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## Article

### Parental Autonomy over Prenatal End-of-Life Decisions

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## INTRODUCTION

The Supreme Court's abortion jurisprudence is premised upon a conflict: a woman's right to end her pregnancy and control her body clashes with the state's interest in protecting her fetus's potential life.<sup>1</sup> But contrary to this assumption, not all abortions involve conflicting interests.<sup>2</sup> Some women obtain abortions because they think it is in their potential child's<sup>3</sup> best interest.<sup>4</sup> This Article focuses on these women and suggests a new constitutional grounding to protect their abortion rights.

When parents discover during pregnancy that their potential child has a life-threatening condition, they are faced with one of the most impossible choices of their lives: end a pregnancy they deeply want or continue a pregnancy knowing their baby could live a short and painful life.<sup>5</sup> There are no right answers for these parents, who can defend their choice to either end or continue the pregnancy based on the love they have for their child. These decisions are currently governed by ill-fitting abortion laws, under which many state abortion bans begin at the moment most women first discover their potential child's diagnosis.<sup>6</sup> I contend that these parents have an additional abortion right—*independent* of a woman's general right to a pre-viability abortion—as parents making end-of-life decisions for their potential child. Except in rare circumstances, parental end-of-life

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1. See *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 846 (1992) (“[T]he State has legitimate interests from the outset of the pregnancy in protecting . . . the life of the fetus . . .”); see also *Roe v. Wade*, 410 U.S. 113, 150 (1973) (holding that the state's interest in protecting life arguably “extends . . . to prenatal life”).

2. See discussion *infra* Part III.C.

3. In most reproductive justice literature, authors strictly use the term fetus to avoid personification of the fetus and focus on the woman's rights. Though I agree with that linguistic choice when discussing unwanted pregnancies, I am intentionally using the word “potential child” here and throughout the paper to refer to the fetuses of desired pregnancies. In these instances, the parents—even those who choose to end the pregnancy—typically see their fetus as a child. In Part III.C.3, I defend this choice against the criticism that it could create a slippery slope towards personhood.

4. See *infra* Part III.C.1.

5. See *infra* Part III.C.1.

6. See *infra* Part III.B.1.

decision-making is constitutionally protected after birth,<sup>7</sup> and this Article argues that it should also be protected before birth at any point in the pregnancy. This right would ensure that parents making end-of-life decisions during pregnancy have access to abortion even after state bans take effect. It would sit on top of a woman's general right under *Planned Parenthood v. Casey*<sup>8</sup> to abortion before viability for any reason—albeit burdened by governmental regulation—which should not be disturbed.

When infants or children get very sick after birth, their parents must make complicated end-of-life choices, including when to stop or withdraw life-sustaining treatment.<sup>9</sup> These decisions are constitutionally protected on the grounds that parents have a liberty interest in the care and custody of their child.<sup>10</sup> If a doctor disagrees with the parents' choice, she cannot override the parents' decision without a court order.<sup>11</sup> Though courts will consider such cases under a best interest of the child (BIC) framework, parents enjoy a presumption that they are acting in their child's best interests—a presumption the state must rebut before a court will order treatment.<sup>12</sup> Typically, courts will defer to parental choice to stop treatment, even if the child will die, when the treatment itself is invasive, may not cure the child's condition, or will expose the child to pain or other risks.<sup>13</sup> In those instances, the state cannot prove that the decision to withhold or withdraw treatment is improper.<sup>14</sup>

Parents facing a severe prenatal diagnosis are making the same kinds of end-of-life decisions—they are balancing for their potential child the pain of expected treatment, the odds of survival with and without treatment, the quality of life expected after treatment ends, and myriad other variables. This parental decision-making should be protected prenatally to at least the same degree it is protected after birth. Otherwise, parents are given constitutional protection from state interference in their healthcare decisions for living children,<sup>15</sup> but not potential children. This is paradoxical. One would imagine that

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7. See *infra* Part II.

8. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833 (1992).

9. See discussion *infra* Part II.A.

10. See *Parham v. J.R.*, 442 U.S. 584, 602 (1979).

11. See *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 630 (1986) ("Indeed, it would almost certainly be a tort as a matter of state law to operate on an infant without parental consent.").

12. *Id.* at 628–29 n.13.

13. See *infra* Part II.A.

14. See *infra* Part II.A.

15. See *infra* Part II.A.

parents should have even greater leeway to make end-of-life decisions prenatally given that the state's interest in a potential child must be less than its interest in a living child. And of course, the potential child is being kept alive not by machines and medicine, but through the physical sacrifice of the mother, whose placenta delivers it oxygen, hydration, and nutrition.<sup>16</sup>

Though abortion may not initially seem like the end-of-life decisions parents make for living infants and children, where treatment is withheld or withdrawn, it is in reality quite similar. Many abortions in this context occur by first cutting the umbilical cord between the mother and potential child, thereby withdrawing his or her source of oxygen, hydration, and nutrition.<sup>17</sup> This act is no different than removing a ventilator or feeding tube from a child who cannot survive without it.<sup>18</sup>

Unfortunately, many parents only learn of their potential child's life-threatening diagnosis after the state has already banned abortion. Active state bans<sup>19</sup> begin as early as twenty to twenty-two weeks in eighteen states.<sup>20</sup> These bans unfortunately coincide with the anatomy scan, the mid-pregnancy ultrasound that is designed to diagnose fetal health conditions.<sup>21</sup> Most women who discover a problem on the anatomy scan cannot obtain an abortion before twenty-two weeks, especially given the likelihood of additional testing, second opinions, and other abortion regulations that delay decision-making.<sup>22</sup> Moreover, fetal problems can also be diagnosed even later in pregnancy,<sup>23</sup>

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16. Mathilde Cohen, *The Law of Placenta*, 31 YALE J.L. & FEMINISM 337, 344 (2020) (describing how the placenta "acts as every organ the fetus needs to survive"); Greer Donley, *Regulation of Encapsulated Placenta*, 86 TENN. L. REV. 225, 229 (2018).

17. Kristina Tocce, Kara K. Leach, Jeanelle L. Sheeder, Kandice Nielson & Stephanie B. Teal, *Umbilical Cord Transection to Induce Fetal Demise Prior to Second-Trimester D&E Abortion*, 88 CONTRACEPTION 712, 713 (2013).

18. See *infra* Part III.C.2.

19. See *infra* Part III.B.1 (explaining that many states are currently attempting to move their abortion bans up much earlier in the pregnancy—as early as six weeks—but these bans have all been enjoined pending litigation).

20. *State Bans on Abortion Throughout Pregnancy*, GUTTMACHER INST. (Jan. 1, 2020), <https://www.guttmacher.org/state-policy/explore/state-policies-later-abortions> [https://perma.cc/3Z3C-5AZB].

21. Michael Bethune, Ekaterina Alibrahim, Braidy Davies & Eric Yong, *A Pictorial Guide for the Second Trimester Ultrasound*, 16 AUSTRALASIAN J. ULTRASOUND MED. 98, 98 (2013).

22. See *infra* Part III.B.1.

23. Cf. *Birth Defects in Children*, STAN. CHILD.'S HEALTH, <https://www.stanfordchildrens.org/en/topic/default?id=overview-of-birth-defects-90-P02113> [https://perma.cc/YVS7-X9UM] (noting that some birth defects may not be diagnosed until birth).

impeding parental rights even in the majority of states that ban abortion at twenty-four weeks or at viability.<sup>24</sup> It is therefore common for women facing a life-threatening fetal diagnosis to be forced to either continue the pregnancy knowing their child may die shortly after birth or travel across state lines at enormous expense to end the pregnancy.<sup>25</sup>

Reconceptualizing these abortions as parental health decisions that are presumptively protected would provide additional rights to these parents—supplementing the rights that already exist under traditional abortion jurisprudence. Under this framework, it would be an unconstitutional invasion of parental autonomy for a state to ever ban this particular type of abortion unless the state could prove that the abortion was clearly not in the potential child's best interest. Because the right to privacy under *Casey* already prohibits the state from banning abortions before viability,<sup>26</sup> this parental autonomy right would largely kick in after a state's abortion ban begins. In this way, it would mimic the health-or-life exception, whereby states must guarantee the right to abortion at any point in the pregnancy when the pregnancy threatens the mother's health or life.<sup>27</sup> Though this new right would impact only a small number of women, it represents a novel way to restore abortion protections after decades of them being slowly chipped away. It also grounds an abortion right in an entirely different jurisprudence, which is particularly attractive at this moment given that traditional abortion rights are more fragile now than they have been in decades.<sup>28</sup> Finally, it builds on efforts to frame abortion as a

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24. See *State Bans on Abortion Throughout Pregnancy*, *supra* note 20.

25. See, e.g., DAVID S. COHEN & CAROLE JOFFE, OBSTACLE COURSE: THE EVERYDAY STRUGGLE TO GET AN ABORTION IN AMERICA 210–12 (2020) (describing the experiences of women forced to carry their pregnancies to term); see *infra* Part III.A (describing the experience of traveling across state lines to obtain an abortion).

26. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 927 (1992) (Blackmun, J., concurring in part).

27. See *State Bans on Abortion Throughout Pregnancy*, *supra* note 20.

28. In 2018, Justice Kennedy retired. He had recently joined the *Whole Woman's Health v. Hellerstedt* opinion, that invalidated Texas's TRAP laws, 136 S. Ct. 2292, 2299 (2016), and was seen as the swing vote on abortion rights. Once Justice Kavanaugh was confirmed in his place, there was genuine fear that even the most basic abortion rights were at risk. Conservative states, believing they finally had a sympathetic Supreme Court, started passing aggressive legislation attempting to overturn *Roe v. Wade* and *Planned Parenthood v. Casey*. On June 29, 2020, the Supreme Court issued its first decision on abortion with Justice Kavanaugh on the Court. See *Juno Med. Servs. L.L.C. v. Russo*, 140 S. Ct. 2103 (2020). Surprising many abortion rights advocates, the Court upheld the district court's invalidation of a TRAP law in Louisiana that was identical to one of the laws it had previously invalidated in *Whole Woman's Health*. *Id.* at 2112–13. The deciding vote in that case came from Chief Justice Roberts. As feared, Justice

parenting decision and to change the dialogue surrounding abortion and disability.<sup>29</sup>

Section I describes the variation in fetal anomaly, separating possible diagnoses into three categories: those that cause certain childhood death (Category I), those that cause a substantial possibility of childhood death with severe morbidity among survivors (Category II), and those that cause only disability (Category III). These categories set up the framework for thinking through which types of diagnoses would justify a parent's decision to refuse or withdraw life-sustaining treatment. Section II then explores the constitutionally protected autonomy right that allows parents to make health decisions for their living children unobstructed from state interference. It also describes the limitations of this right: the state can interfere in parental decision making when it can prove that the parents' decision is against the child's best interest. The section concludes by mapping the case law onto the categories, arguing that in general, parents have the authority under the BIC standard to withhold or withdraw life-sustaining treatment from children and infants facing a Category I or II diagnosis, but not a Category III diagnosis.

Section III then argues that the parental right to make end-of-life decisions for children should be extended to parents before birth. This Section begins by describing the failure of traditional abortion law to protect parents seeking to terminate on the basis of severe fetal anomaly. It then argues that abortion in the face of severe fetal anomaly

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Kavanaugh voted to remand the case. *Id.* at 2223 (Kavanaugh, J., dissenting). Though the case was an unexpected victory, Chief Justice Roberts made clear that his decision was based entirely on precedent—i.e., that had the issue been one of first impression, he would not have voted to invalidate the law. *Id.* at 2133 (Roberts, C.J., concurring) (“I joined the dissent in *Whole Woman’s Health* and continue to believe that the case was wrongly decided. The question today however is not whether *Whole Woman’s Health* was right or wrong, but whether to adhere to it in deciding the present case.”). As a result, it is still reasonable to assume that Chief Justice Roberts will be sympathetic to any abortion regulation that raises an issue of first impression, even if it greatly reduces abortion access. See Leah Litman, June Medical as the New Casey, TAKE CARE BLOG (June 29, 2020), <https://takecareblog.com/blog/june-medical-as-the-new-casey> [https://perma.cc/Z8NR-4FET]. Justice Ginsburg’s death was announced as this Article was going to press. See Rebecca R. Ruiz, Amy Coney Barrett Signed an Ad in 2006 Urging Overturning the ‘Barbaric Legacy’ of Roe v. Wade, N.Y. TIMES (Oct. 1, 2020), <https://www.nytimes.com/2020/10/01/us/elections/amy-coney-barrett-roe-v-wade.html> [https://perma.cc/4SQM-RTGD] (finding that President Trump quickly moved to nominate Judge Amy Coney Barrett, whose pro-life record is well documented, to fill her spot on the Court). If the Senate confirms Judge Amy Coney Barrett, it is unclear if any constitutional abortion rights will survive.

29. Jamie R. Abrams, *The Polarization of Reproductive and Parental Decision-Making*, 44 FLA. ST. U. L. REV. 1281, 1310 (2017).

involves the same motivation and same action as withdrawing life-sustaining treatment from a dying child. Any material differences between the two—namely, that a potential child is not a legal person and that the expectant mother's autonomy rights are also at issue—support even stronger autonomy rights for expectant parents. As a result, the same parental autonomy rights that protect parents after birth must also protect a parent's decision before birth to terminate a pregnancy on the basis of Category I and II diagnoses. This Section also explores the practical consequences of this argument, including whether it creates a slippery slope to personhood. Finally, this Section concludes by situating the argument within the larger debates around abortion. It suggests that this Article can build on efforts to see abortion as a parenting decision and to improve the dialogue surrounding abortion and disability.

### I. VARIATION IN FETAL ANOMALY

According to best estimates, at least 3% of babies in the United States will have a birth defect.<sup>30</sup> Many birth defects<sup>31</sup> can be diagnosed prenatally, at which point they are typically referred to as fetal anomalies.<sup>32</sup> Roughly 150,000 fetuses are diagnosed with a fetal anomaly each year in the United States.<sup>33</sup> There is a wide range of diagnoses that can be made prenatally—some conditions are manageable with

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30. *Updated National Birth Prevalence Estimates for Selected Birth Defects in the United States, 2004–2006*, CTRS. FOR DISEASE CONTROL & PREVENTION (Nov. 1, 2018), <https://www.cdc.gov/ncbddd/birthdefects/features/birthdefects-keyfindings.html> [<https://perma.cc/9MQ4-AV2F>]. This statistic likely undercounts the prevalence of birth defects given that it does not include pregnancies that are terminated because of fetal anomalies diagnosed before twenty weeks; however, it does count abortions after twenty weeks if they occur in the hospital. See *Update on Overall Prevalence of Major Birth Defects—Atlanta, Georgia, 1978–2005*, CTRS. FOR DISEASE CONTROL & PREVENTION (Jan. 11, 2008), <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5701a2.htm> [<https://perma.cc/LS7U-WSDQ>].

31. *What Are Birth Defects?*, CTRS. FOR DISEASE CONTROL & PREVENTION (Dec. 5, 2019), <https://www.cdc.gov/ncbddd/birthdefects/facts.html> [<https://perma.cc/32PN-8M9Z>] (defining birth defects as structural variations “present at birth that … may affect how the body looks, works, or both”).

32. *Fetal Anomalies*, MERCY (2020), <https://www.mercy.net/service/fetal-anomaly> [<https://perma.cc/P6AS-VVJ8>].

33. Marguerite Maguire, Alexis Light, Miriam Kuppermann, Vanessa K. Dalton, Jody E. Steinauer & Jennifer L. Kerns, *Grief After Second-Trimester Termination for Fetal Anomaly: A Qualitative Study*, 91 CONTRACEPTION 234, 234 (2015).

treatment,<sup>34</sup> while others are terminal.<sup>35</sup> Because most fetuses that survive the first trimester become healthy babies, parents are often unprepared for the possibility that a routine prenatal exam could end with a devastating diagnosis for their potential child.<sup>36</sup>

This Article does not attempt to list every possible fetal diagnosis. Rather, it creates three general categories under which a prenatal diagnosis could fall based on the diagnoses' severity: (1) those that cause certain, and likely imminent, childhood death, (2) those that cause frequent childhood death with severe morbidity among survivors, and (3) those that are unlikely to be life threatening, but will cause disability. It may not always be clear in which category a diagnosis fits, especially given that a single condition can have varying severity and can worsen or improve during gestation.<sup>37</sup> And as treatments improve, the category under which a particular diagnosis might fall could change. Nevertheless, doctors should be trusted to categorize a condition based on their medical judgment and understanding of the current medical treatments. Doctors are frequently asked to prognosticate in similar ways with children, and there is no reason to distrust their ability to do the same with fetuses.

These categories aim to give the reader a sense of the broad range of prenatal diagnoses. They will resurface later in the Article as a mechanism to define the boundaries of the right to abortion on the basis of severe fetal anomaly. I will argue that because parents of living children can only withdraw or withhold lifesaving treatment when their living child faces a Category I or II diagnosis, the right to abortion on the basis of severe fetal anomaly should also be limited to those instances. Thus, while parents will be free under the rights established in *Casey* to obtain an abortion before viability for any reason,<sup>38</sup> including a Category III diagnosis, the right to a post-viability abortion on

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34. For instance, a baby can have cleft palate, where the baby's lips or mouth do not form properly. See *Facts About Cleft Lip and Cleft Palate*, CTRS. FOR DISEASE CONTROL & PREVENTION (Dec. 5, 2019), <https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html> [https://perma.cc/DS7C-7QF8].

35. For instance, a baby can develop anencephaly, where the child's skull and brain are not formed. These babies cannot survive. *Facts About Anencephaly*, CTRS. DISEASE CONTROL & PREVENTION (Dec. 5, 2019), <https://www.cdc.gov/ncbddd/birthdefects/anencephaly.html> [https://perma.cc/DP2P-VTQS].

36. See Jill Wieber Lens, *Tort Law's Devaluation of Stillbirth*, 19 NEV. L.J. 955, 964 (2019) (noting that expectant parents are primarily worried about the possibility of miscarriage in the first trimester and are unprepared for other prenatal complications like stillbirth).

37. See *infra* Part I.B (noting that some Category II conditions could fall within Category I at their most mild, but also within Category III).

38. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 846 (1992).

the basis of severe fetal anomaly should only be guaranteed after parents receive a Category I or II diagnosis.

#### A. CATEGORY I: CERTAIN, AND LIKELY IMMINENT, CHILDHOOD DEATH

The most severe types of fetal anomaly are those that will cause certain—and most likely, imminent—childhood death.<sup>39</sup> The most common of these conditions include, for example, anencephaly, where the fetus's skull and brain are not formed;<sup>40</sup> Trisomy 13 or Trisomy 18, which are chromosomal disorders causing multi-organ dysfunction;<sup>41</sup> and bilateral renal agenesis, where the fetus does not develop kidneys;<sup>42</sup> though others exist.<sup>43</sup> For these parents, the question is not if their potential child will die in childhood—most often, in infancy—but when and how the child will die.<sup>44</sup>

Historically, these conditions have been called “fatal” or “lethal” fetal anomalies and categorized as being incompatible with life.<sup>45</sup> That terminology, however, has become more controversial as some parents reject the implication that their child’s short existence was not “life” or that all non-palliative care is futile.<sup>46</sup> Indeed, recent treatments for some of these conditions have led to improvements in longevity that render death less imminent.<sup>47</sup> Even so, one-third to three-

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39. See Steven R. Leuthner, *Palliative Care of the Infant with Lethal Anomalies*, 51 PEDIATRIC CLINICS N. AM. 747, 747 (2004) (“Congenital anomalies rank as the primary cause of infant mortality, making up approximately 20% of all infant deaths.”).

40. *Facts About Anencephaly*, *supra* note 35.

41. Robert E. Meyer, Gang Liu, Suzanne M. Gilboa, Mary K. Ethen, Arthur S. Aylsworth, Cynthia M. Powell, Timothy J. Flood, Cara T. Mai, Ying Wang & Mark A. Canfield, *Survival of Children with Trisomy 13 and Trisomy 18: A Multi-State Population-Based Study*, 170 AM. J. MED. GENETICS 825, 826 (2015).

42. Alana N. Thomas, Laurence B. McCullough, Frank A. Chervenak & Frank X. Placencia, *Evidence-Based, Ethically Justified Counseling for Fetal Bilateral Renal Agenesis*, 45 J. PERINATAL MED. 585, 585 (2017).

43. See Leuthner, *supra* note 39, at 749 box1 (listing other “lethal anomaly diagnoses”). But see *infra* Part I.B (explaining many other “lethal” diagnoses are severe versions of conditions in Category II that are not always lethal).

44. See Leuthner, *supra* note 39, at 753 (describing survival times for severe lethal anomalies).

45. See Tracy K. Koogler, Benjamin S. Wilfond & Lainie Friedman Ross, *Lethal Language, Lethal Decisions*, 33 HASTINGS CTR. REP. 37, 37–38 (2003).

46. Erin Digitale, *Compatible with Life?*, STAN. MED. (2018), <https://stanmed.stanford.edu/2018fall/genetic-disorders-incompatible-life-options.html> [https://perma.cc/WNQ3-34R5]; Koogler et al., *supra* note 45, at 38.

47. See Digitale, *supra* note 46 (describing more aggressive treatments of Trisomy 18 patients leading to longer lives); Koogler et al., *supra* note 45, at 38; Jacqueline E. Nguyen, Jason L. Salemi, Jean P. Tanner, Russell S. Kirby, Ronald P. Sutsko, Terri L. Ashmeade, Hamisu M. Salihu & Laura L. Drach, *Survival and Healthcare Utilization of*

quarters of these babies will die in utero or during the birth process,<sup>48</sup> and the vast majority of those that live to meet their parents will die within days or months.<sup>49</sup> For example, the median survival time for babies with bilateral renal agenesis is less than one day,<sup>50</sup> and there has been only one documented case of a baby with that condition surviving the neonatal period.<sup>51</sup> For babies with anencephaly, the average survival time is fifty-one minutes,<sup>52</sup> and the one-year mortality is almost 100%.<sup>53</sup> The median life expectancy of a baby with Trisomy 13 or Trisomy 18 is five to twelve days.<sup>54</sup> Due to more aggressive medical interventions, however, some recent studies suggest that roughly 10% of babies born alive with Trisomy 13 or Trisomy 18 can survive to ten years old,<sup>55</sup> but they will experience a range of profound motor and intellectual disabilities and still never make it to adulthood.<sup>56</sup> Furthermore, because elective termination and stillbirth are more common with more severe phenotypes of Trisomy 13 and 18, the survival statistics may be inflated.<sup>57</sup>

Most parents who receive a fetal diagnosis in Category I choose to terminate. The termination rate after the diagnosis of anencephaly is somewhere between 83–86%.<sup>58</sup> After a confirmed diagnosis of

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*Infants Diagnosed with Lethal Congenital Malformations*, 38 J. PERINATOLOGY 1674, 1679–80 (2018) (noting that infants born with severe birth defects may survive for some time and incur substantial hospital costs).

48. See, e.g., Joan K. Morris & George M. Savva, *The Risk of Fetal Loss Following a Prenatal Diagnosis of Trisomy 13 or Trisomy 18*, 146A AM. J. MED. GENETICS 827, 829 (2008); Isabela Nelly Machado, Sílvia Dante Martinez & Ricardo Barini, *Anencephaly: Do the Pregnancy and Maternal Characteristics Impact the Pregnancy Outcome?*, 2012 ISRN OBSTetrics & GYNECOLOGY 1, 3.

49. See, e.g., Machado et al., *supra* note 48, at tbl.2.

50. Nguyen et al., *supra* note 47, at 1680.

51. Thomas et al., *supra* note 42, at 585–86.

52. Machado et al., *supra* note 48.

53. There have only been a few cases of babies with anencephaly surviving to two years old. Holly Dickman, Kyle Fletke & Roberta E. Redfern, *Prolonged Unassisted Survival in an Infant with Anencephaly*, 2016 BMJ CASE REP. 1, 2.

54. Katherine E. Nelson, Laura C. Rosella, Sanjay Mahant & Astrid Guttmann, *Survival and Surgical Interventions for Children with Trisomy 13 and 18*, 316 JAMA 420, 422 (2016) (finding median survival time for children born with Trisomy 13 or 18 to be six to 12.5 days); Meyer et al., *supra* note 41, at 827 (finding median survival time for children born with Trisomy 13 or 18 to be five and eight days, respectively).

55. Nelson et al., *supra* note 54, at 424–25.

56. See Deborah A. Bruns, *Developmental Status of 22 Children with Trisomy 18 and Eight Children with Trisomy 13: Implications and Recommendations*, 167A AM. J. MED. GENETICS 1807, 1807–08 (2015); Meyer et al., *supra* note 41, at 834–35.

57. Nguyen et al., *supra* note 47, at 1682.

58. Candice Y. Johnson, Margaret A. Honein, W. Dana Flanders, Penelope P. Howards, Godfrey P. Oakley Jr. & Sonja A. Rasmussen, *Pregnancy Termination Following*

Trisomy 18 or Trisomy 13, roughly 84% and 89% of parents (respectively) will terminate.<sup>59</sup> And those parents that choose to carry to term are typically referred to a perinatal palliative care specialist to help them prepare for the significant possibility of stillbirth, discuss treatment and palliative care options, understand what to expect in their child's dying process, and make the most of the limited time they have with their child, whether it is minutes, days, months, or very rarely, years.<sup>60</sup> A majority of these parents (85%) describe themselves as religious, and many parents cite a personal or religious sense of moral obligation as the predominant reason for continuing the pregnancy.<sup>61</sup> For babies born alive, the standard of care is to provide them with only palliative treatment, and their parents unquestionably have the right to refuse all non-palliative care, allowing them to die.<sup>62</sup>

There is one other group of potential children that fit within this category: healthy, but extremely premature babies who will be born before they can survive outside the womb. Though these potential children are not sick, babies born before twenty-three weeks have only a 5–6% chance of survival with a 98–100% risk of morbidity,<sup>63</sup> although long-term survival without disability has occurred.<sup>64</sup> Due to the dismal survival statistics, hospitals typically will not resuscitate

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*Prenatal Diagnosis of Anencephaly or Spina Bifida: A Systematic Review of the Literature*, 94 BIRTH DEFECTS 857, 861 (2012); Caroline Mansfield, Suellen Hopfer & Theresa M. Marteau, *Termination Rates After Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review*, 19 PRENATAL DIAGNOSIS 808, 810 tbl.1 (1999) (noting that the termination rate for anencephaly is about 84%).

59. A.M. Tonks, A.S. Gornall, S.A. Larkins & J.O. Gardosi, *Trisomies 18 and 13: Trends in Prevalence and Prenatal Diagnosis—Population Based Study*, 33 PRENATAL DIAGNOSIS 742, 745 (2013).

60. Krishelle L. Marc-Aurele, Andrew D. Hull, Marilyn C. Jones & Dolores H. Pretorius, *A Fetal Diagnostic Center's Referral Rate for Perinatal Palliative Care*, 7 ANNALS PALLIATIVE MED. 177, 177–78 (2018); Leuthner, *supra* note 39, at 750–55.

61. Jennifer Guon, Benjamin S. Wilfond, Barbara Farlow, Tracy Brazg & Anne Janvier, *Our Children Are Not a Diagnosis: The Experience of Parents Who Continue Their Pregnancy After a Prenatal Diagnosis of Trisomy 13 or 18*, 164 AM. J. MED. GENETICS 308, 310–11 (2013).

62. See *infra* Part II.C.

63. Am. Coll. of Obstetricians & Gynecologists, *Periviable Birth*, 130 OBSTETRIC CARE CONSENSUS e187, e188 (2017).

64. Carlo Dani, Chiara Poggi, Costantino Romagnoli & Giovanna Bertini, *Survival and Major Disability Rate in Infant Born at 22–25 Weeks of Gestation*, 37 J. PERINATAL MED. 599, 606 (2009). The youngest known survivor was born at twenty-one weeks and four days. Kaashif A. Ahmad, Charlotte S. Frey, Mario A. Fierro, Alexander B. Kenton & Frank X. Placencia, *Two-Year Neurodevelopmental Outcome of an Infant Born at 21 Weeks' 4 Days' Gestation*, 140 PEDIATRICS 1, 1 (2017).

infants born alive before twenty-three weeks.<sup>65</sup> If a pregnant woman's water breaks before this crucial time, doctors may only be able to delay birth by an average of 4–8 days (and in the meantime, both the mother and child risk infection).<sup>66</sup> As a result, as many as half of women with premature rupture of membranes before twenty-two weeks choose to terminate the pregnancy.<sup>67</sup> For parents who choose to continue the pregnancy, some healthcare providers typically only offer palliative care when the baby is born before twenty-two weeks.<sup>68</sup>

#### B. CATEGORY II: COMMON CHILDHOOD DEATH WITH SEVERE MORBIDITY AMONG SURVIVORS

Unlike Category I—which guarantees childhood or infant death—Category II encompasses conditions with a greater range of outcomes. As seen from the examples below, parents whose potential children are diagnosed with conditions in this category are often told that their child has a significant chance of stillbirth or childhood death, a significant chance of life limited by severe disability, and some chance at a life with minimal or no disability.<sup>69</sup> Doctors typically cannot predict whether the particular child will be on the worst or best end of the spectrum—they can only describe the possible variation.<sup>70</sup>

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65. Ahmad et al., *supra* note 64, at 2; Mark R. Mercurio, *The Aftermath of Baby Doe and the Evolution of Newborn Intensive Care*, 25 GA. ST. U. L. REV. 835, 848 (2009).

66. See Julie E. Robertson, Sarka Lisonkova, Tang Lee, Dane A. De Silva, Peter von Dadelzen, Anne R. Synnes, K. S. Joseph, Robert M. Liston & Laura A. Magee, *Fetal, Infant and Maternal Outcomes Among Women with Prolapsed Membranes Admitted Before 29 Weeks Gestation*, 11 PLOS ONE, DEC. 21, 2016, at 1, 4 (2016) (finding the median latency period between diagnosis of a prolapsed membrane and delivery to be four days); Elsa Lorde, Héloïse Torchin, Pierre Delorme, Pierre-Yves Ancel, Laetitia Marchand-Martin, Laurence Foix-L'Hélias, Valérie Benhammou, Catherine Gire, Claude d'Ercole, Norbert Winer, Loïc Sentilhes, Damien Subtil, François Goffinet & Gilles Kayem, *Preterm Premature Rupture of Membranes at 22–25 Weeks' Gestation: Perinatal and 2-Year Outcomes Within a National Population-Based Study (EPIPAGE-2)*, 219 AM. J. OBSTETRICS & GYNECOLOGY 298.e1, 298.e4 tbl.1 (2018) (finding the median latency period between a premature membrane rupture and delivery to be eight days).

67. Fatima McKenzie & Brownsyne Tucker Edmonds, *Offering Induction of Labor for 22-Week Premature Rupture of Membranes: A Survey of Obstetricians*, 35 J. PERINATOLOGY 553, 553 (2015).

68. Joseph W. Kaempf, Mark W. Tomlinson, Betty Campbell, Linda Ferguson & Valerie T. Stewart, *Counseling Pregnant Women Who May Deliver Extremely Premature Infants: Medical Care Guidelines, Family Choices, and Neonatal Outcomes*, 123 PEDIATRICS 1509, 1513 (2009).

69. *See id.*

70. Cf. *Hydrocephalus*, STAN. CHILD.'S HEALTH, <https://www.stanfordchildrens.org/en/topic/default.page?id=hydrocephalus-90-P02367> [https://perma.cc/6KLH-6WZZ] (noting that hydrocephalus's health impacts depend on a variety of factors).

It is worth noting that some of the conditions in this category, at their most severe, might fall within Category I, while at their most mild, might fall within Category III.

Examples of prenatal diagnoses that fit in Category II include: hydrocephalus or severe ventriculomegaly, where fluid accumulates in the brain and prevents brain tissue from forming;<sup>71</sup> hypoplastic left (or right) heart syndrome, where half of the baby's heart does not develop;<sup>72</sup> fetal hydrops, where the baby experiences swelling that compromises major organs;<sup>73</sup> and many other genetic or structural abnormalities. Premature babies born between twenty-three and twenty-five weeks also fit in this category.<sup>74</sup> These diagnoses do not have uniform outcomes—even severe forms of a particular diagnosis contain gradations that affect prognosis.<sup>75</sup> For instance, the gestational age of onset can influence the prognosis of a given diagnosis—typically the earlier the condition develops, the worse the child's outcome will be.<sup>76</sup> As a result, like all complex health conditions, the family must trust their doctors' experience to give the best prediction of outcome based on the particulars of their child's test results.

Though prognoses in Category II can be unclear, there are data to help physicians guide patients. As noted above, some of these studies may present a more optimistic prognostic picture: the most severe cases of any diagnosis are more likely to end in termination, leaving a healthier subset of infants for the study.<sup>77</sup> In one study of babies born with severe ventriculomegaly, 37% were either stillborn or died as neonates;<sup>78</sup> of the survivors, 50% had major neurological morbidity (including blindness, cerebral palsy, inability to walk, and severe

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71. *Id.*

72. See *Facts About Hypoplastic Left Heart Syndrome*, CTRS. FOR DISEASE CONTROL & PREVENTION (Nov. 12, 2019), <https://www.cdc.gov/ncbddd/heartdefects/hlhs.html> [https://perma.cc/FF55-T3YT].

73. See *Hydrops Fetalis*, STAN. CHILD.'S HEALTH, <https://www.stanfordchildrens.org/en/topic/default?id=hydrops-fetalis-90-P02374> [https://perma.cc/9JKH-CSVU].

74. Dani et al., *supra* note 64, at 603.

75. For instance, ventriculomegaly is considered severe when the fluid measures at least 15 millimeters. Sarah-Jane Lam & Sailesh Kumar, *Evolution of Fetal Ventricular Dilatation in Relation to Severity at First Presentation*, 42 J. CLINICAL ULTRASOUND 193, 193 (2014).

76. *Id.* at 196.

77. See, e.g., *id.*

78. M.M. Kennelly, S.M. Cooley & P.J. McParland, *Natural History of Apparently Isolated Severe Fetal Ventriculomegaly: Perinatal Survival and Neurodevelopmental Outcome*, 29 PRENATAL DIAGNOSIS 1135, 1138 fig.1 (2009) (showing that of the nineteen infants prenatally diagnosed with severe ventriculomegaly, two died neonatally and five were stillborn).

developmental delay), 40% had mild neurological morbidity, and 10% had a normal outcome.<sup>79</sup> The survival rate was reduced to 35% when additional extra-cranial abnormalities were observed.<sup>80</sup> In another study, 38% of babies born with hydrocephalus died in the first year, and roughly half of the survivors had severe developmental delays or cerebral palsy.<sup>81</sup> Similarly, a study found that only 48% of babies diagnosed with fetal hydrops survive the first month (39% are stillborn or die as neonates); of the survivors, 39% have either a neurodevelopmental delay or other co-morbidity.<sup>82</sup> The children with hypoplastic left heart syndrome are less likely to survive childhood: only 27% survive the first year, but of those survivors, 90% maintain long-term survival.<sup>83</sup> For extremely premature infants, only 23–27% of babies born at 23 weeks will survive; only 42–59% at 24 weeks will survive, and 67–76% at 25 weeks will survive.<sup>84</sup> Severe and moderate neurological morbidity is also likely among these prematurity survivors.<sup>85</sup>

A majority of parents also terminate after a Category II diagnosis. For instance, a recent study showed that roughly 60% of pregnancies diagnosed with congenital hydrocephalus are terminated.<sup>86</sup> Another study for ventriculomegaly revealed that 75% of women terminated after receiving a severe ventriculomegaly diagnosis (although only 5% of women terminated for mild ventriculomegaly and 25% for moderate ventriculomegaly).<sup>87</sup> Termination rates for hypoplastic left heart syndrome are roughly 60%.<sup>88</sup> Most parents who choose to

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79. *Id.* at 1139 tbl.2.

80. *Id.* at 1136.

81. Ester Garne, Maria Loane, Marie-Claude Addor, Patricia A. Boyd, Ingeborg Barisic & Helen Dolk, *Congenital Hydrocephalus—Prevalence, Prenatal Diagnosis and Outcome of Pregnancy in Four European Regions*, 14 EUR. J. PAEDIATRIC NEUROLOGY 150, 153 (2010).

82. Susan Santo, Sahar Mansour, Basky Thilaganathan, Tessa Homfray, Aris Pageorghiou, Sandra Calvert & Amar Bhinde, *Prenatal Diagnosis of Non-Immune Hydrops Fetalis: What Do We Tell the Parents?*, 31 PRENATAL DIAGNOSIS 186, 189–91 (2011).

83. Csaba Siffel, Tiffany Riehle-Colarusso, Matthew E. Oster & Adolfo Correa, *Survival of Children with Hypoplastic Left Heart Syndrome*, 136 PEDIATRICS e864, e866 (2015).

84. Am. Coll. of Obstetricians & Gynecologists, *supra* note 63.

85. *Id.* at e188–89.

86. Garne et al., *supra* note 81, at 152 fig.2 (noting that 42 of the 70 pregnancies diagnosed prenatally were ended).

87. Lam & Kumar, *supra* note 75, at 196.

88. Karim Tarabit, Thi Thanh Thao Bui, Nathalie Lelong, Anne-Claire Thieulin, François Goffinet & Babak Khoshnood, *Clinical and Socioeconomic Predictors of Pregnancy Termination for Fetuses with Congenital Heart Defects: A Population-Based Evaluation*, 33 PRENATAL DIAGNOSIS 179, 181 tbl.1, 183 nn.22–23 (2013).

continue the pregnancy after learning of a Category II diagnosis have some discretion in deciding whether to withhold non-palliative treatment after birth.<sup>89</sup> As explored in Section II.C, the standard of care is to follow parental choice to either pursue aggressive intervention or withhold care.<sup>90</sup>

### C. CATEGORY III: SURVIVAL WITH DISABILITY

The final category includes diagnoses where the child is expected to survive, but will experience a disability. The range of disabilities in this category is vast. Certain physical anomalies exist in this category, including, for instance, cleft lip or palate, where the fetus's lips or roof of the mouth do not properly close;<sup>91</sup> limb reduction, where a fetus's arm or leg is either missing or reduced;<sup>92</sup> and clubfeet, where the fetus's feet are twisted out of position.<sup>93</sup> These physical differences are frequently managed with surgery or other medical treatments, but can still cause challenges for the children and families.<sup>94</sup> It is important to note that some of the conditions in this category can be associated with additional life-threatening anomalies, the presence of which would increase the severity of the diagnosis into another category.<sup>95</sup> For instance, a baby with a cleft lip might also have Trisomy 18 and therefore still have a Category I diagnosis.

Category III also includes anomalies that cause or increase the risk of intellectual disabilities.<sup>96</sup> Some are mild versions of conditions in Category II, like isolated, mild ventriculomegaly, where the fluid accumulation in the baby's brain is less than 12 mm<sup>97</sup> These babies

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89. See *infra* Part II.C.

90. See *infra* Part II.C.

91. *Facts About Cleft Lip and Cleft Palate*, *supra* note 34.

92. *Facts About Upper and Lower Limb Reduction Defects*, CTRS. DISEASE CONTROL & PREVENTION (Dec. 5, 2019), <https://www.cdc.gov/ncbddd/birthdefects/ul-limbreductiondefects.html> [<https://perma.cc/2RR4-ZXJX>].

93. *Clubfoot*, MAYO CLINIC (2020), <https://www.mayoclinic.org/diseases-conditions/clubfoot/symptoms-causes/syc-20350860> [<https://perma.cc/7547-3VAE>].

94. See, e.g., *Facts About Cleft Lip and Cleft Palate*, *supra* note 34 (explaining a cleft lip or palate often causes problems with a baby's speech and eating, but early surgical intervention can mitigate many difficulties).

95. *Trisomy 13 and Trisomy 18 in Children*, STAN. CHILD.'S HEALTH (2020), <https://www.stanfordchildrens.org/en/topic/default?id=trisomy-18-and-13-90-P02419> [<https://perma.cc/TMH8-QPWD>].

96. J Ouahba, D Luton, E Vuillard, C Garle, P Gressens, N Blanc, M Elmaleh, P Evrard & JF Oury, *Prenatal Isolated Mild Ventriculomegaly: Outcome in 167 Cases*, 113 BRIT. J. OBSTETRICS & GYNAECOLOGY 1072, 1072 (2006).

97. *Id.*

typically survive and most have a normal outcome; although, a minority (roughly 12%) will experience mild to severe developmental delays or neurological disease.<sup>98</sup>

But perhaps the most common diagnosis in this category is Trisomy 21, known colloquially as Down Syndrome, where the baby has an extra copy of chromosome 21.<sup>99</sup> This syndrome causes a variety of physical and intellectual differences.<sup>100</sup> Of the babies born with Trisomy 21, roughly 7% will die in the first year of life and 10% in the first five years.<sup>101</sup> These numbers, however, are slightly misleading because Trisomy 21 has a variable expression and causes at least one other anomaly in 64% of affected children.<sup>102</sup> For instance, 40–50% of Trisomy 21 babies have congenital heart defects.<sup>103</sup> One study that examined outcomes based on this distinction found that the ten-year mortality rate for Trisomy 21 babies with congenital heart defects was 44.1% compared to 4.5% in Trisomy 21 babies without heart defects.<sup>104</sup> In a newer study, the five-year mortality rate was 16% for Trisomy 21 babies with multiple cardiac anomalies compared to 1% for Trisomy 21 babies without other co-morbidities.<sup>105</sup> Thus, if one excludes Trisomy 21 babies with additional anomalies, who might fit in Category II, an isolated Trisomy 21 diagnosis most likely indicates disability, not death.<sup>106</sup>

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98. See *id.* at 1077; Patrizia Vergani, Anna Locatelli, Nicola Strobelt, Maria Cavalzone, Patrizia Ceruti, Giuseppe Paterlini & Alessandro Ghidini, *Clinical Outcome of Mild Fetal Ventriculomegaly*, 178 AM. J. OBSTETRICS & GYNECOLOGY 218, 220 (1998).

99. *Facts About Down Syndrome*, CTRS. DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html> [<https://perma.cc/DK4R-GEVD>].

100. *Id.*

101. Jane Halliday, Veronica Collins, Merilyn Riley, Danielle Yousseff & Evelyn Muggli, *Has Prenatal Screening Influenced the Prevalence of Comorbidities Associated with Down Syndrome and Subsequent Survival Rates?*, 123 PEDIATRICS 256, 259 (2009); S.E. Goldman, R.C. Urbano & R.M. Hodapp, *Determining the Amount, Timing and Causes of Mortality Among Infants with Down Syndrome*, 55 J. INTELL. DISABILITY RSCH. 85, 89 (2010).

102. See Claude Stoll, Beatrice Dott, Yves Alembik & Marie-Paule Roth, *Associated Congenital Anomalies Among Cases with Down Syndrome*, 58 EUR. J. MED. ETHICS 674, 675 (2015).

103. C. Frid, P. Drott, B. Lundell, F. Rasmussen & G. Annerén, *Mortality in Down's Syndrome in Relation to Congenital Malformations*, 43 J. INTELL. DISABILITY RSCH. 234, 236 (1999); Halliday et al., *supra* note 101.

104. Frid et al., *supra* note 103.

105. Halliday et al., *supra* note 101.

106. *Id.*

As one might expect, the termination rates are generally much lower in Category III than the other categories.<sup>107</sup> For mild ventriculomegaly, the termination rate is only 5%.<sup>108</sup> Roughly 10% of parents choose to terminate for an isolated limb reduction deficiency.<sup>109</sup> For isolated cleft lip or palate, only 4% of parents choose to terminate.<sup>110</sup> The exception is for Trisomy 21. Roughly 60–90% of parents choose to terminate after a Trisomy 21 diagnosis.<sup>111</sup> The standard of care for babies born with Category III diagnoses is to provide them with any aggressive treatment they need.<sup>112</sup> If parents refuse treatment, physicians will often seek assistance from the state to obtain a judicial order for treatment.<sup>113</sup>

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Taken together, there is a broad range of prenatal diagnoses—some involve devastating outcomes, while others do not. Given this vast range, it is unhelpful to group all fetal anomalies together, as some recent legislation does.<sup>114</sup> In the next section, the Article lays the groundwork for the right to abortion on the basis of fetal anomaly by describing the rights parents currently have to make end-of-life decisions for their living children. Because parents may only withdraw life-sustaining treatment when their child is suffering from a Category I or II diagnosis, the right to a post-viability abortion on the basis of severe fetal anomaly would also be limited to Category I and II diagnoses. This limitation would ensure that parental rights are consistent before and after birth and clarify that it is the life-threatening nature of the condition that justifies the right, not a disability alone.

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107. Tarabit et al., *supra* note 88, at 181, 183 nn.22–23.

108. *Id.*

109. C. Stoll, A. Wiesel, A. Queisser-Luft, U. Froster, S. Bianca, M. Clementi & EU-ROSCAN Study Group, *Evaluation of the Prenatal Diagnosis of Limb Reduction Deficiencies*, 20 PRENATAL DIAGNOSIS 811, 815 (2000).

110. Maurizio Clementi, Romano Tenconi, Fabrizio Bianchi, Claude Stoll & EU-ROSCAN Study Group, *Evaluation of Prenatal Diagnosis of Cleft Lip with or Without Cleft Palate and Cleft Palate by Ultrasound: Experience from 20 European Registries*, 20 PRENATAL DIAGNOSIS 870, 872 (2000).

111. Jaime L. Natoli, Deborah L. Ackerman, Suzanne McDermott & Janice G. Edwards, *Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995–2011)*, 32 PRENATAL DIAGNOSIS 142, 150 (2012).

112. *Id.*

113. See *infra* Part II.C.

114. See *infra* Part III.A (describing a recent disability selective abortion ban in Michigan).

## II. PARENTAL AUTONOMY RIGHTS OVER A CHILD'S MEDICAL CARE

Parents should be able to make the same end-of-life decisions for their child prenatally that they can make postnatally. The first step in this argument must therefore be to explain existing parental rights with regard to a child's healthcare. In general, the Constitution protects parental decisions to withhold or withdraw life-saving treatment for their child unless the state can affirmatively prove that such withdrawal is against the child's best interest. The state generally cannot meet this burden when the treatment may not be effective, is invasive, risky, or painful, and the child's quality of life after treatment is low.

### A. CONSTITUTIONAL AND NORMATIVE BASIS FOR PARENTAL AUTONOMY RIGHTS

The U.S. Constitution recognizes a "fundamental liberty interest of natural parents in the care, custody, and management of their child" through the Fourteenth Amendment.<sup>115</sup> The Supreme Court has historically "reflected Western civilization concepts of the family as a unit with broad parental authority over minor children."<sup>116</sup> The Court "long ago rejected any notion that a child is 'the mere creature of the State'" and "recognized that natural bonds of affection lead parents to act in the best interests of their children."<sup>117</sup> Given this "presumption that fit parents act in their children's best interests," "there is normally no reason for the State to inject itself into the private realm of the family to further question fit parents' ability to make the best decisions regarding their children."<sup>118</sup> The presumption that parents act in their child's best interests is grounded in our liberal legal tradition that assumes parents act for their children out of love.<sup>119</sup>

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115. *Santosky v. Kramer*, 455 U.S. 745, 753 (1982); *see also Troxel v. Granville*, 530 U.S. 57, 66 (2000) (plurality opinion) ("In light of this 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.").

116. *Parham v. J.R.*, 442 U.S. 584, 602 (1979); *see also Santosky*, 455 U.S. at 745 (requiring a child be considered "permanently neglected" when that finding is supported by a "fair preponderance of the evidence").

117. *Parham*, 442 U.S. at 602; *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) ("It is cardinal with us that the custody, care and nurture of the child reside first in the parents....").

118. *Troxel*, 530 U.S. at 58 (internal quotations omitted).

119. See Elizabeth S. Scott & Clare Huntington, *Conceptualizing Legal Childhood in the Twenty-First Century*, 118 MICH. L. REV. 1371, 1427 (2020). It is worth noting that scholars have criticized this assumption. *Id.* at 16–17. However, to the extent parents have constitutionally protected parenting rights after birth, my Article simply argues those should be extended after birth. *See generally infra* Part III.

Pursuant to this general recognition of parental authority, parents are responsible for making healthcare decisions for their children and must consent to medical treatment before such treatment can be initiated.<sup>120</sup> As the Supreme Court has stated, “it would almost certainly be a tort as a matter of state law [for a doctor] to operate on an infant without parental consent.”<sup>121</sup> Of course, this parental autonomy right is not without limits. The state can request that a court overrule a parent’s medical decision if it is clearly against the child’s best interest.<sup>122</sup> And if there is evidence that parents are denying a child medical treatment that is “relatively innocuous in comparison to the dangers of withholding medical care,” then “courts have unhesitatingly authorized medical treatment over a parent’s . . . objection.”<sup>123</sup> The paradigmatic example is when a Jehovah’s Witness refuses a blood transfusion for his or her child even though there is a very high likelihood that it would save the child’s life and the procedure itself is not too invasive. In these instances, courts routinely step in, overrule the parents’ decision, and order a blood transfusion despite a lack of parental consent.<sup>124</sup>

Occasionally, courts will go further and order invasive treatment over parental objection, but generally do so only when clear medical consensus about the proper treatment exists, the treatment has a high likelihood of success, the treatment is not too invasive or painful, and the child will certainly die without it. For example, in *Custody of a Minor*, the Massachusetts Supreme Court held that the state could compel, over parental objection, chemotherapy in a toddler to treat his leukemia.<sup>125</sup> The court permitted state interference in this case on the grounds that the child would die without treatment, that chemotherapy was “quite effective,”<sup>126</sup> and that the side-effects were relatively minor and short term—mainly stomach cramps and constipation.<sup>127</sup> Other courts have found similarly in comparable cases.<sup>128</sup>

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120. *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 628 n.13 (1986).

121. *Id.* at 630.

122. *Newmark v. Williams*, 588 A.2d 1108, 1117 (Del. 1991).

123. *Id.*

124. See, e.g., *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944); *In re McCauley*, 565 N.E.2d 411, 414 (Mass. 1991); *In re Cabrera*, 552 A.2d 1114, 1120 (Pa. Super. Ct. 1989); *In re L.S.*, 87 P.3d 521, 527 (Nev. 2004).

125. *Custody of a Minor*, 379 N.E.2d 1053, 1062 (Mass. 1978).

126. *Id.* at 1063, 1066 (explaining the treatment was more likely than not to generate a long-term cure and was overwhelmingly successful in the short term).

127. *Id.* at 1066.

128. See, e.g., *In re Eric B.*, 235 Cal. Rptr. 22, 27 (Cal. Ct. App. 1987) (upholding the lower court’s decision to order cancer monitoring for a child over parental objection

Courts, however, do not overrule parental choice flippantly. Rather, “the parental right is sacred” and “can be invaded for only the most compelling reasons.”<sup>129</sup> Otherwise, “the requisite of parental consent to medical care for children [would] become[] meaningless if [simply the] refusal to consent automatically triggers” state intervention.<sup>130</sup> Though courts faced with these dilemmas analyze the issue under a BIC framework, the Supreme Court has held that there is a strong presumption that parents act in their child’s best interest.<sup>131</sup> To override parental choice, the state must therefore rebut this presumption.<sup>132</sup> It is not enough for the state to show that parents failed to make the absolute best choice; rather “the best interest standard requires only that parents choose what they themselves ‘think’ is best for the patient” within their “wide ‘zone of discretion,’” which includes

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on the basis that the child “faced an appreciable risk of harm from a deadly disease. Medical opinion testimony was uncontradicted on this point” and “[t]he risks entailed by the monitoring are minimal.”); *In re Anthony L.*, No. G038368, 2007 WL 3349424, at \*5 (Cal. Ct. App. Nov. 13, 2007) (upholding lower court decision to force low-risk surgery that would save the child’s life because “the risk involved in the proposed surgery is relatively low, the chance of success in terms of curing Anthony’s condition is quite good, and the danger to Anthony if he doesn’t have the surgery is potentially life-threatening”); *PJ ex rel. Jensen v. Wagner*, 603 F.3d 1182, 1198 (10th Cir. 2010) (finding—in the context of a 1983 lawsuit by the parents—that the state actors were entitled to qualified immunity because there was no clearly established right for the parents to refuse life-saving medical care for their son when seven doctors agreed his early-stage cancer could be favorably treated with chemotherapy and he would die without it); *In re Willmann*, 493 N.E.2d 1380, 1390 (Ohio Ct. App. 1986) (upholding a lower court decision authorizing amputation over parental objection when there was medical consensus that it was necessary to treat a child’s cancer and it had a 60% chance of cure).

129. *Newmark v. Williams*, 588 A.2d 1108, 1115 (Del. 1991).

130. Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, 86 YALE L.J. 645, 651 (1977).

131. See *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 628 n.13 (1986) (“[T]here is a presumption, strong but rebuttable, that parents are the appropriate decisionmakers for their infants.” (quoting PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBS. IN MED. & BIOMEDICAL & BEHAV. RSCH., DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 212 (1983))).

132. *Id.*; Thaddeus Mason Pope, *The Best Interest Standard for Health Care Decision Making: Definition and Defense*, 18 AM. J. BIOETHICS 36, 37 (2018) [hereinafter *The Best Interest Standard*]; Goldstein, *supra* note 130, at 648; *Newmark*, 588 A.2d at 1110; *Custody of a Minor*, 379 N.E.2d 1053, 1062 (Mass. 1978) (holding that the state could compel, despite parental objection, chemotherapy in a toddler to treat his leukemia); *In re Phillip B.*, 156 Cal. Rptr. 48, 52 (Cal. Ct. App. 1979) (refusing to order heart surgery that would increase the lifespan of a child with Down Syndrome because it also carried risks); *In re Hofbauer*, 393 N.E.2d 1009, 1014 (N.Y. 1979) (holding that parents were not neglecting their child by choosing an unconventional treatment because it had not been expressly rejected in the medical field).

"suboptimal decisions."<sup>133</sup> "[W]hen more than one reasonable option is available," parents are entitled to choose amongst them.<sup>134</sup> "A court may not infringe upon the parental prerogative just because the judge thinks that the court could make a 'better decision.'"<sup>135</sup> As a result, courts typically (though not always) respect parental choice for difficult medical decisions about children and infants—ones without an obvious answer.<sup>136</sup>

The most difficult medical decisions, the decisions least likely to have clear answers, occur at the end of a child's life. Sadly, parents must occasionally decide whether to withdraw or withhold life-sustaining treatment when their child is very sick. This highly personal decision, which asks parents to weigh a treatment's probability of success against their child's quality of life during and after treatment, is often respected by courts even when it means allowing the child to die.<sup>137</sup> In these cases, parents are essentially exercising their child's constitutional right to refuse or withdraw life-sustaining treatment—

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133. Thaddeus Mason Pope, *Parental Treatment Refusals: What Your Responsibilities Are When Mom and Dad Decline Cancer Treatment for a Child*, ASCO Post (July 25, 2019) [hereinafter *Parental Treatment Refusals*], <https://ascopost.com/issues/july-25-2019/parental-treatment-refusals> [<https://perma.cc/5BLL-MKU6>]; *The Best Interest Standard*, *supra* note 132 ("Indeed, even authoritative bioethics sources confirm that a mere failure of the surrogate to optimize the patient's best interest is not sufficient to trigger justified intervention by third parties." (quotations omitted)).

134. Mary Crossley, *Rescuing Baby Doe*, 25 GA. ST. U. L. REV. 1043, 1054–56 (2009).

135. *The Best Interest Standard*, *supra* note 132, at 37.

136. See *infra* text accompanying notes 159–64; see also *In re Hofbauer*, 393 N.E.2d at 1014 ("This inquiry cannot be posed in terms of whether the parent has made a 'right' or a 'wrong' decision, for the present state of the practice of medicine, despite its vast advances, very seldom permits such definitive conclusions."); see also *In re Nikolas E.*, 720 A.2d 562, 565 (Me. 1998) (refusing to order a mother to pursue aggressive HIV treatment for her child because her decision was "rational and reasoned"); *In re Phillip B.*, 156 Cal. Rptr. at 52. But see *In re Hamilton*, 657 S.W.2d 425, 429 (Tenn. Ct. App. 1983) (finding that cancer treatment could be ordered over parental consent even when there was only a 25–50% chance of long-term survival); *In re Gianelli*, 834 N.Y.S.2d 623, 630 (N.Y. Sup. Ct. 2007) (refusing to respect parental choice to withdraw life-support on a child with a terminal illness who was not expected to die for years and who was "alert, responsive, seemingly pain free," and able to feel "emotional enjoyment"). Courts are especially likely to defer to parents who decide to withdraw or withhold life-sustaining treatment when their child is in a persistent vegetative state, even if he or she could survive long-term on a ventilator. See generally *In re AB*, 768 N.Y.S.2d 256 (N.Y. Sup. Ct. 2003); *In re L.H.R.*, 321 S.E.2d 716 (Ga. 1984); *In re Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984); *In re P.V.W.*, 424 So. 2d 1015 (La. 1982); *In re Guardianship of Crum*, 580 N.E.2d 876 (Ohio Prob. Ct. 1991).

137. See, e.g., *Newmark*, 588 A.2d at 1110; cases cited in *supra* note 136; *Parental Treatment Refusals*, *supra* note 133 (noting that parents are allowed to "refuse potentially life-saving therapy when it is unlikely to be effective or when the side effects are overly burdensome").

a right that extends to those who are incompetent to make end-of-life decisions themselves.<sup>138</sup>

In considering "whether it is in a dependent child's best interests to withhold or withdraw life-sustaining medical treatment,"<sup>139</sup> some courts have suggested looking to the following factors:

- (1) the child's present levels of physical, sensory, emotional and cognitive functioning;
- (2) the quality of life, life expectancy and prognosis for recovery with and without treatment, including the futility of continued treatment;
- (3) the various treatment options, and the risks, side effects, and benefits of each;
- (4) the nature and degree of physical pain or suffering resulting from the medical condition;
- (5) whether the medical treatment being provided is causing or may cause pain, suffering, or serious complications;
- (6) the pain or suffering to the child if the medical treatment is withdrawn;
- (7) whether any particular treatment would be proportionate or disproportionate in terms of the benefits to be gained by the child versus the burdens caused to the child;
- (8) the likelihood that pain or suffering resulting from withholding or withdrawal of treatment could be avoided or minimized;
- (9) the degree of humiliation, dependence and loss of dignity resulting from the condition and treatment;
- (10) the opinions of the family, the reasons behind those opinions, and the reasons why the family either has no opinion or cannot agree on a course of treatment;
- (11) the motivations of the family in advocating a particular course of treatment; and
- (12) the child's preference, if it can be ascertained, for treatment.<sup>140</sup>

Other courts rely on a less exhaustive set of factors that focus on the patient's prognosis with and without treatment, the risks and pain of treatment, and the quality of life the child can expect after treatment.<sup>141</sup> In other words, courts are sensitive to the delicate nature of

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138. See, e.g., *In re AMB*, 640 N.W.2d 262, 292 (Mich. Ct. App. 2001) ("The right to refuse lifesaving medical treatment is not lost because of the incompetence or the youth of the patient." (quoting *In re Rosebush*, 491 N.W.2d 633, 636 (Mich. Ct. App. 1992))); *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261, 279 (1990) (assuming without deciding that all people, including those incompetent to make medical decisions, have the constitutional right to refuse or withhold medical treatment).

139. *In re Christopher I.*, 131 Cal. Rptr. 2d 122, 133 (Cal. Ct. App. 2003), *reh'g denied* (Mar. 10, 2003).

140. *Id.* at 134; *J.N. v. Superior Ct.*, 67 Cal. Rptr. 3d 384, 391 (Cal. Ct. App. 2007); *Woods v. Commonwealth*, 142 S.W.3d 24, 35 (Ky. 2004).

141. See, e.g., *In re AMB*, 640 N.W.2d at 293 (explaining the best interest standard as considering: "[E]vidence about the patient's present level of physical, sensory, emotional, and cognitive functioning; the degree of physical pain resulting from the medical condition, treatment, and termination of the treatment, respectively; the degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options." (alteration in original) (quotations omitted)); accord *In re Guardianship of Grant*, 747 P.2d 445, 457 (Wash. 1987); accord *In re Conroy*, 486 A.2d 1209, 1234 (N.J. 1985); *In re Eric B.*, 235 Cal. Rptr. 22, 27 (Cal. Ct. App. 1987) ("Several relevant factors must be taken into consideration before a state insists upon medical treatment

parental healthcare decisions when the child suffers from a terminal or seriously debilitating condition, especially when the treatment options are not exceedingly likely to save the child's life, will leave the child with significant pain or disability, and may themselves cause suffering.

For instance, in *Newmark v. Williams*, parents were told their three-year-old son, Colin, had a deadly form of lymphoma, which appeared metastatic.<sup>142</sup> Colin would die in roughly eight months without treatment, but intensive chemotherapy had only a 40% chance of success.<sup>143</sup> Colin's parents, who were Christian Scientists, refused.<sup>144</sup> The Supreme Court of Delaware overruled a lower court decision that forced Colin to begin treatment, finding that the lower court failed to consider the "special importance and primacy of the familial relationship," "the gravity of Colin's illness," "the invasiveness of the proposed chemotherapy[,] and the considerable likelihood of [its] failure."<sup>145</sup> The court noted that Colin would likely need multiple transfusions, a feeding tube, a catheter, and other "highly invasive" procedures to help him survive the chemotherapy.<sup>146</sup> Yet the benefit of these invasions was questionable—" [t]he aggressive form of chemotherapy that Dr. Meek prescribed for Colin was more likely to fail than succeed."<sup>147</sup>

The court noted that all "[p]arents must have the right at some point to reject medical treatment for their child."<sup>148</sup> And the state's intrusion in that impossible decision only piles onto the tragedy: "Parents undertake an awesome responsibility in raising and caring for their children. No doubt a parent's decision to withhold medical care is both deeply personal and soul wrenching. It need not be made worse by the invasions which both the State and medical profession sought on this record."<sup>149</sup> Thus, the court put "Colin's ultimate fate" in the hands of "his parents and their faith."<sup>150</sup>

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rejected by the parents. The state should examine the seriousness of the harm the child is suffering or the substantial likelihood that he will suffer serious harm; the evaluation for the treatment by the medical profession; the risks involved in medically treating the child; and the expressed preferences of the child." (quoting *In re Phillip B.*, 156 Cal. Rptr. 48, 51 (Cal. Ct. App. 1979)).

142. *Newmark v. Williams*, 588 A.2d 1108, 1111 (Del. 1991).

143. *Id.*

144. *Id.*

145. *Id.* at 1115.

146. *Id.* at 1118–20.

147. *Id.* at 1120.

148. *Id.*

149. *Id.* at 1120–21.

150. *Id.* at 1121.

Scholars have endorsed this deference to parental decisions in gray zones—when there is no societal consensus that the treatment is either morally or medically appropriate.<sup>151</sup> For these uncertain decisions, the parents are the best navigators of what is appropriate for their child. Joseph Goldstein put it best when he wrote:

No one has a greater right or responsibility and no one can be presumed to be in a better position, and thus better equipped, than a child's parents to decide what course to pursue if the medical experts cannot agree or, assuming their agreement, if there is no general agreement in society that the outcome of treatment is clearly preferred to the outcome of no treatment. *Put somewhat more starkly, how can parents in such situations give the wrong answer since there is no way of knowing the right answer?*<sup>152</sup>

Thus, according to Goldstein, “[t]here would be no justification . . . for coercive intrusion by the state in those life-or-death situations.”<sup>153</sup> Why? Because “a prime function of law is to prevent one person’s truth (here about health, normalcy, the good life) from becoming another person’s tyranny.”<sup>154</sup> Goldstein’s argument highlights the normative underpinning of the requirement that the *state* bears the burden of proving that the parents’ choice is *wrong*, rather than the parents bearing the burden of proving their choice is right.<sup>155</sup>

#### B. SPECIAL TREATMENT OF INFANTS

Historically, courts have been very deferential to parental health decisions for newborns, even when parents refuse life-saving treatment and allow their child to die.<sup>156</sup> As explored below, however, this deference to parental authority created substantial political controversy in the 1980s and sparked a national conversation about disability rights; eventually, a federal law was passed that attempted to discourage some parental decisions to withhold care to disabled newborns.<sup>157</sup> But as explained in Section II.C, parents still enjoy wide

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151. Goldstein, *supra* note 130, at 654–55.

152. *Id.* (emphasis added).

153. *Id.* at 653.

154. *Id.* at 664.

155. *Id.* at 655.

156. See *infra* text accompanying notes 159–64; see also M.N. v. S. Baptist Hosp. of Fla., Inc., 648 So. 2d 769 (Fla. Dist. Ct. App. 1994) (remanding the case for further consideration so the trial court could fully weigh all competing interests before authorizing medical treatment for appellant’s infant child without appellant’s consent); see also *In re Hofbauer*, 393 N.E.2d 1009, 1014 (N.Y. 1979) (holding that parents were not neglecting their child by choosing an unconventional treatment because it had not been expressly rejected in the medical field).

157. Goldstein, *supra* note 130, at 654–55.

discretion in choosing to withhold or withdraw life-sustaining treatment for newborns who have a Category I or II diagnosis.<sup>158</sup>

The first infant case that reached national attention involved Baby Doe, who was born in 1982.<sup>159</sup> Doe was born with Down Syndrome and an esophageal condition, which if treated, would have saved the baby's life.<sup>160</sup> Doe's parents, however, chose to forgo the life-saving surgery and withhold hydration and nutrition, allowing their baby to die largely based on the Down Syndrome diagnosis.<sup>161</sup> The state courts in Indiana upheld the parents' choice, and the baby died six days later.<sup>162</sup> The judge who decided the case later explained that "it could not be said that the parents were not acting in the best interests of the child, even though other parents might have acted differently" because "the great weight of the medical testimony" suggested "that even if the proposed surgery was successful, the possibility of a minimally adequate quality of life was non-existent."<sup>163</sup> The Indiana Supreme Court refused to intervene.<sup>164</sup>

It is worth pausing here to note that as the quality of life and medical treatment have improved for children with Down Syndrome, and awareness and appreciation for disability rights has grown, courts today would not reach the same result.<sup>165</sup> Even in the 1980s, many argued that the belief that a child born with Down Syndrome could not live a good life reflected ableist stereotypes.<sup>166</sup> Partially due to these concerns, shortly after Baby Doe's death, the Reagan administration promulgated a rule (the Rule) under the Rehabilitation Act which prevented hospitals from withholding care from disabled infants; the Rule also created extensive mechanisms to ensure violations of the Rule were reported.<sup>167</sup> Many viewed this Rule as a serious overstep that intruded into the private decisions of doctors and parents.<sup>168</sup> The

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158. See *infra* Part II.C.

159. Phoebe A. Haddon, *Baby Doe Cases: Compromise and Moral Dilemma*, 34 EMORY L.J. 545, 573 (1985).

160. *Id.*

161. *Id.*; Kathryn Moss, *The "Baby Doe" Legislation: Its Rise and Fall*, 15 POL'Y STUD. J. 629, 631 (1987).

162. Haddon, *supra* note 159.

163. Marzen v. U.S. Dep't of Health & Hum. Servs., 632 F. Supp. 785, 789 (N.D. Ill. 1986).

164. *Id.*

165. Mercurio, *supra* note 65, at 844.

166. See Martha A. Field, *Killing "the Handicapped"—Before and After Birth*, 16 HARV. WOMEN'S L.J. 79, 88 (1993); Crossley, *supra* note 134, at 1047.

167. Bowen v. Am. Hosp. Ass'n, 476 U.S. 610, 612–18 (1986).

168. *Id.*

American Medical Association, American Hospital Association, and others sued under the Administrative Procedures Act (APA), arguing that the Rule was arbitrary and capricious.<sup>169</sup>

In the meantime, pursuant to the Rule, the government had received a complaint about a baby in New York, Baby Jane Doe, whose parents had chosen to forgo treatment.<sup>170</sup> Jane Doe was born with many serious disorders, including spina bifida, microcephaly, and hydrocephalus.<sup>171</sup> Multiple surgeries could have corrected the hydrocephalus and spina bifida, but the parents refused treatment.<sup>172</sup> A court in New York refused to disturb the parents' decision, noting that the "concededly concerned and loving parents have made an informed, intelligent, and reasonable determination based upon and supported by responsible medical authority."<sup>173</sup> As a result, it held "the parents' determination to be in the best interest of the infant."<sup>174</sup> An appeals court in New York affirmed this decision, criticizing the "unusual, and sometimes offensive, activities," which sought to "displace parental responsibility for and management of [Jane Doe's] medical care."<sup>175</sup> The court found it "distressing" that parents facing the "anguish of the birth of a child with severe physical disorders" were "subjected . . . to litigation through all three levels of our State's court system."<sup>176</sup>

The United States Supreme Court eventually heard the APA challenge to the Rule and concluded that it was arbitrary and capricious and therefore illegal.<sup>177</sup> A plurality of the Court relied on the fact that hospitals cannot provide care without parental consent, and therefore found that the hospitals were simply adhering to parental preferences, not discriminating against disabled newborns, when they abided by requests not to treat a disabled newborn.<sup>178</sup>

Congress quickly moved thereafter to create some protections for disabled newborns, but opted for a compromise that appeased (and frustrated) all relevant stakeholders.<sup>179</sup> It passed the Child Abuse

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169. *Id.* at 613.

170. *Id.* at 620–22.

171. *Weber v. Stony Brook Hosp.*, 467 N.Y.S.2d 685, 686 (N.Y. App. Div.), *aff'd*, 60 N.Y.2d 208 (N.Y. 1983).

172. *Id.*

173. *Id.* at 687.

174. *Id.*

175. *Weber*, 60 N.Y.2d at 211.

176. *Id.* at 213.

177. *Bowen v. Am. Hosp. Ass'n*, 476 U.S. 610, 646–47 (1986).

178. *Id.* at 630.

179. See *Haddon*, *supra* note 159, at 582–84; *Crossley*, *supra* note 134, at 1045.

Amendments of 1984 (CAA), which added medical neglect as a form of child abuse and conditioned federal funds on the creation of procedures to respond to reports of “withholding of medically indicated treatment.”<sup>180</sup> The law, however, did not prohibit parents or doctors from withholding care; rather, it required states to establish a mechanism to report possible medical neglect, after which the state could decide whether or not to pursue litigation in family court regarding the child’s care.<sup>181</sup> The law explicitly excluded from the definition of “withholding of medically indicated treatment” decisions to withhold care when:

- (A) the infant is chronically and irreversibly comatose;
- (B) the provision of such treatment would—
  - (i) merely prolong dying;
  - (ii) not be effective in ameliorating or correcting all of the infant’s life-threatening conditions; or
  - (iii) otherwise be futile in terms of the survival of the infant; or
- (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.<sup>182</sup>

Though the United States Department of Health and Human Services (HHS) initially promulgated regulations that added bite to these regulations,<sup>183</sup> as of 2015, all of the promulgated rules have been repealed.<sup>184</sup> The law now stands on its own.<sup>185</sup>

There is little evidence that the CAA were ever routinely enforced: “Judging from the reported cases, the impact [of the CAA] has been virtually nil.”<sup>186</sup> To start, the enforcement mechanism was weak:

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180. Haddon, *supra* note 159, at 581–82; 42 U.S.C. § 5106a(b)(2)(C). Withholding of medically indicated treatment is defined as “failure to respond to the infant’s life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician’s or physicians’ reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions ....” *Id.* § 5106g(a)(5).

181. 42 U.S.C. § 5106a(b)(2)(C).

182. *Id.* § 5106g(a)(5).

183. 45 C.F.R. § 1340 app. at 326 (1998) (interpreting “virtually futile to mean that the treatment is highly unlikely to prevent death in the near future”); *id.* at 324 (stating that the “merely prolong dying” provision does not apply “where the prognosis is not for death in the near future, but rather the more distant future”).

184. Removal of Child Abuse and Neglect Prevention and Treatment Act Implementing Regulations, 80 Fed. Reg. 16577 (Mar. 30, 2015).

185. Child Abuse Amendments of 1984, Pub. L. No. 98-457, 98 Stat. 1749 (1984).

186. ALAN MEISEL, KATHY L. CERMINARA & THADDEUS M. POPE, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING 10–12 (3d ed. 2004); *see also* Moss, *supra* note 161, at 646–47 (concluding shortly after the law went into effect that “physicians can continue to justify most decisions regarding selective nontreatment of severely disabled

the law did not authorize sanctions against parents or doctors, but rather threatened the removal of federal funding from states, and only if the reporting procedures were not implemented.<sup>187</sup> Though there was some evidence that the law initially caused a chilling effect amongst doctors,<sup>188</sup> perinatal palliative care (rather than aggressive treatment) is now routine practice for infants with serious life-threatening conditions.<sup>189</sup> For instance, Mark Mercurio, a neonatologist and director of Yale's Pediatric Ethics Program, noted that despite the CAA, "[i]t is now widely accepted by neonatologists and medical ethicists in the U.S. that, in certain settings, withholding life-sustaining treatment from some newborns is acceptable."<sup>190</sup> Though these parental health decisions in the context of infant illness or disability have been politicized, parents are routinely asked to make the same decisions in the case of extreme prematurity with less controversy.<sup>191</sup>

### C. PARENTAL AUTONOMY RIGHTS BY CATEGORY

Section I created three categories of fetal anomalies.<sup>192</sup> Of course, many of the potential children with these anomalies are born—either because the condition was not diagnosed prenatally or because the parents chose to continue the pregnancy.<sup>193</sup> For these babies, the

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infants and so have had to make few changes in their practices"); George J. Annas, *The Case of Baby Jane Doe: Child Abuse or Unlawful Federal Intervention*, 74 AM. J. PUB. HEALTH 727, 728 (1984) (noting that "HHS has not been able to uncover even one case of child abuse or neglect in more than a year of operating its 'hotline'").

187. Moss, *supra* note 161, at 641.

188. See, e.g., Steven R. Leuthner & Robin Pierucci, *Experience with Neonatal Palliative Care Consultation at the Medical College of Wisconsin—Children's Hospital of Wisconsin*, 4 J. PALLIATIVE MED. 39, 45 (2001) ("The 1985 Baby Doe Regulations have lead [sic] to overtreatment of sick newborns").

189. See Jatinder Bhatia, *Baby Doe: Does It Really Apply Now?—Palliative Care of the Ill Neonate*, 25 GA. ST. U. L. REV. 901, 908 (2009) (concluding that "Baby Doe is no longer an issue" that prevents physicians from following parental requests for palliative care).

190. Mercurio, *supra* note 65, at 862.

191. I identified only two court cases involving care of an extremely premature infant. In both cases, the parents sued the hospital for resuscitating their extremely premature infant. HCA, Inc. v. Miller *ex rel.* Miller, 36 S.W.3d 187, 190 (Tex. App. 2000), aff'd, 118 S.W.3d 758 (Tex. 2003); Montalvo v. Borkovec, 647 N.W.2d 413, 421 (Wis. Ct. App. 2002). Though the parents lost, the fact that the parents affirmatively sued to enforce their rights—instead of being the victim of the state attempting to remove their rights—demonstrates how differently these cases are treated.

192. See *supra* Parts I.A-C.

193. See *supra* Parts I.A-C (highlighting percentages of pregnancies that are terminated after certain fetal anomalies are diagnosed).

parents and medical team must decide on a course of action after birth.<sup>194</sup> Examining the medical and legal standards for these treatment decisions after birth sheds light on when parents should be able to exercise the same authority before birth through abortion.

For babies born with Category I and III diagnoses, the standards of care are clear. For the former, parents not only have the unfettered right to refuse all non-palliative care, but doctors at times can even refuse parental requests for aggressive treatment if they think the treatment is futile.<sup>195</sup> Doctors recommend only palliative care for babies born with Category 1 anomalies, viewing aggressive treatment to extend life as prolonging suffering:

If the diagnosis is a definitive lethal anomaly for which providing any intensive care might be considered irresponsible, then palliative care should be the recommended option, and there is no need to provide the infant with any trial of aggressive treatment. Examples of this situation include infants with anencephaly or chromosome-proven trisomy 13 or 18.<sup>196</sup>

Professional organizations also advise against resuscitation for babies in this category.<sup>197</sup> As a result, the vast majority babies born with Category I diagnoses are not provided active treatment after the baby is born.<sup>198</sup>

The standard of care for Category I diagnoses conforms with the law: the CAA would not apply because the care would be "futile in terms of the survival of the infant,"<sup>199</sup> and the state could never rebut the presumption that the parents were acting in the child's best

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194. See *infra* Part II.C.

195. Mercurio, *supra* note 65, at 854 (describing the American Academy of Pediatrics as asserting that resuscitation should be avoided when "congenital anomalies are associated with almost certain early death, and unacceptably high morbidity is likely among the rare survivors" (quoting TEXTBOOK OF NEONATAL RESUSCITATION 9–5 (Am. Acad. of Pediatrics ed., 5th ed. 2006))); *International Guidelines for Neonatal Resuscitation: An Excerpt From the Guidelines 2000 for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care: International Consensus on Science*, PEDIATRICS, Sept. 2000, at 1, 13–14 <https://pediatrics.aappublications.org/content/pediatrics/106/3/e29.full.pdf> [<https://perma.cc/H9Z8-5DFG>] ("Noninitiation of resuscitation in the delivery room is appropriate for infants with confirmed gestation <23 weeks or birth weight <400 g, anencephaly, or confirmed trisomy 13 or 18."). In certain cases, doctors cannot refuse to provide care on the basis of futility. *In re Baby K*, 16 F.3d 590, 598 (4th Cir. 1994).

196. Leuthner, *supra* note 39, at 750.

197. Guon et al., *supra* note 61, at 309; Mercurio, *supra* note 65, at 854.

198. Heidi J. Kamrath, Erin Osterholm, Rachael Stover-Haney, Thomas George, Susan O'Connor-Von & Jennifer Needle, *Lasting Legacy: Maternal Perspectives of Perinatal Palliative Care*, 22 J. PALLIATIVE MED. 310, 313 (2019); Guon et al., *supra* note 61, at 313.

199. 42 U.S.C. § 5106g(a)(5).

interest in refusing care after a terminal diagnosis.<sup>200</sup> It would surely be reasonable for the parents to conclude that any non-palliative treatment would only expose their child to suffering without generating any benefits.<sup>201</sup>

For Category III diagnoses, the standard of care is equally clear: doctors have an ethical duty to treat these babies, and if the parents refuse, doctors would likely notify the state.<sup>202</sup> "In our NICU today, if a parent of a child with Trisomy 21 were to refuse repair of duodenal atresia or tracheoesophageal fistula, a court order would be sought and almost certainly obtained."<sup>203</sup> Perhaps the biggest impact the CAA had was to change how physicians and parents perceived infants with Category III diagnoses: "Notably, while neonatologists generally support the parental right to refuse treatment in certain situations, the threshold for that right appears to have moved. Specifically, in the case of Trisomy 21, the standard of care for many years has now been to provide" all medically-necessary treatment, reflecting "a clearer understanding of the prognosis for 'quality of life' for people with Trisomy 21."<sup>204</sup> Thus, for a Category III diagnosis, providing all life-prolonging treatment is the standard of care. Without a doubt, the Baby Doe controversy helped move the disability rights perspective forward, ensuring that children with non-life-threatening disabilities would be treated as all other children.<sup>205</sup>

The law also supports the standard of care for infants born with Category III diagnoses. Under common law, a state would most likely prove that a parent's refusal of life-saving care for a child with a Category III diagnosis was against the child's best interest.<sup>206</sup> "[A] severe disability may justify withholding medical treatment from an infant... only when the burdens resulting from the disability are so extreme that, from the infant's perspective, continued life offers no overriding benefit."<sup>207</sup> It is difficult to argue that babies born with a physical difference or even Down Syndrome can gain no benefit from life.<sup>208</sup>

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200. See *supra* Part II.C.

201. See cases discussed *supra* note 136.

202. Mercurio, *supra* note 65, at 844.

203. *Id.* at 852.

204. *Id.* at 844.

205. Crossley, *supra* note 134; Adrienne Asch & Michelle Fine, *Shared Dreams: A Left Perspective on Disability Rights and Reproductive Rights*, in WOMEN WITH DISABILITIES: ESSAYS IN PSYCHOLOGY, CULTURE, AND POLITICS 297–98 (Michelle Fine & Adrienne Asch eds., 1988).

206. Mercurio, *supra* note 65, at 844.

207. JANET L. DOLGIN & LOIS L. SHEPHERD, BIOETHICS AND THE LAW 687 (4th ed. 2019).

208. See Field, *supra* note 166, at 86–88.

Rather, most courts today would likely have no hesitation ordering medical treatment over parental objection in these cases.<sup>209</sup>

Though Category II is harder, I think both law and medicine agree that a parent's decision to withdraw care should generally be respected. Medical standards recognize that there is no clear treatment decision in this category—treatment is neither futile nor obligatory.<sup>210</sup> In this middle ground, parents are the appropriate decision makers. The American Medical Association has said, “[p]hysicians should recognize, and help parents appreciate, that it is not necessary to have prognostic certainty to withdraw life-sustaining treatment, since prognostic certainty is often unattainable and may unnecessarily prolong the infant’s suffering.”<sup>211</sup> Similarly, the American Academy of Pediatrics has said that “[p]arents should be given a great deal of discretion” over the treatment of their critically-ill newborns; “even if the physician believes the procedure in question should be performed, an informed parent’s refusal should generally be respected” unless “the chance of a good outcome with the procedure is so high that it is clearly in the child’s best interest to undergo the procedure.”<sup>212</sup> It has also said that “[w]hen the fetus’ prognosis is uncertain, decisions regarding obstetric management must be made by the parents” and “families should be supported in these often difficult and sometimes controversial decisions.”<sup>213</sup>

Byrne and Goldsmith published a study that examined physician practice, concluding that for the group of babies with “indeterminate” morbidity and mortality outcomes, “parental choice [about whether

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209. See Mercurio, *supra* note 65, at 844.

210. *Treatment Decisions for Seriously Ill Newborns, Code of Medical Ethics Opinion 2.2.4.* AMA (Nov. 14, 2016), <https://www.ama-assn.org/delivering-care/ethics/treatment-decisions-seriously-ill-newborns> [<https://perma.cc/B2QU-ABV8>].

211. *Id.*

212. Mark R. Mercurio & Alaina K. Pyle, *Critically Ill Newborns*, in AMERICAN ACADEMY OF PEDIATRICS BIOETHICS RESIDENT CURRICULUM: CASE-BASED TEACHING GUIDES 90, 95 (Douglas S. Diekema, Steven R. Leuthner & Felipe Vizcarondo eds., 2017), <https://www.aap.org/en-us/Documents/Bioethics-CriticallyIllNewborns.pdf> [<https://perma.cc/7UGQ-8FZ4>].

213. Hugh MacDonald, *Perinatal Care at the Threshold of Viability*, 110 PEDIATRICS 1024, 1025–26 (2002); see also Karen Kavanaugh, Teresa A. Savage & Marguerite Wydra, *Supporting Parents’ Decision Making Surrounding the Anticipated Birth of an Extremely Premature Infant*, 23 J. PERINATAL & NEONATAL NURSING 159, 166 (2009) (finding that support from healthcare providers is crucial when parents are deciding how to proceed upon learning they are at risk for delivering extremely prematurely).

to resuscitate the infant] should be the main deciding factor.”<sup>214</sup> In that category, the authors listed: “[b]abies who are 23 to 25 weeks gestation” and “[b]abies with major abnormalities that predict extreme morbidity or early death.”<sup>215</sup> The authors contrasted this category with two others: babies “with almost certain death,” for whom resuscitation is almost never indicated (including anencephaly, Trisomy 13, Trisomy 18, and babies born before 23 weeks); and babies that have “high rate of survival and acceptable risk of morbidity,” for whom “resuscitation is nearly always indicated.”<sup>216</sup> Similarly, another set of experts have outlined the standard of care for perinatal palliative care, concluding the following set of infants should be eligible for programs that only focus on comfort care:

1. Very likely lethal conditions (e.g., anencephaly, bilateral renal agenesis)
2. Probably lethal conditions with some hope of longer life (e.g., Trisomies 13 and 18)
3. Possibly lethal conditions with complex clinical course (e.g., hypoplastic left heart, congenital diaphragmatic hernia)
4. Any condition likely to have a complex and/or chronic course (e.g., multiple congenital anomalies, rare chromosomal conditions, brain anomalies, extreme prematurity, severe intrauterine growth restriction).<sup>217</sup>

Thus, medical practice seems relatively clear that parents facing a Category II diagnosis in their infant have the right to choose either aggressive care or palliative care only.

The law also supports this position. As a baseline, the law protects parental choice most when there is no clear answer about the proper treatment.<sup>218</sup> Parents are presumed to act in their child’s best interests, and the state must overcome this presumption by showing that the parents’ choice is wrong.<sup>219</sup> This burden is impossible to meet when there is no consensus on the right treatment: “how can parents in such situations give the wrong answer since there is no way of knowing the right answer?”<sup>220</sup> Parents are necessarily making decisions “about which there is no societal consensus” when they consider whether poor survival odds justify the pain of treatment, how to

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214. Steven Byrne & Jay P. Goldsmith, *Non-Initiation and Discontinuation of Resuscitation*, 33 CLINICS PERINATOLOGY 197, 215 (2006); see also Bhatia, *supra* note 189, at 907 (providing an overview of Byrne and Goldsmith’s suggestions).

215. Byrne & Goldsmith, *supra* note 214.

216. *Id.*

217. PERINATAL PALLIATIVE CARE: A CLINICAL GUIDE 8 (Erin M. Denney-Koelsch & Denise Côté-Arsenault eds., 2020).

218. See, e.g., *supra* Part II; cases discussed *supra* note 136.

219. See *Bowen v. Am. Hosp. Ass’n*, 476 U.S. 610, 628 n.13 (1986).

220. Goldstein, *supra* note 130, at 655.

create the most peaceful death when survival is impossible or improbable, and whether the quality of life a child can expect after treatment is acceptable.<sup>221</sup>

In cases from *Newmark* to *Jane Doe*, courts have refused to overrule a parental health decision when ordering care may cause suffering that may not be justified by the mortality rate and quality of life outcomes.<sup>222</sup> Prolonging life is not always in the child's best interests, and it should be the parents who get to determine when the painful fight for life is worth the range of possible results. Thus, parents can reasonably decide that withholding care is the best option for their child in the case of a Category II diagnosis.

The CAA are the most difficult part of this analysis as the exceptions most likely do not extend to Category II diagnoses.<sup>223</sup> Nevertheless, the CAA should not be a significant hurdle here. First, if physicians respect parental choice in these instances, which is the standard of care, then these parents will not be reported and the cases will never end up in court.<sup>224</sup> Some providers or hospital employees, however, may report parents in this category, especially if they are ideologically motivated. But even in these instances—assuming the state pursues a judicial order—the court will evaluate the parents' decision according to the BIC standard.<sup>225</sup> As established above, parents would generally win under this standard.<sup>226</sup> In other words, the CAA do not create a new legal framework to evaluate medical neglect in infants; they do nothing more than condition federal funds on the development of procedures for the reporting of medical neglect.<sup>227</sup> It would be anomalous—and potentially unconstitutional—for the government to create a harsher standard for evaluating parental decision-making for infants than other minor children.<sup>228</sup>

This Section explored the constitutional basis and limitations of parental rights to make end-of-life decisions for children. With that foundation in mind, Section III argues that these rights should be extended to expectant parents. Recognition of parental autonomy rights

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221. *Id.* at 654; see also Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 2 (2000).

222. See *supra* Part II.

223. 42 U.S.C. § 5106g(a)(5).

224. See *supra* note 211 and accompanying text.

225. See *supra* note 131 and accompanying text.

226. See *supra* note 131 and accompanying text.

227. 42 U.S.C. § 5106a(b)(2)(C).

228. MEISEL ET AL., *supra* note 186, at 10–32.

before birth would ensure that expectant parents can obtain an abortion at any point in the pregnancy after receiving a Category I or II diagnosis. This right would be independent of a woman's additional right under traditional abortion jurisprudence to obtain an abortion before viability for any reason, although subject to state regulation.

### III. THE CONSTITUTIONAL RIGHT TO PRENATAL END-OF-LIFE DECISION-MAKING

This Section argues that there should be a constitutional right—grounded in Fourteenth Amendment's protection of parental autonomy—for expectant parents to make end-of-life decisions for their child prenatally through abortion. This right would supplement traditional abortion rights, such as the right under *Casey* to a pre-viability abortion for any reason,<sup>229</sup> although limited by state regulation.<sup>230</sup> As a result, it would be invoked only when traditional abortion rights fail, especially after states have banned abortion. Thus, in practice, this right would operate like the health-or-life exception, which the Supreme Court requires for any abortion ban. The health-or-life exception, like the one I am proposing, is grounded in a different right than the right to privacy: the right to self-defense. Separately grounding the right to abortion on the basis of severe fetal anomaly in the right to parental autonomy would protect it even if the Supreme Court were to limit or overturn traditional abortion rights grounded in *Roe* and *Casey*'s right to privacy—a possibility that seems more realistic after Justice Kennedy's retirement and Justice Ginsburg's death. And if *Roe* and *Casey* are not abridged, this new right would sit on top of them, expanding access to abortion at a pivotal time when abortion rights are extremely fragile.<sup>231</sup>

This Section begins with Margot Finn's story, which emotionally grounds the analysis and demonstrates the similarities between abortion on the basis of severe fetal anomaly and parental decisions to withdraw life-sustaining treatment for children. Next, the Section discusses the failure of traditional abortion rights to protect expectant parental autonomy—in particular, state “viability” bans<sup>232</sup> and disability-selective abortion bans limit parental choice.<sup>233</sup> The Section next argues that expectant parents should be treated the same as parents when it comes to medical decisions for their potential children—

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229. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833 (1992).

230. *Id.*

231. See *supra* note 28.

232. See *infra* Part III.B.1.

233. See *infra* Part III.B.2.

they are making the same choices, for the same reasons, using a similar mechanism. And any differences between the two groups would actually suggest that expectant parents should have greater rights over their potential children. It is here that I address the personhood critique and argue that the right supported in this Article would not grant personhood to potential children. This Section concludes with a discussion of how this argument fits within the larger abortion conversation.

#### A. MARGOT'S STORY

Margot's pregnancy was planned.<sup>234</sup> As the miscarriage risk faded around nine weeks, she started relaxing into her pregnancy.<sup>235</sup> Around that time, she started a pregnancy journal where she wrote letters to her "future kid."<sup>236</sup> At eighteen weeks, with nine letters to her baby, Margot went in for her anatomy ultrasound.<sup>237</sup> At the end of that exam, she was told that part of her baby's brain was slightly dilated and filled with fluid, but this dilatation was only at the upper end of normal.<sup>238</sup> She was told there was a 95% chance that this problem would resolve itself and her baby would be fine.<sup>239</sup> So she and her care team decided to repeat the scan a month later to make sure the problem had dissipated.<sup>240</sup> In the meantime, she settled further into her pregnancy, now knowing her baby was a girl.<sup>241</sup>

At twenty-two weeks, and with thirteen letters written to her future daughter, she went in for her follow-up ultrasound alone, convinced that she would be in the 95%.<sup>242</sup> Instead, her baby girl had developed ventriculomegaly.<sup>243</sup> It was in that appointment that her doctors first started discussing abortion, specifically that Michigan's abortion law only allowed terminations until twenty-four weeks.<sup>244</sup> That day, she scheduled a battery of tests and appointments—

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234. *One Mom's Late-Term Abortion*, LONGEST SHORTEST TIME, at 05:30 (Mar. 1, 2019) [hereinafter Podcast], <https://longestshortesttime.com/episode-194-one-moms-late-term-abortion> [https://perma.cc/RB3P-EPWP].

235. *Id.* at 06:12.

236. *Id.* at 06:19.

237. *Id.* at 06:44.

238. *Id.* at 06:54.

239. *Id.* at 07:45.

240. *Id.* at 07:25.

241. *Id.* at 08:15.

242. *Id.* at 08:30–09:38.

243. *Id.*

244. *Id.* at 10:05, 12:58.

amniocentesis, fetal MRI, genetic counseling.<sup>245</sup> It was Halloween, and she spent the day crying “as many hours as were available.”<sup>246</sup> At this point in time, the doctors told her that there was still a 70% chance that her baby would have a good life, even if she suffered from cognitive impairments or developmental delays.<sup>247</sup> Margot decided she could not end the pregnancy with those odds.<sup>248</sup> Though she was forfeiting her last chance to have an abortion in Michigan, she knew that if her daughter’s illness progressed, she could afford to travel to Colorado for an abortion—one of the few states where women can obtain an abortion after twenty-four weeks.<sup>249</sup>

At twenty-eight weeks, with more letters written to her daughter, she went in for her next scan.<sup>250</sup> At that point, her baby girl was diagnosed with moderate to severe lissencephaly.<sup>251</sup> Margot describes the prognosis that was relayed to her in the following way:

We could expect her to live for two to six years while suffering from frequent respiratory infections and intermittently choking on her own saliva. Her cognitive development would be arrested or even reversed by painful seizures. She might have been able to smile socially and/or track motion with her eyes, but maybe not. Eventually, one of the bouts of pneumonia or choking episodes or complications from one of the surgeries needed to sustain basic life functions would have killed her.<sup>252</sup>

At that point, she and her husband decided to end the pregnancy. She wanted to avoid giving her daughter a fate “worse than death.”<sup>253</sup> She felt forced to choose between life and peace for her daughter—knowing she could only give her daughter one of those two gifts—and chose peace.<sup>254</sup> According to Margot, “[t]he only thing that could have been worse than [my daughter] dying would have been to continue knitting her small body together with my body” only to “feel personally responsible for every bit of her suffering thereafter, wishing I could give her peace and being unable to do it.”<sup>255</sup>

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245. *Id.* at 10:36–11:10.

246. *Id.* at 11:16.

247. *Id.* at 13:10.

248. *Id.* at 13:30.

249. *Id.* at 13:48.

250. *Id.* at 15:55.

251. *Id.* at 15:58; Margot Finn, *I Had a Late-Term Abortion. President Trump and Pro-Lifers Have No Right to Call Me a Murderer*, SLATE (Feb. 7, 2019, 5:30 PM), <https://slate.com/technology/2019/02/late-term-abortion-support-group-lessons-trust-myself-women.html> [https://perma.cc/FF4U-LATP].

252. Finn, *supra* note 251.

253. *Id.*

254. *Id.*

255. *Id.*

Because abortion was now illegal in Michigan, Margot and her husband were forced to travel to one of the few clinics left in the United States that still does abortions after twenty-four weeks.<sup>256</sup> She paid \$12,500 out of pocket for the procedure and thousands more in travel costs.<sup>257</sup> Her procedure was four-days long.<sup>258</sup> First, her baby's heart was stopped by an injection.<sup>259</sup> Then, doctors inserted dilators into her cervix over the course of three days.<sup>260</sup> Finally, they induced labor and delivery.<sup>261</sup> She had minimal pain medication as she gave birth to her stillborn daughter.<sup>262</sup> Her milk came in days later.<sup>263</sup>

Margot describes the loss of her daughter as the "shattering aftermath," "the kind of grief that cleaves your life into a before and an after...."<sup>264</sup> Though she now has two healthy children, she honors her first daughter in many ways on the day of her death.<sup>265</sup> She decided against seeing her daughter after birth or having her daughter cremated—not because she was callous, but because she thought it would hurt too much.<sup>266</sup> She says she would think differently about that choice today, knowing that nothing would protect her from her grief, and learning that other women have found poignant meaning in those memories.<sup>267</sup> Like many other women who have experienced a similar tragedy, she believes her daughter made her a mother even though she did not survive.<sup>268</sup>

#### B. THE FAILURE OF TRADITIONAL ABORTION RIGHTS TO PROTECT PRENATAL END-OF-LIFE DECISIONS

Since 1973, abortion rights have been grounded in the right to privacy recognized under the Fourteenth Amendment.<sup>269</sup> Though the

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256. Podcast, *supra* note 234, at 18:04.

257. *Id.* at 18:26.

258. *Id.* at 19:05.

259. *Id.* at 19:10.

260. *Id.* at 19:18.

261. *Id.* at 19:36.

262. Finn, *supra* note 251.

263. Podcast, *supra* note 234, at 26:05.

264. Finn, *supra* note 251.

265. Podcast, *supra* note 234, at 29:00.

266. *Id.* at 29:45.

267. *Id.* at 29:55.

268. *Id.* at 31:45.

269. See *Roe v. Wade*, 410 U.S. 113, 153 (1973) ("This right of privacy, whether it be founded in the Fourteenth Amendment's concept of personal liberty and restrictions upon state action, as we feel it is, or, as the District Court determined, in the

contours of the right have changed over time, the framework for evaluating the right to abortion has remained largely stable since 1992.<sup>270</sup> Until recently, anti-abortion activists have largely waged a war on the margins—attempting to slowly chip away abortion rights over time.<sup>271</sup> However, this model has changed dramatically after Justice Kennedy retired; in the past eighteen months, conservative states have launched a campaign to dismantle the foundation of abortion rights, including de facto bans on all abortion.<sup>272</sup> Though these aggressive laws have all been enjoined<sup>273</sup> and will not stand unless the central holding of *Roe* and *Casey* is overturned, there is genuine concern that the Supreme Court could overturn some, if not all, abortion protections.<sup>274</sup> The fear of this possibility only increased after the news of Justice Ginsburg's death broke.<sup>275</sup> In that scenario, the arguments advanced in this Article will become all the more important. By grounding the right to abortion on the basis of severe fetal anomaly in the right to parental autonomy—an entirely different jurisprudence—this right would exist even if *Roe* and *Casey* were overturned or limited further. Thus, if states are allowed to ban abortion once a heartbeat is detected at six weeks or under a theory of fetal pain at eighteen weeks, this right would ensure that women seeking an abortion on the basis of severe fetal anomaly could still obtain an abortion after that point.

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Ninth Amendment's reservation of rights to the people, is broad enough to encompass a woman's decision whether or not to terminate her pregnancy.").

270. Neal Devins, *How Planned Parenthood v. Casey (Pretty Much) Settled the Abortion Wars*, 118 YALE L.J. 1318, 1322 (2009) (arguing that *Casey* stabilized the abortion debate by creating a "template that helps states determine what types of abortion regulations can be constitutionally pursued").

271. *Id.* at 1340–44 (describing limited state attempts to increase abortion regulations within the *Casey* framework, including through informed consent laws, fetal pain laws, and TRAP laws).

272. See *Radical Attempts to Ban Abortion Dominate State Policy Trends in the First Quarter of 2019*, GUTTMACHER INST. (Apr. 2019), <https://www.guttmacher.org/article/2019/04/radical-attempts-ban-abortion-dominate-state-policy-trends-first-quarter-2019> [https://perma.cc/9XPV-S47E].

273. See, e.g., Robinson v. Marshall, 415 F. Supp. 3d. 1053, 1059 (M.D. Ala. 2019) (enjoining enforcement of Alabama's abortion ban because it "contravenes clear Supreme Court precedent").

274. See *supra* note 28 (discussing the increased likelihood that the Supreme Court will be sympathetic to abortion regulations).

275. See Ruiz, *supra* note 28 (explaining that after Justice Ginsburg's death, President Trump nominated Judge Amy Coney Barrett to replace Justice Ginsburg on the Supreme Court and Judge Coney Barrett signed a newspaper ad advocating for overturning *Roe v. Wade*).

Again, this would mimic the health-or-life exception which must always be available to women even after state bans take effect.<sup>276</sup>

In *Roe v. Wade*, the Supreme Court first recognized a constitutional right to abortion under the Due Process Clause of the Fourteenth Amendment.<sup>277</sup> Under *Roe*, abortion rights were grounded in the right to privacy and evaluated under a trimester framework.<sup>278</sup> In the first trimester, women were guaranteed access to abortion unobstructed by state interference.<sup>279</sup> In the second trimester, the state could enact regulations that hindered abortion, but only if they advanced its interest in protecting maternal health.<sup>280</sup> And finally, starting at fetal viability—roughly the third trimester of pregnancy—the state was free to ban abortion, except when the health or life of the mother was at risk.<sup>281</sup>

Twenty years later, in *Planned Parenthood v. Casey*, the Supreme Court was asked to reconsider *Roe*.<sup>282</sup> Though five justices declined to reverse “*Roe*’s central holding,” the plurality opinion dramatically altered the doctrine.<sup>283</sup> The Court replaced the trimester framework with a viability framework.<sup>284</sup> As with *Roe*, states could ban abortion after viability unless the mother’s health or life was at risk.<sup>285</sup> But unlike *Roe*, the state was permitted to regulate abortion as early as conception so long it did not pose an undue burden on the pregnant woman.<sup>286</sup> According to the Court, a law posed an “undue burden” if it had “the purpose or effect of placing a substantial obstacle in the path of a woman seeking an abortion of a nonviable fetus.”<sup>287</sup>

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276. Stephen G. Gilles, *Roe’s Life-or-Health Exception: Self-Defense or Relative-Safety?*, 85 NOTRE DAME L. REV. 525, 526 (2010).

277. 410 U.S. 113, 153 (1973).

278. *Id.* at 164–65; Linda J. Wharton, Susan Frietsche & Kathryn Kolbert, *Preserving the Core of Roe: Reflections on Planned Parenthood v. Casey*, 18 YALE J.L. & FEMINISM 317, 324 n.36 (2006).

279. *Roe*, 410 U.S. at 164.

280. *Id.*

281. *Id.* at 164–65.

282. 505 U.S. 833, 844 (1992) (plurality opinion).

283. *Id.* at 865.

284. *Id.* at 878.

285. *Id.* at 879; *State Bans on Abortion Throughout Pregnancy*, *supra* note 20 (explaining that a few states only have an exception for the mother’s life, not health, and they have not been legally challenged).

286. *Casey*, 505 U.S. at 878–79; Wharton et al., *supra* note 278, at 330–31.

287. *Casey*, 505 U.S. at 877.

It quickly became clear in applying the undue burden standard that it had much less bite than its predecessor.<sup>288</sup> The Court upheld most of the challenged provisions of the Pennsylvania's Abortion Control Act.<sup>289</sup> The Court held that it was not unduly burdensome for the state to require all women to wait twenty-four hours to obtain an abortion after receiving a comprehensive consent process,<sup>290</sup> to require minors to obtain parental consent before an abortion (with the possibility of judicial bypass),<sup>291</sup> and to require abortion providers to keep and disclose abortion records to the state.<sup>292</sup> The Court also upheld the law's health exception as sufficiently broad, even though it was only triggered if a pregnancy either threatened a woman's life or "create[d] serious risk of substantial and irreversible impairment of a major bodily function."<sup>293</sup> The only portion of the law deemed invalid under the undue burden standard was a spousal notification requirement, which the Court thought would substantially burden domestic violence victims.<sup>294</sup>

Later opinions have affirmed the health-or-life exception, but also noted that when scientific uncertainty exists as to whether an abortion law could harm a woman's health, that uncertainty alone will not invalidate the law.<sup>295</sup> The Court has never explained the justification for the health-or-life exception, but scholars have suggested that it must be either grounded in a person's right to self-defense or in the view that the state cannot force a woman to carry a pregnancy that is more dangerous to her than an abortion.<sup>296</sup> The Court has vacillated between these two rationales—the latter being more protective of women's rights because abortion is safer than pregnancy in most cases.<sup>297</sup> But at a minimum, the exception guarantees a woman's right

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288. See Vanessa Laird, *Planned Parenthood v. Casey: The Role of Stare Decisis*, 57 MOD. L. REV. 461 (1994) (discussing *Casey*'s treatment of *Roe* and its failure to provide certainty in abortion jurisprudence).

289. *Casey*, 505 U.S. at 879–901 (evaluating the constitutionality of the act under the Court's undue burden test).

290. *Id.* at 880–87.

291. *Id.* at 899–900.

292. *Id.* at 900–01.

293. *Id.* at 879 (quoting 18 PA. STAT. AND CONS. STAT. ANN. § 3203 (1990)).

294. *Id.* at 892–93, 901.

295. See, e.g., *Gonzales v. Carhart*, 550 U.S. 124, 163–64 (2007) (upholding an act that was uncertain to pose health risks to women seeking abortions because "[m]edical uncertainty does not foreclose the exercise of legislative power in the abortion context").

296. Gilles, *supra* note 276, at 527–30.

297. *Id.* at 529–30. It is worth noting that a liberal health exception could be used to permit an abortion on the basis of severe fetal anomaly—certainly, most women's

to defend herself when a doctor concludes that the pregnancy poses a significant risk to her health or life.<sup>298</sup>

*Casey* is still the best metric by which to judge the constitutional floor of abortion rights. Though the Court appeared to strengthen the undue burden standard in *Whole Woman's Health v. Hellerstedt*<sup>299</sup> by requiring an examination of the law's benefits in addition to its burdens,<sup>300</sup> Chief Justice John Roberts's concurrence in *Juno Medical Services* made clear that he would reject that expansion and go no further than *Casey*'s description of the right.<sup>301</sup> *Casey* and its progeny left intact two general abortion rights: the right to abortion for any reason before fetal viability, subject to state regulation,<sup>302</sup> and the right to abortion for the life or health of the mother at any point in the pregnancy.<sup>303</sup> Some states do not regulate to the constitutional floor and their citizens therefore enjoy abortion freedoms beyond those recognized by the Supreme Court.<sup>304</sup> But many states, especially those in conservative areas, have legislated to the floor—banning abortion after a certain point in pregnancy and creating numerous regulations before viability designed to close abortion facilities and deter as many abortions as possible.<sup>305</sup> As discussed in more depth below, these states have also successfully passed laws that seek to lower the constitutional floor slowly over time, winnowing away the rights at the

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mental and physical health would be jeopardized by the prospect of having to birth a dying or potentially-dying child. *See, e.g.*, Isaacson v. Horne, 716 F.3d 1213, 1232 (9th Cir. 2013) (Kleinfeld, J., concurring) (noting that, under an abortion statute that contained a health exception, severe fetal anomaly could be a basis for allowing an abortion even after the point it would normally be banned).

298. Gilles, *supra* note 276, at 583.

299. 136 S. Ct. 2292 (2016).

300. *See* Linda Greenhouse & Reva B. Siegel, *The Difference a Whole Woman Makes: Protection for the Abortion Right After Whole Woman's Health*, 126 YALE L.J.F. 149, 156 (2016), <https://www.yalelawjournal.org/forum/the-difference-a-whole-woman-makes> [https://perma.cc/NE76-PMVE].

301. June Med. Servs. L.L.C. v. Russo, 140 S. Ct. 2103, 2139 (2020) (Roberts, C.J., concurring) ("*Casey*'s requirement of finding a substantial obstacle before invalidating an abortion regulation is therefore a sufficient basis for the decision, as it was in *Whole Woman's Health*. In neither case, nor in *Casey* itself, was there call for consideration of a regulation's benefits, and nothing in *Casey* commands such consideration.").

302. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 879 (1992).

303. *Id.*

304. Colorado and six other states, for instance, allow abortions at any point in the pregnancy. *An Overview of Abortion Laws*, GUTTMACHER INST. (Jan. 1, 2020), <https://www.guttmacher.org/state-policy/explore/overview-abortion-laws> [https://perma.cc/SEU4-N2VQ].

305. *Id.*

margins.<sup>306</sup> These laws have dramatically reduced access to abortion in the South and Midwest.<sup>307</sup> The variability among state laws is huge and growing in recent years as some liberal states push to protect and expand abortion rights, while some conservative states attempt to ban the procedure entirely.<sup>308</sup>

Though all abortion laws impact women seeking abortions on the basis of severe fetal anomaly, some state abortion laws are particularly burdensome to these women: those that ban abortion after a certain point in the pregnancy and those that ban “disability-selective” abortion. These laws are explored in more depth below. This Section argues that these laws fail the parents whose abortions were a part of constitutionally protected end-of-life decision-making for their potential child.

### 1. Viability Creep

Since *Roe* and *Casey*, forty-three states have enacted abortion bans that outlaw the procedure at some point in the pregnancy (unless necessary to save the health or life of the mother).<sup>309</sup> One primary way that states have attempted to chip away at women’s abortion rights is to slowly move forward the line defining viability. The Supreme Court has never defined viability at a particular point in time. In *Roe*, the Court defined viability as “the interim point at which the fetus . . . is, potentially able to live outside the mother’s womb, albeit with artificial aid.”<sup>310</sup> The Court did note, however, that “[v]iability is usually placed at about seven months (28 weeks) but may occur earlier, even at 24 weeks.”<sup>311</sup> By the time *Casey* was decided, “advances in neonatal care [had] advanced viability to a point somewhat earlier.”<sup>312</sup> In 1992, the Court noted that viability could start around twenty-three to twenty-four weeks, and left open the possibility that further medical advances could continue to move that milepost forward.<sup>313</sup> Thus,

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306. See *infra* Part III.B.1.

307. See *infra* Part III.B.1.

308. See Isaac Stanley-Becker, ‘Not on My Watch’: As Abortion Bans Multiply, Some States Move to Affirm a Woman’s Right to Choose, WASH. POST (May 29, 2019), <https://www.washingtonpost.com/nation/2019/05/29/not-my-watch-abortion-bans-multiply-some-states-move-affirm-womans-right-choose/> [https://perma.cc/VHU3-KTGF].

309. See *State Bans on Abortion Throughout Pregnancy*, *supra* note 20.

310. *Roe v. Wade*, 410 U.S. 113, 160 (1973).

311. *Id.*

312. Planned Parenthood of Se. Pa. v. *Casey*, 505 U.S. 803, 860 (1992).

313. *Id.*

viability is, to some extent, a moving target,<sup>314</sup> but a target that doctors define for each pregnancy:

[I]t is not the proper function of the legislature or the courts to place viability, which essentially is a medical concept, at a specific point in the gestation period. The time when viability is achieved may vary with each pregnancy, and the determination of whether a particular fetus is viable is, and must be, a matter for the judgment of the responsible attending physician.<sup>315</sup>

The American College of Obstetricians and Gynecologists (ACOG) agrees that viability is a medical determination, which "may vary with each pregnancy and is a matter for the judgment of the responsible health care provider."<sup>316</sup> ACOG defines the gray period in which viability is uncertain as the periviable period; it starts at the beginning of twenty weeks and ends at the conclusion of twenty-five weeks.<sup>317</sup> Babies born before twenty-three weeks have only a five to six percent chance of survival with a ninety-eight to one hundred percent risk of morbidity.<sup>318</sup> The youngest premature baby to ever survive was born at twenty-one weeks and four days.<sup>319</sup> At twenty-three weeks, however, twenty-three to twenty-seven percent of babies born will survive; at twenty-four weeks, forty-two to fifty-nine percent will survive, and at twenty-five weeks, sixty-seven to seventy-six percent will survive.<sup>320</sup>

Given these statistics, viability cannot be said to begin before twenty-three weeks—in *Casey's* words, there would not be a "*realistic possibility* of maintaining and nourishing a life outside the womb."<sup>321</sup> Notwithstanding this fact, many states have created abortion bans that start before twenty-three weeks. Seventeen states have current abortion bans that start at twenty-two weeks into the pregnancy (as defined by gestational age—i.e., the first day of the woman's last period).<sup>322</sup> One state also has a current abortion ban starting at twenty weeks.<sup>323</sup> In the past year, eight states have attempted to ban abortion at much earlier in the pregnancy—from conception to eighteen

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314. *Id.*

315. *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 64 (1976).

316. *Abortion Policy*, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS, <https://www.acog.org/clinical-information/policy-and-position-statements/statements-of-policy/2017/abortion-policy> [<https://perma.cc/S8M3-5988>].

317. Am. Coll. of Obstetricians & Gynecologists, *supra* note 63.

318. *Id.*

319. Ahmad et al., *supra* note 64.

320. Am. Coll. of Obstetricians & Gynecologists, *supra* note 63.

321. *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 870 (1992) (emphasis added).

322. *State Bans on Abortion Throughout Pregnancy*, *supra* note 20.

323. *Id.*

weeks—but those laws have all been enjoined pending litigation.<sup>324</sup> One of the most troubling implications of these twenty to twenty-two week abortion bans is that they ban abortion at the time when many women first discover that their baby is sick, although Mississippi, Georgia, Louisiana, South Carolina, and West Virginia have an exception for lethal fetal anomalies.<sup>325</sup> In fact, some of these bans have been promoted as a way to reduce abortions on the basis of fetal anomaly.<sup>326</sup> There are an additional three states that ban abortion at twenty-four weeks, which gives women a little more time, but not enough.<sup>327</sup>

Though the timing of fetal diagnosis can vary greatly, parents most commonly receive a fetal diagnosis of an anatomical condition during the anatomy ultrasound, which occurs roughly halfway through the pregnancy (around twenty weeks).<sup>328</sup> The purpose of the anatomy ultrasound is to evaluate the fetus's development and identify problems,<sup>329</sup> though most women are ignorant to this fact as they eagerly await an opportunity to see their baby. In fact, if the doctors fail to diagnose a serious condition on these scans, then parents can sue the doctor in a wrongful birth lawsuit after their child is born.<sup>330</sup> Most anatomical conditions cannot be diagnosed sooner than this mid-pregnancy ultrasound because the organs are not sufficiently

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324. *Id.* (explaining that one state has banned abortion at conception, four states at six weeks, one state at eight weeks, and two states at eighteen weeks).

325. *Id.*

326. Mary Ziegler, *The Disability Politics of Abortion*, 2017 UTAH L. REV. 587, 626 (2017).

327. *State Bans on Abortion Throughout Pregnancy*, *supra* note 20.

328. See Bethune et al., *supra* note 21; *Second Trimester Abortion*, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS, <https://www.acog.org/clinical/clinical-guidance/practice-bulletin/articles/2013/06/second-trimester-abortion> [https://perma.cc/YC29-Y748].

329. Bethune et al., *supra* note 21.

330. Dov Fox, *Reproductive Negligence*, 117 COLUM. L. REV. 149, 166 (2017); Sofia Yakren, "Wrongful Birth" Claims and the Paradox of Parenting a Child with a Disability, 87 FORDHAM L. REV. 583, 586 (2018).

developed before this point.<sup>331</sup> Thus, parents often discover their child's problem right as abortion becomes illegal.<sup>332</sup>

Chromosomal issues can be diagnosed earlier in the pregnancy if parents take advantage of first trimester screening programs.<sup>333</sup> But these screening programs are not diagnostic, so the results reveal only the fetus's increased risk of having a condition.<sup>334</sup> As a result, even when parents utilize first trimester screening, many will not get a diagnosis until after additional testing is completed in the second trimester, which can again push women up against the abortion deadline.<sup>335</sup>

And even if parents learn of a potential problem before the state's deadline, it can take weeks after the anatomy scan or diagnostic genetic test for parents to complete the extra tests and second opinions necessary to feel as confident as possible that they understand the diagnosis and prognosis.<sup>336</sup> Furthermore, if the parents choose to terminate, it can take weeks or more after the decision is made to get an appointment for an abortion, collect the thousands of dollars of out-

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331. Yvonne Cargill & Lucie Morin, *Content of a Complete Routine Second Trimester Obstetrical Ultrasound Examination and Report*, 31 J. OBSTETRICS & GYNAECOLOGY CAN. 272, 274 (2009) (noting that more anatomical conditions are found during mid-pregnancy ultrasounds occurring after eighteen weeks); *Ultrasound Exams*, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS, <https://www.acog.org/patient-resources/faqs/special-procedures/ultrasound-exams> [https://perma.cc/7HRN-NK9Z] (“A first-trimester ultrasound exam is not standard because it is too early to see many of the fetus’s limbs and organs in detail.”).

332. See, e.g., Finn, *supra* note 251; *The Mom Who Had an Abortion at 7 Months Pregnant*, CUT (Apr. 19, 2018), <https://www.thecut.com/2018/04/how-i-got-this-baby-mom-who-had-an-abortion-at-7-months.html> [https://perma.cc/YZ8M-FMQK]; Sarah McCommon, *Abortion in the Third Trimester: A Rare Decision Now in the Political Spotlight*, NPR (Apr. 30, 2019), <https://www.npr.org/2019/04/30/718546468/opponents-fight-efforts-to-protect-late-term-abortion-rights> [https://perma.cc/8HPD-GMPC].

333. See, e.g., Tony Yew Teck Tan, *Combined First Trimester Screen or Noninvasive Prenatal Testing or Both*, 56 SING. MED. J. 1, 1 (2015) (describing the effective first trimester tests available to detect Down syndrome).

334. *Id.*

335. See Hayley White, Comment, *A Critical Review of Ohio’s Unconstitutional “Right to Life Down Syndrome Non-Discrimination” Bill*, 29 GEO. MASON U. C.R.L.J. 87, 92 (2018) (describing the first and second trimester tests conducted to detect Down Syndrome); *Prenatal Genetic Testing Chart*, AM. COLL. OBSTETRICIANS & GYNECOLOGISTS, <https://www.acog.org/Patients/FAQs/Prenatal-Genetic-Testing-Chart-Infographic> [https://perma.cc/S2PB-M6Q5] (describing first and second trimester diagnostic tests for genetic disorders).

336. See, e.g., Ali P., *04.24.19 Introducing Adam Ray*, A. RAY RESILIENCE (Aug. 26, 2019), <https://alipeaslee.wixsite.com/arayofresilience/post/04-24-19-introducing-adam-ray> [https://perma.cc/VCP7-DSGY].

of-pocket cash to pay for the procedure, comply with the state-mandated waiting periods, and ultimately obtain the abortion.<sup>337</sup> These additional weeks or months of testing and logistical hurdles will frequently delay the abortion enough to time-bar it.<sup>338</sup> And like Margot, some women who receive negative health information in the first or second trimester that initially seems manageable are forced to reevaluate their choice later in the pregnancy when they are told the baby's condition has worsened.<sup>339</sup> Others may first learn of the problem in the third trimester.<sup>340</sup> For the women in any of these situations, a twenty to twenty-four week ban will either outright deny them an abortion, rush an incredibly fraught decision, or force them to travel out of state, adding additional stress, cost, and trauma.<sup>341</sup>

It is worth noting that twenty states simply ban abortion at "viability."<sup>342</sup> By not creating a fixed definition of when viability begins, these states create flexibility for doctors to determine viability on a case-by-case basis as the Court originally imagined.<sup>343</sup> This flexibility

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337. RACHEL K. JONES & JENNA JERMAN, GUTTMACHER INST., TIME TO APPOINTMENT AND DELAYS IN ACCESSING CARE AMONG U.S. ABORTION PATIENTS 3-4 (2016), [https://www.guttmacher.org/sites/default/files/report\\_pdf/delays-in-accessing-care.pdf](https://www.guttmacher.org/sites/default/files/report_pdf/delays-in-accessing-care.pdf) [<https://perma.cc/G9DY-5X4A>]; Rachel Bertsche, *What Kind of Mother Is 8 Months Pregnant and Wants an Abortion?*, YAHOO NEWS (Oct. 20, 2016), <https://www.yahoo.com/news/what-kind-of-mother-is-8-months-pregnant-and-117104430132.html> [<https://perma.cc/8JXK-97SK>] (describing that the narrator needed to come up with \$25,000 in a weekend to obtain the abortion).

338. See, e.g., Ali P., *supra* note 336 ("I will forever grieve the death of my child but also the fact that I had to run to a different state to terminate my pregnancy- Away [sic] from our dogs, our friends, our family, our home, our safe place.").

339. Finn, *supra* note 251.

340. See, e.g., Lisa Belkin, 'We Are Not Monsters': Parents Go Public About Late-Term Abortions, HUFFPOST (Feb. 18, 2019), [https://www.huffpost.com/entry/we-are-not-monsters-parents-go-public-about-late-term-abortions\\_l\\_5c6afe6de4b01cea6b8815ff](https://www.huffpost.com/entry/we-are-not-monsters-parents-go-public-about-late-term-abortions_l_5c6afe6de4b01cea6b8815ff) [<https://perma.cc/DY8K-7624>]; Bertsche, *supra* note 337; Jia Tolentino, How Abortion Law in New York Will Change, and How It Won't, NEW YORKER NEWS DESK (Jan. 19, 2019), <https://www.newyorker.com/news/news-desk/how-abortion-law-in-new-york-will-change-and-how-it-wont> [<https://perma.cc/G66J-ZRVP>].

341. See, e.g., COHEN & JOFFE, *supra* note 25 (noting the impact of state bans on hospitals' willingness to perform abortions and the burden these hospital policies impose on women seeking abortions).

342. *An Overview of Abortion Laws*, *supra* note 304.

343. See, e.g., DEL. CODE ANN. tit. 24, § 1702 (2020) ("Viability" means the point in a pregnancy when, in a physician's good faith medical judgment based on the factors of a patient's case, there is a reasonable likelihood of the fetus's sustained survival outside the uterus without the application of extraordinary medical measures."); CAL. HEALTH & SAFETY CODE § 123464 (West); MD. CODE ANN., HEALTH-GEN. § 20-209 (West) ("[V]iable" means that stage when, in the best medical judgment of the attending physician based on the particular facts of the case before the physician, there is a reasonable likelihood of the fetus's sustained survival outside the womb.").

is especially important for women seeking an abortion based on severe fetal anomaly—even if a healthy baby might be viable in the third trimester, an unhealthy baby may never be viable, or at least not at the moment of termination.<sup>344</sup> Thus, in these states, women who choose to terminate based on fetal anomaly have greater protections.

Courts have overturned some abortion bans that started too soon. For instance, Arizona attempted to ban abortion starting at twenty weeks, and the Ninth Circuit Court of Appeals found the ban unconstitutional.<sup>345</sup> The court was particularly worried that the ban would prevent “abortions in cases of fetal anomaly or pregnancy failure.”<sup>346</sup> The Ninth Circuit Court of Appeals also struck down Idaho’s twenty-two-week abortion ban.<sup>347</sup> When Utah attempted to ban abortions starting at 20 weeks, the Tenth Circuit similarly found the law unconstitutional.<sup>348</sup> District courts have also invalidated North Carolina’s 20-week ban<sup>349</sup> and Arkansas’s 18-week ban.<sup>350</sup> Nevertheless, the eighteen states mentioned above have active bans that start before viability,<sup>351</sup> and the Supreme Court has never heard an appeal on these cases.<sup>352</sup>

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344. See Carson Strong, *Fetal Anomalies: Ethical and Legal Considerations in Screening, Detection, and Management*, 30 CLINICS PERINATOLOGY 113, 119–22 (2003) (discussing the legal dilemma faced by physicians who must determine whether a fetus with a genetic anomaly is viable when considering whether to abort it after twenty-four-week state bans have gone into effect); see also *State Bans on Abortion Throughout Pregnancy*, *supra* note 20 (explaining that some states make this explicit: Delaware and Utah explicitly create exceptions for a lethal fetal anomaly after viability, while Maryland has an exception for all fetal anomalies after viability).

345. Isaacson v. Horne, 716 F.3d 1213, 1225 (9th Cir. 2013).

346. *Id.* at 1228.

347. The Idaho law banned abortions twenty weeks post-fertilization, or twenty-two weeks into the pregnancy. McCormack v. Herzog, 788 F.3d 1017, 1029 (9th Cir. 2015).

348. Jane L. v. Bangerter, 102 F.3d 1112, 1118 (10th Cir. 1996).

349. Bryant v. Woodall, 363 F. Supp. 3d 611, 630 (M.D.N.C. 2019).

350. Little Rock Fam. Plan. Servs. v. Rutledge, 398 F. Supp. 3d 330, 380 (E.D. Ark. 2019).

351. *State Bans on Abortion Throughout Pregnancy*, *supra* note 20.

352. See *Cases—Abortion and Contraceptives*, OYEZ, <https://www.oyez.org/issues/423> [<https://perma.cc/2NMB-SA2H>] (listing Supreme Court cases heard on abortion issues, with none concerning the laws in question).

## 2. Disability-Selective Abortion Bans

Over the past decade, states have started passing disability-selective abortion bans.<sup>353</sup> Advanced as anti-discrimination laws,<sup>354</sup> these bans can have intuitive appeal to many. But as argued in Section III.D, many abortions on the basis of fetal anomaly are not sought to prevent a disabled child from entering the world, but to save a child with a life-threatening condition from a potentially short and painful life. Furthermore, these bans represent a novel opportunity for the state to investigate a woman's reason for wanting an abortion and prevent it if the state judges that reason improper.<sup>355</sup> Supreme Court precedent does not allow states to ban pre-viability abortions based on "bad" reasons.<sup>356</sup>

Of course, disability-selective bans greatly impact the abortion services that women can receive after learning of a poor prenatal diagnosis. A North Dakota law—passed in 2013—makes the following a class A misdemeanor:

[A] physician may not intentionally perform or attempt to perform an abortion with knowledge that the pregnant woman is seeking the abortion solely . . . [b]ecause the unborn child has been diagnosed with either a genetic abnormality or a potential for a genetic abnormality.<sup>357</sup>

The law defines "genetic abnormality" as "any defect, disease, or disorder that is inherited genetically."<sup>358</sup> The term includes any physical disfigurement, scoliosis, dwarfism, Down syndrome, albinism, amelia, or any other type of physical or mental disability, abnormality, or disease."<sup>359</sup> In other words, it is broad enough to cover nearly every poor prenatal diagnosis, even non-genetic structural problems that could have a genetic component.<sup>360</sup> In North Dakota, a Class A misdemeanor is punishable by "a maximum penalty of imprisonment for three hundred sixty days, a fine of three thousand dollars, or both . . ."<sup>361</sup>

Utah has a similar disability-selective abortion ban on the books, but it is limited to only Down Syndrome (Trisomy 21).<sup>362</sup> It also

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353. Greer Donley, *Does the Constitution Protect Abortions Based on Fetal Anomaly?: Examining the Potential for Disability-Selective Abortion Bans in the Age of Prenatal Whole Genome Sequencing*, 20 MICH. J. GENDER & L. 291, 303 (2013).

354. *Id.* at 303–06.

355. *See id.* at 326–27.

356. *Id.* at 327.

357. 14 N.D. CENT. CODE § 14-02.1-04.1(1) (2019).

358. *Id.* § 14-02(7).

359. *Id.* § 14-02.1-02(7).

360. *See* Donley, *supra* note 353, at 304.

361. 12 N.D. CENT. CODE § 12.1-32-01(5) (2019).

362. UTAH CODE ANN. § 76-7-302.4 (West 2019).

contains a trigger clause—i.e., a clause providing that it will not go into effect until “a court of binding authority holds that a state may prohibit the abortion of an unborn child [before viability] if the sole reason for the abortion is that the unborn child has or may have Down syndrome.”<sup>363</sup> There is good reason for this trigger clause. All courts to consider the issue have held that disability-selective abortion bans violate the central holding in *Roe* and *Casey*: that a state cannot outright prohibit a woman from obtaining a pre-viability abortion (even if it can make those abortions more difficult to obtain).<sup>364</sup> Scholars likewise agree: the Constitution does not permit states to condition a woman’s right to pre-viability abortion on the reasons she seeks it.<sup>365</sup>

The Seventh Circuit—one of two circuits to consider the issue—invalidated a disability-selective abortion ban in Indiana.<sup>366</sup> The Indiana law banned abortion on the basis of “Down syndrome, disability, or related characteristics,” excluding “lethal fetal anomal[ies].”<sup>367</sup> The law also required that abortion facilities cremate fetal remains themselves, separate from other “surgical byproduct.”<sup>368</sup> The Seventh Circuit held that both parts of the law were unconstitutional.<sup>369</sup> As to the disability-selective ban, the court found that the “provisions [pose] far

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363. *Id.* § 9(3).

364. *Preterm-Cleveland v. Himes*, 294 F. Supp. 3d 746, 755 (S.D. Ohio 2018) (“The State cannot dictate what factors a woman is permitted to consider in making her choice. The State’s attempt to carve out exceptions to a categorical right [to pre-viability abortions] where none exist fails as a matter of law.”); *Little Rock Fam. Plan. Servs. v. Rutledge*, 398 F. Supp. 3d 330, 384 (E.D. Ark. 2019) (“[T]he State may not prohibit a woman from exercising that right [to pre-viability termination] solely upon the basis on which a woman makes her decision.”); *Reprod. Health Servs. of Planned Parenthood of the St. Louis Region, Inc. v. Parson*, 389 F. Supp. 3d 631, 636 (W.D. Mo. 2019) (enjoining the state from enforcing a law which would have prohibited pre-viability Down Syndrome terminations, on grounds that “all judicial rulings so far preclude such a legislative override” of “any aspect of a woman’s right to abort a non-viable fetus”).

365. See, e.g., *Donley, supra* note 353, at 325–27; Marc Spindelman, *On the Constitutionality of Ohio’s “Down Syndrome Abortion Ban,”* 79 OHIO ST. L.J. FURTHERMORE 19, 32–33 (2018); Carole J. Petersen, *Reproductive Autonomy and Laws Prohibiting “Discriminatory” Abortions: Constitutional and Ethical Challenges*, 96 U. DET. MERCY L. REV. 605, 618–19 (2019).

366. *Planned Parenthood of Ind. & Ky., Inc. v. Comm’r of the Ind. State Dep’t of Health*, 888 F.3d 300, 306 (7th Cir. 2018), cert. denied on disability-selective abortion issue *sub nom. Box v. Planned Parenthood of Ind. & Ky., Inc.*, 139 S. Ct. 1780, 1782 (2019) (per curiam).

367. *Box*, 139 S. Ct. at 1783 (Thomas, J., concurring).

368. *Planned Parenthood of Ind. & Ky., Inc.*, 888 F.3d at 303–04.

369. *Id.* at 306, 309–10, vacated as to fetal tissue disposition issue, reh’g en banc granted, 727 F. App’x 208 (7th Cir. 2018) (mem.), reh’g vacated after recusal destroyed majority, opinion reinstated, 917 F.3d 532 (7th Cir. 2018), cert. granted as to fetal tissue disposition issue, judgment rev’d *sub nom.*; *Box*, 139 S. Ct. at 1782 .

greater than a substantial obstacle; they are absolute prohibitions on abortions prior to viability which the Supreme Court has clearly held cannot be imposed by the State.”<sup>370</sup> Appellants moved for a rehearing en banc, but only as to the decision on fetal remains.<sup>371</sup> The court initially granted the rehearing, but ultimately denied the motion—after a judge’s subsequent recusal denied Appellants the required majority—over a dissent by Judge Easterbrook, which Judge Amy Coney Barrett joined.<sup>372</sup> Curiously, the dissent noted that the disability-selective ban (which was not at issue) was worthy of reconsideration by the entire court *en banc*.<sup>373</sup> He argued that “*Casey* did not consider the validity of an anti-eugenics law,” which in his view, might create a legitimate exception to *Casey*:

Does the Constitution supply a right to evade regulation by choosing a child’s genetic makeup after conception, aborting any fetus whose genes show a likelihood that the child will be short, or nearsighted, or intellectually average, or lack perfect pitch—or be the “wrong” sex or race? *Casey* did not address that question. We ought not impute to the Justices decisions they have not made about problems they have not faced.<sup>374</sup>

Appellants requested certiorari, which the Supreme Court granted, but only as to the Seventh Circuit’s invalidation of the fetal remains statute.<sup>375</sup> As to the disability-selective abortion ban, the Supreme Court “expresse[d] no view on the merits.”<sup>376</sup> Rather, the Court noted that because the Seventh Circuit was the only circuit to have considered a disability-selective abortion ban, the Court would “follow our ordinary practice of denying petitions insofar as they raise legal issues that have not been considered by additional Courts of Appeals.”<sup>377</sup> Justice Thomas wrote separately to suggest that Indiana’s disability-selective abortion ban may be constitutional.<sup>378</sup> He compared disability-selective abortions to eugenics, and argued that *Casey* may not protect such abortions even prior to viability: “Enshrining a constitutional right to an abortion based solely on the race, sex, or disability of an unborn child, as Planned Parenthood advocates, would

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370. *Planned Parenthood of Ind. & Ky., Inc.*, 888 F.3d at 306.

371. *Planned Parenthood of Ind. & Ky., Inc.*, 727 F. App’x at 208 (mem).

372. *Planned Parenthood of Ind. & Ky., Inc.*, 917 F.3d at 533, 536.

373. See *id.* at 536 (Easterbrook, J., dissenting).

374. *Id.*

375. *Box v. Planned Parenthood of Ind. & Ky., Inc.*, 139 S. Ct. 1780, 1781 (2019) (per curiam).

376. *Id.* at 1782.

377. *Id.*

378. *Id.* at 1783–93 (Thomas, J., concurring).

constitutionalize the views of the 20th-century eugenics movement."<sup>379</sup>

Scholars have appropriately criticized Thomas's use of the term eugenics in this context, noting that eugenics sought to deny minorities and disabled individuals their right to have children by forced sterilization, contraception, or abortion; in other words, it limited fundamental reproductive rights.<sup>380</sup> On the other hand, access to abortion on the basis of fetal anomaly does not remove individuals' reproductive rights by preventing them from having a child they want; it expands their reproductive rights by giving them choices. "When hopeful parents screen for debilitating ailments, and opt to end an otherwise-wanted pregnancy, they aren't trying to weed out people with disabilities from the next generation."<sup>381</sup> Rather, "abortion empowers individuals to make reproductive decisions, where eugenics denied people that choice."<sup>382</sup>

Nevertheless, some courts have "speculated that the Supreme Court's language in *Box* implicitly invited appellate judges to review the merits of prohibitions of discriminatory abortions ...."<sup>383</sup> And it appears this invitation will be answered. In January 2019, the Sixth Circuit heard an appeal to an injunction that prevented Ohio's disability-selective abortion ban from going into effect.<sup>384</sup> Like Indiana, Ohio's ban was also limited to Down Syndrome.<sup>385</sup> The Sixth Circuit also concluded that Ohio's ban violated *Casey*'s "categorical" right to a pre-viability abortion.<sup>386</sup> Judge Batchelder dissented, largely for the same eugenics-based arguments raised by Justice Thomas.<sup>387</sup> In a move that has concerned abortion rights activists, the Sixth Circuit decided to reconsider the case *en banc*<sup>388</sup> and heard arguments in March

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379. *Id.* at 1792.

380. Dov Fox, *Abortion, Eugenics and Personhood in the Supreme Court*, FERTILITY & STERILITY CONSIDER THIS (Jan. 25, 2020), <https://www.fertsterdialog.com/posts/58704-fox-consider-this> [https://perma.cc/YQF5-BBYZ]; see also Samuel R. Bagenstos, *Disability and Reproductive Justice*, 14 HARV. L. & POL'Y REV. (forthcoming 2020); Petersen, *supra* note 365, at 609–10.

381. Fox, *supra* note 380.

382. *Id.*

383. Reprod. Health Servs. of Planned Parenthood of the St. Louis Region, Inc. v. Parson, 389 F. Supp. 3d 631, 636 (W.D. Mo. 2019).

384. Preterm-Cleveland v. Himes, 940 F.3d 318, 320 (6th Cir. 2019).

385. *Id.*

386. *Id.* at 323.

387. *Id.* at 325–28 (Batchelder, J., dissenting).

388. Preterm-Cleveland v. Himes, 944 F.3d 630, 631 (2019).

2020.<sup>389</sup> Given that President Trump has appointed more active judges on the Sixth Circuit than every Democratic president combined,<sup>390</sup> this case could create the first circuit split on the issue and entice the Supreme Court to review the merits of these bans.

The issue of disability-selective abortion bans is unlikely to disappear anytime soon, especially given the sympathetic ear Judge Easterbrook, Judge Barrett, and Justice Thomas gave such laws<sup>391</sup> and the increase in similar abortion legislation proposed or passed in 2019 and 2020.<sup>392</sup> Though this Article advances an affirmative argument to create the right to abortion on the basis of severe fetal anomaly, the arguments could also be used defensively as another reason to oppose disability-selective abortion bans that are expansive enough to include Category I or II diagnoses.

State abortion laws are currently failing to protect parents seeking to terminate on the basis of severe fetal anomaly.<sup>393</sup> Because *Casey* allows states to ban abortion after viability, traditional abortion doctrine will always fail to sufficiently protect these women. The next section argues that abortion decisions in the context of a Category I or II diagnosis should be protected by an entirely different constitutional right—a parent’s right to make end-of-life decisions for their child. This parental autonomy right will prohibit the state from banning abortion at any point in the pregnancy when it is based on a Category I or II diagnosis.

### C. ABORTION AS A PARENTAL AUTONOMY RIGHT IN THE CASE OF SEVERE FETAL ANOMALY

If the Constitution protects parental decisions to withhold life-sustaining treatment when a child has a poor prognosis and treatment

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389. *Sixth Circuit Court of Appeals Hears Oral Arguments in Case Challenging Ohio Abortion Ban*, Preterm v. Himes, ACLU OHIO (Mar. 11, 2020), <https://www.acluohio.org/archives/press-releases/sixth-circuit-court-of-appeals-hears-oral-arguments-in-case-challenging-ohio-abortion-ban-preterm-v-himes> [https://perma.cc/9LEK-ZYE2].

390. Tim Ryan, *Trump Flips Another Circuit to Majority GOP Appointees*, COURT-HOUSE NEWS SERVS. (Nov. 20, 2019), <https://www.courthousenews.com/trump-flips-another-circuit-to-majority-gop-appointees> [https://perma.cc/UQT9-J64A].

391. Planned Parenthood of Ind. & Ky., Inc. v. Comm'r of the Ind. State Dep't of Health, 917 F.3d 532, 536 (7th Cir. 2018) (Easterbrook, J., dissenting); Box v. Planned Parenthood of Ind. & Ky., Inc., 139 S. Ct. 1780, 1783 (2019) (Thomas, J., dissenting).

392. See *supra* Part III.B.

393. See *supra* Part II.

would be painful,<sup>394</sup> then how can parents lack this right for a potential child still in utero? If anything, the state's interest in protecting a potential child must be less than its interest in protecting a living infant or child, especially when a woman's autonomy is also at issue. Yet the law does not currently recognize this analogous right. Instead, the rights of these parents have been swept under an ill-fitting abortion doctrine grounded in the right to privacy<sup>395</sup>—a doctrine that may be limited or eliminated all together in the next decade. This Section defends the analogy between parents and expectant parents to justify the extension of the parental rights to expectant parents. It suggests that any differences between the two groups support stronger expectant parental rights.

### 1. Same Motivation

On the most basic level, when parents are confronted with a potentially life-threatening diagnosis in their child, they face the same considerations whether it is before or after birth. Parents and expectant parents are evaluating the same diagnoses, the same prognoses, and the same range of possible outcomes. This is especially true in the case of newborns, who are often born with the exact same conditions that are diagnosed in pregnancy.<sup>396</sup>

Parents and expectant parents also share the same motivations in deciding whether to pursue aggressive treatment or allow their child to die—including a determination of what is in the best interests of the child.<sup>397</sup> One expectant mother said, “If I can make a choice [to terminate] where it’s the best outcome for my child to not have to suffer, that’s what I’m going to choose. And I will choose it every day....”<sup>398</sup> Parents hope to save their child from the suffering of a short or painful life or the years of painful procedures that might still end in early death.<sup>399</sup> “We made sure our son was not born only to

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394. See, e.g., *Parham v. J.R.*, 442 U.S. 584, 602–03 (1979); *Newmark v. Williams*, 588 A.2d 1108, 1117 (Del. 1991); *Parental Treatment Refusals*, *supra* note 133 (“[Parents] may even refuse potentially life-saving therapy when it is unlikely to be effective or when the side effects are overly burdensome.”).

395. *Roe v. Wade*, 410 U.S. 113, 153 (1973); *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 915–16 (1992).

396. See, e.g., *Nguyen et al.*, *supra* note 47.

397. See, e.g., *Belkin*, *supra* note 340 (“[I]t wasn’t about me and continuing my pregnancy, it was about my son and saving him from his body ....”).

398. VICE News, *What It’s Like to Have a Second-Trimester Abortion*, YOUTUBE, at 3:57 (July 10, 2019), <https://youtu.be/q8-vbOhCqJ0?t=237>.

399. See, e.g., Sarah Schulte, *Illinois May Expand Abortion Rights as Other States Restrict; Senate Expected to Vote Friday*, ABC 7 CHI. (May 30, 2019), <https://>

suffer. He died in a warm and loving place, inside me.”<sup>400</sup> “The thought of hearing him gasp for air and linger in pain was our nightmare.”<sup>401</sup> “We could not protect our daughter from trisomy 18, but we could shield her from any pain or agony that would come with it. All parents should be able to protect their unborn children in this way—to spare them from having to feel pain.”<sup>402</sup> Many parents see abortion as “the palliative care procedure” their child “needed to prevent [their] suffering.”<sup>403</sup> Parents often note that by ending the pregnancy, they “have taken the physical and emotional suffering on [them]selves instead of allowing [the potential child] to feel it.”<sup>404</sup> “It takes enormous strength, love, and altruism to do what is needed and say goodbye to your baby, and then face a society that calls you ‘murderer’ and worse.”<sup>405</sup>

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abc7chicago.com/politics/illinois-may-expand-abortion-rights-as-other-states-restrict-senate-expected-to-vote-friday/5323775 [https://perma.cc/JTW5-AGMM] (“We decided we couldn’t put our daughter through that, it would have been a very very short life and not a pleasant one . . .”); Bertsche, *supra* note 337 (“I had to think about a baby who was probably not going to live very long, and the longer she lived, the more pain she would be in. That realization—that I was more scared of her living than of her dying—is what made the choice for me.”); Natalia Megas, *The Agony of Ending a Wanted Late-Term Pregnancy: Three Women Speak Out*, GUARDIAN (Apr. 18, 2017), https://www.theguardian.com/society/2017/apr/18/late-term-abortion-experience-donald-trump [https://perma.cc/S6V-KRGG] (“[I]f it meant Cate was going to suffer, we just couldn’t do that to her.”); Tolentino, *supra* note 340 (“If the child was born, he would suffer, and would not live long; [his mother] wanted to minimize his suffering to whatever extent she could.”); Trinity Hundredmark, *Excerpt from 5.16.19 Press Conference with Senator Gillibrand at GA Capitol*, YOUTUBE, at 2:55 (June 19, 2019), https://youtu.be/wjliRg81umU?t=175 (“I wanted more for her to not be in pain. For her to not know a minute of suffering. For her to only know peace.”).

400. Judy Nicastro, Opinion, *My Abortion, at 23 Weeks*, N.Y. TIMES (June 20, 2013), https://www.nytimes.com/2013/06/21/opinion/my-abortion-at-23-weeks.html [https://perma.cc/6U4Y-TYEV].

401. *Id.*

402. Allison Chang, *Our Child Received a Devastating Diagnosis Before She Was Born. We Decided to Protect Her*, STAT (Jan. 7, 2019), https://www.statnews.com/2019/01/07/devastating-diagnosis-before-birth-trisomy-18 [https://perma.cc/Q4UG-6HJF].

403. Hevan Lunsford, *Hevan Lunsford: I Can’t Just Be a Mother Grieving the Loss of Her Son*, AL.COM (May 17, 2019), https://www.al.com/opinion/2019/05/i-can-t-just-be-a-mother-grieving-the-loss-of-her-son-hevan-lunsford.html [https://perma.cc/2EYG-ZDHT].

404. Sara Ahmed, *This Story of One Woman’s Late-Term Abortion Is a Powerful Reminder of Why Reproductive Rights Matter*, BABBLE (Jan. 11, 2017), https://www.babble.com/parenting/late-term-abortion-story-reproductive-rights-matter [https://perma.cc/GU3G-B9FU]; see also Hundredmark, *supra* note 399, at 3:09 (“I knew that carrying her to term would only be fulfilling my own selfish desires. It would do nothing to alleviate her pain and it would do nothing to end her suffering.”).

405. Anne Mellinger-Birdsong, *I Can Love My Baby, Grieve My Loss, and Still Have Had an Abortion*, STILL STANDING MAG. (Oct. 29, 2018), https://stillstandingmag.com/

"Ending my pregnancy was the most selfless act of love I have ever committed."<sup>406</sup>

Parents are also extremely motivated to avoid the death, and corresponding grief, that comes with the loss of a wanted pregnancy.<sup>407</sup> Those who choose termination in this context typically grieve their potential children in the same way parents grieve natural fetal death.<sup>408</sup> It can be devastating.<sup>409</sup> Though no two families are the same, many parents see their child as forever a part of their family: "[T]he tricky thing about motherhood is it's a transformation that can't be undone. I'm a parent without a child now; a parent who misses her son and will for a long time. Maybe always."<sup>410</sup> To memorialize their babies after termination, many parents have pictures taken at the hospital, name their child, collect footprints, cremate or bury their baby, or create annual traditions to remember him or her.<sup>411</sup> For some women, however, the best way to cope with their loss is a clean

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2018/10/29/i-can-love-my-baby-grieve-my-loss-and-still-have-had-an-abortion  
[<https://perma.cc/QAS2-NA3X>].

406. Missy Kurzweil, *Later Abortion: A Love Story*, JEZEBEL (Feb. 21, 2019), <https://jezebel.com/later-abortion-a-love-story-1832631748> [<https://perma.cc/69PT-R939>]; *see also* Chelsea McIntosh, *Opinion: My Abortion Not Your Business, Politicians*, CINCINNATI.COM (Mar. 16, 2019), <https://www.cincinnati.com/story/opinion/2019/03/16/opinion-my-abortion-not-your-business-politicians/3129807002> [<https://perma.cc/MJ9M-3GCY>] ("I was making this choice out of love.").

407. See, e.g., Kurzweil, *supra* note 406 ("No one 'wants' a later abortion.... Like me, [other mothers who terminated such pregnancies] would give anything to exchange their abortion for a healthy, living child."); Lunsford, *supra* note 403 ("I carry trauma with me that is so deep and intertwined with my soul, I know I will never recover."); Ahmed, *supra* note 404 ("[Terminating a wanted pregnancy] has been the hardest experience of my life.... I will never be the same.").

408. See, e.g., VICE News, *supra* note 398, at 6:35 ("I wasn't recovering from an abortion, I was recovering from a loss of a child.").

409. See, e.g., Hundredmark, *supra* note 399, at 3:32 ("A part of me died that day, but there is not one ounce of me that regrets this decision [to terminate]."); *Triploidy-The Story of Zachary*, TERMINATIONS REMEMBERED (July 15, 2019), <https://terminationsremembered.com/triploidy-termination-of-pregnancy-for-medical-reasons> [<https://perma.cc/NY87-UL6G>] ("Instead the first wave of grief caught me off guard as I realized that I would go to the hospital with a baby and leave with a box."); Maguire et al., *supra* note 33 (reporting that many parents experience intense grief for months, with 17% reporting post-traumatic stress disorder two to seven years post-procedure).

410. Kurzweil, *supra* note 406.

411. See, e.g., *No Choice: Valerie Peterson*, MOYERS ON DEMOCRACY, <https://billmoyers.com/story/no-choice-valerie-peterson> [<https://perma.cc/E6TB-ADKY>].

break where they do not embrace motherhood or create memories, which is equally valid and occurs after stillbirth as well.<sup>412</sup>

Just as parents are presumed to be acting in their child's best interest when they choose to withhold life-sustaining treatment,<sup>413</sup> expectant parents should also be presumed to be acting in their potential child's best interest when they terminate on the basis of severe fetal anomaly.<sup>414</sup> Of course, parents should also be presumed to be acting in their child's best interests when they choose not to terminate. Termination is not the only reasonable parenting choice in this situation—far from it—but it is a reasonable parenting choice that should therefore be protected.

Some may suggest that we should not trust expectant parents to act in their potential child's best interests because they may have selfish reasons to also favor termination—namely, to avoid the financial and emotional strains of caretaking a seriously ill child.<sup>415</sup> To the

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412. See, e.g., Jenny Kutner, *Women Who Have Had Abortions on Why They're Proud Not to Be Moms on Mother's Day*, MIC (May 4, 2016), <https://www.mic.com/articles/142643/women-who-have-had-abortions-on-why-they-re-proud-not-to-be-moms-on-mother-s-day> [https://perma.cc/Z56D-Q65A] ("With the two procedures I had, even though I miscarried one, I still don't look at it as me having a child before having my son. I don't believe I'm a parent to any other child but the one I have now.").

413. See *Troxel v. Granville*, 530 U.S. 57, 58 (2000) (plurality opinion) ("There is a presumption that fit parents act in their children's best interests . . ." citing *Parham v. J.R.*, 442 U.S. 584, 602 (1979)).

414. Compare I. Glenn Cohen, *Beyond Best Interests*, 96 MINN. L. REV. 1187, 1209–11 (2012) (arguing the BIC standard was an inappropriate rationale to regulate reproductive behaviors when it discouraged the conception of certain children on the basis that the resulting child would suffer harms and using the non-identity problem to argue that so long as the children had a life worth living, it was more harmful to prevent their existence through regulation than to allow them to exist with subsequent harms), *with infra* pp. 157–58 (explaining Cohen's argument is inapplicable here because even assuming a particular child's only chance at life is to be born with these anomalies, if the parents believe that existence could be more painful than joyful, it would fit an exception to the non-identity problem).

415. See, e.g., Cassy Fiano, *Selfish Convenience: Why People Abort Children with Down Syndrome*, NAT'L RIGHT TO LIFE NEWS (Oct. 13, 2013), <https://www.nationalrighttolifenews.org/2013/10/selfish-convenience-why-people-abort-children-with-down-syndrome> [https://perma.cc/6MFR-DPVQ] ("The abortion isn't for the sake of the child; it's for the sake of the parent. They don't want an inconvenient child, a baby who may require them to work a little harder than they planned."); Murray Vasser, *Why Do We Kill the Handicapped? Out of Selfishness, Not Compassion*, LIFE-NEWS (July 19, 2013), <https://www.lifenews.com/2013/07/19/why-do-we-kill-the-handicapped-out-of-selfishness-not-compassion> [https://perma.cc/6E2N-MVFH] ("This leads me to suspect that the real reason our society [aborts potential children diagnosed with Down Syndrome] is not out of compassion, but rather out of selfishness. . . . We kill handicapped people because we do not have the time to deal with them . . . .").

extent this is true, it is also true when parents are making end-of-life choices for their children after birth, when the emotional and financial strains are real.<sup>416</sup> Why would we presume that parents' love for their child after birth outweighs any possible selfish interests, but not before birth? Of course, it is entirely possible—and not legally or ethically troubling—for parents to act in a way they believe is in the best interests of both their child *and* their family. If a doctor disagrees and concludes that the parents' decision is not in the child's best interest, her recourse in a post-viability pregnancy unprotected by *Casey* would be to involve the state.<sup>417</sup> At that point, the question for the court would be not what is subjectively motivating the parents' decision, but whether objectively the state has met its burden in proving that the parental decision is against the child's best interests.<sup>418</sup>

If expectant parents are presumed to be acting in their potential child's best interest, it would be difficult for the state to prove that those parents are acting against the potential child's best interests when they terminate a pregnancy because of a Category I or II diagnosis. This is for the same reasons that courts defer to parental choice to withhold treatment for living children facing the same diagnoses.<sup>419</sup> As a result, the right to withdraw life-sustaining treatment after a Category I or II diagnosis through abortion should be extended to expectant parents. The opposite result allows the state to force a woman to carry a pregnancy to term, to watch the potential child grow inside her for months, to endure all the risks of pregnancy and birth, only to suffer the child's death either during pregnancy or shortly after birth.<sup>420</sup> Because of this reality, the majority of parents choose to terminate after receiving a Category I and II diagnoses.<sup>421</sup> Thus, we know

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416. Field, *supra* note 166, at 95 (noting that, after birth, parents are influenced by personal motives when deciding whether to withdraw or withhold life-sustaining treatment).

417. Cf. *Parental Treatment Refusals*, *supra* note 133 (discussing a doctor's duty to "report suspected child neglect due to treatment refusal to state authorities" in the context of a disagreement with parents over a child's best interest).

418. See *supra* Part II.

419. See *supra* Part II.C.

420. Claire Cullen-Delsol, *I Was Forced to Carry an Unviable Pregnancy to Term. This Is My Diary*, VICE (May 18, 2018), [https://www.vice.com/en\\_us/article/3kjgzb/ireland-abortion-fatal-fetal-abnormality](https://www.vice.com/en_us/article/3kjgzb/ireland-abortion-fatal-fetal-abnormality) [<https://perma.cc/49PW-XYHK>] ("I'm so angry. I'm only 22 weeks pregnant. I'm going to have to stay pregnant for at least another 15 or 16 weeks. I'm going to have to deliver and then lose my child. In the meantime I'm going to have to go to work, drop the kids off at school, and deal with all the attention pregnant women get. 'When are you due?' people will ask me. I can't cope with that.").

421. See *supra* Part I.

empirically that there is “no societal consensus about the ‘rightness’ of always deciding for ‘life’” in this context.<sup>422</sup>

Though this Article excludes Category III diagnoses from the post-viability abortion right, I sincerely hope this Article is not read to judge women who choose to terminate in this situation. They too often abort out of love for their child and fear that they may not have the resources to ensure the child’s health and happiness. But the decision to exclude this category is grounded in the law from which the right derives—parental decision making for infants and children. For living children, it is clear that life-sustaining treatment cannot be denied simply on the basis of a Category III diagnosis.<sup>423</sup> Moreover, by clarifying that the right centers around life-threatening diagnoses, it mitigates concerns that a potential child’s disability alone provides a sufficient reason for termination.<sup>424</sup> These women remain protected under *Casey* for terminations before viability,<sup>425</sup> and Trisomy 21 is one of the conditions most commonly diagnosed before any state’s abortion bans take effect.<sup>426</sup>

## 2. Same Action

One could argue that abortion is fundamentally different from the withdrawal of life-sustaining treatment. But the reality is that the

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422. Cf. Goldstein, *supra* note 130, at 654 (disclaiming such consensus in cases concerning minor children).

423. See Mercurio, *supra* note 65, at 852 (“[I]f a parent of a child with Trisomy 21 [a Category III condition] were to refuse [life-sustaining treatment], a court order would be sought and almost certainly obtained.”).

424. See, e.g., Brief of Amici Curiae Fondation Jerome Lejeune, Saving Down Syndrome, and Down Pride in Support of Petitioners at 15, *Box v. Planned Parenthood of Ind. & Ky., Inc.*, 139 S. Ct. 1780 (2019) No. 18-483 (“Targeting a class of human beings for death simply because they have been discovered to have Down syndrome or another immutable characteristic before birth or after birth goes against all that civilized society should stand for.”).

425. See, e.g., Little Rock Fam. Plan. Servs. v. Rutledge, 398 F. Supp. 3d 330, 384 (E.D. Ark. 2019) (“[T]he State may not prohibit a woman from exercising that right [to pre-viability termination] solely upon the basis on which a woman makes her decision.”).

426. Compare Cara T. Mai, Jennifer L. Isenburg, Mark A. Canfield, Robert E. Meyer, Adolfo Correa, Clinton J. Alverson, Philip J. Lupo, Tiffany Riehle-Colarusso, Sook Ja Cho, Deepa Aggarwal & Russell S. Kirby, *National Population-Based Estimates for Major Birth Defects, 2010–2014*, 111 BIRTH DEFECTS RSCH. 1420, 1424–26 tbl.3 (2019) (providing statistics showing Trisomy 21 as one of the most common birth defects in the United States), and *Down Syndrome*, MARCH DIMES, <https://www.marchofdimes.org/complications/down-syndrome.aspx> [<https://perma.cc/R3RU-KRVU>] (detailing Trisomy 21 screening procedures by gestational age), with *State Bans on Abortion Throughout Pregnancy*, *supra* note 20 (listing gestational-age thresholds for state abortion bans).

procedures are quite the same. A fetus is only surviving through the hydration, nutrition, and oxygenation of the mother as supplied by the umbilical cord and placenta.<sup>427</sup> The umbilical cord therefore acts as a feeding tube and ventilator to the potential child. In fact, many dilation and evacuation abortion procedures (D&E) start with the physician cutting the umbilical cord or removing the placenta to allow the fetus to die in the womb before the fetus's body is removed.<sup>428</sup> Fetal demise typically occurs within a few minutes after the cord is cut.<sup>429</sup> Such abortions should therefore be treated as analogous to the removal of a ventilator for a child who cannot breathe on her own. Sometimes abortion occurs through labor and delivery—this can be because the pregnancy is too far along for a D&E to be done safely, the parents want a fetal autopsy, or the parents hope to meet their child.<sup>430</sup> For labor and delivery abortions, if the baby survives birth, he or she will typically die shortly after the umbilical cord is severed if care is not administered.<sup>431</sup> Thus, abortions using either D&E or labor and delivery can act as a withdrawal of life-support.

Some abortion providers, however, cause fetal demise through an injection that stops the fetus's heart; others do not induce fetal demise prior to the procedure and the fetus typically dies during the D&E.<sup>432</sup> These situations present a more challenging case, as the provider is causing death not by withdrawing life-sustaining care, but by affirmatively inducing death. There is a clear distinction in the law between these two scenarios. Though the Supreme Court presumed in *Cruzan v. Missouri Department of Health* that competent persons enjoy a

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427. See Stephanie A. Schuette, Kara M. Brown, Danielle A. Cuthbert, Cynthia W. Coyle, Katherine L. Wisner, M. Camille Hoffman, Amy Yang, Jody D. Ciolino, Rebecca L. Newmark & Crystal T. Clark, *Perspectives from Patients and Healthcare Providers on the Practice of Maternal Placentophagy*, 23 J. ALT. & COMPLEMENTARY MED. 60, 60 (2017).

428. Kristina Tocce, Kara K. Leach, Jeanelle L. Sheeder, Kandice Nielson & Stephanie B. Teal, *Umbilical Cord Transection to Induce Fetal Demise Prior to Second-Trimester D&E Abortion*, 88 CONTRACEPTION 712, 713 (2013).

429. *Id.* at 714 (concluding that fetal death occurred an average of 3.35 minutes, plus or minus 2.11 minutes, after umbilical transection).

430. See Obos Abortion Contributors, *Dilation and Evacuation Abortion, OUR BODIES OURSELVES* (Apr. 2, 2014), <https://www.ourbodiesourselves.org/book-excerpts/health-article/dilation-and-evacuation-abortion> [https://perma.cc/PVZ3-7SY3]; *Second Trimester Abortion*, *supra* note 328.

431. See *Fact Checking Rhetoric on Infants Surviving Abortions: Babies Are Rarely Born Alive and When They Are Doctors Don't Kill Them*, KAISER HEALTH NEWS (Feb. 27, 2019), <https://khn.org/morning-breakout/fact-checking-rhetoric-on-infants-surviving-abortions-babies-are-rarely-born-alive-and-when-they-are-doctors-dont-kill-them> [https://perma.cc/QP2V-VE3F].

432. Tocce et al., *supra* note 428, at 712–13 (discussing D&E abortions both with and without fetal injection to induce demise).

"constitutionally protected right to refuse lifesaving hydration and nutrition" and other life-sustaining treatment,<sup>433</sup> the Court later held in *Washington v. Glucksberg* that competent persons do not enjoy a constitutionally protected right to physician-assisted suicide.<sup>434</sup> The Court explained the right to refuse or withdraw life-sustaining treatment is grounded in the longstanding right to bodily autonomy—historically, forced medical care was treated as a battery.<sup>435</sup> By contrast, affirmatively causing death through suicide was traditionally condemned.<sup>436</sup> The Court determined that "the two acts are widely and reasonably regarded as quite distinct."<sup>437</sup> Though bioethicists have long debated whether there is any ethically relevant difference between killing versus letting die,<sup>438</sup> physicians tend to adhere to this distinction in practice.<sup>439</sup>

This distinction would seem to suggest that even if parents are constitutionally entitled to withdraw life-support from their child (absent a finding that doing so is against their child's best interest), parents do not have a constitutional right to demand that a doctor affirmatively hasten the child's death. Thus, in the context of abortion, even if parents can consent to an abortion where the umbilical cord is cut, effectively withdrawing life-sustaining treatment, they may not be able to consent to an abortion where fetal demise is caused by an injection.

This dilemma is at least theoretically easy to avoid, however. For D&E abortions, physicians can commence the procedure by cutting the umbilical cord instead of stopping the fetus's heart.<sup>440</sup> In fact, many doctors think this is a preferable clinical approach to fetal injection—it eliminates an unnecessary step that delays the abortion, adds expense, and creates additional maternal pain.<sup>441</sup> The answer is a little more complicated starting in the third trimester when a D&E abortion

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433. *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261, 278–79 (1990).

434. *Washington v. Glucksberg*, 521 U.S. 702, 735 (1997).

435. *Id.* at 725.

436. *Id.* at 728–30 ("The history of the law's treatment of assisted suicide in this country has been and continues to be one of the rejection of nearly all efforts to permit it.").

437. *Id.* at 725.

438. See, e.g., H.V. McLachlan, *The Ethics of Killing and Letting Die: Active and Passive Euthanasia*, 34 J. MED. ETHICS 636 (2008).

439. See Mercurio, *supra* note 65, at 862.

440. Tocce et al., *supra* note 428.

441. But see *id.* at 712–13 (noting that it may be challenging for doctors to learn a new technique, and requiring them to change procedures could make abortion riskier, at least in the short term).

may be less safe than induction abortion.<sup>442</sup> Third trimester labor and delivery abortions often rely on the fetal injection shot described above so that doctors do not have an ethical duty to treat the baby if he or she is born alive.<sup>443</sup> Though this is a very important step in third-trimester abortions of healthy babies—for whom doctors *would* have an ethical duty to treat<sup>444</sup>—it is unnecessary for abortions based on severe fetal anomaly. As explained above, parents have the constitutional right to decide whether or not to withhold care for a newborn with a Category I or II diagnosis.<sup>445</sup> Thus, there is no need to end the fetus's life before birth because, if the baby survives labor and delivery, the parents can simply withhold all non-palliative care.<sup>446</sup> This solution, however, does depend on doctors properly following the standard of care, which is not always guaranteed, especially in certain parts of the country.<sup>447</sup>

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442. See Janet E. Gans Epner, Harry S. Jonas & Daniel L. Seckinger, *Late-Term Abortion*, 280 JAMA 724, 727 tbl.4 (1998) (showing higher abortion-related mortality rates for D&E procedures than labor inductions at more than 20 weeks gestation, a reverse of the trend at 20 weeks and below).

443. See Frank A. Chervenak & Laurence B. McCullough, *An Ethically Justified Practical Approach to Offering, Recommending, Performing, and Referring for Induced Abortion and Feticide*, 201 AM. J. OBSTETRICS & GYNECOLOGY 560.e1, 560.e4–e5 (2009) (“[E]xPELLING the near-viable fetus or a viable fetus with a severe anomaly from the uterus could result in a live birth and . . . feticide can prevent this outcome.”); Michael F. Greene & Jeffrey L. Ecker, *Abortion, Health, and the Law*, 350 NEW ENG. J. MED. 184, 185 (2004) (describing how physician liability under the Partial-Birth Abortion Ban Act of 2003 “could be obviated by performing a . . . fetal injection . . . that will reliably cause the death of the fetus in utero before the start of the dilation and evacuation”).

444. See Chervenak & McCullough, *supra* note 443, at 560.e2 (“Beneficence-based obligations to the fetus exist when the fetus . . . is presented to the physician and when it is of sufficient maturity that, given the availability of biotechnological support, it can survive into the neonatal period and later achieve moral status . . . ”).

445. See *supra* Part II.C.

446. See *supra* Part II.C.

447. It is worth noting that ideologically motivated doctors do not always follow the standard of care. See Jeffrey Blustein & Alan R. Fleischman, *The Pro-Life Maternal-Fetal Medicine Physician: A Problem of Integrity*, 25 HASTINGS CTR. REP. 22, 23–24 (1995) (“[W]e cannot plausibly maintain that pro-life maternal-fetal physicians’ antiabortion views will have no influence whatsoever on the care they actually provide their patient.”). Even though parents are entitled to withhold treatment for newborns with Category I or II diagnoses, some doctors may resuscitate a critically ill infant without the parents’ consent after an induction abortion. In that situation, parents can sue under tort but may not be met with a sympathetic ear in the courts. In one case, for instance, parents sued a hospital after their extremely premature baby was resuscitated against their wishes. *HCA, Inc. v. Miller ex rel. Miller*, 36 S.W.3d 187, 190 (Tex. App. 2000), aff’d, 118 S.W.3d 758 (Tex. 2003). The child survived, but with “severe physical and mental impairments and will never be able to care for herself.” *Id.* On appeal, the Texas Supreme Court affirmed the dismissal of the parents’ claim on grounds that the

It is also worth noting that the country as a whole is moving towards a recognition of the right to physician aid in dying.<sup>448</sup> Nine states and Washington D.C. now permit physician-assisted suicide for terminally-ill individuals.<sup>449</sup> While the analogy is not perfect,<sup>450</sup> where physician-assisted suicide is legal, it may also be possible for physicians to affirmatively induce fetal demise assuming the potential child met the conditions under the statute.

Taking all of this together, abortions based on severe fetal anomaly (Category I and II diagnoses) can be performed in a way that fetal demise is caused by simply removing the fetus's life support. In these instances, abortion is just like other parental decisions to withdraw life-sustaining medical treatment for their critically ill infant or child. The right would simply extend existing parental rights to before birth.

### 3. Any Differences Support Stronger Parental Rights for Expectant Mothers

Though the end-of-life decision-making for children and potential children are similar in the most legally relevant ways, there are two differences between parents and expectant parents. The first is that parents are making decisions for a child, while expectant parents are making decisions for potential child. The second is that expectant mothers are not only parents to the potential child, but also keeping the child alive through a sacrifice to their bodily autonomy. Both differences suggest that expectant parents, especially expectant mothers, should have stronger parental autonomy rights than parents of living children.

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hospital was allowed to save the child's life immediately after birth for the purpose of evaluating whether or not refusing treatment was in the best interests of the child. *Miller*, 118 S.W.3d at 768–69.

448. *Death with Dignity Acts*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/learn/death-with-dignity-acts> [<https://perma.cc/AS5E-Q7FV>].

449. *Id.*

450. This analogy has two primary weaknesses: First, the states that have legalized physician-assisted suicide only permit the doctor to prescribe life-ending drugs (known generally as physician-assisted suicide) but not to administer life-ending drugs (known generally as euthanasia). *How Death with Dignity Laws Work*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/learn/access/#Eligibility> [<https://perma.cc/L56W-F48W>]. Unless doctors could concoct a way for the parents to administer the drug themselves—for instance, to press down on the syringe containing the drug after the doctor has properly placed it in the fetus—these laws would not allow the doctor to administer the drug herself. Second, these state laws also apply only to terminally ill individuals. *Id.* Only fetuses with Category I diagnoses would likely qualify.

*a. Potential Children Lack Personhood*

One of the strongest differences between end-of-life decisions in pregnancy and those made for children after birth is that potential children are not people.<sup>451</sup> *Roe* made clear that fetuses are not persons under the Constitution,<sup>452</sup> and that a state's interest in regulating abortion rests in its interest in protecting "potential life," not life.<sup>453</sup> After all, not all pregnancies end in a live birth: at least 10-20 percent of known pregnancies end in miscarriage<sup>454</sup> and less than 1 percent end in stillbirth.<sup>455</sup> These numbers are much higher when a fetus has health conditions.<sup>456</sup> Until birth, the fetus's rights are based on its potential for life.

Some may worry that the argument advanced in this Article creates a slippery slope to personhood, thereby harming abortion rights in the long run. By using a standard developed for children in the context of fetuses, there is a concern that the fetus would be problematically equated with a person. Abortion rights advocates "consciously avoid the parent/child framing for political and strategic reasons. These boundaries are black and white; the 'third rail' of advocacy."<sup>457</sup> I do not take this concern lightly as I vigorously reject attempts to give fetuses personhood status under the law. Nevertheless, I am not convinced that acknowledging parental autonomy in prenatal end-of-life decision-making would lead to personhood.

First and foremost, the right is not based on when the fetus becomes a person, but when a person becomes a parent. The legal hook of this argument resides in the liberty interest parents enjoy "in the care, custody, and management of their child."<sup>458</sup> A fetus does not need to be a person for parents to have presumptive control over their potential child's medical decisions. In fact, the early cases that created

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451. See *Roe v. Wade*, 410 U.S. 113, 150–58 (1973).

452. *Id.* at 158.

453. *Id.* at 150.

454. *Miscarriage*, MAYO CLINIC, <https://www.mayoclinic.org/diseases-conditions/pregnancy-loss-miscarriage/symptoms-causes/syc-20354298> [https://perma.cc/8TRS-EQV8] (last updated July 16, 2019).

455. *Stillbirth*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/ncbddd/stillbirth/facts.html> [https://perma.cc/B9NY-S5SU] (last reviewed Aug. 13, 2020).

456. See *supra* Part I.

457. Jamie R. Abrams, *The Polarization of Reproductive and Parental Decision-Making*, 44 FLA. ST. U. L. REV. 1281, 1319–20 (2017).

458. *Santosky v. Kramer*, 455 U.S. 745, 753 (1982); see also *Troxel v. Granville*, 530 U.S. 57, 66 (2000) (citing to numerous cases recognizing parental autonomy in child-rearing).

parental autonomy rights imagined children not as people, but as the property of their parents.<sup>459</sup> Of course, children are no longer seen as property,<sup>460</sup> but the origins of the right prove that parenthood does not require personhood.

There is one area of the law that recognizes this exact distinction between the rights of personhood and parenthood: wrongful death of a potential child.<sup>461</sup> Those wrongful death cases permit recovery based solely on the significance of the *parent's* loss, independent of the status of the fetus. Jill Wieber Lens, one of the leading scholars on still-birth, notes:

A wrongful death claim . . . does not create any legal right for the baby. . . . It is the parents' claim and it awards the parents damages for the lost affectional tie, the loss of their relationship with their baby. "The parent's loss does not depend on the legal status of the child; indeed the absence of the child is the crux of the suit."<sup>462</sup>

There is even text in *Roe* supporting this distinction.<sup>463</sup> In discussing wrongful death suits to remedy prenatal injuries, the Court dismissed the possibility that these laws created personhood status for fetuses, noting that the wrongful death laws "vindicate the *parents'* interest and is thus consistent with the view that the fetus, at most, represents only the potentiality of life."<sup>464</sup> This area of the law provides additional precedent for severing the connection between personhood and parenthood.<sup>465</sup>

There has also been a growing consensus that parenthood begins during pregnancy. First, expectant parents often see themselves as parents to their potential child; this is especially true after late pregnancy loss, where expectant parents strongly identify as parents to their deceased child.<sup>466</sup> Denying the relationship that many expectant parents develop with their potential child over the course of pregnancy "is neither persuasive nor credible."<sup>467</sup> Second, legal scholars

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459. Barbara Bennett Woodhouse, "*Who Owns the Child?*": Meyer and Pierce and the Child as Property, 33 WM. & MARY L. REV. 995, 1112–16 (1992).

460. See Justin Witkins, *A Time for Change: Reevaluating the Constitutional Status of Minors*, 47 FLA. L. REV. 113, 115–25 (1995) (describing the evolution of child rights).

461. See Wieber Lens, *supra* note 36, at 1009–10.

462. *Id.* (quoting Dunn v. Rose Way Inc., 333 N.W.2d 830, 833 (Iowa 1983)).

463. See *Roe v. Wade*, 410 U.S. 113, 162 (1973).

464. *Id.* (emphasis added).

465. See *id.*

466. Jill Wieber Lens, *Miscarriage, Stillbirth, & Reproductive Justice*, WASH. U. L. REV. (forthcoming) (manuscript at 40–41), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3549430](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3549430) (discussing the emotional connection parents form while pregnant and how that bond continues after a stillbirth).

467. Wieber Lens, *supra* note 36, at 1012.

have recently highlighted the parenting labor that occurs during pregnancy—in particular, the disparate burdens that fall on women.<sup>468</sup> These scholars note that expectant parents are making parenting choices when they, for instance, choose and assemble the crib, car seat, and other essentials, select a pediatrician, add their child to day-care waitlists, or take parenting and birthing classes.<sup>469</sup> Pregnant women, in particular, make daily sacrifices to protect their potential child—like avoiding drugs and alcohol, potentially harmful foods, and certain activities—which are all parenting choices.<sup>470</sup> And after stillbirth, which is defined as prenatal death occurring after 20 weeks,<sup>471</sup> parents are entitled to a birth or death certificate (depending on the jurisdiction) and are responsible for the final disposition of the body, just as parents are after a child dies.<sup>472</sup> Many states describe the parents of a stillborn baby as “parents” even though the fetus never took a breath and was therefore never a person under the Constitution.<sup>473</sup> In other words, the lived reality is that parenthood begins before birth, even though birth marks the moment when the potential child becomes a person under the Constitution.

Thus, the doctrinal hook of this argument, which is based on the rights that *parenthood* bestows, should not create a slippery slope to personhood, which is based on the rights the Constitution bestows at birth.<sup>474</sup> And given the myriad of practical consequences that would result from defining personhood at conception under the law—including the possibility that certain kinds of popular contraception and infertility treatments could be banned—attempts to bestow full personhood at conception have been largely, although not entirely, ineffective, even in the south.<sup>475</sup>

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468. David Fontana & Naomi Schoenbaum, *Unsexing Pregnancy*, 119 COLUM. L. REV. 309, 326–32 (2019) (describing various types of care work that occur during pregnancy).

469. *Id.*

470. *Id.*

471. *Stillbirth*, *supra* note 455.

472. Wieber Lens, *supra* note 466 (manuscript at 42–43, 47–48).

473. *Id.* (manuscript at 42–43).

474. See, e.g., *Amadio v. Levin*, 501 A.2d 1085, 1098 (1985) (Zappala, J., concurring) (“According to Pollock and Gray as referenced in Black’s Law Dictionary, in the development of the law a ‘natural person’ is not simply a human being, but a human being to whom rights and duties are ascribed. ‘Personhood’ as a legal concept arises not from the humanity of the subject but from the ascription of rights and duties to the subject.”).

475. Maya Manian, *Lessons from Personhood’s Defeat: Abortion Restrictions and Side Effects on Women’s Health*, 74 OHIO ST. L.J. 75, 99–100 (2013) (summarizing the many “unintended consequences” of personhood laws on women’s health broadly and

In my view, the reproductive rights movement loses credibility and legitimacy by ignoring the value that many women, including pro-choice women, attribute to a wanted pregnancy. For instance, the reproductive rights community has “maintained a studied silence on the topic” of miscarriage and stillbirth to avoid “acknowledg[ing] there was something of value lost” when the pregnancy ended because that value could be equated with personhood.<sup>476</sup> “The reproductive rights movement has thus lost an opportunity to support women by ‘surrender[ing] the discourse of pregnancy loss to antichoice activists.’”<sup>477</sup> This denial of fetal value creates a disconnect for many women, even those who have not personally experienced fetal loss. The reality is that women carrying wanted pregnancies—no matter how strongly they support abortion rights—frequently call their fetus a baby, become attached to that “baby” at some point during pregnancy, and care deeply about that “baby’s” health and safety.<sup>478</sup> Professor Carol Sanger suggests that “[t]his is not inconsistency but rather an awareness of context”—in particular, the contextual difference between wanted and unwanted pregnancies.<sup>479</sup> Perhaps it is time for abortion

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the documented failure of such laws to gain traction in southern states even where anti-abortion laws are prevalent). Personhood would also create absurd legal consequences completely unrelated to reproductive rights. See Carliss N. Chatman, *If a Fetus Is a Person, It Should Get Child Support, Due Process, and Citizenship*, 76 WASH. & LEE L. REV. 91 (2020).

476. Wieber Lens, *supra* note 36, at 1007–08 (quoting Linda L. Layne, *Breaking the Silence: An Agenda for a Feminist Discourse of Pregnancy Loss*, 23 FEMINIST STUD. 289, 294, 305 (1997)).

477. Wieber Lens, *supra* note 466 (manuscript at 19) (quoting LINDA L. LAYNE, MOTHERHOOD LOST: A FEMINIST ACCOUNT OF PREGNANCY LOSS IN AMERICA 239 (2003)).

478. Carol Sanger, “*The Birth of Death*: Stillborn Birth Certificates and the Problem for Law”, 100 CALIF. L. REV. 269, 283 (2012) (“Within months of conception the fetus not only has a sex, a name, and a face, but he or she now owns things, has prenatal preferences (organic food, Mozart, a smoke-free environment), its own page on Facebook, and a registry at Bloomingdales. In short, social birth—the identification and incorporation of a child into its family during pregnancy—commonly precedes biological birth.”).

479. CAROL SANGER, ABOUT ABORTION: TERMINATING PREGNANCY IN TWENTY-FIRST-CENTURY AMERICA 104 (2017); *see also id.* at 103–04 (explaining that “pro-choice women may scoff at ‘I’m a Child, Not a Choice’ placards and at the same time feel excitement looking at the scan of an expected grandchild”).

480. Sanger, *supra* note 478, at 311 (“The statement importantly qualifies the term ‘pregnancy’ by distinguishing between wanted and unwanted pregnancies and respecting mothers’ desires with regard to both. Perhaps it is enough to throw down a marker (this Essay) noting this difference as meaningful for the application of law and hoping for some deeper consideration in consequence.”); Wieber Lens, *supra* note 466 (manuscript at 41–42 n.308) (explaining that another contextual factor might be length of the pregnancy).

activists to confront this dilemma more honestly, instead of avoiding it and implicitly denying the important value many women attribute to their wanted pregnancies.<sup>481</sup> I say this not to minimize the reality that anti-choice legislatures are codifying fetal value with the intent of undermining abortion law,<sup>482</sup> but to suggest that there may be a way forward that does not require an absolutism that feels hollow to many women. The law can both recognize the value of an expectant parent's emotional tie to their potential child, without creating fetal personhood.<sup>483</sup>

Finally, from a practical perspective, this paper should not create a slippery slope to personhood because the right would only be triggered after a state's post-“viability” ban takes effect. As noted above, this right would sit on top of pre-existing abortion rights, such as the right to a pre-viability abortion under *Casey*.<sup>484</sup> Before viability, *Casey* will protect women who seek abortion for any reason, including on the basis of fetal anomaly (albeit with large leeway to the states to burden this choice).<sup>485</sup> After viability, on the other hand, the Supreme Court has already found that the state's interest in protecting potential life can outweigh the mother's interests in terminating the pregnancy.<sup>486</sup> Fundamentally, my argument is simply that *even assuming*

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481. Though it is outside the scope of this Article, I will note that abortion rights are not inconsistent with recognizing some moral value of fetuses, short of constitutional personhood. I hope to write further on this topic.

482. Sanger, *supra* note 478, at 305–08 (noting in the context of these state laws that “[l]egal status is a common—indeed an important—mechanism for the distribution of value and goods in a society, and over time more substantive benefits may attach to that status”).

483. I must note the much more difficult problem associated with states using child abuse and neglect laws to prosecute women who expose their fetuses to risks while pregnant, for instance, by using illegal drugs. See MICHELE GOODWIN, POLICING THE WOMB: INVISIBLE WOMEN AND THE CRIMINALIZATION OF MOTHERHOOD 31, 36 (2020). These actions are often based on an interpretation of the word “child” to include fetal children. *Id.* As with any criminalization, poor women and women of color are disturbingly prosecuted at much higher rates, raising questions about which female bodies the state seeks to control. *Id.* at 21. I am much more worried about my argument being co-opted towards this effort, which harms both women and their children. *Id.* at 42–44. Although, the effort appears to be succeeding throughout the South and Midwest on its own. *Id.* at 30–32. To the extent states are already using this parent-child relationship against women, it is worth exploring how the same argument can be used to promote women's rights.

484. Planned Parenthood of Se. Pa. v. *Casey*, 505 U.S. 833, 846 (1992).

485. *See id.*

486. *See Roe v. Wade*, 410 U.S. 113, 163 (1973); *Casey*, 505 U.S. at 870 (“Viability . . . is the time at which . . . the independent existence of the second life can in reason and all fairness be the object of state protection that now overrides the rights of the woman.”).

viability marks a pivotal moment in the moral worth of the fetus such that abortion can be banned, the state cannot prohibit abortion when it is reasonably in the potential child's best interest. Otherwise, the state would have greater authority to protect potential children (who are not persons) than living children with full constitutional rights. This is anomalous. As explained above, the state's interest in protecting potential children must be weaker than its interest in protecting living children.

*b. Expectant Mothers' Bodily Autonomy Is Also Affected*

The other main difference between parents and expectant parents is that expectant mothers are integrally connected to their potential children. The pregnant woman is giving the potential child life-support through a sacrifice of her own bodily autonomy and health. Thus, any decision that affects a potential child also impacts the bodily autonomy of the expectant mother. Preventing a pregnant woman from terminating in this context not only forces both expectant parents to delay decisions they are entitled to make, but also forces the expectant mother, specifically, to endure the additional trauma of watching her belly grow larger, of experiencing the discomfort and risks of pregnancy for months against her will, of confronting the loss publicly every time a stranger asks about the pregnancy, and ultimately, the physical trauma of birthing a full-term baby that may never survive.<sup>487</sup>

It is because the pregnant woman's bodily autonomy is on the line that her decision must govern when the parents disagree on whether to terminate the pregnancy. Though both parents equally enjoy parental autonomy rights over their potential child, the pregnant woman also has the right to bodily autonomy that will serve as a tie-breaker.<sup>488</sup> The rights are therefore layered: both parents have the right to make end-of-life decisions for their child, but because the woman is sustaining the potential child's life with her own body, she must be the ultimate decisionmaker. *Casey* highlighted this point when it said:

It is an inescapable biological fact that state regulation with respect to the child a woman is carrying will have a far greater impact on the mother's liberty than on the father's. The effect of state regulation on a woman's protected liberty is doubly deserving of scrutiny in such a case, as the State has touched not only upon the private sphere of the family but upon the very bodily integrity of the pregnant woman. The Court has held that "when the wife and the husband disagree on this decision, the view of only one of the

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487. Cullen-Delsol, *supra* note 420.

488. Field, *supra* note 166, at 94.

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two marriage partners can prevail. Inasmuch as it is the woman who physically bears the child and who is the more directly and immediately affected by the pregnancy, as between the two, the balance weighs in her favor.”<sup>489</sup>

Again, this difference between end-of-life decision-making for parents and expectant parents supports even stronger parental rights for expectant mothers given that the mother’s bodily autonomy is also at stake. Combined with the differences between children and potential children, it is clear that the expectant mother’s rights are greater than general parental rights when making end-of-life choices for a potential child, while the state’s interests are weaker. As a result, expectant parents who terminate on the basis of a Category I or II diagnosis should be protected *at least* to the same extent as the parents of living children who chose to withhold or withdraw life-sustaining treatment in the same circumstances.

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In all most relevant ways, the decision to terminate a pregnancy based on a Category I or II diagnosis is the same as the decision to withdraw life-sustaining treatment after a Category I or II diagnosis. Both involve parents acting in the best interest of the child and both involve the withdrawal of life support. Any differences between parents and expectant parents support more expansive rights for expectant parents, especially expectant mothers. Therefore, the parental autonomy rights of expectant parents should be protected at least to the same degree as they are protected for parents by ensuring that women have access to abortion on the basis of severe fetal anomaly at any point in the pregnancy.

#### D. MOVING THE ABORTION DISCUSSION FORWARD

Though abortion for fetal anomaly is a small subset of abortions generally, it is nevertheless worthy of attention. First and foremost, even though the numbers are small, there are real women suffering from the current state of the law—women who are either forced to carry pregnancies to term knowing their child will never leave the hospital,<sup>490</sup> or women who in the midst of a great trauma must travel at significant expense to obtain an abortion.<sup>491</sup> Second, the anti-abortion movement has spent decades chipping away slowly at abortion

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489. *Casey*, 505 U.S. at 896 (citations omitted) (quoting Planned Parenthood of Cent. Mo. v. Danforth, 428 U.S. at 71).

490. Cullen-Delsol, *supra* note 420.

491. See, e.g., COHEN & JOFFE, *supra* note 25 (illustrating one woman’s barrier to care due to inability to travel out of state).

rights.<sup>492</sup> This Article turns that strategy on its head and lays out the possibility of adding in a new abortion right at the moment when the movement is on perpetual defense. It also flips the script and shows women who obtain abortion as caring and loving mothers, instead of the selfish actors wrongly described by anti-choice community. Finally, the topics raised in this Article offer unique ways to move the abortion discussion forward, both in how the abortion rights movement interacts with the disability community and how abortion may be defended as a parenting choice.

Abortions based on fetal anomaly were historically central to the early fight for abortion rights.<sup>493</sup> Starting in the eighties with the Baby Doe controversy, however, the narrative around abortion and disability began to change.<sup>494</sup> The disability rights movement was in full swing—only years away from the passage of the Americans with Disabilities Act.<sup>495</sup> The anti-choice community saw potential to suppress abortion rights by capitalizing on this important movement.<sup>496</sup> It wanted to shape its image as a defender of civil rights, and disability rights became a convenient and natural avenue to do so.<sup>497</sup> As a result, these anti-choice activists started to “present[] pro-choice organizations as heartless and indifferent to the struggles of weak, vulnerable, and handicapped persons.”<sup>498</sup> The anti-choice community lobbied intensely for the Child Abuse Amendments of 1984 (CAA) and participated in the litigation surrounding Baby Jane Doe and the regulatory efforts that preceded the CAA.<sup>499</sup>

Tensions between the reproductive rights and disability rights communities were again strained when the federal government

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492. Lois Uttley, *Medicine and Morality: The Threat to Reproductive Justice*, REPRODUCTIVE JUSTICE BRIEFING BOOK: A PRIMER ON REPRODUCTIVE JUSTICE AND SOCIAL CHANGE 37–38, <https://www.law.berkeley.edu/php-programs/courses/fileDL.php?fID=4051> [<https://perma.cc/GEA2-32Z4>] (describing obstacles women face when obtaining legal reproductive health services due to restrictive anti-abortion laws).

493. Ziegler, *supra* note 326, 604–05.

494. *Id.* at 603–05.

495. *See id.*

496. *Id.*

497. *Id.*

498. *Id.* at 603.

499. *See* Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 HARV. J.L. & GENDER 425, 431 (2006); Lawrence D. Brown, *Civil Rights and Regulatory Wrongs: The Reagan Administration and the Medical Treatment of Handicapped Infants*, 11 J. HEALTH POL. POL'Y & L. 231, 233–35 (1986); C. Everett Koop, *Life and Death and the Handicapped Newborn*, 5 ISSUES L. & MED. 101, 101 (1989); Constance Paige & Elisa B. Karnofsky, *The Antabiortion Movement and Baby Jane Doe*, 11 J. HEALTH POL. POL'Y & L. 255, 258, 263–64 (1986).

banned a particular type of abortion procedure (D&X), dubbed by conservatives as a partial birth abortion.<sup>500</sup> Pro-choice activists defended D&X by arguing that the procedure was often the safest technique for women terminating on the basis of fetal anomaly.<sup>501</sup> The frequent defense of abortion by reference to fetal anomaly frustrated the disability community, who “questioned the ease with which many turned to abortion in fetal-defect cases.”<sup>502</sup> And many disability rights activists felt that leaders in the reproductive rights movement “did not leave room for solutions that acknowledged the moral ambiguity of disability-based abortion.”<sup>503</sup> Some courts have similarly expressed discomfort with any effort that could diminish the value of disabled fetuses.<sup>504</sup>

This Article’s reconceptualization of abortion based on fetal anomaly as a parental autonomy right is vital to repositioning the pro-choice movement alongside the disability community in two ways. First, it excludes Category III diagnoses from the post-viability abortion right, making clear that even though women should be able to obtain a pre-viability abortion for any reason under *Casey*<sup>505</sup>—parental autonomy rights cannot justify abortion on the basis of disability alone after viability. This move fractures the unhelpfully broad term, “disability-selective abortion.” While an abortion on the basis of anencephaly could generally be categorized as a disability-selective abortion, it is categorically different from an abortion on the basis of a cleft palate. By lumping these unlike situations together and focusing on

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500. Ziegler, *supra* note 326, at 608.

501. *Id.*

502. *Id.*

503. *Id.* at 611.

504. Some courts have been unwilling to find in the context of the Hyde Amendment that the state has less of an interest in the potential life of a severely ill fetus than a healthy fetus. *Compare Britell v. United States*, 372 F.3d 1370, 1383 (Fed. Cir. 2004) (“For us to hold . . . that in some circumstances a birth defect or fetal abnormality is so severe as to remove the state’s interest in potential human life would require this court to engage in line-drawing of the most non-judicial and daunting nature. This we will not do.”), *and Doe v. United States*, 419 F.3d 1058, 1064 (9th Cir. 2005), *with Karlin v. Foust*, 188 F.3d 446, 489 n.16 (7th Cir. 1999) (“As we understand the term ‘lethal anomaly’ it means that the child will die at birth. Consequently, the [abortion regulation] . . . serves no legitimate state interest and makes little sense under the circumstances. . . . Thus, irrespective of our analysis below, we hold that the provision of such information [in the case of lethal anomaly] is not mandated under AB 441.”). However, this Article assumes that the state has the same interest in the potential life of all fetuses (regardless of any fetal anomaly) but argues that the state cannot intervene to prevent an abortion when it cannot meet its burden of demonstrating that the parents are acting contrary to the potential child’s best interest.

505. Donley, *supra* note 353, at 326–27.

the fetus's disability these abortions are painted as discriminatory. Excluding Category III diagnoses clarifies that this right is *not* about disability selection, but about end-of-life decision making in the context of life-threatening anomalies.

Second, the right as conceptualized in this Article deflects any debate about when a disability is so severe that life is not worth living. There is no objective answer to this question, and the abortion wars are not the appropriate venue for that conversation. Rather, if recognized, this abortion right would position the parents as the ultimate decision makers, trying to find the answer that most resonates with them for their child. Ironically, it is religious groups that most strongly champion parental autonomy rights, so there might be practical reasons that it would be difficult for them to object to this right.<sup>506</sup>

By changing the framing, the pro-choice community can avoid any claim that the right to abortion on the basis of severe fetal anomaly is the *only* compassionate choice—it's not—but that it is one of many reasonable choices that should be protected. This move will ensure that abortion rights advocates are not disparaging individuals with disabilities or the families that love them to promote reproductive rights. Mary Ziegler recently recognized that this discourse surrounding abortion and disability needs to change:

Conventional disability-based justifications for abortion fit poorly in the reproductive-justice framework. First, presenting disability as an obvious reason to pursue abortion creates tensions between the pro-choice movement and potential allies in the disability-rights movement.... By simply falling back on the assumption that disability-based abortions are justifiable, pro-choice activists miss an important opportunity.<sup>507</sup>

Moreover, strong parental autonomy rights can also complement disability rights. Mary Crossley has argued in the context of critically-ill newborns that failing to respect parental autonomy "diminishes respect for family integrity and thus may itself be risky from the disability perspective."<sup>508</sup> As long as the state can step in when parents act below some minimally acceptable threshold, Crossley suggests that "[f]amily support and advocacy can play an invaluable role in the flourishing of persons with disabilities, both individually and

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506. Jeffrey Shulman, *Who Owns the Soul of the Child?: An Essay on Religious Parenting Rights and the Enfranchisement of the Child*, 6 CHARLESTON L. REV. 385, 392 (2012) (noting that "religious parenting rights enjoy a special constitutional protection from state regulation" after decades of lawsuits from religious parents seeking control over their children).

507. Ziegler, *supra* note 326, at 625.

508. Crossley, *supra* note 134, at 1058.

collectively, and so parents should be empowered to play a lead in decision making throughout the process.”<sup>509</sup>

By refocusing the discussion on parental rights, the pro-choice community can emphasize the need to support parents in making either choice—i.e., expanding access to abortion while also supporting the needs of parents who continue the pregnancy to term.<sup>510</sup> One vital part of this goal is neutral counseling that presents the “most accurate and comprehensive information possible, including realistic perspectives from individuals with the disability in question” without pressuring any particular choice.<sup>511</sup> By guaranteeing the right to abortion at any point in the pregnancy where the baby has a Category I or II diagnosis, parents have more time to consider their options, meet with pediatric specialists, and join support groups to learn about the realities of continuing or ending the pregnancy. A woman deserves “access to abortion services in a timely manner if she decides to terminate her pregnancy, and the supports necessary to sustain her family if she decides to carry the pregnancy to term.”<sup>512</sup>

But perhaps the best way for the reproductive rights community to ensure that women are making a free choice to end their pregnancies is to support continued efforts of the disability-rights community to bring about systemic changes that improve the lives of those with disabilities.<sup>513</sup>

This approach shifts the discussion away from individual and private family decisions—something public policy shies away from—to a broader debate about the kinds of services, education, and supports families and individuals need to embrace disability as a part of the human experience—where positive public policy is sorely needed.<sup>514</sup>

By pushing for a society in which individuals living with disabilities are supported, we remove some of the obstacles and burdens that may encourage unsure parents to terminate a pregnancy after learning of an anomaly. “Parents . . . would have a more meaningful choice if they knew that the government would provide more meaningful financial support.”<sup>515</sup>

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509. *Id.*

510. Ziegler, *supra* note 326, at 627.

511. Sujatha Jesudason & Julia Epstein, *The Paradox of Disability in Abortion Debates: Bringing the Pro-Choice and Disability Rights Communities Together*, 84 CONTRACEPTION 541, 542 (2011); see also Crossley, *supra* note 134, at 1057.

512. Jesudason & Epstein, *supra* note 511.

513. Ziegler, *supra* note 326, at 628–30.

514. Jesudason & Epstein, *supra* note 511.

515. Ziegler, *supra* note 326, at 628.

This Article also fits nicely into recent attempts to view abortion as a parenting decision.<sup>516</sup> For example, Jamie Abrams criticizes the stereotypes that paint women as selfish decision makers when it comes to abortion decisions, but selfless decision makers when it comes to parenting decisions—i.e., by presuming that mothers are always acting in their child's best interests.<sup>517</sup> She notes that neither perception is perfectly accurate.<sup>518</sup> Rather, women make abortion *and* parenting decisions after considering the interests of themselves and their families.<sup>519</sup> For instance, most women who obtain abortions are already mothers and may choose termination because they think it is in the best interest of their living children.<sup>520</sup> Those abortion decisions are also parenting decisions based on the needs of a family as a whole. Abrams suggests that “crossing longstanding boundaries [between abortion and parenting] may be necessary to move the movement forward.”<sup>521</sup>

Abrams advocates for “[a] unified framing of reproductive and parenting decision-making....”<sup>522</sup> She argues this framing “would powerfully debunk troublesome and demonizing myths about *why* women terminate pregnancies.”<sup>523</sup> It would also “challenge[] the monopoly on morality that the pro-life movement currently holds.”<sup>524</sup> This was certainly one goal of this Article—to show women who have abortions as loving mothers, but abortion based on severe fetal anomaly is certainly not the only instance in which this is true. It is worth noting that this framing can backfire when it creates a hierarchy of abortion goodness or perpetuates stereotypes of what it means to be a “good” woman who has an abortion.<sup>525</sup> I have tried to avoid this trap by defending traditional abortion rights for all women, while also promoting the right to terminate on the basis of severe fetal anomaly as a supplement when those abortion rights expire. In other words, unlike previous attempts to discuss abortion on the basis of fetal anomaly, this Article does not “set[] women against one another in a

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516. Abrams, *supra* note 457, at 1309–10.

517. *Id.* at 1289.

518. *Id.* at 1289–98.

519. *Id.*

520. *Id.* at 1302–03.

521. *Id.* at 1319.

522. *Id.* at 1327.

523. *Id.* at 1329.

524. *Id.*

525. SANGER, *supra* note 479, at 226.

competition . . ." as if "... abortion is a limited commodity."<sup>526</sup> Like Abrams, I think it is helpful to showcase the breadth of women's reproductive decisions.

The reproductive justice movement provides precedent for combining parental autonomy and reproductive rights into one framework. Reproductive justice advocates push for reproductive freedom as a whole, beyond abortion care, including "(1) the right to have a child; (2) the right not to have a child; and (3) the right to parent the children we have, as well as to control our birthing options, such as midwifery."<sup>527</sup> The reproductive justice paradigm was an intersectional response, led by women of color, to the reproductive rights movement's narrow focus on abortion access, which had ignored the needs of marginalized women.<sup>528</sup> Its commitment to parental autonomy was based on the terrible reality that women from marginalized communities are frequently prevented from having children they want, giving birth in the manner they prefer, and raising their children without intervention from the state.<sup>529</sup> The right to abortion on the basis of severe fetal anomaly fits nicely at the intersection of the right to parent and the right not to have a child, as it promotes both equally.<sup>530</sup>

This Article takes a step toward a more unified way of thinking about abortion and parenting decisions by highlighting one area in which the decision-making is analogous. It also helps to dispel the selfish mother narrative that surrounds abortion decisions. Finally, it offers an approach that may be appealing to both the reproductive

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526. Rigel C. Oliveri, *Crossing the Line: The Political and Moral Battle over Late-Term Abortion*, 10 YALE J.L. & FEMINISM 397, 431 (1998).

527. Loretta Ross, *What Is Reproductive Justice?*, in REPRODUCTIVE JUSTICE BRIEFING BOOK: A PRIMER ON REPRODUCTIVE JUSTICE AND SOCIAL CHANGE, *supra* note 489, at 4.

528. Wieber Lens, *supra* note 466 (manuscript at 39) (describing the lack of support women of color have expressed feeling from the white-dominated reproductive justice community); Mary Crossley, *Reproducing Dignity: Race, Disability, and Reproductive Controls*, U.C. DAVIS L. REV. (forthcoming 2020) (manuscript at 5–6), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3577227](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3577227) (describing the new focus women of color brought to the reproductive justice movement starting in the 1990s).

529. See Crossley, *supra* note 528 (manuscript at 58–60) (describing the unfair landscape of abuse and neglect accusations women of color face compared to white mothers); Dorothy E. Roberts, *Prison, Foster Care, and the Systemic Punishment of Black Mothers*, 59 UCLA L. REV. 1474, 1478 (2012) (highlighting how the foster care system punishes black mothers); Michele Goodwin, *Prosecuting the Womb*, 76 GEO. WASH. L. REV. 1657 (2008) (highlighting that the state uses fetal protection laws to punish poor pregnant women of color).

530. Wieber Lens, *supra* note 466 (manuscript at 39–43) (arguing for the right to parent to include parenting rights for stillbirth and miscarriage).

justice and disability rights communities, which could help smooth tensions between the groups.

#### CONCLUSION

Parents have a constitutional right to make health decisions for their child. These decisions do not need to be perfect. Even when parents make the choice to withhold or withdraw life-saving treatment for a dying child, courts will respect that decision unless the state can prove that the refusal is against the child's best interest. Unfortunately, these same end-of-life decisions when made before a child's birth have been governed by abortion law, even though the doctrine is ill-fitting and restricts parental autonomy rights. This Article argues that the parental right to withdraw life-sustaining treatment for their child must be extended to expectant parents before birth. In practice, this would mean that expectant parents have a constitutional right to terminate a pregnancy, even after viability, if the termination is based on a life-threatening fetal anomaly. This right would supplement other abortion rights, including the right to an abortion before viability for any reason as articulated in *Planned Parenthood v. Casey*.