of ongoing social processes. . . .<sup>86</sup>

One could, then, accurately describe all human beings who do not live completely isolated lives as being simultaneously autonomous and dependent, with the balance between the two shifting based on changes in age, location, health status, and other factors.

In the context of children and adolescents, the development and existence of autonomy as a component of protecting one’s moral status, meaning the extent to which a person deserves to be an object of moral concerns,<sup>87</sup> is as important as it is for adults. Feinberg explains:

In the continuous development of the relative-adult out of the relative-child there is no point before which the child himself has no part in his own shaping, and after which he is the sole responsible maker of his own character and life plan. Such a radical discontinuity is simply not part of anyone’s personal history. The extent of the child’s role in his own shaping is, instead, a process of continuous growth already begun at birth. . . . From

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<sup>85</sup> “It is impossible to think of human beings except as part of ongoing communities, defined by reciprocal bonds of obligation, common traditions, and institutions . . . . The ideal of the autonomous person is that of an authentic individuals whose self-determination is as complete as is consistent with the requirement that he is, of course, a member of a community.” Feinberg, *supra* note 78, at 45. In a similar vein, Martha Fineman explains, “[t]he very terms of autonomy—as exemplified by economic independence and a detached notion of self-sufficient—might well be redefined or reimagined in the public mind. Independence is not the same as being unattached. Independence from subsidy and support is not attainable, nor is it desirable; we want and need the webs of economic and social relationships that sustain us. It is not beyond our current ability to imagine a new concept of autonomy, one that recognizes that the individual lives within a variety of contexts and is dependent upon them.” FINEMAN, *supra* note 82, at 28.

<sup>86</sup> Feinberg, *supra* note 78, at 45.

<sup>87</sup> See STEPHEN HOLLAND, *BIOETHICS* (2003).

the very beginning, then, the child must—inevitably *will*—have some input in his own shaping, the extent of which will grow continuously even as the child’s character itself does. After that, the child can contribute towards the making of his own self and circumstances in ever increasing degree. These contributions are significant even though the child is in large part (especially in the earliest years) the product of external influences over which he has no control, and his original motivational structure is something he just finds himself with, not something he consciously creates. Always the self that contributes to the making of the newer self is the product of both outside influences *and* an earlier self that was not quite as fully formed. . . . At every subsequent stage the immature child plays a greater role in the creation of his own life, until at the arbitrarily fixed point of full maturity, he is at last fully in charge of himself, his more or less finished character the product of a complicated interaction of external influences.<sup>88</sup>

Like most adults, adolescents have both voluntary and involuntary commitments that impact their autonomy without depriving them of that autonomy. There are “natural” commitments, described by Martha Fineman as inevitable dependencies,<sup>89</sup> formed by youth and biological dependence, but as we age we also make voluntary choices to continue to be influenced in large and small ways by others including parents, teachers, and friends. We commit to being a part of a family and being both a leader and follower in our families. In other words:

If there is such a thing as “personal sovereignty,” that presumably belongs to all competent adults and to no newborn infants, but before the point of qualification for full sovereignty, children must be understood to have various degrees of “local autonomy.” . . . It becomes difficult, however, to think of the near-adult teenager as deriving *all* of his autonomy by parental delegation. A certain minimum, at least, he has by natural right, even if his privileges to use the family car, to stay out past midnight, and the like, are delegated and revocable.<sup>90</sup>

Equally as important is a recognition that an autonomous actor need not always act rationally, or with kindness or compassion. For, “[a] self-

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<sup>88</sup> Feinberg, *supra* note 78, at 34.

<sup>89</sup> FINEMAN, *supra* note 82, at 36.

<sup>90</sup> Feinberg, *supra* note 78, at 46.

governing person is no less self-governed if he governs himself badly, no less authentic for having evil principles, no less autonomous if he uses his autonomy to commit aggression against another autonomous person. The aggressor is morally deficient, but what he is deficient in is not necessarily autonomy."<sup>91</sup> In this way, then, it is false to suggest that young people lack autonomy because they may make decisions that appear irrational, cruel, or otherwise deficient. Autonomy need not rest on an assessment of the decision that might have been made by another, but instead is premised upon the process by which an actor reaches a decision.<sup>92</sup>

In the end, then, to appreciate and protect the moral status of adolescents as persons, it is necessary to recognize that:

[T]he dichotomy between protecting children and protecting their rights to autonomy is false. Children who are not protected, whose welfare is not advanced, will not be able to exercise self-determination: on the other hand, a failure to recognize the personality of children is likely to result in an undermining of their protection with children reduced to objects of intervention."<sup>93</sup>

Ultimately, to serve faithfully the dual purposes of protecting the public health and preserving moral status, the law must seek to regulate adolescent access to healthcare in a manner that is both practical and ethical. Focusing solely on a public health rationale ignores the protection and enhancement of moral status that logically flows from healthcare emancipation statutes. Moral lawmaking requires reflecting on the way in which the law can de-humanize and harm by failing to embrace fully the personhood of a group of people—here, adolescents.

If it is right that healthcare emancipation statutes and the other exceptions to an assumption of adolescent incapacity for making healthcare decisions serve both a public health and ethical purpose, then the quest to fulfill that ethical purpose remains largely unacknowledged and therefore unachieved. Rooted in concerns about adolescents eschewing necessary care rather than acknowledging adolescent autonomy and capacity, the exceptions detailed earlier in this section protect a broader societal interest more than they do the personal status concerns of individual adolescents. The ethical purpose of these statutes therefore feels inconsequential at worst and secondary to serving the public health at best.

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<sup>91</sup> *Id.* at 44.

<sup>92</sup> Gerald Dworkin, *The Concept of Autonomy*, in *THE INNER CITADEL* 62 (John Christman ed., 1989) (“[T]here is no specific content to the decision an autonomous person may take. An autonomous person may be a saint or sinner, a rugged individualist or a conformist, a leader or a follower.”).

<sup>93</sup> FREEMAN, *supra* note 82, at 53.

There are reasons both ethical and practical why acknowledging and protecting the inherent dignity of young people with a more comprehensive system of healthcare autonomy is necessary. Truly protecting both the personhood and the persons of adolescents requires a coherent theory of what role the law should play in regulating family dynamics, access to healthcare, and healthcare provider relationships when adolescents are involved.

## II. WHY THE LAW IS FAILING YOUNG PEOPLE

*With adolescents, respect for persons means balancing respect for the emerging capacity of an adolescent for independent decision-making with the need for continued special protections, where necessary.*<sup>94</sup>

This article advocates that laws regulating adolescent access to healthcare should encourage, or at least not impede, healthcare decision-making that avoids unnecessary fracturing of families, respects the capacity of the involved parties, supports positive healthcare provider-patient relationships, minimizes the need for state interference through the child welfare system or courts, and provides for an environment in which affected parties can make decisions that protect the physical and emotional health of the patient. The primary goal of law in the arena of adolescent healthcare should be to facilitate sound medical decision-making by and for young people through ethically sound legislation. This overarching goal can best be achieved by encouraging family communication, recognizing and supporting real-life decision-making patterns put in place by well-functioning families, and facilitating optimal healthcare provider/patient relationships to maximize the potential for good health outcomes. This section will address the importance of each of these factors and the ways in which the current system of laws fails to achieve them.

### A. FAMILY COMMUNICATION

The law as currently configured discourages family communication in at least two ways. First, by making the parent the only party legally capable of consenting to most adolescent healthcare, the law allows parents to avoid difficult conversations with young people about illness, including terminal illnesses or diseases with particularly difficult treatments.<sup>95</sup> Parents in crisis may choose to keep information from their

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<sup>94</sup> SOCIETY FOR ADOLESCENT MEDICINE, *Guidelines for Adolescent Health Research*, 33 J. OF ADOLESCENT HEALTH 396, 398 (2003).

<sup>95</sup> In the case of young children living with HIV, the American Academy of Pediatrics reports that:

child that the parents feel would be overwhelming or discouraging.<sup>96</sup> Anthropologist Myra Bluebond Langner observed in a study of children dying from leukemia that “[s]ome parents felt that protection also meant shielding the children from knowledge of the prognosis. They rationalized withholding information . . . even using deception with statements like ‘You’ll get better’ . . . on grounds that this protected children from unhappiness and the possibility of an inadvertent premature death.”<sup>97</sup> Often, young people will be well aware that something very serious is wrong with them, and the deception by caregivers and parents will heighten the patient’s sense of alienation, disconnect, and powerlessness created by the illness.<sup>98</sup>

Similarly, when young people find themselves in crisis moments—i.e., pregnant, drug dependent, or infected with an STI—healthcare emancipation statutes allow them to access care without parental knowledge or consent, but do not necessarily give healthcare providers clear guidance about whether, or when, the healthcare provider has the legal authority or legal responsibility to involve an adult caretaker in decision-making. Thus, a young person may engage in independent decision-making even where an informed parent would have been willing and able to provide non-injurious adult guidance. The needs of young people are

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[S]ome parents and health care professionals are reluctant to inform children about their HIV infection status. Data from several centers indicate that between 25% and 90% of school-age children with HIV infection/AIDS have not been told they are infected. Some of the reasons given by family members for not disclosing HIV infection/AIDS status are similar to reasons expressed by parents of children with other serious diseases, which include concerns about the impact that disclosure may have on a child’s emotional health and fear by the parents that the knowledge will negatively affect a child’s will to live. Additional reasons often given by the parents of HIV-infected children include a sense of guilt about having transmitted infection to the child, anger from the child related to knowledge of perinatal transmission, and fear of inadvertent disclosure by the child. Disclosure of status by the child may lead to stigmatization, discrimination, or ostracism toward the child and other family members. Health care professionals and families are also concerned about the difficulty children have keeping a ‘secret’ and limiting the disclosure to selected persons.

*Disclosure of Illness Status to Children and Adolescents with HIV Infection*, 103 *PEDIATRICS* 164, 164 (1999). See also, Carol J. Clafin & Oscar A. Barbarin, *Does “Telling” Less Protect More? Relationships Among Age, Information Disclosure, and What Children with Cancer See and Feel*, 16 *J. PEDIATRIC PSYCHOL.* 169 (1991) (reporting study in which many parents declined to inform young children of their own cancer diagnosis based on a desire to avoid overwhelming the young patient).

<sup>96</sup> See Clafin & Barbarin, *supra* note 95; see also, MYRA BLUEBOND-LANGNER, *THE PRIVATE WORLDS OF DYING CHILDREN* 214-217 (1978).

<sup>97</sup> BLUEBOND-LANGNER, *supra* note 96, at 217.

<sup>98</sup> *Id.* at 135-209 (describing the extensive knowledge about their illness, treatment and hospital surrounding of children with leukemia in spite of “[a] situation in which the parents and the staff unconsciously conspired to keep them in painless ignorance”); see also Jennifer L. Evans, *Are Children Competent to Make Decisions About Their Own Deaths?*, 13 *BEHAV. SCI. & L.* 27, 31 (1995) (“Most healthcare professionals agree that children with fatal illnesses are aware of their prognoses, even if they have not been told directly.”).

better served by encouraging healthcare providers to engage in dialogue with young people about parental involvement and to consider both the wishes of the patient and the risks and benefits of parental involvement based on confidential conversations with the patient.

## B. REAL FAMILIES MAKING REAL DECISIONS

While writing much more broadly on questions of autonomy, dependence, and privacy of the caretaking unit, Martha Fineman offers an abbreviated discussion on issues of children's autonomy within families. She writes,

[T]he determination of typical and atypical modes of operation in caretaker-dependent units presents an empirical question. My assumption is that a careful study would show that the relationship between typical caretakers and dependents is dynamic (it is in motion), fluid (easily changing shape), and interactive (the participants act upon each other). The reciprocal interactive nature of the relationship ensures that it will not be fixed. The reciprocity also means that in regard to family decision making [sic], the dependent will seldom, if ever, be absent.<sup>99</sup>

She continues:

Caretakers typically consider dependents' needs. Often dependents are an explicit part of the process of decision making [sic], and at times they are even in control of it. Just as the relationship is fluid within daily interaction, it is dynamic over time. While the authority of parent over a child will decline as the years pass, an adult child's authority over (and responsibility for) an elderly or ill parent may increase.<sup>100</sup>

While I agree with Fineman about the fluidity of parent (caretaker)/child (dependent) relationships and their interactive nature, I would also contend that the structure of medical decision-making, as reinforced and required by the law, minimizes the role to be played by the dependent who, though not absent, may not be afforded the opportunity to be fully present in healthcare decision-making. As I will argue more explicitly in the pages that follow, true respect for adolescent autonomy requires more than simply informing a young person of what will happen to her and

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<sup>99</sup> FINEMAN, *supra* note 82, at 305.

<sup>100</sup> *Id.* at 306.

demands that the law place greater emphasis on her right to be actively engaged by caretakers and healthcare providers.

The law gives wide latitude to parents to make decisions about healthcare treatment for minor children and companion decisions about whether their children should even be made aware of their own diseases.<sup>101</sup> In circumstances in which a child is too young to comprehend the nature of an illness and the risk and benefits of treatment, it is certainly justifiable or at least understandable to let the parent be sole arbiter of what is best for the child with an understanding that the state can interfere based on reports from other parties about the risk to the health of the child. Parents are the logical decision makers if one presumes that "parents, in contrast to their minor children, possess the intelligence, maturity, and experience needed for adequate and appropriate health care decisionmaking; and. . .that parents usually have an identity of interest with their minor children and will act in their best interests."<sup>102</sup> Nevertheless, even if it is appropriate to withhold information from a young child, cloaking an adolescent in ignorance is much less defensible. At some point, it becomes patently inappropriate, unethical, and practically unwise to make a decisionally-capable individual an outsider in conversations and decisions about her own health.

The discussion that follows rests upon several key assumptions, the most important of which is that in well-functioning families parents encourage adolescents to play a substantial role in decisions about the young person's own health. This initial assumption embraces a belief that most parents respect and love their children and generally avoid acting in ways which will injure those children and that parents want to impart life lessons to their children by encouraging them to care for their health, take personal responsibility for their own well-being, and act in their own best interest so that they can utilize these skills as they age and when their parents are absent. Though they may sometimes resist acknowledging that their babies have become young men and women, I also assume that parents must recognize an adolescent's growing capacity and learn to respond to that capacity for mature, forward thinking decision-making. Importantly, when families are functioning well, parents recognize that young people who feel alienated will be less cooperative with needed care. Finally, I assume that parents recognize that their

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<sup>101</sup> One could argue that investiture by law with the right to consent or withhold consent for healthcare does not automatically confer on parents the right to withhold information from a sick child. In fact, it seems logical to presume that these rights are not necessarily interconnected and become so only as a result of interpretative choices made by the legal profession rather than as a result of an intrinsic need to treat both knowledge and consent as being necessarily the same.

<sup>102</sup> OFFICE OF TECH. ASSESSMENT, *supra* note 6, at 125.



adolescents can and will make good decisions, particularly when supported and offered guidance by trusted adults.

Even though most parents respect and wish to do well for their children, there must also always be concern about the parent who does not act in the best interest of his child for a variety of reasons. Some parents suffer from drug or alcohol addictions that impair their ability to participate regularly and soundly in decision-making about their child's health. Some parents are abusive and may deprive their child of needed care for reasons of spite, punishment, or fear of legal consequences because of the role that they have played in causing their child's harm. For some parents, despite best intentions and grave concern, their instincts may not always serve the interests of a child. As one author explains:

The assumption that parents best understand what is in the best interest of their child is usually sound. However, situations can arise in which the parents' distress prevents them from attending carefully to the child's concerns and wishes. Simply complying with the parents' wishes in such cases is inadequate. It is more helpful and respectful of the child to affirm the parents' responsibility for the care of their child while allowing the child to exercise choice in a measure appropriate to his or her level of development and experience of illness and treatment. This approach does not discount the parents' concerns and wishes, but recognizes the child as the particular patient to whom the healthcare provider has a primary duty of care.<sup>103</sup>

Undoubtedly, a very young child generally cannot fully comprehend and respond to a serious health crisis.<sup>104</sup> By contrast, many, if not most, adolescents can respond to such a crisis, particularly when supported by trusted adults, both by acting in her own interest and in that of those around her.<sup>105</sup> For whatever reason, whether based on defensible or indefensible premises,<sup>106</sup> a parent should not hold hostage a young person

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<sup>103</sup> Christine Harrison et al., *Bioethics for Clinicians: Involving Children in Medical Decisions*, 156 CAN. MED. ASS'N J. 825, 826 (1997).

<sup>104</sup> See *infra* notes 124-141 and accompanying text.

<sup>105</sup> Lois A. Weithorn & Susan B. Campbell, *The Competency of Children and Adolescents to Make Informed Treatment Decisions*, 53 CHILD DEV. 1589, 1595-96 (1982).

<sup>106</sup> I use these terms with a certain bit of looseness. I use the term "defensible premises" to suggest the ability to defend a decision because it is premised upon thorough knowledge of a young person's health situation. I contrast this with "indefensible premises," including, but certainly not being limited to, those held by a parent who refuses to accept that a child is ill or who otherwise will not actively engage in the process of becoming informed before making a healthcare decision for a child.

who, if given the opportunity, has the capacity for thoughtful decision-making.

Adolescents may possess a value system or religious faith that differs from that of their parents; they may desire treatment with which a parent disagrees; or they may be estranged from their parents and simply feel no obligation to involve the parent in their healthcare decisions.<sup>107</sup> Parents may be in crisis and incapable of thinking rationally about the needs of a young person. In these situations, state child welfare agencies and courts have typically been the source of protection for young people. Yet, it is possible that in most situations young people can act in their own best interest if given the legal authority and support to do so.

### C. ADOLESCENT CAPACITY

An important, though not singular, basis of parental consent rules for adolescent healthcare decision-making is the belief that adolescents lack decision-making capacity. Therefore, a discussion of adolescent decisional capacity is a necessary component to any argument about extending the healthcare consent rights of young people.

According to the Hastings Center, decision-making capacity exists when a patient has “(a) the ability to comprehend information relevant to the decision, (b) the ability to deliberate [about choices] in accordance with [personal] values and goals, and (c) the ability to communicate [verbally or nonverbally] with caregivers.”<sup>108</sup> This formulation does not allow for a finding of decision-making capacity where a patient demonstrates “an inability to reach or communicate a decision,”<sup>109</sup> meaning that a patient either “cannot make up his or her mind or vacillates to such a degree that it is impossible to implement a treatment choice”<sup>110</sup> or “the patient is unable effectively to make known his or her wishes regarding treatment.”<sup>111</sup>

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<sup>107</sup> Some courts have protected physicians from tortious liability to parents claiming harm as a result of medical care provided to their minor children without their knowledge or consent. *See, e.g., Carter v. Cangelo*, 105 Cal. App. 3d 348 (1980) (upholding summary judgment for physician as against parents whose daughter was living away from home and had consented to care from the physician). In contrast, where care is provided to a minor for the benefit of a third party and the physician does not obtain parental consent, liability may exist. *See Bonner v. Moran*, 126 F.2d 121 (D.C. Cir. 1941) (holding that physician could be liable for assault and battery where he failed to secure parental consent for a fifteen-year-old boy who subjected himself to an operation for the benefit of another).

<sup>108</sup> THE HASTINGS CTR., GUIDELINES ON TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING (1987); *see also* Jessica Wilen Berg et al., *Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions*, 48 *RUTGERS L. REV.* 345, 351 (1996) (footnote omitted).

<sup>109</sup> Berg et al., *supra* note 108, at 352.

<sup>110</sup> *Id.* at 352-353.

<sup>111</sup> *Id.*

A patient lacks an ability to understand relevant information if she lacks “the ability to comprehend concepts involved, especially in the informed consent disclosure; it does not require the patient to comprehend the situation as a whole.”<sup>112</sup> In order to meet the criteria, the patient must display an ability to appreciate the nature of the situation and its likely consequences by

apply[ing] information that is understood in a context-neutral sense to his or her own situation. . . . Patients who accept that their physicians believe they are ill, but deny that there is a problem in the face of objective evidence to the contrary, would fail this component. . . . On the other hand, refusal of potentially beneficial, even life-saving, treatment does not necessarily indicate that a patient is incompetent.<sup>113</sup>

Patients with decision-making capacity will be able to manipulate information rationally, which “addresses the patient’s reasoning capacity or ability to employ logical thought processes to compare the risks and benefits of treatment options. This criterion does not look at the outcome of a decision, but, like understanding and appreciation, it is concerned with the patient’s decisionmaking process.”<sup>114</sup> Though there is a risk that such a standard would allow finding a lack of decision-making capacity where a patient chose an unconventional path, or any path not recommended by a healthcare provider, appropriate application of this criterion would not allow for such an ends-biased result.<sup>115</sup>

Using these decision-making capacity criteria as a backdrop, it is possible to see that many young people possess such a capacity and could provide knowing, intelligent, and voluntary consent for a range of healthcare treatments. For purposes of healthcare decision-making, the term “knowing” “can be interpreted as one’s understanding of the semantic content of the information that is provided by the professional . . . . [K]nowing can be defined operationally as the match between the information given to the patient and the patient’s own paraphrase of that of which he/she has been informed.”<sup>116</sup>

Intelligent consent “focuses upon the competence of the patient to arrive at the consent decision rationally, not upon others’ opinions con-

<sup>112</sup> *Id.* at 353-354.

<sup>113</sup> *Id.* at 353-356 (footnotes omitted).

<sup>114</sup> *Id.* at 357.

<sup>115</sup> “Inclusion of rational manipulation in a legal standard of competence may seem troublesome because it could lead to incompetence adjudications based simply on the unconventionality of a patient’s decisions. If the legal standard is sensibly applied, however, this fear is unwarranted.” *Id.* at 358 (footnotes omitted).

<sup>116</sup> Grisso & Vierling, *supra* note 1, at 416.

cerning the advisability of the patient's decision itself."<sup>117</sup> In other words, the intelligence prong of informed consent can be viewed as another way of asking whether the patient possesses decision-making capacity.

Finally, voluntariness refers to a person's ability to provide consent "that is not merely an acquiescent or deferent response to authority."<sup>118</sup> Ultimately, a healthcare provider should base an evaluation of decision-making capacity for a young person upon her "ability to understand and communicate relevant information, ability to think and choose with some degree of independence, ability to assess the potential for benefit, risks, or harms as well as to consider the consequences and multiple options, and achievement of a fairly stable set of values."<sup>119</sup>

One study of healthcare provider practices made several useful findings about the relationship between healthcare providers and their adolescent patients. First, over half of the healthcare providers responding to the survey reported that their adolescent patients "understand information about medical treatment and conditions, engage in rational deliberation during the decisional process, and communicate choices and concerns clearly."<sup>120</sup> Even more importantly, "more than four fifths of physicians (86.7 percent, n=150) agreed that adolescent patients demonstrate an ability to understand information about their medical condition and treatment."<sup>121</sup> Other study findings reflected healthcare provider perceptions that their adolescent patients possessed communication skills that allowed them to successfully discuss and share their healthcare preferences and that these choices were the product of rational thought.<sup>122</sup> Further, the majority of healthcare providers did not believe that their adolescent patients were more prone to risk taking in their medical decision-making than are adults.<sup>123</sup> While it would be inappropriate to base a change in law solely upon one small study of healthcare provider attitudes and perceptions, the study results provide a basis for questioning the extent to which the law's attempt to protect young people from their own potentially detrimental medical decision-making is necessary or steeped in reality.

Current laws ignore what many healthcare providers know from experience with young patients and what research has shown, mainly that adolescents possess a developed capacity for decision-making that is on par with that of young adults. One study compared the decision-making

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<sup>117</sup> *Id.* at 418.

<sup>118</sup> *Id.* at 421.

<sup>119</sup> Harrison et al., *supra* note 103, at 827 (citation omitted).

<sup>120</sup> Hartman, *supra* note 24, at 103.

<sup>121</sup> *Id.*

<sup>122</sup> *Id.* at 103-104.

<sup>123</sup> *Id.* at 105.

of two groups of minors, the first group consisting of nine and ten year old children and the second consisting of fourteen and fifteen year olds, against a group of young adults aged twenty-one through twenty-five.<sup>124</sup> Of the three groups, only the latter consisted of individuals presumed competent to make healthcare decisions.<sup>125</sup> The study authors were particularly concerned about the ability of young people to make voluntary decisions given the strong influence of parents and sought to discover how readily a minor could engage in independent decision-making in the face of parental influence or conflict.<sup>126</sup>

Each study participant, all of whom provided written consent to the study along with the parents of the minor participants, was asked to respond to three hypothetical medical dilemmas by selecting a treatment option after being apprised of the nature of the disease and its available treatments.<sup>127</sup> While the researchers offered several caveats about the findings, including the fact that the study group was largely middle and upper-middle class and of average intelligence and that the participants were asked to respond to hypothetical situations,<sup>128</sup> the study does offer some small insight into directions for policymaking.

First, the lead study author, David Scherer, notes, “[y]oung adults and adolescents. . . appear to be approaching medical decision making with a quality of intentionality that is not seen in the decisions made by children.”<sup>129</sup> He adds, “the law can be notified that, at least in regard to medical decisions presented in this research, there is no conclusive evidence to presume that adolescents are incapable of a voluntary consent comparable to that of young adults.”<sup>130</sup> He also includes the caveat that, “it cannot be totally refuted, particularly with younger adolescents, that there may be important differences between adolescents and young adults in the quality and quantity of decision-making autonomy that they may exercise in medical treatment decisions. Consequently, there may be a need for continued state over[s]ight in these matters.”<sup>131</sup> Scherer raises a specific concern about the degree of parental influence acting as a coercive force thus negating the voluntary element of a young person’s consent.<sup>132</sup> The author notes, “[t]here appears to be minimal risk to family integrity by including minors in routine medical decisions affecting

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<sup>124</sup> David G. Scherer, *The Capacities of Minors to Exercise Voluntariness in Medical Treatment Decisions*, 15 LAW & HUM. BEHAV. 431, 436 (1991).

<sup>125</sup> *Id.* at 435.

<sup>126</sup> *Id.* at 436-37.

<sup>127</sup> *Id.* at 435-37.

<sup>128</sup> *Id.* at 445-46.

<sup>129</sup> *Id.* at 444.

<sup>130</sup> *Id.* at 446.

<sup>131</sup> *Id.*

<sup>132</sup> *Id.* at 434-35.

them. Even young adult offspring seem inclined to defer to parental judgment in routine medical matters, when parents feel strongly about a decision.”<sup>133</sup> This finding suggests that concerns about adolescent rebellion leading to bad choices may be overblown and inaccurate.

In another study in which the researchers asked a group of young people to respond to hypothetical health care dilemmas, the researchers reported that:

In general, minors aged 14 . . . demonstrate a level of competency equivalent to that of adults, according to four standards of competency (evidence of choice, reasonable outcome, rational reasons, and understanding), and for four hypothetical dilemmas (diabetes, epilepsy, depression, and enuresis). Younger minors aged 9, however, appeared less competent than adults according to the standards of competency requiring understanding and a rational reasonable process. Yet, according to the standards of evidence of choice and reasonable outcome, even these younger minors appeared competent.<sup>134</sup>

The study authors wrote:

The findings of this research do not lend support to policies which deny adolescents the right of self determination in treatment situations on the basis of a presumption of incapacity to provide informed consent. The age of 18 or 21 as the “cutoffs” [sic] below which individuals are presumed to be incompetent to make determinations about their own welfare do not reflect psychological capacities of most adolescents.<sup>135</sup>

A comprehensive review and analysis of literature in developmental psychology also found that “there is little evidence that minors of age 15 and above as a group are any less competent to provide consent than are adults.”<sup>136</sup> The authors concluded: “[M]inors are entitled to have some form of consent or dissent regarding the things that happen to them in the name of assessment, treatment or other professional activities that have generally been determined unilaterally by adults in the minor’s interest.”<sup>137</sup> In a similar vein, yet another review of the literature on child development led a researcher to determine that “by age 14 years, many minors attain the cognitive developmental stage associated with the psy-

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<sup>133</sup> *Id.* at 446.

<sup>134</sup> Weithorn & Campbell, *supra* note 105, at 1595-96.

<sup>135</sup> *Id.* at 1596.

<sup>136</sup> Grisso & Vierling, *supra* note 1, at 420.

<sup>137</sup> *Id.*

chological elements of rational consent” and further concluded that “minors between 11 and 14 years of age appear to be in a transition period [and] there appear to be no psychological grounds for the general assumption that minors 15 years of age or older cannot provide competent consent.”<sup>138</sup>

Professional groups have taken note of the literature on the cognitive development of adolescents. The American Academy of Pediatrics (“AAP”) notes that “review of the limited relevant empirical data suggests that adolescents, especially those age 14 and older, may have as well developed decisional skills as adults for making informed health care decisions.”<sup>139</sup> The Society for Adolescent Medicine (“the Society”) has also indicated that its membership shares the view that adolescent decisional skills may be as developed as those of adults.<sup>140</sup> Based on this data and their own experience with young patients, these medical professionals have expressed support for granting young people, specifically those who are fourteen or older, greater rights to participation in decisions about their own healthcare.<sup>141</sup>

It is worthwhile to note that “[c]ompetence is not an ‘all or nothing’ quality; it develops gradually, particularly if the child has opportunities to try out budding skills. A child does not always have a *general* level of competence. Rather, a child may be competent in one area, but not in another, and may be competent to take on *part* of a given task, but not the whole.”<sup>142</sup> Furthermore, “while the words ‘competence,’ ‘competent’ and ‘capable’ may cover some of the same qualities as ‘intelligent’ does, they imply abilities that are more than merely cognitive.”<sup>143</sup> In other words, even if a young person lacks competence or decision-making capacity in one arena, that lack would not necessarily preclude a finding of decision-making capacity for the purpose of an individual healthcare decision.

A required aspect of developing decision-making capacity is the grant of opportunities to actually make decisions.<sup>144</sup> In other words:

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<sup>138</sup> Sanford L. Leikin, *Minors’ Assent or Dissent to Medical Treatment*, 102 J. PEDIATRICS 169, 173 (1983).

<sup>139</sup> AMERICAN ACADEMY OF PEDIATRICS COMMITTEE ON BIOETHICS, *Informed Consent, Parental Permission, and Assent in Pediatric Practice*, 95 PEDIATRICS 314, 317 (1995).

<sup>140</sup> See SOCIETY FOR ADOLESCENT MEDICINE, *Access to Healthcare for Adolescents: A Position Paper of the Society for Adolescent Medicine*, 13 J. OF ADOLESCENT HEALTH 162 (1992).

<sup>141</sup> *Id.*

<sup>142</sup> Målfrid Grude Flekkøy, *Psychology and the Rights of the Child*, in CHILDREN AS EQUALS: EXPLORING THE RIGHTS OF THE CHILD 73, 79 (Kathleen Alaimo & Brian Klug eds., 2002).

<sup>143</sup> *Id.*

<sup>144</sup> “With the principle of evolving capacities, we recognize that children *come to have* capacities of moral agency, that these capacities develop in the child with the assistance of caring adults, and are enhanced through meaningful participation in matters where children’s

The important point here is that children *come to develop* capacities for decision-making and for exercising liberties through guidance and practice. Just as a child learns to read or gather roots by actively participating in these endeavors with adults or older children, so too a child learns what is right and wrong, acceptable or unacceptable, by active participation in the moral community. Among the most important capacities a child ought to develop is the capacity to recognize her interests, to prioritize them, and to balance competing interests (both other interests of her own and those of other persons). For the development of these abilities, however, she needs careful and considerate assistance by those persons who have some concern that her best interests are met, and who are able to assess the possible consequences for the sake of certain long term interests, and vice versa.<sup>145</sup>

To be given age-appropriate information about one's own health and make decisions based on consultation with whoever is deemed an appropriate source of advice is a fitting show of respect for a young person's need to grow into full maturity. Even without the support of the law, many healthcare providers working with young people have determined that professionally appropriate and ethically sound care for an adolescent requires that the healthcare provider allocate significant decision-making power to an adolescent patient, including maintaining the confidentiality of the healthcare provider-patient relationship against the parent's desire to know what is taking place with his child.<sup>146</sup> Healthcare providers may assume this posture even though in most states and circumstances the law does not require or necessarily allow this balance.<sup>147</sup>

A shift to greater recognition of the competence of young people has significant and diverse precedent. There are several contexts outside of healthcare in which the law recognizes that children gain greater autonomy as they become older even if they have not yet reached the age of majority. For instance, family courts routinely allow or even require that older children participate in decisions about custody, visitation, and

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own interests are at stake." Christina M. Bellon, *The Promise of Rights for Children: Best Interests and Evolving Capacities*, in CHILDREN AS EQUALS: EXPLORING THE RIGHTS OF THE CHILD 112 (Kathleen Alaimo & Brian Klug eds., 2002) (internal citation omitted).

<sup>145</sup> *Id.* at 111.

<sup>146</sup> Hartman, *supra* note 24, at 110-11.

<sup>147</sup> *See id.* at 112-13.



adoption.<sup>148</sup> Even those who sit in judgment in such courts admit that the participation of the young people who are the subjects of such proceedings, particularly those who are fourteen or older, is warranted and necessary.<sup>149</sup> One judge has written, "When a child fourteen years of age or older states a preference [for custody], courts should accept it as controlling if the preference is expressed after an informed consent dialogue takes place."<sup>150</sup> Though the young person may not always have a veto power, there is unquestionable recognition that she is capable of understanding the proceedings and providing input that can be valuable to the decision-maker.

Similarly, tort law provides no immunity based solely upon the age of an accused tortfeasor.<sup>151</sup> Rather, a person who has not reached the age of majority may avoid liability for intentional torts only if she can make a showing that she lacked "the mental capacity to commit a tort in the first place."<sup>152</sup> Youth and experience may also be relevant to whether an actor has acted negligently.<sup>153</sup> Thus, even very young children may be found liable for tortious activity despite their chronological age.

Even in the healthcare context, there is a certain degree to which adolescents and perhaps even younger children have some modicum of veto power over decisions being made on their behalf. For instance, it is unlikely that a provider would perform an abortion on a developmentally

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<sup>148</sup> According to the Administration for Children and Families, "[a]pproximately 47 States . . . require that older children give consent to their adoption. Twenty-three States . . . set the age of consent at 14 years; 18 States . . . at 12 years; and seven States . . . require consent of children age 10 and above. In some States, the requirement can be dispensed with if the child lacks the mental capacity to consent, or the court finds it in the best interest of the child to dispense with consent." NATIONAL ADOPTION INFORMATION CLEARINGHOUSE, *2003 Adoption State Statute Series Statutes-at-a-Glance: Consent to Adoption*, available at <http://naic.acf.hhs.gov/general/legal/statutes/consent.cfm>; see, e.g., ALASKA STAT. § 25.23.040 (Michie 2003) (requiring consent of potential adoptees who are ten years of age or older unless the court finds that consent is not in the child's best interest); ARK. CODE ANN. § 9-9-206 (Michie 2003) (requiring consent of children ten years of age or older unless the courts find that consent would not be in the child's best interest); GA. CODE ANN. § 19-8-4 (2002) (requiring consent to adoption from child fourteen or older). Similarly, some states direct judges to consider the wishes of the child in custody proceedings. See, e.g., N.J. STAT. ANN. § 9-2:4 (West 2004) (directing a court to consider "the preference of the child when of sufficient age and capacity to reason so as to form an intelligent decision" when making a custody determination).

<sup>149</sup> "With respect to children below the age of six, most judges considered the child's wishes to be irrelevant. By contrast, ninety percent of the judges deemed children's wishes to be either dispositive or extremely important when they were fourteen years old and older." Wallace J. Mlyniec, *A Judge's Ethical Dilemma: Assessing a Child's Capacity to Choose*, 64 *FORDHAM L. REV.* 1873, 1887-88 (1996) (summarizing study in Elizabeth S. Scott et al., *Children's Preference in Custody Decisions*, 22 *GA. L. REV.* 1035, 1042 (1988)).

<sup>150</sup> *Id.* at 1908.

<sup>151</sup> W. PAGE KEETON ET AL., *PROSSER AND KEETON ON TORTS* § 134 (5th ed. 1984).

<sup>152</sup> *Id.*

<sup>153</sup> *Id.*

normal young person who refused the procedure even if her parents demanded it.<sup>154</sup>

#### D. HEALTHCARE PROVIDER-PATIENT RELATIONSHIPS AND OPTIMAL OUTCOMES

The relationship between any patient, adult or a minor, can be one of power imbalance given issues of expertise and authority that are almost universally present in exchanges between medical professionals and their patients. However, the uneven distribution of authority can be even more pronounced when the patient is young:

If adults have little involvement in decision making related to their own care . . . then children have almost none. . . . Children are taken to physicians by adults whenever the child has a problem or the adult has a problem. In the office, many physicians limit their verbal interactions to the adult caretaker, viewing the child primarily as the bearer of pathology (if any is present).<sup>155</sup>

Consultation with a child patient is not a priority for some healthcare providers, although the needs of the patient and the patient's willingness to participate in therapy about which she has no say evolves as a patient moves from child to adolescent.

The relationship between adolescent healthcare providers and their patients requires a shift from the relationship between children and their pediatricians. In the early years of the specialty of adolescent medicine, practitioners recognized the need to alter their previous ways of dealing with young people and "respect for the patients' point of view [became] a crucial component of successful medical care for adolescents."<sup>156</sup> The founder of one early adolescent unit in Boston Children's Hospital, J. Roswell Gallagher, "ensured that from the moment a teenager entered the Adolescent Unit, he or she was treated with the same level of respect and dignity as an adult patient."<sup>157</sup>

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<sup>154</sup> In *Stump v. Sparkman*, a case which hopefully does not reflect modern practice, a healthcare provider did act in accord with the wishes of a parent to conduct unnecessary surgery on an adolescent, performing a sterilization procedure on an adolescent girl based on the mother's concerns about her daughter's promiscuity. See 435 U.S. 349 (1978). The girl was not informed about the nature of the surgery and only discovered what had taken place when, as an adult, she and her husband sought to have a child. *Id.*

<sup>155</sup> Charles E. Lewis, *Decision Making Related to Health*, in CHILDREN'S COMPETENCE TO CONSENT, *supra* note 20, at 76.

<sup>156</sup> PRESCOTT, *supra* note 16, at 77.

<sup>157</sup> *Id.* at 79.

Gallagher insisted that patients be seen separately from their parents so that they would feel that the doctor was truly interested in them rather than their parents. Although parents were the only ones allowed to set up the first appointment, Gallagher recommended that patients themselves be allowed to make all further appointments so that they would not feel they were being forced to come to the clinic. The receptionist would introduce patients to their doctors as “Miss” or “Mr.” Gallagher advised his physicians to avoid a patronizing tone when dealing with patients. “It is important to do everything possible to avoid an authoritarian atmosphere,” wrote Gallagher, for adolescents “quickly recognize, and respond well to a physician who is slow to suggest, more eager to listen than to talk, and who usually listens without apparent approval or disapproval of what he is told.”<sup>158</sup>

Gallagher’s prescription for creating an atmosphere conducive to a good relationship between patient and provider went so far as to recommend that physicians not sit behind their desks when speaking to patients.<sup>159</sup> Gallagher also warned physicians against “pandering too shamelessly to teenagers” which would serve to alienate them.<sup>160</sup> He stressed the importance of making sure that young people were “adequately informed about the nature of their problem and the course of treatment.”<sup>161</sup> Failure to provide this transparency “not only would decrease the likelihood that a teenager would comply with medical advice, but could also lead to unnecessary panic in the young person, and possibly cause unacceptable and self-destructive forms of behavior.”<sup>162</sup> Finally, Gallagher urged that the physician “treat. . .the adolescent patient as a person mean[ing] that physicians did not let parental demands supersede the best interests of the patient.”<sup>163</sup> While this did not mean that the healthcare provider should completely exclude parents from the care being provided to their adolescent children, it did require that the physician maintain a “primary emphasis” on providing assistance to the young person as her healthcare provider.<sup>164</sup>

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<sup>158</sup> *Id.*

<sup>159</sup> *Id.*

<sup>160</sup> *Id.* at 80.

<sup>161</sup> *Id.*

<sup>162</sup> *Id.* at 81.

<sup>163</sup> *Id.*

<sup>164</sup> *Id.* at 100.

The complexities of adolescent medicine continue to create dilemmas for healthcare providers. In a 1999 survey conducted by the AAP, 61.4% of responding healthcare providers identified the “availability of clearly defined state statutes on confidentiality, consent and other legal issues” as “*very effective* in reducing potential barriers to providing adolescent health care.”<sup>165</sup> This finding indicates that both healthcare providers and their adolescent patients would benefit from more integrated and consistently articulated legal approach to standards of consent and confidentiality for young people.

Those offering healthcare to adolescents find themselves entangled in a difficult quandary as they seek to provide care that falls within the ethical precepts of medicine without running afoul of the law. One writer describes the dilemma as follows:

Many health care providers believe that older children, and especially adolescents, are capable of enabling substituted judgment (through expressed preferences) or even of making independent health care decisions. Such beliefs often put providers in conflict between ethical and legal mandates; ethical principles, on the one hand, argue that minors should be enabled to participate in self-directed decision-making to the largest extent possible, while legal constraints, on the other hand, restrict competency. In general, adolescents who are 14 years of age and above are thought to have sufficient decisional capacity to consent to treatment for themselves. Certain experienced providers also believe that children as young as 10, who have battled life-threatening or chronic illness and developed a maturity beyond their years in that particular sphere, also possess health care decisional capacity.<sup>166</sup>

By neglecting to support high quality healthcare provider-patient relationships, the law can discourage or prevent the use of the best medical practices, thus compromising the quality of care offered to an adolescent patient. The law in its convoluted state does not mirror the current state of medical practice in which healthcare providers, particularly pediatricians and specialists in adolescent medicine, have a much broader sense of the ability of young people to understand and meaningfully participate

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<sup>165</sup> AMERICAN ACADEMY OF PEDIATRICS, *Periodic Survey of Fellows, Providing Healthcare to Adolescents: Pediatricians' Attitudes and Practices*, available at <http://www.aap.org/research/periodicsurvey/ps42aexs.htm>.

<sup>166</sup> Sarah Friebert, *Healthcare Decision-making in Pediatric Palliative Care* (March 2004), available at <http://www.nacwltc.org/helpfulArticles/helpfularticles.asp>.

in their own healthcare.<sup>167</sup> Too often, in its attempts to balance the interests of both parents and young people, the law forces healthcare providers to privilege concerns about legal liability over their assessment of the needs of a patient. Thus, in some circumstances, the law constrains the healthcare provider from offering the highest quality of care to an adolescent patient in violation of basic professional obligations.

Consent, specifically informed consent, is a cornerstone of providing non-tortious medical care to a patient.<sup>168</sup> A healthcare provider who treats an individual in a non-emergency situation without first obtaining the informed consent of the patient or a person authorized to make decisions for an incompetent patient subjects herself to serious legal consequences for breaching her professional duty.<sup>169</sup> Informed consent is not simply a way of protecting physicians from legal liability. Rather, it is a primary means of respecting the autonomy of patients because one cannot act autonomously when denied access to information that is pertinent to the decision at hand.<sup>170</sup> As described by the American Medical Association ("AMA"), "[i]nformed consent is more than simply getting a patient to sign a written consent form."<sup>171</sup> At minimum, the AMA recommends that a physician, not a representative, inform the patient of his diagnosis, the nature of the treatment and alternatives as well as the risks and benefits of treatment or foregoing treatment.<sup>172</sup> The obligation to obtain informed consent is both legal and ethical.<sup>173</sup> The idea of informed consent is no less important for adolescents, but the law deems consent offered by parents sufficient to satisfy the physician's duty to her patient.<sup>174</sup>

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<sup>167</sup> Hartman, *supra* note 24, at 87-88.

<sup>168</sup> Sheldon F. Kurtz, *The Law of Informed Consent: From "Doctor is Right" to "Patient Has Rights,"* 50 SYRACUSE L. REV. 1243, 1245 (2000) ("Today, the right of a patient to participate to some extent in medical decision making affecting the patient is universally dictated by the 'informed consent' laws of all states.").

<sup>169</sup> OFFICE OF TECH. ASSESSMENT, *supra* note 6, at 124 ("The doctrine of informed consent holds, therefore, that physicians and surgeons have a duty to give their adult patients the information necessary for making an informed and voluntary choice concerning medical treatment or surgery; the failure by a physician or surgeon to obtain informed consent from a patient may give rise to a civil liability and an award of damages.").

<sup>170</sup> Friebert, *supra* note 166 ("The primary ethical principle in health care decision-making is personal autonomy, or self-determination. True autonomy presupposes informed consent, and is based upon the principle of respect for persons.").

<sup>171</sup> AMERICAN MEDICAL ASSOCIATION, *Informed Consent*, available at <http://www.ama-assn.org/ama/pub/category/4608.html>.

<sup>172</sup> *Id.*

<sup>173</sup> *Id.*

<sup>174</sup> AMERICAN ACADEMY OF PEDIATRICS COMMITTEE ON BIOETHICS, *supra* note 139, at 314 ("We now realize that the doctrine of 'informed consent' has only limited *direct* application in pediatrics. Only patients who have appropriate decisional capacity and legal empowerment can give their informed consent to medical care. In all other situations, parents or other surrogates provide informed permission for diagnosis and treatment of children with the assent of the child whenever appropriate.").

According to the Society, healthcare providers for adolescents should "provide complete and thorough physical and psychosocial evaluation and treatment in an atmosphere of trust and confidentiality."<sup>175</sup> A long list of barriers to care for young people includes, in addition to financial constraints, the difficulties inherent in seeking to provide confidential care in a context in which a third party is responsible for consenting to care for an adolescent.<sup>176</sup> The Society writes:

Most physicians support providing confidential care to adolescents, but many are uncomfortable with family negotiations that may surround independent care and decision-making. Although evidence suggests that adolescents aged 14 years and older are able to make good decisions about their own health, most still benefit from their parents' involvement with treatment, and most still need help in paying for care. The wide variation in state laws pertaining to parental consent further complicates the issues for health professionals, adolescents, and parents. The resulting confusion, coupled with fears of disclosure, diagnosis, and treatment, may cause adolescents to delay or avoid needed care.<sup>177</sup>

Although the Society places a significant value on confidentiality and a strong emphasis on urging young people to involve their parents in care, the law does not consistently support confidentiality in the relationships between medical providers and adolescents. In fact, the availability of confidential relationships between provider and patient is the exception rather than the norm.<sup>178</sup> Confidentiality certainly cannot be assured when a parent or caretaker is the only person who can provide consent for an adolescent's treatment. Therefore, in spite of the Society's determination that when family involvement is "not in the best interest of the adolescent or when parental involvement may prevent the adolescent from seeking care, confidentiality must be assured,"<sup>179</sup> the law often does not allow a healthcare provider to make such assurances.

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<sup>175</sup> See THE SOCIETY FOR ADOLESCENT MEDICINE, *Access to Healthcare for Adolescents: A Position Paper of the Society for Adolescent Medicine*, 13 J. OF ADOLESCENT HEALTH 162 (1992).

<sup>176</sup> *Id.*; see also AMERICAN ACADEMY OF PEDIATRICS, *Confidentiality of Care for Teens Allows Parental Involvement* (July 11, 2002), available at [http://www.aap.org/advocacy/washing/confidentiality\\_care.htm](http://www.aap.org/advocacy/washing/confidentiality_care.htm) ("[C]oncern about confidentiality is one of the primary reasons young people delay seeking healthcare services for sensitive issues. . . . There is evidence that mandatory parental consent laws may have an adverse impact on some families and that it increases the risk of medical and psychological harm to adolescents.").

<sup>177</sup> THE SOCIETY FOR ADOLESCENT MEDICINE, *supra* note 175.

<sup>178</sup> See *supra* text accompanying notes 21-48.

<sup>179</sup> THE SOCIETY FOR ADOLESCENT MEDICINE, *supra* note 175.

The need for proxy consent complicates the relationship between a healthcare provider and an adolescent patient. The AAP acknowledges that the concept of proxy consent, generally exemplified by parents consenting to care on behalf of their children, is problematic. They write:

Thus “proxy consent” poses serious problems for pediatric healthcare 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.<sup>180</sup>

Proxy consent is often inadequate, particularly for adolescent patients, because it reinforces the idea that adolescents are incapable of participating in the world around them in a meaningful way. Recognizing the need to include young patients in decision-making about their care, the AAP recommends that healthcare providers obtain assent from their adolescent patients and defines the elements of assent as:

1. Helping the patient achieve developmentally appropriate awareness of the nature of his or her condition.
2. Telling the patient what he or she can expect with tests and treatment(s).
3. Making a clinical assessment of the patients’ [sic] understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).
4. Soliciting an expression of the patient’s willingness to accept the proposed care. Regarding this final point, we note that no one should solicit a patient’s views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived.<sup>181</sup>

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<sup>180</sup> AMERICAN ACADEMY OF PEDIATRICS COMMITTEE ON BIOETHICS, *supra* note 139, at 315. Interestingly, the healthcare provider who served as a driving force behind the effort to get the AAP to endorse a statement on children and assent, expressed some dismay about the position ultimately taken by the organization based on concerns that compromise language in the document “threaten[ed] to undermine or thwart the basic purpose of the statement” and could “make. . . a mockery of the whole idea of assent.” William G. Bartholome, *Letter to the Editor*, 96 PEDIATRICS 981, 981 (1995).

<sup>181</sup> AMERICAN ACADEMY OF PEDIATRICS COMMITTEE ON BIOETHICS, *supra* note 139, at 315-316.

Showing similar respect for adolescent assent in treatment, the Society writes:

Seeking the assent of a minor who is not legally authorized to consent demonstrates respect for the decision-making skills of a non-autonomous individual to the extent that he or she is able to participate in the decision. This is particularly relevant for adolescents who are cognitively mature but below the age of legal majority and still dependent upon adults for their basic health care decisions. Respect for the decision-making capabilities of an adolescent demands both confidentiality and privacy.<sup>182</sup>

Assent and the knowledge that it implies are also important because they help to increase a young person's interest in participating in treatment. For:

In order to achieve maximum compliance,<sup>183</sup> the patient must not only be actively involved, but also a participant in his or her own care. Participation will include discussions related to choice of therapy as well as what mode of administration such therapy might necessitate. . . . The healthcare provider can no longer be the mere administrator of treatments, but must become involved in a relationship marked by mutual respect and concern.<sup>184</sup>

The ability to give consent, not just assent, specifically in the context of chronic diseases, "may be crucial to carry out a given treatment protocol. With the acquisition of further knowledge about the child's disease, the child learns to feel more in control of not only the therapy but also of his or her life . . . . A more positive self-image often follows this sense of body control and this in turn leads to an increase in compliance."<sup>185</sup> Some healthcare providers that advocate increased healthcare decision-making rights for adolescents state that integrating young peo-

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<sup>182</sup> THE SOCIETY FOR ADOLESCENT MEDICINE, *A Position Paper of the Society for Adolescent Medicine: Confidential Healthcare for Adolescents*, 21 J. OF ADOLESCENT HEALTH 408-415 (1997).

<sup>183</sup> The language of compliance, as used here and in many other medical contexts, has a negative connotation that I do not support. To the extent that a healthcare provider seeks to engage in a top-down approach to medicine in which the patient is seen as an object to be manipulated into compliance with a physician's recommendation, the use of the term is anathema to the type of provider-patient relationship that this proposal imagines and seeks to encourage.

<sup>184</sup> Michael A Grodin & Joel J. Alpert, *Informed Consent and Pediatric Care*, in Melton et al., *supra* note 20, at 103.

<sup>185</sup> *Id.* at 102. See also AMERICAN ACADEMY OF PEDIATRICS, *supra* note 95, at 164. ("Children with a variety of chronic disease, including those with cancer, have exhibited better



ple into the decision-making process will "(1) increase their ownership of the decision and encourage them to obtain the necessary follow-up care, (2) increase their ability to make such decisions in the future, and (3) perhaps make healthcare less threatening and more attractive to them as future healthcare consumers."<sup>186</sup>

Assent, as used in the medical context, is a valuable concept without a comparable legal counterpart. However, even if there were such a concept in the law, it would likely fail to adequately protect and respect young people. There are at least two important components of healthcare decision-making. The first component is knowledge, meaning that a person can play no meaningful role in decisions about his own health if he is not aware of his own health status. The second component is consent, meaning the ability to make decisions about how to respond to illness. Granting the right of assent addresses the knowledge component of healthcare decision-making but does not address the consent component.

To the extent that knowledge and consent are intertwined concepts, denying either of these prongs to adolescents is certainly problematic. Granting a right to assent, essentially a right to notice and comment, must necessarily be seen as secondary to a right to consent<sup>187</sup> and does not fully address the detriment to young people in both tangible and intangible ways that exists as a consequence of a failure to generally recognize their capacity for competent decision-making. Assent still means that someone other than the adolescent patient has the final, legally relevant say in what course of treatment the patient will pursue. While a right to assent, or knowledge and input, is certainly better than nothing at all, such a right does not address issues of confidential care and does not acknowledge an adolescent's capacity for decision-making in conjunction with an informed consent dialogue.

### III. FIXING THE SYSTEM

*Those who have experienced . . . irksome constraints justified wholly on paternalistic grounds, will testify that their resentment is not mere frustration or antipathy. Rather it has the full flavor of moral indignation and*

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coping skills and fewer psychosocial problems when appropriately informed about the nature and consequences of their illness.").

<sup>186</sup> Janet A. Deatrack et al., *Children Should Be Seen and Heard*, HEALTH PROGRESS, April 1990, at 76.

<sup>187</sup> Assent is secondary to consent in that the former is essentially assumed within the context of the latter. If a patient is to give legally binding consent to healthcare, a healthcare provider must first inform the patient of the nature of the illness and the risks and benefits involved in treatment. If there is only a right to knowledge, then healthcare providers may have less incentive to engage in in-depth and honest conversations with the adolescent and focus instead on the parents who will offer consent.

*outrage. Their grievance is not simply that they have been unnecessarily inconvenienced or "irked," but rather that in some way they have been violated, invaded, belittled.*<sup>188</sup>

An assumption of general adolescent incapacity, with exceptions for certain times of crisis that may burden or threaten the public health, does not recognize young people as autonomous human beings who exist within family networks in which other parties share an interest in their lives and health. Recognizing this inter-connectedness, it is possible to imagine a regime that strikes a balance between the autonomy and dependence of adolescents. On one hand, most of those who are fourteen and older are mentally or psychologically capable of providing knowing, intelligent, and voluntary consent for healthcare treatment. Simultaneously, the unique relationship between parent and child and the strong public and legal support for reinforcing, rather than severing, those ties demands acknowledgement of the emotional and financial dependence that young people may have and their potential need for support and guidance in making medical decisions.

Recognizing that the grant of authority for which I advocate is not without its detractors, this section responds to some of the most contentious issues involved in an attempt to reconfigure adolescents in the eyes of the law and in the context of healthcare and family structure. First, I articulate the tenets of the shared-decision-making model which I propose should apply in the healthcare arena and explain what expanded rights to knowledge and consent this model confers on young people. Next, I confront the objections of those who view such a proposal as unduly interfering with parental rights and explain why the proposal is an appropriate way to shift the current legal dynamic of power imbalance between parents, adolescents, and healthcare providers.

#### A. A MODEL FOR AUTONOMOUS HEALTHCARE DECISION-MAKING BY ADOLESCENTS

I advocate an alternative conception of the legal personhood of adolescents and a concomitant re-structuring of the allocation of healthcare decision-making power among family members, specifically parents or other adult caretakers, and adolescents. In so doing, I join with others who have urged, "a paradigmatic shift in thinking about adolescence that entails a legal framework predicated on adolescent decisional ability."<sup>189</sup> Making this shift and "[a]pproaching adolescence from the standpoint of

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<sup>188</sup> Feinberg, *supra* note 78, at 27.

<sup>189</sup> Rhonda Gay Hartman, *Adolescent Autonomy: Clarifying an Ageless Conundrum*, 51 HASTINGS L.J. 1265, 1269 (2000).

decisional ability, rather than presumptive decisional incapacity, comports with contemporary social norms, encourages clear rules in contrast to convoluted exceptions, and optimizes development for meaningful adolescent decision-making.”<sup>190</sup>

Cultural evolution, the expansion of scientific knowledge, and respect for the adolescent all provide a valid basis for transforming the legal landscape to embrace a model of shared healthcare decision-making within families.<sup>191</sup> The legal system should support a more balanced relationship between the goals of protecting adolescents from themselves and granting them rights that allow them to take actions to protect their own interests. Striking this balance requires working within the familial unit and recognizing the power of that unit while avoiding romanticization and unattainable aspiration. Rather than a myopic focus on eighteen as a magic year, more precise and multi-disciplinary thinking suggests the law should create a younger age at which people have a legal right to substantially and substantively participate in decisions about their own healthcare and, in some circumstances, act independently in the healthcare arena. This proposal does not envision or advocate across the board emancipation from the disabilities of age for young people. Rather, it focuses on a particular area where adolescent decision-making would accrue to the benefit of the patient.

Any change in the law’s treatment of young people in the healthcare context must start from the premise that children are not monolithic, meaning that all of those who are legally minors, because they are below the age of eighteen, should not be labeled immature, incapable, and decisionally dependent. Protectionist policies necessary to maintain the health of young children—those under the age of fourteen—are not automatically appropriate for adolescents who have the capacity to comprehend and respond to their own healthcare circumstances. Either/or reasoning focused on 100% autonomy or 100% lack of autonomy is an inappropriate view of the interests at stake here.<sup>192</sup> No member of a functioning family is radically autonomous and each family member is regularly called upon to understand her exercise of rights within the broader context of an impact on family members.

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<sup>190</sup> *Id.*

<sup>191</sup> This proposal does not advocate a healthcare decision-making model that disregards the individual and focuses on the family as the patient. To the contrary, I find value in the idea of recognizing the reality of autonomy that interacts with the interdependence of family connections, but that is not supplanted by those connections. For a discussion of some of the problems with family medicine, see Martha Minow, *Who’s the Patient?*, 53 MD. L. REV. 1173, 1181-86 (1994).

<sup>192</sup> See LAURA M. PURDY, IN THEIR BEST INTEREST 228-229 (Cornell University Press 1992) (“A protectionist approach cognizant of the value of freedom should be able to get beyond the either/or reasoning (individuals are either fully incompetent or fully responsible) that has tended to plague the legal treatment of children.”).

As described earlier, the model of autonomy upon which this shared decision-making model rests is one that embraces rather than ignores the idea of community, interdependence, and cooperative decision-making. In this proposal, most of the decision-making will require joint consent by patient and parent, rather than assent by one and consent by the other. In this way, the proposal seeks to elevate the adolescent to a position of greater power while preserving a place for the parent in much of the healthcare decision-making for adolescents. In some ways, the shared decision-making model is akin to a learner's permit for healthcare decision-making. Before young people reach eighteen and are completely unfettered, at least legally, from parental dominance in healthcare decision-making, they will have opportunities to share in the process of self-regulation with both healthcare providers and parents to offer support and guidance. This graduated process conforms to the idea that making good decisions is a learned behavior and that "the right kind of growing up in the law takes place over time rather than on a particular birthday."<sup>193</sup>

As the world changes and adolescents grow up exposed to adult-like experiences at earlier ages, restricting young people from exercising the skills they acquire in the course of their own lives as well as lessons they glean from observing the lives of others is injurious to both their physical and psychological health. That young people lack life experiences to draw upon when confronted with difficult decisions is also true of many young adults or even older adults when faced with a unique or unexpected medical crisis. In such circumstances, the lack of experience does not transform these adults into children who cannot make decisions. Instead, we count on their ability to confer with others including friends, family members, and healthcare providers to make informed choices that best reflect their outlook on life. The same could be expected of adolescents when given the opportunity to act as decision-makers, along with their parents, about their own lives and health.

Further, many forces will work to limit the circumstances in which young people seek care without involving their parents. These forces include healthcare provider pressure to involve parents, the adolescent patient's need and desire for support and encouragement from parents in making decisions, and financial dependence to the extent that it provides an incentive to involve parents in healthcare decisions. Finally, just as a healthcare provider could question the decision-making capacity of an adult who does not appear capable of providing informed consent, the same option would exist when providing care to young people.

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<sup>193</sup> FRANK ZIMRING, *THE CHANGING LEGAL WORLD OF ADOLESCENCE* 103 (The Free Press 1982).

The law can recognize that adolescents are more competent than it has heretofore acknowledged on a large scale and simultaneously maintain a concern that for some young people, lack of life experiences, and insufficient opportunities to act as the architect of their own lives may impair their ability to think through all of the ramifications of a given decision. It may be appropriate, then, to mandate access to certain services that will help the young person make difficult life decisions if she chooses not to enlist her parents help in making those decisions. However, denying her complete access to independent decision-making is not the appropriate response to concerns about protecting young people from their own bad judgment. Ultimately,

To respect a child's autonomy is to treat that child as a person and as a rights-holder. It is clear that we can do so to a much greater extent than we have assumed hitherto. But it is also clear that the exercising of autonomy by a child can have a deleterious impact on that child's life chances. It is true that adults make mistakes too (and also make mistakes when interfering with a child's autonomy). Having rights means being allowed to take risks and make choices.<sup>194</sup>

The shared decision-making model proposed here affords two levels of protection for adolescents. The first level is a knowledge tier. This knowledge tier, like assent as recommended by the AAP and the Society, seeks to ensure that healthcare providers make a young patient aware of her own medical condition, its potential impact on her health, available treatment options, and the risks and benefits of participating or failing to participate in any particular treatment protocol. As the AAP recognizes, "Social forces tend to concentrate authority for health care decisions in the hands of [healthcare providers] and parents and this tendency diminishes the moral status of children. Thus, those who care for children need to provide measures to solicit assent and to attend to possible abuses of 'raw' power over children when ethical conflicts occur."<sup>195</sup>

The second tier, generally unavailable to young people outside the limited context of the mature minor doctrine or healthcare emancipation statutes, is a consent tier. The consent tier reinforces the right to knowledge by giving young people the right to consent or refuse to consent to treatment thus making them partners in decisions about their own health, which has not been supported or required by the law except in limited

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<sup>194</sup> FREEMAN, *supra* note 82, at 36.

<sup>195</sup> AMERICAN ACADEMY OF PEDIATRICS COMMITTEE ON BIOETHICS, *supra* note 139, at 317.

circumstances. More importantly, adolescent consent is valuable for its own sake because it acknowledges adolescent capacity and autonomy.

State laws on healthcare decision-making for adolescents aged fourteen to seventeen should rest upon a presumption of decisional capability commensurate with that of young adults, at least in the context of healthcare decision-making. Therefore, to acknowledge this capacity and ensure that young people are given considerable opportunities to participate in decisions about their own healthcare, it is necessary to articulate a right to healthcare decision-making for young people ages fourteen and older that simultaneously supports their inherent right to human dignity, recognizes their limited experience, and respects the interest of their parents.

A model statute under this regime would allow a young person who is at least fourteen years old but less than eighteen years old to access healthcare and make binding decisions about diagnosis and treatment in conjunction with her parent or caretaker assuming no objection from the patient about parental involvement thus triggering exceptions to the presumption of shared decision-making. In other words, the power to make decisions would be equally shared by patient and parent. Healthcare in this context refers to care intended to diagnose or treat medical diseases or conditions, including psychological ailments. This care would need to be provided by a licensed medical provider in good standing within the medical community. Medical care does not refer to care intended only to provide aesthetic enhancement, including body piercing, tattooing, and many, though not all, categories of cosmetic surgery.<sup>196</sup>

Recognizing that many families are fractured and that there might be situations in which a patient chose to share information with one parent and not the other, healthcare providers would not be required to obtain the consent of both parents before providing care requested by a qualifying adolescent patient. Similarly, where a custody determination had been made, only the custodial parent need participate in healthcare decision-making for the patient. Importantly, this model encourages the adolescent patient to decide which adult with decision-making power she wished to involve in her care. The healthcare provider would then need to obtain valid informed consent for healthcare from the patient as well as her preferred adult caretaker.

A primary component of this model is recognition that in most instances young people will be well served, or at least not harmed, by involving an adult caretaker in their healthcare decision-making process. However, just as many state statutes already recognize, there are some

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<sup>196</sup> Cosmetic surgery intended to alleviate a physical or mental disease or condition might be an appropriate context to allow a young person to make informed decisions about healthcare.

circumstances in which it is appropriate and perhaps necessary to allow a young person to make decisions without the knowledge or consent of an adult caretaker. Thus, this proposed model incorporates three primary exceptions to the baseline requirement of shared decision-making between the adolescent patient and the adult caretaker of her choosing.

First, if a young person balks at including parents in decision-making, the healthcare provider shall respect the wishes of the adolescent patient and provide care without the knowledge or consent of a parent or other adult caretaker. An approach that allows young people to determine the level of involvement of adult caretakers is already the road taken in some state statutes, allowing young people to make healthcare decisions related to pregnancy, STIs, substance abuse treatment, and mental health treatment.<sup>197</sup> Under such a model, a young woman seeking an abortion who did not wish to involve parents in her decision-making would not be compelled to do so. Of course, if the healthcare provider determines that the young person is not capable of making decisions because of mental health concerns, immaturity, or some other form of incapacity that precludes the patient from understanding a diagnosis or proposed treatment even when explained in a manner appropriate to the patient's age and intelligence level, the physician should seek out another decision maker for the patient.

Second, a healthcare provider need not stand by and watch an adolescent make a decision with a substantial risk of resulting in death or permanent impairment without seeking to involve an adult decision-maker. Even though the patient has decisionmaking capacity, the physician may seek out parental involvement where the decision being made by the young patient posed the potential for dire consequences for a young patient.

Third, if a parent lacks capacity to consent to care for a young person because of a lack of maturity, mental health concerns, or some other form of incapacity, then a healthcare provider may rely solely upon the informed consent of the decisionally capable young person. Each of these exceptions will be discussed in greater depth in the sections that follow.

## B. THE ROLE OF THE FAMILY: THE ADOLESCENT PATIENT

Under the shared decision-making model envisioned here, an adolescent patient would be a central component of any decision-making process regarding her own health. Only in rare circumstances would that patient be denied the opportunity to play an integral role in decisions being made about her own health.

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<sup>197</sup> See *supra* text accompanying notes 39-48.

The adolescent patient has many responsibilities under this model. In some instances, she will be responsible for identifying a healthcare provider and identifying her own need for healthcare. As a patient, she could demand that her healthcare provider offer her an opportunity or opportunities for private and confidential conversations with the healthcare provider even if a parent or caretaker has accompanied the young person to the healthcare provider's office. These private conversations would afford the young person the opportunity to share thoughts with the healthcare provider that she might not wish to share with her parent or caretaker for any number of reasons. Further, in the context of these private conversations, the young person would have the opportunity to disclose concerns that she might have about involving her parent or caretaker in her ongoing medical decisions. Without permission from the young person, the context of the conversations should remain confidential.

Where a young person did not object to including a parent in her decision-making process, she would be responsible for identifying that person and letting the physician know that this was the individual with whom she would share decision-making power. At that point, along with her parent or caretaker, the adolescent patient would be responsible for listening to information offered by a healthcare provider, seeking clarity where needed, and participating in decision-making about appropriate treatment based on her desires and wishes. Thus, in consultation with a trusted adult and a healthcare provider, an adolescent patient would play a central, if not defining, role in decisions about her own health.

To the extent that a patient did not wish to have a parent know about or consent to care on her behalf, she would need to demonstrate her ability to make independent decisions and articulate her concerns about having her parent or caretaker involved in decisions about her healthcare. The threshold for parental exclusion should be set low meaning that the young person would not have to offer proof of detriment but need only articulate a reasoned desire not to involve a parent in decision-making.

Where a young person sought to access care without the knowledge or consent of an adult caretaker, she would not only need to possess decision-making capacity, but she might also need to demonstrate to the provider that she is capable of paying for the services sought. Being afforded the right to make a broad category of healthcare decisions without parental knowledge or consent might appear to offer little to those adolescents who would be unable to access care without relying on the financial resources of their parents and perhaps these young people would in fact feel that the law continued to do them a disservice. However, the fact that all of those who might possess a right might lack the



financial resources to exercise that right does not make the right less worthy of existence.

For many young people, the right to shared decision-making with parents or caregivers, except in limited circumstances, will not mean that they will routinely seek to access care without the knowledge and consent of parents. Instead, the baseline presumption is one of parent and patient sharing the emotional and intellectual responsibility of care with an understanding that in most families the financial burden will belong to the parent. Thus, parents will be in a position in which they or their insurance provider will cover the cost of healthcare for the adolescent.

Where the need is great enough, resourceful young people will find the means to pay for care that they need but are unwilling to share information about with their parents. Already, in the context of abortion and STI treatment, young women who seek to terminate pregnancies without the knowledge or consent of their parents and young people who seek treatment for STIs must find the financial resources to pay for their own care.<sup>198</sup> Lack of financing does not mean that the right should be withheld. To the extent that young people seek out health care for which they cannot pay and which they do not wish to discuss with their parents, it may be appropriate to allow them access to public benefits programs that can cover the cost of their healthcare.<sup>199</sup> Similarly, physicians may wish

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<sup>198</sup> The question of financial responsibility for healthcare provided to a minor can become complicated at times. When parents consent to care, “they are invariable legally responsible for payment of the value of that care.” MORRISSEY ET AL., *supra* note 15, at 142. However, where a statute authorizes a minor to consent to care or the minor is emancipated and independently consents to care, he bears financial responsibility for that care. *Id.* at 143. Thus, “it is unlikely that the parents would be held liable for payment for services to which they did not consent unless they affirmatively agreed to do so.” *Id.* (citation omitted). The harder case is when a minor is not emancipated and seeks care without parental approval. In such a case, it has been suggested that “generally, the parents of a minor living at home can be held liable for necessary medical services rendered to that minor—even if they have not given their consent—provided they are financially able to do so.” *Id.* Of course, this begs the question of what type of care falls under the rubric of necessary. The author’s description of the law in this arena suggests that where a minor sought and received care that was “unnecessary,” the parents could not be held financially liable for that care. Also, where a young person deliberately sought care without parental consent or knowledge, he would assume financial responsibility for that care or be forced to share information about that care with his parents. “In summary, minors consenting to their own health care are, in almost all circumstances, liable for payment. Under more limited circumstances, such as emergency care, parents could also be looked to for payment even if they did not first consent to treatment.” *Id.* at 144.

<sup>199</sup> In the context of emergency healthcare as required by the Emergency Medical Treatment and Active Labor Act (EMTALA), the AAP writes, “Although state and federal programs exist to pay for children’s health care needs, uncompensated charges may result from the EMTALA requirement of treatment for all without regard to payment. The [Emergency Department] should ensure that the financial issues surrounding a patient’s treatment do not result in a breach of patient confidentiality, particularly if an unintended parental notification may result from the receipt of an itemized medical bill. The healthcare provider should discuss these ramifications of unaccompanied care with the minor patient as appropriate for the patient’s level of maturity and understanding and seek assent from the patient for parental

to refer patients to facilities that provide care on a sliding scale, may be willing to set up payment plans for young patients, or may even choose to provide low or no-cost services in some cases.<sup>200</sup>

Some would also decry the increased pressure placed on adolescents by this proposal because it may require them to participate in conversations with which they are uncomfortable or that require complex decision-making. First, the proposal involves young people in a variety of decision-making processes thus giving them opportunities to “practice” their skills in less charged environments and making them more likely to make informed, reasoned decisions when faced with more challenging questions.

Second, increasing autonomy is a step in the process of moral development for young people:

Both cognitive-developmental and social learning theorists emphasize that significance of participation in role-taking in determining the rate of moral development. Essentially, moral-development theorists conceptualize achievement of milestones in cognitive development as necessary but not sufficient for progress in moral development. For example, from a cognitive developmental perspective, formal operational thought (the capacity to think abstractly) is necessary for the attainment of principled moral reasoning. However, attainment of such reasoning based on abstract ethical principles also requires extensive experience with resolving ethical problems in social interaction and exposure to diverse, “higher” points of view.<sup>201</sup>

Thus, by allowing young people to give consent to routine care, we create better healthcare consumers over the long-term.

By requiring that young people play an active role in discussions and decisions about their own healthcare, this proposal seeks not only to impact the actions of parents and healthcare providers, but also to create opportunities for positive growth and acceptance of self-regulation in young people.<sup>202</sup> While the burden created here may be heavy in some

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involvement, as may be required by patient privacy laws in some states, or honor the patient’s wish for confidential care.” AMERICAN ACADEMY OF PEDIATRICS, *Policy Statement, Consent for Emergency Medical Services for Children and Adolescents*, 111 PEDIATRICS 703, 704 (2003) (citations omitted).

<sup>200</sup> MORRISSEY ET AL., *supra* note 15, at 147.

<sup>201</sup> Gary B. Melton, *Decision Making by Children*, in Melton et al., *supra* note 20, at 27 (citations omitted).

<sup>202</sup> “As suggested by deCharms [sic] findings, there is reason to believe that increased autonomy would increase children’s performance in those spheres in which they had the opportunity to make choices. For example, the affirmative act of making a choice might induce

circumstances, that burden is part of autonomy, and we do not aid adolescents in learning how to direct their own destiny if we are afraid of giving them control over that destiny. By placing them on equal footing with their parents, the law teaches young people lessons about intra-family respect and lessens reliance on outdated notions of parental dominance.

### C. THE ROLE OF THE FAMILY: THE PARENT OR CARETAKER

As currently configured, the law privileges parents over their adolescent children when it comes to making healthcare decisions. As such, where there is a conflict between parent and adolescent about appropriate healthcare treatment, the parent's wish would generally take precedence over the preferences of the young person. A shared decision-making model as described in this article encourages and supports conversation and compromise between parent and child. Under this model, in most circumstances, a parent would continue to possess a right and obligation to consent to care for his child which would involve listening to information offered by a healthcare provider, seeking clarity where needed, and participating in decision-making about appropriate treatment based not only on his desires, but also with appreciation of the wishes and needs of the adolescent patient. Thus, both patient and parent would be privy to information about the patient's health and would make an appropriate decision about care and treatment in consultation with each other and with the healthcare provider.

In some set of cases, parents would not be involved in care because of a decisionally capable patient's request to exclude parents from decision-making about healthcare. Physicians would be obliged to honor such requests, except to the extent that the young person sought to make a decision with a substantial certainty of leading to death or permanent impairment.

In those rare cases in which a patient and parent disagreed about an appropriate course, the parent would not be without recourse. As an initial option, the parent could acquiesce in the patient's position and trust that that the patient has made the most appropriate decision for herself. Assuming that this option was not satisfactory, the parent might also con-

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cognitive dissonance if a child did not follow through on an educational or treatment program to which he or she had consented. Choice results in increased perceived value of the chosen object or event. Consequently, the freedom to decide might increase the child's motivation to perform well in the program. Furthermore, to the extent to which such programs are in themselves stressful, participation in the decision-making process might serve as an "innoculation" against the stress to follow and increase the probability of the child's sustained involvement in the program. In this regard, Holmes and Urie (1975) found that a preparatory interview to establish and discuss expectations for psycho-therapy reduced premature terminations among children aged 6 to 12." *Id.* at 30-31.

tinue to engage in discussion with the patient and perhaps seek third party assistance to help mediate the disagreement. Barring the success of this option, the parent might also seek legal intervention in the conflict, an option that will be discussed further in a subsequent section.

While a parent might seek to use threats to engage an adolescent in needed healthcare, many parents already recognize that treating young people with respect, including seeking out and actively responding to their concerns, is a much more worthwhile means of engaging them. Enlisting the cooperation of a young person in any course of treatment is also worthwhile given the opportunities for sabotaging treatment that can arise when such treatment does not take place in a monitored setting. Young people can opt not to take doses of medication while away from their parents, can eat foods that they have been told to avoid, and can engage in a range of other behaviors that undermine treatment provided to them. Thus, in the interest of family harmony and the maximization of benefit, it makes sense to provide young people with a clear legal mechanism for reinforcing a worthwhile family dynamic.

#### D. THE HEALTHCARE PROVIDER'S ROLE

The role of the healthcare provider articulated here is undoubtedly a central one and one filled with pressures and difficulties, as is true of the roles played by the parent and the patient. However, the role of the healthcare provider in providing care to a young patient is, at its core, always a delicate one when performed within the confines of professional duties and ethics.

Any healthcare provider working with a patient aged fourteen to seventeen would seek the consent of both patient and parent for purposes of diagnosis and treatment of any medical ailment and would document that consent in whatever manner she normally would use to document parental consent. Therefore, for routine care that would normally not mandate written consent, oral consent from patient and parent would continue to be appropriate. For other types of care for which the healthcare provider normally required written consent, such consent would be secured from patient and parent.

As is the case with adults and healthcare treatment, a healthcare provider would need to ensure that consent was informed before proceeding with any type of healthcare treatment,<sup>203</sup> which would require an initial finding that the young person has decision-making capacity. Spe-

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<sup>203</sup> Many commentators have raised questions about the concept of informed consent in the context of healthcare for adults. *See, e.g.*, JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 48-84 (1984) (discussing the history of the informed consent requirement and the difficulties of making such a requirement actually work to the benefit of patients). While a critique of informed consent is beyond the scope of this article, it is worth noting that provid-

cifically, the healthcare provider must assess the young person's ability to offer consent that is knowing, intelligent, and voluntary. Importantly, a healthcare provider need not make a global determination on decision-making capacity, but may find that a young person is capable of making some decisions and not others.<sup>204</sup> Further, the required level of capacity may increase based on the seriousness of the illness or treatment being discussed.<sup>205</sup>

Informed consent, as is required for all adult patients, would mandate that the physician provide information about the patient's condition and the risks and benefits of any proposed healthcare course of action.<sup>206</sup> The healthcare provider would need to provide this information in a manner appropriate to the age and ability of the patient and in language understandable to the patient. This is no different from requiring that a healthcare provider ensure that a patient with a language barrier or a patient who is hearing or sight impaired is provided with the proper tools to understand information conveyed in an informed consent process and freely consents to healthcare.

Where a physician is working with a patient and an adult caretaker or parent and the adolescent patient lacks decision-making capacity, it would be appropriate to allow the adult to provide singular consent for treatment of the adolescent patient with the understanding that this would not mean that the adolescent patient did not have the right to continue to be apprised of her condition and encouraged to at least provide assent to treatment even if consent was inappropriate.

The more difficult circumstance would be where the adolescent who lacked decision-making capacity requested that the healthcare provider refrain from sharing information about her health status with her parent or guardian. Where a decision would have innocuous consequences or could be delayed in the interest of ongoing discussion with the adolescent patient, it is unlikely that the healthcare provider would feel obligated to disclose information to parents that a patient shared in

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ers would need to ensure that they engaged in conversations with adolescents that were appropriate to the patient's age, maturity, and level of intelligence.

<sup>204</sup> Given that decision-making capacity is made "in reference to a particular decision, it may, in some patients, be considered adequate to make some decisions but not others." *Id.* at 462; see also Judith Ann Erlen, *The Child's Choice: An Essential Component in Treatment Decisions*, 15 CHILDREN'S HEALTH CARE 156, 156 (Winter 1987) ("In other words, there is variable competence, with competence no longer considered to be an either/or concept."); Eugene C. Grochowski & Shirley Bach, *The Ethics of Decision Making with Adolescents: What a Healthcare Provider Ought to Know*, 5 ADOLESCENT MED. 485, 487 (October 1994) ("Thus, at any given time, a patient may have the capacity to make a simple, straightforward medical decision but not a more complex one.").

<sup>205</sup> "The more serious the consequences of decisions, the more rigorous the evaluation and standards for [decision-making capacity] should be." Lantos & Miles, *supra* note 28, at 462.

<sup>206</sup> AMERICAN MEDICAL ASSOCIATION, *supra* note 171.

confidence, but she would also not be obligated to provide care to a patient who could not offer valid consent.<sup>207</sup> Where the patient lacking decision-making capacity sought to make a decision potentially leading to death or permanent impairment, the physician should have a professional and legal obligation to seek out parental or other adult guidance for the young person. This discretion should not be used to simply usurp the independent decision-making of a minor with decision-making capacity who simply disagrees with her healthcare provider.

In some circumstances, a parent, rather than the patient, may appear to a physician to lack decision-making capacity. This situation might arise with a parent with a substance abuse problem or mental illness. Here, it would be appropriate for the physician to provide treatment based solely on the informed consent of the adolescent patient with decision-making capacity rather than resorting to court intervention.<sup>208</sup>

While it would not be appropriate for a healthcare provider to simply substitute his judgment for that of the parent or patient based on some evaluation of the patient's best interest, it is not inappropriate to ask a provider to evaluate, as she would with an adult patient, whether the decision being made by the patient or surrogate decision-maker was being made freely, with understanding of consequences and appreciation for alternative options.

Confidentiality and the trust bred by providing access to confidential healthcare must remain a cornerstone of providing care for young people. Recognizing that there is an "inherent duality during the adolescent years"<sup>209</sup> in which "the young person is both a dependent member of the family unit and an increasingly emancipated individual who is moving into the outside world,"<sup>210</sup> the grant of confidentiality "is something more than a pragmatic response to protective needs; it also conveys recognition of and respect for the young person's emergent autonomy."<sup>211</sup> Healthcare providers should seek to involve parents in decision-making about adolescents unless the healthcare provider determines that breaching the patient's confidentiality may prevent the young person from seeking care or might place the young person at risk for violence or

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<sup>207</sup> In fact, where an adolescent seems to lack decision-making capacity, it could be argued that a healthcare provider would violate her duty to the patient by accepting a consent that she knew to be invalid.

<sup>208</sup> In such a situation, a healthcare provider who has a statutory obligation to report abuse or neglect might be obligated to report the parent to the appropriate child services agency. *See, e.g.,* ARK. CODE ANN. § 12-12-507 (2003) (requiring healthcare providers and others to report suspected child abuse); CONN. GEN. STAT. § 17a-101 (defining various healthcare providers as mandated reporters of suspected abuse). However, court adjudication would not be necessary in order for decisions to be made about the patient's healthcare.

<sup>209</sup> MORRISSEY ET AL., *supra* note 15, at 135.

<sup>210</sup> *Id.*

<sup>211</sup> *Id.*

other adverse consequences at the hands of the parent or guardian.<sup>212</sup> In such cases, the healthcare provider should be entitled to provide care to the young person without seeking the consent of a parent or caretaker unless the young person's decision would, with substantial certainty, lead to death or permanent disfigurement. Such an exception comports with the AAP's position that "it is necessary and appropriate for the healthcare provider to inform a parent when there is a life-threatening emergency with their child"<sup>213</sup> though "in most circumstances there is a critical need to ensure that an adolescent's health information is protected."<sup>214</sup>

Where there is conflict between the parents and the patient, the healthcare provider should work to promote dialogue among family members and seek consensus about proceeding with treatment. It may be necessary to refer the family for supportive services or counseling to help them work through their conflict in a manner that ultimately benefits all parties. To the extent that physicians are not connected to such networks, this proposal recommends that such outreach occur. Undoubtedly, there are those healthcare providers who will be uncomfortable with playing the role of counselor and mediator, but their obligation to their patients includes providing appropriate referrals when possible and necessary.

To protect those who provide care to young people, the failure to inform a parent about care being provided to a young person could not, standing alone, establish that a healthcare provider breached a duty to a parent or an adolescent patient. The expectation in the regime envisioned by the current proposal is that healthcare providers will inform patients of a preference for shared decision-making while making clear that a decisionally-capable patient may choose confidential care. In such a system, a physician should not be liable for following the wishes of a competent adolescent patient and would not be liable to parents by virtue of maintaining confidentiality where a patient made such a request assuming no serious risk of death or permanent impairment. Similarly, an adolescent patient could seek redress for negligence in the provision of care but could not seek damages based solely upon a physician's decision to notify a parent where a life threatening or permanently impairing condition was involved and/or the patient lacked decision-making capacity. Liability, of course, could continue to be premised upon a showing of actual negligence in the care provided.

While the burden placed on healthcare providers in this regime may seem excessive, and perhaps inappropriate to some, in practice it asks

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<sup>212</sup> SOCIETY FOR ADOLESCENT MEDICINE, *supra* note 175.

<sup>213</sup> AMERICAN ACADEMY OF PEDIATRICS, *supra* note 176.

<sup>214</sup> *Id.*

healthcare providers to act in accordance with ethical and professional standards that have not yet been fully embraced by the law. Some providers describe the ethical obligation of a healthcare provider caring for an adolescent patient in stark terms. Where a patient evidences decision-making capacity, a healthcare provider "is obliged to determine and respect the preferences of that patient."<sup>215</sup> Where a patient lacks decision-making capacity, "healthcare providers are obliged to provide protection against decisions by patients, families, or institutions that are not in the patient's best interest."<sup>216</sup> These authors also provide guidance on the ethical obligation of a healthcare provider where a patient or his family refuses treatment, writing, "[r]efusal by an adolescent is acceptable only if they [sic] show understanding of the implications of their decision. Unwillingness on the part of adolescent patients or their parents to enter into discussions about the risks and benefits of therapy makes informed refusal impossible."<sup>217</sup> The ethical pronouncements obviously create a significant burden on a physician working with adolescents that mandates evaluating the capacity of the adolescent and her family and responding to requests for or against treatment accordingly.

J. Roswell Gallagher, an early practitioner of adolescent medicine, clearly saw the role of adolescent healthcare providers as one that required the taking on of a difficult and delicate role in the life of a young person. As described by one historian:

Gallagher argued that physicians who treated this age group [adolescents] should not only recognize the adolescent's natural need for independence, but should use the doctor-patient relationship as a way of facilitating adolescent individuation. In the process, Gallagher created a new role for physicians. Not only would doctors provide adolescents with good health care, they would also serve as guides on the arduous path toward adulthood.<sup>218</sup>

A healthcare provider's ethical and professional obligation to a patient will always require a delicate balancing of interests and may sometimes require a healthcare provider to assume an uncomfortable role as an advocate, mediator, counselor, and confidante.<sup>219</sup> These are roles that

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<sup>215</sup> Lantos & Miles, *supra* note 28, at 462.

<sup>216</sup> *Id.*

<sup>217</sup> *Id.* at 463.

<sup>218</sup> PRESCOTT, *supra* note 16, at 76.

<sup>219</sup> One physician explains:

Decisions about the best course of therapy for a child often involve issues beyond medicine. A child's social structure, environment, and parental involvement all affect these decisions. The physician is placed in the role of an advocate for the child. Although this advocacy role is somewhat uncomfortable at times, it is one of the



the healthcare provider must play even where the law seems to provide black and white answers about how to proceed in the face of a parent-child conflict. This proposal gives the healthcare provider wider latitude to act in accordance with her professional judgment without untoward interference by the law.

#### E. THE ROLE OF THE STATE & THE COURTS

Under the shared decision-making model offered here, the option of seeking a court order would remain available for a parent or provider who felt that a young person or parent was making a decision that would ultimately work to her detriment. This option should be exercised sparingly and with caution. Referrals for family counseling or mediation might be a more appropriate option where families are willing, time is not of the essence, and violence is not an issue. As healthcare providers have noted, the availability of the resort to court “allows healthcare providers to intervene along a spectrum from recommendation to persuasion to coercion. This power must be used responsibly, and should not be taken as license to ignore patients with the capacity to make decisions.”<sup>220</sup>

When faced with a difficult decision about treatment for an adolescent, a judge should engage in ethical decision-making meaning that she should “decid[e] cases not on the basis of personal experiences, societal beliefs, or personal assessments about ‘how things should be’ but on the facts presented in court, the law as it has developed, and on scientific rather than conventional wisdom regarding life around [her].”<sup>221</sup> Though courts are given little guidance about how to make such an assessment, the evaluation would essentially be a “mature minor” assessment. The court’s goal should be to determine whether the adolescent has the capacity for mature and thoughtful decision-making and can therefore make a treatment decision that is informed, intelligent, and voluntary. An adolescent would need to show that she could articulate her health problem and its consequences as well as indicate an understanding of the available treatment options and why she has made a particular decision about that treatment. Only where a young person lacks decision-making

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features of medicine as a profession, rather than the merely technical exercise of human body repair and maintenance.

Daniel A. Beals, *Bioethics in Pediatric Practice*, June 30, 2004, available at <http://www.emedicine.com/ped/topic2769.htm>.

<sup>220</sup> Lantos & Miles, *supra* note 28, at 466.

<sup>221</sup> Mlyniec, *supra* note 149, at 1874. While I agree that judges must be aware of and take into consideration the available scientific and medical evidence, it is similarly important to evaluate the more amorphous details of family dynamics and psycho-social issues that are also critically important to any evaluation of the emotional and physical impact of an order in a family court case involving a medical treatment dispute.

capacity should a court make a determination as to what course of action would be in that young person's best interest.

A court faced with evaluating the competency of an adolescent should seek appropriate expert testimony from those who work with adolescents to aid in determining whether the particular adolescent possesses the appropriate level of capacity to allow her to make independent healthcare decisions. The court should also consider the seriousness of the patient's illness and the recommended treatment with a particular focus on whether the young person's decision would be irreversible and substantially certain to result in death or permanent impairment. Thus, in extreme cases, there would continue to be a mechanism protecting young people from rash or poorly conceived decisions.

Given the charge to decide ethically and assess the competency of the minor rather than the popularity of her decision, in a case in which a young person sought lifesaving or curative treatment to which the parents refused agreement, it is unlikely that a court would side with the parents as against the young person. Similarly, where the court found that a young person was refusing life saving or curative care with benefits that outweighed its risks, treatment would also likely be ordered. This, of course, differs from the applicable standard for adult patients, which allows a competent adult to refuse treatment that is life saving or curative.<sup>222</sup> In such extreme circumstances, the need to ensure the advanced decision-making capacity of the young patient is heightened. Thus, a compromise in this area reflects the recognition that there may be a small set of circumstances in which youth should preclude a patient from making a deadly or permanently impairing decision.

This proposal views state intervention as a failure and as an option of very last resort. State involvement in intrafamily disputes calls for the interference of strangers who seek to impose their vision of the world on a deeply personal conflict between parent and child. Where the law invests rights in an adolescent, resorting to state intervention may not become necessary because, in the appropriate case, the healthcare provider can form the same patient-healthcare provider relationship that would be formed with an adult patient. Third party intervention would only be necessary if the healthcare provider feared that the patient lacked decision-making capacity. Unlike state action, vesting an adolescent with rights does not intrude on what would otherwise be a private relationship. Although the parents may wish to pursue court action to enforce a desire to direct the care provided to their child, such state intervention would happen at the bequest of, rather than in opposition to, the wishes of the

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<sup>222</sup> *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 262 (1990); see also *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976).

parents. Therefore, the parents would retain some power over the direction of their family.

One could argue that allowing state interference places a neutral party between parent and child. Unfortunately, there is no guarantee that the state, as embodied by its child welfare system and the myriad actors who play a role in that system, has the capacity for neutrality.<sup>223</sup> Thus, the choice of offering greater protection to a right to autonomous health-care decision-making for adolescents already existing in piecemeal fashion offers significant opportunities for, among other things, enhancing respect for families, not just parents, encouraging growth and expanding the self-sufficiency of adolescents, and lessening the threat of state intervention in families.

#### F. THE MODEL IN PRACTICE

In practice, the relationships between many providers, adolescent patients, and parents would not go through radical changes to the extent that the patient was already the center of the relationship and included as a partner in decision-making. Where such cooperation was not the case, physicians and parents would have an obligation, now legal as well as ethical, to ensure that a young patient was an equal decision-maker in her own healthcare. It seems likely that circumstances would continue to exist in which young people with certain health issues, specifically pregnancy, STIs, substance abuse or mental health issues, would still seek out confidential care with a healthcare provider and provide consent for their own care, assuming that they harbor decision-making capacity as assessed by the treating healthcare provider. Under such a regime, it would also be possible for young women to access abortion services without obtaining parental consent or a judicial bypass, reflecting ongoing recognition of the unique nature of a decision to carry a pregnancy to term or to seek an abortion.

Under this shared decision-making model, where both parent and adolescent agree on a course of action, either favoring or rejecting the advice of a physician, both parties get their wish.<sup>224</sup> Where an adoles-

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<sup>223</sup> See Carol B. Stack, *Cultural Perspectives on Child Welfare*, 12 N.Y.U. REV. L. & SOC. CHANGE 539 (1983-1984) (discussing the ways in which class and cultural issues continue to raise difficult questions in the child welfare context); Dorothy Roberts, *Racial Harm*, COLOR LINES, Sept. 2002, at 45 (describing racism in the nation's child welfare system); see also Alice M. Hines et al., *Factors Related to the Disproportionate Involvement of Children of Color in the Child Welfare System: A Review and Emerging Themes*, 26 CHILD. AND YOUTH SERVICES REV. 507 (2004) (discussing the overrepresentation of children of color in the child welfare system).

<sup>224</sup> This assumes, of course, that the parties are not making a decision that the physicians feels is medical neglect thereby triggering an obligation to report to child welfare authorities and potentially leading to a family court proceeding and a treatment order issued by a court.

cent possesses decision-making capacity and requests that her parents not be involved in particular healthcare decisions, the physician should respect that choice, assuming that the patient's decision does not carry a substantial risk of death or permanent impairment. However, where there is disagreement between competent decision-makers, with either the parent or the adolescent expressing a wish not to participate in a course of treatment, no treatment can take place pending subsequent actions to reach an agreement or, in a worst-case scenario, a court order. This provides incentive for families to work together to reach consensus and may prevent a young person from being subjected to care to which she objects. Rather than letting a parent or young person unilaterally make a decision, a model of shared family decision-making elevates the moral status of the young person by acknowledging her decision-making capacity, while recognizing that adult guidance may be in her best interest.

A shared decision-making model avoids extremes in healthcare decision-making for adolescents. It rejects a vision of a familial unit in which parents are paramount, barring decisions that work to the detriment of young people, but also rejects the idea that most adolescents would not benefit from the participation of an adult in decisions about healthcare. The vision of family upon which this proposal rests is one of families as cooperative units in which young people are confronted with both the burdens and benefits of being a rights-bearing player in the healthcare arena. An adolescent's obvious interest in her own health, combined with her growing capacity to understand her health situation, evaluate alternatives based on her own value system, and articulate her healthcare preferences, must coexist with a parent's interest in protecting the child.

The form of autonomy granted to young people in this context is grounded in connectedness and community. Therefore, it seeks to include parents or caretakers as a vital component of healthcare decision-making for adolescents while according greater respect to the young person as a thinking entity with an inherent right to be intimately involved in any decisions made concerning her own health.

#### IV. IN DEFENSE OF SHARED DECISION-MAKING FOR ADOLESCENT HEALTHCARE

*A family-centered approach considers the effects of a decision on all family members, their responsibilities toward one another and the burdens and benefits of a*

*decision for each member, while acknowledging the special vulnerability of the child patient.*<sup>225</sup>

There are many reasons why different constituencies might object to a shared decision-making model for adolescent healthcare decision-making. The strongest objection would likely come from parents concerned both for the health of their children and the deterioration of their parental authority. This section tackles the issue of parental authority and the state's interest in preserving that authority.

#### A. RATIONAL LIMITS ON THE RIGHT TO CARE AND CUSTODY

One cannot reasonably discuss extending greater rights to adolescents without acknowledging that extending such rights necessarily impacts, while not necessarily undermining, the rights afforded to the parent or guardian. As one commentator explained:

When there is a question regarding access to medical treatment for an adult, the focus is sharply on the relationship of the individuals to the state. The debate is usually framed in terms of the proper imposition of the state's *parens patriae* power over individual autonomy. When minors are involved, however, the interests and capacities of the parents are also a central concern. The effect of policy and case law must be assessed in a broader framework, with simultaneous consideration given to the individual minor's rights, to parental rights and family integrity, and to the state's duties and powers.<sup>226</sup>

As such, parental rights are a necessary part of any analysis of extending rights to young people. How to strike a balance between the rights of parents and the rights and needs of young people is an ongoing puzzle, in part because the realities of the lives of adolescents continue to change and evolve with the culture. As one observer writes:

[S]ociety and the law face a central conundrum in defining and regulating families. Society clings to traditional images of childhood, but the social and cultural universe within which those images made sense and could, in theory at least, be actualized, has largely disappeared. Although society continues to voice a strong commitment to traditional notions of childhood, the world within which actual children function and develop contrasts

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<sup>225</sup> Harrison et al., *supra* note 103, at 826.

<sup>226</sup> Britner et al., *supra* note 27, at 37.

dramatically and increasingly with the world of the traditional family. As a result the ethic of nineteenth- and early twentieth-century domestic life still predominates in social understanding of childhood, but the domestic world to which that ethic once attached itself no longer exists. The lives of actual children can be harmonized less and less often with social images of childhood. In consequence, the difficulty of preserving the ethic of childhood without familiar social anchors is evident.<sup>227</sup>

In other words, while the law regulates the adolescents of another era, today's young people face challenges and seek out experiences at younger ages and with more devastating consequences. This truth presents a key part to evaluating the parental role in adolescent decisionmaking.

It is also important to acknowledge that while the shared decision-making model proposed in this article would impact the rights of parents, that impact need not be negative. As one advocate for children explains, "The provision of human rights is not a zero sum game; acknowledging that children have human rights serves to strengthen, rather than to diminish, the human rights of their parents."<sup>228</sup>

Children and adolescents do not live outside of the purview of the Constitution, as the Supreme Court has held on several occasions.<sup>229</sup> The Justices wrote in 1976: "Constitutional Rights do not mature and come into being magically only when one attains the state-defined age of majority. Minors, as well as adults, are protected by the Constitution and possess constitutional rights."<sup>230</sup>

Arguably, the decisionally capable minor's claim to a right to control her body, Constitutional or otherwise, is stronger than the right to custody and control asserted by a parent and the state's power to protect its vulnerable citizens. Long ago, the Supreme Court wisely acknowledged that a child is "not the mere creature of the State."<sup>231</sup> By the same token, an adolescent is not the mere creature of her parents. She possesses an inherent right to bodily integrity, independent of any rights her parents acquire by virtue of possessing the title of parents and the rights

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<sup>227</sup> Janet L. Dolgin, *The Fate of Childhood: Legal Models of Children and the Parent-Child Relationship*, 61 ALB. L. REV. 345, 419 (1997).

<sup>228</sup> Barbara Bennett Woodhouse, *From Property to Personhood: A Child-Centered Perspective on Parents' Rights*, 5 GEO. J. FIGHTING POVERTY 313, 315 (Summer 1998).

<sup>229</sup> See, e.g., *Tinker v. Des Moines Independent Community School District*, 393 U.S. 503, 511 (1969) ("Students in school as well as out of school are 'persons' under our Constitution. They are possessed of fundamental rights which the State must respect, just as they themselves must respect their obligations to the State.").

<sup>230</sup> *Planned Parenthood v. Danforth*, 428 U.S. 52, 74 (1976).

<sup>231</sup> *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925).

and responsibilities that come with that title. Further, scientific studies show that she is, at least theoretically, capable of wielding these rights in positive and self-protective ways.<sup>232</sup> The individual right to determine one's own fate and the fundamental role that this right plays in determining personhood cannot be underestimated. Allowing parents to usurp the right of self-determination belonging to a decisionally-capable young person denies the young person an essential component of her humanity.

To the extent that one believes that adolescents are in fact competent decision-makers, that fact standing alone may be sufficient to warrant lowering the age of healthcare consent. For:

When a child demonstrates the capacity for effective choice in a certain context and with regard to some action of decision, then the child has a claim to some degree of control over that action or decision. The claim holds against those who are in the position of responding to the decision and who are also charged with protecting the child's best interests. Respecting a child's claim to control entails allowing the child to exercise her liberty, to make significant choices, or to direct her affairs, and for others to comply accordingly.<sup>233</sup>

However, there may be other reasons why, even in the face of decision-making capacity, young people should not make their own healthcare decisions. One of the strongest arguments in this regard is that extending rights to young people is an attempt to equalize players in a parent-child relationship that has an inherent element of dependence. Such an attempt to equalize can only lead to fragmentation, conflict, and confusion. Fragmentation, however, is most likely within family units that are already on the brink of fracture.<sup>234</sup> As noted by Dr. Renee Jenkins in testimony before Congress on behalf of the AAP, "Research has

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<sup>232</sup> See *supra* text accompanying notes 124-141.

<sup>233</sup> Bellon, *supra* note 144, at 113.

<sup>234</sup> Hyman Rodman, *Understanding the United States Supreme Court's Position on Parental Consent Requirements: In Defense of Danforth and Bellotti. A Response to Crutchfield*, 30 FAMILY RELATIONS 183 (1981) ("Parents are more likely to be consulted in a harmonious family with good parent-child relationships. But if family harmony is lacking, and if parent-child relationships are poor, should the state insist upon parental consent or parental notification in order to 'maintain' something that is not there."); see also *Planned Parenthood v. Danforth*, 428 U.S. 52, 76 (1976) ("It is difficult however, to conclude that providing a parent with absolute power to overrule a determination, made by the healthcare provider and his minor patient will serve to strengthen the family unit. Neither is it likely that such veto power will enhance parental authority or control where the minor and the nonconsenting parent are so fundamentally in conflict and the very existence of the pregnancy already has fractured the family structure. Any independent interest the parent may have in the termination of the minor daughter's pregnancy is no more weighty than the right of the competent minor mature enough to have become pregnant.").

shown that a majority of adolescents voluntarily share information with their parents after they consult privately with a healthcare provider. . . . This is predicated not by laws but on the quality of the relationships within the family."<sup>235</sup> Parents who have worked to foster respectful and caring relationships with their children will, hopefully, find that an adolescent seeking healthcare advice will turn to his parents for needed advice and support.

Evaluating the potential conflict between parent and adolescent requires correctly framing the issue, not as one of whether a parent is capable of discerning and acting upon the best interests of a child. Instead, the issue is whether a young person is able to discern what is in her own best interest and act accordingly. Where a qualified actor exists, allowing a third party, no matter how capable, caring, or loving, to wholly consume the decision-making capacity of the capable actor is a less than optimal ordering of human relationships. This is true even in the context of loving parents and sick young people.

Protecting families demands respect for all members of a familial unit and thus requires providing rights to both parents and their minor children. If one believes in the inherent dignity of adolescents, then one must recognize that this dignity is diminished by exclusion of a young person from conversations and decision-making about her health, thus depriving her of the opportunity to determine the course of her own life. With the rights of parents also come duties and responsibilities. A parent's role is to provide direction and guidance as a child learns to ascertain and assert her own interests, wants, and desires. By providing legal reinforcement for the types of health care decision-making in which many well-functioning families likely already engage, the law can simultaneously protect young people, nurture families, and respect parents.

There are those parents who will view any change in the status of the right to determine the healthcare choices of their adolescent child as a substantial and unwarranted deprivation of rights. This same argument can be made about the existing web of state statutes that presently provide limited healthcare decision-making rights to adolescents, yet it appears that these statutes have not been widely challenged. Arguably there is a subtle, but significant, benefit that accrues to parents from such statutes. In some cases, these laws may lead a young person to access necessary healthcare that he would not seek if discussion with a parent were a prerequisite—a benefit that ultimately accrues to the parent who wants a safe and healthy child more than she wants a child who asks her permission before making sure that he is well. Further, allowing young people to make independent healthcare decisions contributes to their

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<sup>235</sup> AMERICAN ACADEMY OF PEDIATRICS, *supra* note 176.



ability to think about and act in accordance with their own best interests, thereby helping them become self-sufficient adults.<sup>236</sup>

Conceding a natural inequality and necessary dependence between children and parents does not require that adolescents be completely shut out of the rights given to their parents. As Barbara Bennett Woodhouse explains:

Empowering one individual to control another implicates human rights that attach even to those who are inherently dependent, lacking either the mature capacity or the practical autonomy to act on their own behalf. Rights to bodily integrity, to identity, to maintain intimate relationships, and to freedom of faith and thought do not depend on equality.<sup>237</sup>

In most circumstances, parents and their offspring will not be at odds about appropriate treatment for a young person's illness.<sup>238</sup> In such cases, the transfer of a right to knowledge and consent for the young person will help the patient form an optimal bond with her healthcare provider and increase the chance for deriving maximum benefit from cooperating with treatment while showing respect for the family unit and the interdependence of parent and child. Where there is conflict between parents and their adolescent children, which will inevitably occur in some small portion of cases,<sup>239</sup> the central question becomes how best to support whole families, not just parents, and protect the interests of adolescents in the face of such conflicts. This article's proposal allows these disputes to remain within the family by granting legal protection to the adolescent's interest in her own bodily autonomy, thereby showing greater deference and respect for the sanctity of the family than does an automatic shift to a state-run child protective system.

Devaluing the parental role need not be seen as an inevitable consequence of acknowledging adolescent autonomy. Allowing adolescents to participate in or direct their own healthcare can lead to an increase in

<sup>236</sup> See *supra* text accompanying notes 201-202.

<sup>237</sup> Barbara Bennett Woodhouse, *The Dark Side of Familial Privacy*, 67 GEO. WASH. L. REV. 1247, 1255 (June/Aug. 1999).

<sup>238</sup> There are those who disagree with this assertion and argue that conflict is much more common than harmony. One of the healthcare providers who worked for years to get the AAP to approve a policy on issues of consent and assent in healthcare for children wrote:

I would argue that "identity" or "harmony" between the interests of parents and those of their children are what is rare. Conflict is the norm. Unfortunately, the very common difference between the desires and interests of children and those of their parents are [sic] frequently ignored by both parents and providers. . . . We do ourselves and our patients a disservice when we deceive ourselves with this hopelessly "romantic" view of what goes on in families.

William G. Bartholome, *Letter to the Editor*, 96 PEDIATRICS 981, 981 (Nov. 1995).

<sup>239</sup> *Id.*

parental perception of an adolescent's social age<sup>240</sup> and reinforce lessons conveyed about responsibility and thoughtfulness. Furthermore, as suggested earlier, it is likely that many, if not most, adolescents will continue to consult with and make decisions in tandem with their parents. The difference will be that the adolescents will have greater opportunities for engaging in mature and thoughtful decision making which will, in turn, accrue to their benefit as they move toward adulthood.

Certainly, asking that parents share decision-making with their adolescent children,

does not imply that parental involvement is not important; parental involvement is a recognized part of the optimal health care for adolescents. The pediatrician is not placing himself in an adversarial position in relation to the parents when he obtains their adolescent offspring's consent or when he maintains the confidentiality of what the adolescent has told him, although the parents may not always perceive that this is the case. In reality, the pediatrician shares the same goal that the parents have: to protect and restore the adolescent health.<sup>241</sup>

In the end, any perceived loss of parental power is justified if it is a necessary prerequisite to according an appropriate level of personhood to adolescents.

## CONCLUSION

*Above almost all else, we seek a legal policy that preserves the life chances for those who make serious mistakes, as well as preserving choices for their more fortunate. . . contemporaries.*<sup>242</sup>

No child or adolescent is simply a bystander in her own healthcare, nor is she just a body to be acted upon. As such, there should always be ways of involving that young person in decisions about her own care, with the understanding that the level of involvement may exist on a sliding scale given the individual characteristics of the patient child involved. As one author has written:

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<sup>240</sup> Social age refers to the ways in which parents' perception of the age and dependency of their children is impacted by the degree to which those children are granted opportunities for autonomy that then impact their level of maturity. Anne Solberg, *Negotiating Childhood: Changing Constructions of Age for Norwegian Children*, in *CONSTRUCTING AND RECONSTRUCTING CHILDHOOD: CONTEMPORARY ISSUES IN THE SOCIOLOGICAL STUDY OF CHILDHOOD* 118, 134 (Alison James & Alan Prout eds., 1990).

<sup>241</sup> Silber, *supra* note 66, at 409.

<sup>242</sup> ZIMRING, *supra* note 193, at 91-92.

Based on detailed knowledge about the real competence of children, it should be possible to protect them when necessary, without *over*protecting them. . . . It should not be forgotten, however, that protection of children is not a form of discrimination: *all* people need protection at some point or other in their lives and in a variety of difficult situations. Equally, the fact that children are dependent is not a reason to deny their participation rights. In the first place, everyone is dependent on other people at least some of the time, without thereby losing such rights. In the second place, even when adults are totally dependent on others, their autonomy can be provided for, based on their inherent dignity as human beings. Dependent or not, the participation rights of adults are subject to restrictions, bearing in mind the rights of others and the needs of the community. The same applies to children.<sup>243</sup>

Presently, the law fails to recognize the body of scientific literature indicating the ability of young people to make informed decisions about their own healthcare and the degree to which granting adolescent autonomy in this area can improve the relationship between a healthcare provider and an adolescent patient. Furthermore, current legal regulations work against a norm of family communication, ignore the reality of the lives of many families, and gives short shrift to the moral function of law to the extent that it devalues the moral status of adolescents by denying their autonomy. To rectify needless imbalance, it is necessary to embrace the concept of bodily autonomy for young people by recognizing their right to be apprised of their own health status, fully informed about the meaning of that status, offered available treatment options, and granted the opportunity to meaningfully participate in making an informed decision about treatment.

The way that society regulates youth reflects our values and morals and helps shape the adults that these young people will become. The legal system's piecemeal and limited offerings of rights to adolescents does not succeed in keeping young people safe from themselves and does not maintain the cohesiveness of families. Too often, the legal system works against a cooperative healthcare provider-patient relationship and ignores or devalues the capabilities of young people.

I propose a shift in the legal framework in which youth is not automatically synonymous with a lack of decision-making capacity. Rather, based on knowledge about the cognitive abilities of adolescents and the

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<sup>243</sup> Flekkøy, *supra* note 142, at 75 (citation omitted).

ethical and professional standards by which healthcare providers try to provide care to young people, it is appropriate to allow young people to share decision-making power with their parents and seek out confidential care when desired and necessary. Making this shift shows tremendous respect for young people and acknowledges their moral status as autonomous human beings. Further, it encourages a model family structure in which young people engage with their parents about important issues, but in which parental interest in controlling children does not automatically trump a young person's needs.

