Parental Autonomy over Prenatal End-of-Life Decisions

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Greer Donley*

Abstract: When parents learn that their child has a life-limiting, often devastating, prenatal diagnosis, they are faced with the first (and perhaps, only) healthcare decisions they will make for their child. Many choose to end the pregnancy because they believe it is in the child’s best interest to avoid a short and painful life. I argue that these decisions should be protected in the same way that parental healthcare decisions are constitutionally protected after birth—including the refusal or withdrawal of life-saving treatment for an infant or child who is dying. This constitutional right, grounded in an entirely different jurisprudence than traditional abortion rights, would prohibit states from banning terminations for severe fetal anomaly at any point in the pregnancy. It would therefore mimic the health-or-life exception, which is required for abortion bans that begin after fetal viability. The Article distinguishes prenatal diagnoses that carry a significant, or certain, risk of childhood death from those that cause only disability. Only termination decisions based on the former would fall within the right, although decisions based on the latter would still be protected before viability under Planned Parenthood v. Casey.

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This is a draft. The final article will be published in Volume 105 of the Minnesota Law Review. Once the article is in print, I will replace this draft with the final version. In the meantime, I welcome feedback!

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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. But contrary to this assumption, not all abortions involve conflicting interests. Some women obtain abortions because they think it is in their potential child’s best interest. 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 gut-wrenching choices of their lives: end a pregnancy they deeply want or continue a pregnancy knowing their baby could live a short and painful life. 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 baby’s diagnosis. I contend that these parents have an additional abortion right—indeed 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 decision-making is constitutionally protected after birth, 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 to abortion before viability for any reason—albeit with 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. These decisions are constitutionally protected on the grounds that parents have a liberty

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1 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.

2 See Section III.B.1.

interest in the care and custody of their child. If a doctor disagrees with the parents’ choice, she cannot override the parents’ decision without a court order. 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. 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. In those instances, the state cannot prove that the decision to withhold or withdraw treatment is improper.

Parents facing a severe fetal 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, but not potential children. This is paradoxical. One would imagine that 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.

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. This act is no different than removing a ventilator or feeding tube from a child who cannot survive without it.

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6 See Section II.
7 Id.
8 See Section III.C.2.
Unfortunately, many parents only learn of their potential child’s life-threatening diagnosis after the state has already banned abortion. Active state bans begin as early as twenty to twenty-two weeks in eighteen states. These bans unfortunately coincide with the “anatomy scan,” the mid-pregnancy ultrasound that is designed to diagnose fetal health conditions. 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. Moreover, fetal problems can also be diagnosed even later in pregnancy, impeding parental rights even in the majority of states that ban abortion at twenty-four weeks or at viability. 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.

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, 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. 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. Finally,

9 Many states are currently attempting to move their abortions bans up much earlier in the pregnancy—as early as six weeks—but these bans have all been enjoined pending litigation. See Section III.B.1.


11 See Section III.B.1.


13 Id.
it builds on efforts to see abortion as a parenting decision more generally and to change the dialogue surrounding abortion and disability.

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 allow parents to make health decisions for their 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 is no different than withdrawing life-sustaining treatment from a dying child. 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.\textsuperscript{14} Many birth defects\textsuperscript{15} can be diagnosed prenatally, at which point they are typically referred to as fetal anomalies. Roughly 150,000 fetuses are diagnosed with a fetal anomaly each year in the United States.\textsuperscript{16} There is a wide range of diagnoses that can be made prenatally—some conditions are manageable with treatment,\textsuperscript{17} while others are terminal.\textsuperscript{18} 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.

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


\textsuperscript{15} Birth defects are defined as “a structural change[] present at birth that . . . may affect how the body looks, works, or both.” What Are Birth Defects?, CTRS. FOR DISEASE CONTROL & PREVENTION (June 9, 2018), https://www.cdc.gov/ncbddd/birthdefects/facts.html.

\textsuperscript{16} Marguerite Maguire et al., Grief After Second-Trimester Termination for Fetal Anomaly: A Qualitative Study, 91 CONTRACEPTION 234, 235 (2015).

\textsuperscript{17} 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, https://www.cdc.gov/ncbddd/birthdefects/cleftlip.html (last reviewed Nov. 21, 2017).

\textsuperscript{18} 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. FOR DISEASE CONTROL, https://www.cdc.gov/ncbddd/birthdefects/anencephaly.html (last reviewed Nov. 21, 2017).
during gestation. 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 also 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, including a Category III diagnosis, the right to a post-viability abortion on 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. 19 The most common of these conditions include, for example, anencephaly, where the fetus’s skull and brain are not formed; 20 Trisomy 13 or Trisomy 18, which are chromosomal disorders causing multi-organ dysfunction; 21 and bilateral renal agenesis, where the fetus does not develop kidneys; 22 though others exist. 23 For these parents, the


20 See *Facts about Anencephaly*, supra note 18.


23 There are many other rare conditions that are always considered lethal. For a list of “lethal anomaly diagnoses,” see Leuthner, *supra* note 19, at 749. But many other “lethal” diagnoses are severe versions of conditions that are not always lethal.
question is not if their potential child will die in childhood—most often, in infancy—but when and how the child will die.

Historically, these conditions have been called “fatal” or “lethal” fetal anomalies and categorized as “incompatible with life.”24 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.25 And recently, treatments for some of these conditions have led to improvements in longevity that render death less imminent.26 Nevertheless, a third to three-quarters of these babies will die in utero or during the birth process,27 and the vast majority of those that live to meet their parents will die within days or months. For example, the median survival time for babies with bilateral renal agenesis is one day,28 and there has been only one documented case of a baby with bilateral renal agenesis surviving the neonatal period.29 For babies with anencephaly, the average survival time is fifty-one minutes,30 and the one-year mortality is 100%.31 The mean life expectancy of a baby with Trisomy 13 or Trisomy 18 is five to twelve days.32 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

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26 See Digitale, supra note 25 (describing more aggressive treatments of Trisomy 18 patients leading to longer lives); Koogler et al., supra note 24, at 38; Jacqueline E. Nguyen et al., Survival and Healthcare Utilization of Infants Diagnosed with Lethal Congenital Malformations, 38 J. OF PERINATOLOGY 1674, 1679–80 (2018).


28 Nguyen et al., supra note 26, at 1680.

29 Thomas et al., supra note 22, at 587.

30 Machado et al., supra note 27.

31 There have been only a few cases of babies with anencephaly surviving to two years old. Holly Dickman et al., Prolonged Unassisted Survival in an Infant with Anencephaly, 2016 BMJ CASE REPORT 1 (2016).

32 Katherine E. Nelson et al., Survival and Surgical Interventions for Children with Trisomy 13 and 18, 316 J. AM. MEDICAL ASSN. 421, 424 (2016); Meyer et al., supra note 21, at 827.
old, but they will experience a range of profound motor and intellectual disabilities and still never make it to adulthood. Furthermore, because elective termination and stillbirth are more common with more severe phenotypes of Trisomy 13 and 18, the survival statistics may be inflated.

Most parents who receive a fetal diagnosis in this category choose to terminate. The termination rate after the diagnosis of anencephaly is somewhere between 83–86%. After a confirmed diagnosis of Trisomy 18 and Trisomy 13, roughly 84% and 89% of parents respectively will terminate. 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 the dying process, and make the most of the limited time they have with their child, whether it is minutes, days, or months. For many of these parents, the predominant hope in continuing the pregnancy is the chance to meet their baby alive before saying goodbye. For these babies born alive, the standard of care is to provide only palliative treatment for the baby, and parents unquestionably have the right to refuse all non-palliative care and allow their child to die.

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33 Nelson et al., supra note 32, at 424.
35 Nguyen et al., supra note 26, at 1682.
36 Candice Y. Johnson et al., Pregnancy Termination Following Prenatal Diagnosis of Anencephaly or Spina Bifida: A Systematic Review of The Literature, 94 BIRTH DEFECTS 857 (2015); Caroline Mansfield et al., 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 (1999) (noting internationally, the termination rate for anencephaly is 84%, but it is 100% in the United States).
38 Krishelle L. Marc-Aurele et al., A Fetal Diagnostic Center’s Referral Rate for Perinatal Palliative Care, 7 ANNALS OF PALLIATIVE MEDICINE 177, 177–78 (2018); Leuthner, supra note 19, at 750–54.
39 Jennifer Guon et al., 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. OF MEDICAL GENETICS 308, 312 (2013).
40 See Section II.C.
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, only 2–15% of those born before twenty-two weeks will survive despite the most aggressive intervention. And the survivors typically experience serious disabilities, although long-term survival without disability has occurred. Due to the dismal survival statistics, hospitals typically will not resuscitate infants born alive before twenty-three weeks. If a pregnant woman’s water breaks before this crucial time, doctors often can only delay birth by 4–8 days (and in the meantime, both the mother and child are risk infection). As a result, half of women with premature rupture of membranes before twenty-two weeks choose to terminate the pregnancy. The parents who choose to continue the pregnancy are typically only offered palliative care for if the baby is born before twenty-two weeks.

B. Category II: Common Childhood Death with Severe Morbidity among Survivors

Unlike the first category—which guarantees childhood or infant death—this next category encompasses conditions with a greater range of outcomes. As seen from the examples below, parents of potential children diagnosed with conditions in this


42 Dani et al., supra note 41. The youngest known survivor was born at twenty-one weeks and four days. Kaashif A. Ahmad et al., Two-Year Neurodevelopmental Outcome of an Infant Born at 21 Weeks’ 4 Days’ Gestation, 140 PEDIATRICS 1 (2017).


45 McKenzie & Edmonds, supra note 41.

category are often told that the 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. 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. 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; hypoplastic left (or right) heart syndrome, where half of the baby’s heart does not develop; fetal hydrops, where the baby experiences swelling that compromises major organs; and many other genetic or structural abnormalities. Premature babies born between twenty-three and twenty-five weeks also fit in this category. These diagnoses do not have uniform outcomes—even severe forms of a particular diagnosis contain gradations that affect prognosis. And the prognosis can also be influenced by gestational age of onset—typically the earlier the condition develops, the worse the child’s outcomes will be. 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 the prognosis in this category can be unclear, there are some data to help physicians guide patients. But as noted above, some of these studies may present a more optimistic prognostic picture as the most severe cases of any diagnosis are more likely to end in termination, leaving a healthier subset for the study group. In


50 For instance, ventriculomegaly is considered severe when the fluid measures at least 15 mm. Sarah-Jane Lam & Sailesh Kumar, Evolution of Fetal Ventricular Dilatation in Relation to Severity at First Presentation, 42 J. OF CLINICAL ULTRASOUND 193, 193 (2014). However, some babies’ fluid can measure over 25 mm, their prognosis is worse than those whose fluid measures less than 20 mm.

51 See id., at 196.
one study of babies born with severe ventriculomegaly, 37% were either stillborn or died as neonates; of the survivors, 50% had major neurological morbidity (including blindness, cerebral palsy, inability to walk, and severe developmental delay), 40% had mild neurological morbidity, and 10% had a normal outcome.\textsuperscript{52} The survival rate was reduced to 35% when additional extra-cranial abnormalities were observed.\textsuperscript{53} In another study, 38% of babies born with hydrocephalus died in the first year, and roughly half of the survivors had mental retardation or cerebral palsy.\textsuperscript{54} Similarly, only 48% of babies diagnosed with fetal hydrops survive to adulthood (39% are stillborn or die as neonates); of the survivors, 39% have either a neurodevelopmental delay or other co-morbidity.\textsuperscript{55} The children with hypoplastic left heart syndrome tend to have lower early survival, but less long-term issues if they survive: only 27% survive the first year, but of those survivors, 90% maintain long-term survival.\textsuperscript{56} For extremely premature infants, only 23–27% of babies born at 23 weeks will survive; only 42–59% will survive at 24 weeks, and 67–76% will survive at 25 weeks.\textsuperscript{57} Severe and moderate neurological morbidity is also likely among prematurity survivors.\textsuperscript{58}

A majority of parents also terminate after a Category II diagnosis. For instance, a recent study showed that roughly 60% of pregnancies diagnosed with hydrocephalus are terminated.\textsuperscript{59} 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

\textsuperscript{52} M.M. Kennelly et al., \textit{Natural History of Apparently Isolated Severe Fetal Ventriculomegaly: Perinatal Survival and Neurodevelopmental Outcome}, 29 \textit{Prenatal Diagnosis} 1135, 1136 (2009).

\textsuperscript{53} Id.

\textsuperscript{54} Ester Garne et al., \textit{Congenital Hydrocephalus—Prevalence, Prenatal Diagnosis and Outcome of Pregnancy in Four European Regions}, 14 \textit{European J. Paediatric Neurology} 150, 153 (2010).


\textsuperscript{58} Id.

\textsuperscript{59} Garne et al., \textit{supra} note 54, at 152 (noting that 42 of the 70 pregnancies diagnosed prenatally were ended).
and 25% for moderate ventriculomegaly). Termination rates for hypoplastic left heart syndrome are roughly 60%. Most parents who choose to continue the pregnancy after learning of a Category II diagnosis have some discretion in deciding whether to withhold non-palliative treatment after birth. As explored in Section II.C, the standard of care is to follow parental choice to either pursue aggressive intervention or withhold care.

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; limb reduction, where a fetus’s arm or leg is either missing or reduced; and clubfeet, where the fetus’s feet are twisted out of position. These physical differences are frequently managed with surgery or other medical treatments, but can still cause challenges for the children and families. It is important to note that many of the conditions in this category are often associated with additional life-threatening anomalies, the presence of which could increase the severity of the diagnosis into another category. 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. 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

60 Lam & Kumar, supra note 50, at 195.
61 Karim Tarabit et al., Clinical and Socioeconomic Predictors of Pregnancy Termination for Fetuses with Congenital Heart Defects: A Population-Based Evaluation, 33 Prenatal Diagnosis 179, 181, 183 nn.22 & 23 (2013).
62 See Section II.C.
63 Facts about Cleft Lip and Cleft Palate, supra note 17.
66 For instance, a cleft lip or palate often causes problems with a baby’s speech and eating, but early surgical intervention can mitigate many difficulties. See Facts about Cleft Lip and Cleft Palate, supra note 17.
mm. These babies typically survive and most have a normal outcome; although, a minority (roughly 12%) will experience mild to severe developmental delays or neurological disease.

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. This syndrome causes a variety of physical and intellectual differences. There is a high chance of prenatal death with Trisomy 21 babies—roughly 20–45% will be miscarried or stillborn. Of the babies born with Trisomy 21, roughly 7% will die in the first year of life and 10% in the first five years. 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. For instance, 40–50% of Trisomy 21 babies have congenital heart defects. In 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. 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. Thus, if one excludes Trisomy 21 babies with other anomalies, who might fit in Category II, an isolated Trisomy 21 indicates disability, not death.

68 See id. at 1077; Patrizia Vergani et al., Clinical Outcome of Mild Fetal Ventriculomegaly, 178 AM. J. OBSTETRICS & GYNECOLOGY 218, 220 (1998).
73 C. Frid et al., Mortality in Down’s Syndrome in Relation to Congenital Malformations, 43 J. INTELLECTUAL DISABILITY RESEARCH 234, 236 (1999); Halliday et al., supra note 71, at 259.
74 Frid et al., supra note 73, at 236.
75 Halliday et al., supra note 71, at 259.
As one might expect, the termination rates are generally much lower in Category III than the other categories. For mild ventriculomegaly, the termination rate is only 5%.\textsuperscript{76} Roughly 10% of parents choose to terminate for an isolated limb reduction deficiency.\textsuperscript{77} For isolated cleft lip or palate, only 4% of parents choose to terminate.\textsuperscript{78} The exception is for Trisomy 21. Roughly 60--90% of parents choose to terminate after a Trisomy 21 diagnosis.\textsuperscript{79} The standard of care for babies born with Category III diagnoses is to provide them with any aggressive treatment they need. If parents refuse treatment, physicians will often seek assistance from the state to obtain a judicial order for treatment.\textsuperscript{80}

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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 of outcomes, it is unhelpful to group all fetal anomalies together. 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.

\textbf{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 is to therefore explain existing parental rights with regard to a child’s healthcare. In general, the Constitution protects

\textsuperscript{76} Tarabit et al., \textit{supra} note 61, at 181, 183 nn.22 & 23.

\textsuperscript{77} C. Stoll et al., \textit{Evaluation of the Prenatal Diagnosis of Limb Reduction Deficiencies}, 20 \texttt{PRENATAL DIAGNOSIS} 811, 815 (2000).

\textsuperscript{78} Maurizio Clementi et al., \textit{Evaluation of Prenatal Diagnosis of Cleft Lip with or Without Cleft Palate and Cleft Palate by Ultrasound: Experience from 20 European Registries}, 20 \texttt{PRENATAL DIAGNOSIS} 870, 872 (2000).


\textsuperscript{80} See Section II.C.
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, or 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.81 Supreme Court “jurisprudence historically has reflected Western civilization concepts of the family as a unit with broad parental authority over minor children.”82 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.”83 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.”84 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.85

Pursuant to this general recognition of parental authority, parents must make healthcare decisions for their children, including to consent to medical treatment before such treatment can be

81 Santosky v. Kramer, 455 U.S. 745, 753 (1982). See also Troxel v. Granville, 530 U.S. 57, 66 (2000) (“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.”) (plurality op.).
83 Id.; 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.”).
84 Troxel v. Granville, 530 U.S. 57, 58 (2000) (internal quotations omitted) (plurality op.).
85 Clare Huntington & Elizabeth S. Scott, Conceptualizing Legal Childhood in the Twenty-First Century, Mich. L. R. 37 (forthcoming 2020, available on SSRN). It is worth noting that some have criticized this assumption. See 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.
initiated.86 “Indeed, it would almost certainly be a tort as a matter of state law [for a doctor] to operate on an infant without parental consent.”87 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 not in the child’s best interest. And if there is evidence that the 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.” 88 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 permit a blood transfusion despite a lack of parental consent.89

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 In re Custody of Minor, the Massachusetts Supreme Court held that the state could compel, over parental objection, chemotherapy in a toddler to treat his leukemia.90 The court permitted state interference in this case on the grounds that the child would die without treatment, that chemotherapy was “quite effective,”91 and that the side-effects were relatively minor and short term—mainly stomach cramps and constipation.92 Other courts have found similarly in comparable cases.93

87 Id. at 630.
91 Id. at 750. The treatment was more likely than not to generate a long-term cure, and was overwhelmingly successful in the short term. Id. at 738–39.
92 Id. at 751–52.
93 See, e.g., In re Eric B., 189 Cal. App. 3d 996, 1005 (Ct. App. 1987) (upholding the lower court’s decision to order cancer monitoring in a child over parental objection 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
Courts, however, do not overrule parental choice flippantly. Rather, “the parental right is sacred” and “can be invaded for only the most compelling reasons.”94 Otherwise, “the requisite of parental consent to medical care for children [would] become[] meaningless if [simply the] refusal to consent automatically triggers” state intervention.95 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.96 To override parental choice, the state must therefore rebut this presumption.97 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 “suboptimal decisions,”98 “[W]hen more than one reasonable option is available,” parents are entitled

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, 24 Ohio App. 3d 191, 199 (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).

94 Newmark, 588 A.2d at 1115.
96 See Bowen, 476 U.S. at 628 n.13 (“there is a presumption, strong but rebuttable, that parents are the appropriate decisionmakers for their infants” (quoting the President’s Commission on Bioethics)).
to choose amongst them. "A court may not infringe upon the parental prerogative just because the judge thinks that the court could make a ‘better decision.’" As a result, courts typically (though not always) respect parental choice for difficult medical decisions about children and infants—ones without an obvious answer.

The most difficult medical decisions, the decisions least likely to have clear answers, occur at the end of a child’s life. Unfortunately, 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. In these cases, parents are essentially exercising their child’s constitutional right to refuse or withdraw life-sustaining treatment—a right that extends to


100 The Best Interest Standard, supra note 97, at 37.

101 See discussion of Newmark, 588 A.2d at 1110 below. See also Matter of Hofbauer, 47 N.Y.2d 648, 656 (1979) (“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.”); In re Nikolas E., 720 A.2d 562, 566 (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., 92 Cal. App. 3d 796, 803 (Ct. App. 1979) (refusing to order heart surgery on a child with Down Syndrome that would increase his life span because it also carried risks). But see In re Hamilton, 657 S.W.2d 425 (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, 15 Misc. 3d 565, 574 (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 and satisfaction”). 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 s/he could survive long-term on a ventilator. See Matter of AB, 768 N.Y.S.2d 256 (Sup. Ct. 2003); In re L.H.R., 321 S.E.2d 716 (Ga. 1984); In re Barry, 445 So. 2d 365 (Fla. App. 2d Dist. 1984); In re P.V.W., 424 So. 2d 1015 (La. 1982); In re Guardianship of Crum, 580 N.E.2d 876. But see In re D.H., 834 N.Y.S.2d 623 (Sup. 2007).

102 See, for example, Newmark, 588 A.2d at 1110 and the cases cited in footnote 101; The Best Interest Standard, supra note 97 (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”).

Electronic copy available at: https://ssrn.com/abstract=3555943
those who are incompetent to make end-of-life decisions themselves.\textsuperscript{103}

In considering “whether it is in a dependent child’s best interests to withhold or withdraw life-sustaining medical treatment,”\textsuperscript{104} 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.\textsuperscript{105}

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

\textsuperscript{103} See, e.g., \textit{In re AMB}, 248 Mich. App. 144, 198–99 (2001) (“The right to refuse lifesaving medical treatment is not lost because of the incompetence or the youth of the patient.”); \textit{Cruzan}, 497 U.S. at 279 (assuming without deciding that all people, including those incompetent to make medical decisions, have the constitutional right to refuse or withhold medical treatment).

\textsuperscript{104} \textit{In re Christopher I.}, 106 Cal. App. 4th 533, 550 (2003), as modified on denial of reh’g (Mar. 10, 2003).

treatment, and the quality of life the child can expect after treatment. In other words, courts are sensitive to the delicate nature of 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. Colin would die in roughly eight months without treatment, but intensive chemotherapy had only a 40% chance of success. Colin’s parents, who were Christian Scientists, refused. 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.” 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. 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.”

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106 See, e.g., In re AMB, 248 Mich. App. at 200 (“[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.”); In re Guardianship of Grant, 109 Wash. 2d 545, 568, 747 P.2d 445 (1987) (accord); Matter of Conroy, 98 N.J. 321, 370 (1985) (accord); In re Eric B., 189 Cal. App. 3d 996, 1005 (Cal. Ct. App. 1987) (“Several relevant factors must be taken into consideration before a state insists upon medical treatment 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.”).

107 Newmark, 588 A.2d at 1111.

108 Id.

109 Id.

110 Id.

111 Id. at 1118–20.

112 Id. at 1120.
The court noted that all “[p]arents must have the right at some point to reject medical treatment for their child.”\textsuperscript{113} 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.”\textsuperscript{114} Thus, the court put “Colin’s ultimate fate” in the hands of “his parents and their faith.”\textsuperscript{115}

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. In 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. \textit{Put somewhat more starkly, how can parents in such situations give the wrong answer since there is no way of knowing the right answer?}\textsuperscript{116}

Thus, according to Goldstein, “[t]here would be no justification . . . for coercive intrusion by the state in those life-or-death situations.”\textsuperscript{117} 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.”\textsuperscript{118} Goldstein’s argument highlights the normative underpinning of the requirement that the state bears the burden of proving that the parents’ choice is \textit{wrong},

\begin{itemize}
  \item \textsuperscript{113} Id.
  \item \textsuperscript{114} Id. at 1120–21.
  \item \textsuperscript{115} Id.
  \item \textsuperscript{116} Goldstein, \textit{supra} note 95, at 654–55 (emphasis added).
  \item \textsuperscript{117} Id. at 653.
  \item \textsuperscript{118} Id. at 664.
\end{itemize}
rather than the parents bearing the burden of proving their choice is right.\textsuperscript{119}

B. \textbf{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.\textsuperscript{120} This deference to parental authority created substantial political controversy 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. But as explained in Section II.C, parents still enjoy wide discretion in choosing to withhold or withdraw life-sustaining treatment for severely ill newborns.

The first infant case that reached national attention involved Baby Doe, who born in 1982. Doe was born with Down Syndrome and an esophageal deformity, which if repaired, would have saved the baby’s life. Doe’s parents, however, chose to forgo the life-saving surgery and withhold hydration and nutrition, allowing their baby to die.\textsuperscript{121} The state courts in Indiana upheld the parents’ choice and the baby died six days later.\textsuperscript{122} 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.”\textsuperscript{123} The Indiana Supreme Court refused to intervene.\textsuperscript{124}

It is worth pausing here to note that as quality of life, medical treatment, and general awareness have improved for children with Down Syndrome, courts today would most likely not reach the same

\textsuperscript{119} Id. at 655.

\textsuperscript{120} See discussion below about the litigation surrounding the Baby Doe cases; see also M.N. v. S. Baptist Hosp. of Fla., Inc., 648 So. 2d 769 (Fla. Dist. Ct. App. 1994); \textit{In re Holbauer}, 393 N.E.2d at 656.


\textsuperscript{122} Haddon, \textit{supra} note 121, at 573.


\textsuperscript{124} Id.
result. Even in the 1980s, many argued that the belief that a child with Down Syndrome could not live a good life reflected ablest stereotypes. In part due to these concerns, shortly after Baby Doe’s death, the Reagan administration promulgated a rule (the Rule) under the Rehabilitation Act; the Rule prevented hospitals from withholding care from disabled infants and created extensive mechanisms to ensure violations of the Rule were reported. Many viewed this Rule as serious overstep that intruded into the private decisions of doctors and parents. The American Medical Association, American Hospital Association, and others sued under the Administrative Procedures Act (APA), arguing that the Rule was arbitrary and capricious.

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. Jane Doe was born with many serious disorders, including spina bifida, microcephaly, and hydrocephalus. Multiple surgeries could have corrected the hydrocephalus and spina bifida, but the parents refused treatment. 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." As a result, it held "the parents’ determination to be in the best interest of the infant." 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." The court found "distressing" that parents facing the "the anguish of the birth of a child with severe physical disorders"

125 Mercurio, supra note 43, at 844.
128 Id. at 613.
129 Id. at 620–22.
131 Id.
132 Id. at 687.
133 Id.
were “subjected . . . to litigation through all three levels of our State’s court system.”135

Eventually, the United States Supreme Court heard the APA challenge to the Rule and concluded that it was arbitrary and capricious and therefore illegal.136 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.137

Congress quickly moved thereafter to create some protections for disabled newborns, but opted for a compromise that appeased (and frustrated) all relevant stakeholders.138 It passed the Child Abuse 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.”139 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.140 The law explicitly excluded from the definition of “withholding 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

135 Id. at 213.
136 Bowen, 476 U.S. at 646-47.
137 Id. at 630.
138 Haddon, supra note 121, at 582; Crossley, supra note 99, at 1615.
139 Haddon, supra note 121, 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.” 42 U.S.C. § 5106g(5) (West).
(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.\textsuperscript{141}

Though the United States Department of Health and Human Services (HHS) initially promulgated regulations that added bite to these regulations,\textsuperscript{142} as of 2015, all of the promulgated rules have been repealed.\textsuperscript{143} The law now stands on its own.

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.”\textsuperscript{144} To start, the enforcement mechanism was weak: 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.\textsuperscript{145} Though there some evidence that the law initially caused a chilling effect amongst doctors,\textsuperscript{146} perinatal palliative care (rather than aggressive treatment) is now routine practice for infants with serious life-threatening conditions.\textsuperscript{147} 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

\textsuperscript{141} 42 U.S.C. § 5106g(5).

\textsuperscript{142} See 45 C.F.R. § 1340 app., at 300–01 (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”); id. at 302 (interpreting “virtually futile” to mean that “the treatment is highly unlikely to prevent death in the near future”).


\textsuperscript{144} ALAN MEISEL, KATHY L. CERMINARA & THADDEUS MASON POPE, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING 10–11 (3d ed. 2004). See also Moss, supra note 121, 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 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 “HHHS has not been able to uncover even one case of child abuse or neglect in more than a year of operating its ‘hotline’”).

\textsuperscript{145} Moss, supra note 121, at 641.

\textsuperscript{146} 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. OF PALLIATIVE MED. 1 (2001).

\textsuperscript{147} Jatinder Bhatia, M.D., 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).
life-sustaining treatment from some newborns is acceptable.”\textsuperscript{148} 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 without as much controversy.\textsuperscript{149}

C. Parental Autonomy Rights by Category

Section I created three categories of fetal anomalies. 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. For these babies, the parents and medical team must decide on a course of action after birth. 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.\textsuperscript{150} Doctors recommend only palliative care for babies born with anomalies in this category, viewing aggressive treatment to prolong life as prolonging suffering:

\textsuperscript{148} Mercurio, supra note 43, at 862.

\textsuperscript{149} 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, 256 Wis. 2d 472, 489 (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.

\textsuperscript{150} Mercurio, supra note 43, 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”); \textit{International Guidelines for Neonatal Resuscitation: An Excerpt From the Guidelines 2000 for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care: International Consensus on Science}, 106 \textit{PEDIATRICS} 1, 13–14 (2000), \url{https://pediatrics.aappublications.org/content/pediatrics/106/3/e29.full.pdf} (“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. \textit{In re} Baby K, 16 F.3d 590 (4th Cir. 1994).
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.\footnote{151}

Professional organizations also advise against resuscitation for babies in this category.\footnote{152} As a result, the vast majority babies born with Category I diagnoses are not provided active treatment after the baby is born.\footnote{153}

The standard of care for Category I diagnoses conforms with the law: not only would the CAA not apply because the care would be “futile in terms of the survival of the infant,”\footnote{154} but the state could never rebut the presumption that the parents were acting in the child’s best interest in refusing care.\footnote{155} 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.\footnote{156}

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.\footnote{157} “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.”\footnote{158} 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

\footnote{151}{Leuthner, supra note 19, at 750.}
\footnote{152}{Guon et al., supra note 39, at 309; Mercurio, supra note 43, at 854.}
\footnote{153}{Heidi J. Kamrath et al., Lasting Legacy: Maternal Perspectives of Perinatal Palliative Care, 22 J. OF PALLIATIVE MEDICINE 310, 313 (2019); Guon et al., supra note 39, at 313.}
\footnote{154}{42 U.S.C. § 5106g(5).}
\footnote{155}{See Section II.C.}
\footnote{156}{See cases discussed, supra note 101.}
\footnote{157}{Mercurio, supra note 43, at 844.}
\footnote{158}{Id. at 852.}
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.” 159 
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. 160

The law supports this standard of care. Under common law, 
a state would most likely prove that a parent’s refusal of care for a 
child with a Category III diagnosis was against the child’s best 
interest. 161 “[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.” 162 It is difficult to argue 
that babies born with a physical difference or even Down Syndrome 
can gain no benefit from life. 163 Rather, most courts today would 
likely have no hesitation ordering medical treatment over parental 
objection in these cases. 164

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. 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.” 165 Similarly, 
the American Academy of Pediatrics has said that “[p]arents should 
be given a great deal of discretion” to parents of critically-ill 
newborns; “even if the physician believes the procedure in question

159 Id. at 844.
160 Crossley, supra note 99; Michelle Fine & Adrienne Asch, Women with 
Disabilities: Essays in Psychology, Culture, and Politics, 297–98 
(Michelle Fine & Adrienne Asch eds., 1988).
161 Mercurio, supra note 43, at 844.
162 Crossley, supra note 99, at 1626.
163 Field, supra note 126.
164 See Mercurio, supra note 43, at 844.
165 Code of Medical Ethics Opinion 2.2.4, Treatment for Seriously Ill Newborns, 
AM. MED. ASSN., https://www.ama-assn.org/delivering-care/ethics/treatment-
decisions-seriously-ill-newborns.
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.” 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.”

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 to resuscitate the infant] should be the main deciding factor.” In that category, the authors listed: “babies who are 23 to 25 weeks gestation” and “babies with major abnormalities that predict extreme morbidity or early death.” 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 almost always indicated. Thus, medical practice seems relatively clear that when a child’s prognosis is neither dismal nor rosy, parents have the right to choose what outcome they think is best for the child.

The law also supports this position. As a baseline, under common law, parental choice governs most when there is no clear answer about the proper treatment. 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. This burden is impossible to meet when there is no consensus on the right treatment: “how can parents in such situations give the wrong

166 AMERICAN ACADEMY OF PEDIATRICS BIOETHICS RESIDENT CURRICULUM: CASE-BASED TEACHING GUIDES, AM. ACADEMY PEDIATRICS 95 (2017).
168 Steven Bryne & Jay P. Goldsmith, Non-initiation and Discontinuation of Resuscitation, 33 CLINICS IN PERINATOLOGY 197, 215 (2008); Bhatia, supra note 147, at 907.
169 Id.
170 Id.
171 See, e.g., Section II and cases discussed at note 101.
172 See Bowen, 476 U.S. at 628 n.13.
answer since there is no way of knowing the right answer?” 173 Parents are necessarily making decisions “about which there is no societal consensus” when they consider whether survival odds justify the pain of treatment, what is the most peaceful death when survival is impossible or improbable, and whether the quality of life a child can expect after treatment is acceptable.174

In cases from Newmark to Jane Doe, courts have refused to overrule a parental health decision when ordering care may cause suffering that is not justified by the mortality rate and quality of life outcomes.175 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, under common law, 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.176 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. Some doctors, 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 best interests of the child. As established above, parents would generally win under this standard. 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.177 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.178

173 Goldstein, supra note 95, at 654–55.
174 Id. at 651; see also Jennifer L. Rosato, Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?, 73 TEMPLE L. REV. 1, 2 (2000).
175 See Section II.
176 42 U.S.C. § 5106g(5).
178 MEISEL, CERMINARA & POPE, supra note 144, at 10–32.
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 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, although limited by state regulation. 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 parental autonomy rights would protect it even if the Supreme Court were to overturn traditional abortion rights grounded in Roe and Casey’s right to privacy. And if Roe and Casey remain good law, this new right would sit on top of them, expanding access to abortion at a pivotal time.

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 and disability-selective abortion bans limit parental choice. The Section next argues that expectant parents should be treated the same as parents when it comes to medical decisions for their potential children—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 than parents. 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.\textsuperscript{179} As the miscarriage risk faded around nine weeks, she started relaxing into her pregnancy; around that time, she started a pregnancy journal where she wrote letters to her “future kid.”\textsuperscript{180} At eighteen weeks, with nine letters to her baby, Margot went in for her anatomy ultrasound. 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.\textsuperscript{181} She was told there was a 95% chance that this problem would resolve itself and her baby would be fine.\textsuperscript{182} So she and her care team decided to repeat the scan a month later to make sure the problem had dissipated.\textsuperscript{183} In the meantime, she settled further into her pregnancy, now knowing her baby was a girl.\textsuperscript{184}

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%.\textsuperscript{185} Instead, her baby girl had developed ventriculomegaly.\textsuperscript{186} 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.\textsuperscript{187} That day, she scheduled a battery of tests and appointments—amniocentesis, fetal MRI, genetic counseling.\textsuperscript{188} It was Halloween, and she spent the day crying “as many hours as were available.”\textsuperscript{189} 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


\textsuperscript{180} Id. at 6:15.

\textsuperscript{181} Id. at 6:50.

\textsuperscript{182} Id. at 7:40.

\textsuperscript{183} Id. at 7:25.

\textsuperscript{184} Id. at 8:15.

\textsuperscript{185} Id. at 8:30–9:30.

\textsuperscript{186} Id.

\textsuperscript{187} Id. at 10, 14:10.

\textsuperscript{188} Id. at 10:40.

\textsuperscript{189} Id. at 11:30.
delays. Margot decided she could not end the pregnancy with those odds. 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.

At twenty-eight weeks, with more letters to her daughter, she went in for her next scan. At that point, her baby girl was diagnosed with moderate to severe lissencephaly. 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.

At that point, she and her husband decided to end the pregnancy. She wanted to avoid giving her daughter a “fate worse than death.” 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. 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

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190 Id. at 14:20.
191 Id. at 14:30.
192 Id. at 14:30.
193 Id. at 35:20; 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), https://slate.com/technology/2019/02/late-term-abortion-support-group-lessons-trust-myself-women.html?fbclid=IwAR0NjVBSqMuTLP7ZfagsCoTROFiOGxZoegTXxssbxsXqnsopXPvRA85-M.
194 Finn, supra note 193.
195 Id.
196 Id.
thereafter, wishing I could give her peace and being unable to do it.”

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. She paid $12,500 out of pocket for the procedure and thousands more in travel costs. Her procedure was four-days long. First, her baby’s heart was stopped by an injection. Then, doctors inserted dilators into her cervix over the course of three days. Finally, they induced labor and delivery. She had minimal pain medication as she gave birth to her stillborn daughter. Her milk came in days later.

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.” Though she now has two healthy children, she honors her first daughter in many ways on the day of her death. 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. 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. Like many other women who have experienced a similar tragedy, she believes her daughter made her a mother, even though she did not survive.
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. Though the contours of the right have changed over time, the framework for evaluating the right to abortion has remained largely stable since 1992. Until recently, anti-abortion activists have largely waged a fight on the margins—attempting to slowly chip away abortion rights over time. However, this model has changed dramatically with the new makeup of the Supreme Court; in the past year, conservative states have launched a campaign to dismantle the foundation of abortion rights, including de facto bans on all abortion. Though these aggressive laws have all been enjoined 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. 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. Thus, if states are allowed to ban abortion once a heartbeat is detected at six 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.

In Roe v. Wade, the Supreme Court first recognized a constitutional right to abortion under the Due Process Clause of the Fourteenth Amendment. Under Roe, abortion rights were grounded in the right to privacy and evaluate under a trimester framework. In the first trimester of pregnancy, women were guaranteed access to abortion unobstructed by state interference. In the second trimester, the state could enact regulations that hindered abortion, but only if they advanced its interest in protecting


maternal health.216 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.217

Twenty years later, in Planned Parenthood v. Casey, the Supreme Court was asked to reconsider Roe. Though five justices declined to reverse “Roe’s central holding,” the plurality opinion dramatically altered the doctrine.218 The Court replaced the trimester framework with a viability framework.219 As with Roe, states could ban abortion after viability unless the mother’s health or life was at risk.220 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.221 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.”222

It quickly became clear in applying the undue burden standard that it had much less bite than its predecessor.223 The Court upheld most of the challenged provisions of the Pennsylvania’s Abortion Control Act. 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,224 to require minors to obtain parental consent before an abortion (with the possibility of judicial bypass),225 and to require abortion providers to keep and disclose abortion records to the state.226 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

216 Id.
217 Id.
219 Id. at 833–34.
220 Id. at 837.
221 Id.; Wharton et al., supra note 214, at 330–31.
222 Id. at 877.
224 Id. at 880–87.
225 Id. at 899–900.
226 Id. at 900–01.
function.” 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.

The Court did, however, reiterate Roe’s holding that even after viability, abortion must always be available to women when their health or life is threatened, albeit, as noted above, the health exception can be narrow. Later opinions have affirmed this holding, 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. 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. The Court has vacillated between these two rationales—the latter being more protective of women’s rights. But at a minimum, the exception guarantees a woman’s right to defend herself.

Casey still defines the parameters of the constitutional floor of abortion rights. It left intact two general rights: the right to abortion for any reason before fetal viability, subject to state regulation, and the right the right to abortion for the life or health of the mother at any point in the pregnancy. Some states do not regulate to the constitutional floor and their citizens therefore enjoy abortion freedoms beyond those recognized by the Supreme Court. 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

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227 Id. at 879–80.
228 Id. at 983–84.
229 Id. at 879.
232 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 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) (concurrence).
abortion facilities and deter as many abortions as possible.\textsuperscript{234} 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 margins.\textsuperscript{235} The variability among state laws is huge, and growing in recent years as some liberal states push to protect abortion rights, while some conservative states attempt to ban the procedure entirely.\textsuperscript{236}

Some state abortion laws are particularly burdensome to women seeking an abortion on the basis of severe fetal anomaly—those that ban abortion after a certain point in the pregnancy and those ban “disability-selective” abortion. These laws are explored in more depth below. This Section argues that these laws fail the parents who use abortion as an end-of-life decision and demonstrate that additional rights are needed.

1. Viability Creep

Since \textit{Roe} and \textit{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).\textsuperscript{237} 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 \textit{Roe}, the Court defined viability as “[t]he interim point at which the fetus . . . is potentially able to live outside the mother’s womb, albeit with artificial aid.”\textsuperscript{238} 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.”\textsuperscript{239} By the time \textit{Casey} was decided, “advances in neonatal care have advanced viability to a point somewhat earlier.”\textsuperscript{240} In 1992, the Court noted that viability could start around 23–24 weeks, and left open the possibility that further medical advances could continue to

\textsuperscript{234} Id.
\textsuperscript{235} \textit{See} Section III.B.1.
\textsuperscript{237} \textit{See} State Bans on Abortion Throughout Pregnancy, supra note 10.
\textsuperscript{238} \textit{Roe}, 410 U.S. at 160.
\textsuperscript{239} Id.
\textsuperscript{240} \textit{Casey}, 505 U.S. at 860.
move that milepost forward. Thus, viability is, to some extent, a moving target, 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.

The American College of Obstetrics & 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.” ACOG defines the grey period in which viability is uncertain as the periviable period; it starts at the beginning of 20 weeks and ends at the conclusion of 25 weeks. Babies born before 23 weeks have only a 5–6% chance of survival with a 98–100% risk of morbidity. The youngest premature baby to ever survive was born at 21 weeks and 4 days. At 23 weeks, however, 23–27% of babies born will survive; at 24 weeks, 42–59% will survive, and at 25 weeks, 67–76% will survive.

Given these statistics, viability cannot be said to begin before 23 weeks—in Casey’s words, there would not be a “realistic possibility of maintaining and nourishing a life outside the womb.” Notwithstanding this fact, many states have created abortion bans that start before 23 weeks. Seventeen states have current abortion bans that start at 22 weeks into the pregnancy (as defined by gestational age—i.e., the first day of the women’s last

241 Id.
242 Id.
245 Periviable Birth, supra note 57.
246 Id.
247 Kaashif A. Ahmad, Two-Year Neurodevelopmental Outcome of an Infant Born at 21 Weeks’ 4 Days’ Gestation, 140 PEDIATRICS 1, 1 (2017).
248 Periviable Birth, supra note 57.
249 Casey, 505 U.S. at 870.
period).\textsuperscript{250} One state also has a current abortion ban starting at 20 weeks.\textsuperscript{251} (In the past year, eight states have attempted to ban abortion at much earlier in the pregnancy—from conception to 18 weeks.\textsuperscript{252}) One of the most troubling implications of these 20-22 week abortion bans is that they ban abortion at the time when many women first discover that their baby is sick. In fact, some of these bans have been promoted as a way to reduce abortions on the basis of fetal anomaly.\textsuperscript{253} There are an additional three states that ban abortion at 24 weeks, which gives women a little more time, but not enough.\textsuperscript{254}

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 half-way through the pregnancy (around 20 weeks).\textsuperscript{255} The purpose of the anatomy ultrasound is to evaluate the fetus’s development and identify problems,\textsuperscript{256} 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.\textsuperscript{257} Most anatomical conditions cannot be diagnosed sooner than this mid-pregnancy ultrasound because the organs are not sufficiently developed before this point.\textsuperscript{258}

Chromosomal issues can be diagnosed earlier in the pregnancy if parents take advantage of first-trimester screening

\textsuperscript{250} State Bans on Abortion Throughout Pregnancy, supra note 10.
\textsuperscript{251} Id.
\textsuperscript{252} One state has banned abortion at conception, four at 6 weeks, one at 8 weeks, and two at 18 weeks. Id.
\textsuperscript{253} Mary Ziegler, The Disability Politics of Abortion, UTAH L. REV. 587, 626 (2017).
\textsuperscript{254} State Bans on Abortion Throughout Pregnancy, supra note 10.
\textsuperscript{256} Bethune et al., supra note 255, at 98.
\textsuperscript{258} Bethune et al., supra note 255, at 98.
But these screening programs are not diagnostic, so the results reveal only the fetus’s increased risk of having a condition. 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. Because eighteen states have active abortion bans starting between twenty and twenty-two weeks, parents may not discover their child’s problem until after abortion is already illegal in their state.

And even if parents first learn of a potential problem before the state’s deadline, it can take weeks after the anatomy scan for parents to complete the extra tests and second opinions necessary to feel as confident as possible that they understand the diagnosis and prognosis. And if the parents choose to terminate at that point, it typically takes additional weeks after the decision is made to get an appointment for an abortion, to find the thousands of dollars of out of pocket cash to pay for the procedure, comply with the state-mandated waiting periods, and ultimately obtain the abortion.

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259 See, e.g., Tony Yew Teck Tan, Combined First Trimester Screen or Noninvasive Prenatal Testing or Both, 56 SINGAPORE MEDICAL J. 1, 1 (2015).

260 Id.


263 See e.g., Finn, supra note 193; The Mom Who Had an Abortion at 7 Months Pregnant, THE CUT (Apr. 19, 2018), https://www.thecut.com/2018/04/how-i-got-this-baby-mom-who-had-an-abortion-at-7-months.html?fbclid=IwAR2ylRT0c_alYhiUQKi7vOvanLTa2RQQtzbw5MGbHzANYeVv-Q2AahJmu2Y; Sarah McCammon, 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?fbclid=IwAR3udCBfxEwg0tClxQF9i-AdTJnpSa3eDX-roiSUugHCLOFsTJ1cP2ULz6I.


These additional weeks of testing and logistical hurdles may delay the abortion enough to time bar it, leaving women with only out-of-state options that add additional stress and trauma. And like Margot, some women who receive negative health information in the first or second trimester that initially seems manageable are forced to re-evaluate their choice later in the pregnancy when they are told the baby’s condition has worsened. Others may first learn of the problem in the third trimester. For these women in any of these situations, a 20 to 24-week ban will either outright deny them an abortion or rush an incredibly fraught decision.

It is worth noting that twenty states simply ban abortion at “viability.” 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. This flexibility 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. Thus, in these states, women who choose to terminate based on fetal anomaly have greater protections.

_of-mother-is-8-months-pregnant-and-117104430132.html (describing that she needed to come up with $25,000 in a weekend to obtain the abortion).

266 See e.g., Ali P, supra note 264 (“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 from our dogs, our friends, our family, our home, our safe place.”)

267 Finn, supra note 193.


269 An Overview of Abortion Laws, supra note 233.

270 See, e.g., DEL. CODE ANN. tit. 24, § 1702 (West 2018) (“‘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 2012) (same); MD. CODE ANN., Health-Gen. § 20-209 (West 2005) (same).

Courts have overturned some abortions bans that started too soon. For instance, Arizona attempted to ban abortion starting at 20 weeks, and the Ninth Circuit found the ban unconstitutional.\textsuperscript{272} The court was particularly worried that the ban would prevent “abortions in cases of fetal anomaly or pregnancy failure.”\textsuperscript{273} The Ninth Circuit also struck down Idaho’s 22-week abortion ban.\textsuperscript{274} When Utah attempted to ban abortions starting at 20 weeks, the Tenth Circuit similarly found the law unconstitutional.\textsuperscript{275} District courts have also invalidated North Carolina’s 20-week ban\textsuperscript{276} and Arkansas’s 18-week ban.\textsuperscript{277} Nevertheless, the eighteen states mentioned above have active bans that start before viability.

2. \textit{Disability-Selective Abortion Bans}

Over the past decade, states have started passing disability-selective abortion bans. Advanced as anti-discrimination laws, 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 dying child from the pain of a short life. Furthermore, these bans represent a novel opportunity for the state to investigate a woman’s reason for wanting an abortion, and prevent her goal if it judges that reason improper.\textsuperscript{278} Supreme Court precedent does not allow states to ban pre-viability abortions based on “bad” reasons.\textsuperscript{279}

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

\begin{itemize}
\item \textsuperscript{272} \textit{Isaacson}, 716 F.3d at 1225.
\item \textsuperscript{273} Id. at 1228.
\item \textsuperscript{274} The Idaho law banned abortions 20-weeks post-fertilization, or 22 weeks into the pregnancy. McCormack v. Herzog, 788 F.3d 1017, 1029 (9th Cir. 2015).
\item \textsuperscript{275} Jane L. v. Bangerter, 102 F.3d 1112, 1115 (10th Cir. 1996).
\item \textsuperscript{276} Bryant v. Woodall, 363 F. Supp. 3d 611, 630 (M.D.N.C. 2019).
\item \textsuperscript{278} Greer Donley, \textit{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 M. J. GENDER & LAW, 291, 326–27 (2013).
\item \textsuperscript{279} Id.
\end{itemize}
[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.280

The law defines “genetic abnormality” as “any defect, disease, or disorder that is inherited genetically. The term includes any physical disfigurement, scoliosis, dwarfism, Down syndrome, albinism, amelia, or any other type of physical or mental disability, abnormality, or disease.”281 In other words, it is broad enough to cover nearly every poor prenatal diagnosis, even non-genetic structural problems. In North Dakota, a Class A misdemeanor is punishable by “maximum penalty of imprisonment for three hundred sixty days, a fine of three thousand dollars, or both . . . .”282

Utah similarly has a disability-selective abortion ban on the books, but it is limited to only Down Syndrome (Trisomy 21).283 It also contains a trigger clause—i.e., a clause providing that it will not go into effect until there is “binding authority” 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.”284 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).285 And scholars agree that the Constitution does not

281 Id. at 14-02.1-02.
284 Id. at 9(3).
permit states to condition a woman’s right to pre-viability abortion on the reasons she seeks it.\textsuperscript{286}

The only circuit court to consider the issue—the Seventh Circuit—invalidated a general disability-selective abortion ban in Indiana. The Indiana law banned abortion on the basis of “Down Syndrome, disability, or related characteristics,” excluding “lethal fetal anomalies.”\textsuperscript{287} The law also required that aborted fetal remains be either buried or cremated.\textsuperscript{288} The Seventh Circuit held that both parts of the law were unconstitutional.\textsuperscript{289} As to the disability-selective ban, the court found that the “provisions [pose] far 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.”\textsuperscript{290} Plaintiffs moved for a rehearing en banc, but only as to the decision on fetal remains. The court denied the motion over a dissent by Judge Easterbrook.\textsuperscript{291} Curiously, Easterbrook noted that the disability-selective ban (which was not at issue) was worthy of reconsideration by the entire court en banc.\textsuperscript{292} 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:\textsuperscript{293}

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


\textsuperscript{287} Box v. Planned Parenthood of Indiana & Kentucky, Inc., 139 S. Ct. 1780, 1783 (2019).

\textsuperscript{288} Id.

\textsuperscript{289} Planned Parenthood of Indiana & Kentucky, Inc. v. Comm’r of Indiana State Dep’t of Health, 888 F.3d 300, 306 (7th Cir.), reh’g en banc granted, judgment vacated, 727 F. App’x 208 (7th Cir. 2018), vacated, 917 F.3d 532 (7th Cir. 2018), and opinion reinstated, 917 F.3d 532 (7th Cir. 2018), and cert. granted in part, judgment rev’d on other grounds, Box v. Planned Parenthood of Indiana & Kentucky, Inc., 139 S. Ct. 1780 (2019).

\textsuperscript{290} Id.

\textsuperscript{291} Id.

\textsuperscript{292} Id. (Easterbrook, J., dissenting).

\textsuperscript{293} Id.
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.

The plaintiffs requested certiorari, which the Supreme Court granted, but only as to the Seventh Circuit’s invalidation of the fetal remains statute. As to the disability-selective abortion ban, the Supreme Court “expressed no view on the merits.”

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.”

Justice Thomas wrote separately to suggest that Indiana’s disability-selective abortion ban may be unconstitutional. 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 constitutionalize the views of the 20th-century eugenics movement.”

Scholars have appropriately criticized Thomas’s use of the term eugenics in this context, noting that eugenics historically sought to deny minorities and disabled individuals their reproductive rights; access to abortion on the basis of fetal anomaly, however, expands reproductive rights. “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.”

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294 *Box*, 139 S. Ct. at 1782.
295 *Id.* at 1783 (Thomas, J., concurring).
296 *Id.* at 1783–93.
297 *Id.* at 1792.
299 Fox, *supra* note 298.
individuals to make reproductive decisions, where eugenics denied people that choice.”

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. . . .”301 The issue of disability-selective abortion bans is unlikely to disappear anytime soon, especially given the sympathetic ear given by Easterbrook and Thomas and the increase in similar disability-selective abortion legislation proposed or passed in 2019.302 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.

Taken together, state abortion laws are currently failing to protect parents seeking to terminate on the basis of severe fetal anomaly. And 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 would be painful, 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—a doctrine that may be limited or eliminated all together in the next

300 Id.

301 Parson, 389 F. Supp. 3d at 636.

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, the decisions are the same whether it is before or after birth—the parents and expectant parents are evaluating the same diagnoses, the same prognoses, and the same 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.

Parents and expectant parents also share the same motivations—including a determination of what is in the best interests of the child—in deciding whether to pursue aggressive treatment or allow the child to die. One mother wrote, “[i]f I can make a choice [to terminate] where it is the best outcome for my child to not have to suffer, that’s what I’m going to choose. Everyday.”

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. “We made sure our son was not born only

303 See, e.g., Belkin, supra note 268 (“it wasn’t about me and continuing my pregnancy, it was about my son and saving him from his body.”).


305 See, e.g., Sarah Schulte, *Ill. May Expand Abortion Rights as Other States Restrict; Senate Expected To Vote Friday*, ABC 7 EYEWITNESS NEWS (May 30, 2019), https://abc7chicago.com/politics/illinois-may-expand-abortion-rights-as-other-states-restrict;-senate-expected-to-vote-friday/5323775/?fbclid=IwAR0NjVBsQMuTLP7ZfagsCoTROFiOGxZoegTXxc ssbrsXqns-PXPvRA85-M (“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 265 (“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*, THE GUARDIAN (Apr. 18, 2017), https://www.theguardian.com/society/2017/apr/18/late-term-abortion-experience-donald-trump?fbclid=IwAR0mEmCXFXbTV rPG2Gck9Vj1pAcT2N9FmoXhLS40TyyljJBT0h8D6XbZ4 (“if it meant Cate was going to suffer, we just couldn’t do that to her.”); Jia Tolentino, *How Abortion Law in N.Y. Will Change, And How it Won’t*, NEW YORKER (Oct. 20, 2016), https://www.newyorker.com/news/news-desk/how-abortion-law-in-new-york-will-change-and-how-it-wont (“if the child was born, he would suffer, and would
to suffer. He died in a warm and loving place, inside me. The thought of hearing him gasp for air and linger in pain was our nightmare. “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.” Many parents see abortion as “the palliative care procedure” their child “needed to prevent [their] suffering.” 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.” “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.” “Ending my pregnancy was the most selfless act of love I have ever committed.”

not live long; she 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 (June 19, 2019), https://www.youtube.com/watch?v=wjlIRg8tumU&feature=youtu.be&fbclid=IwAR3dk-QcINxDIUMT_hAksla9nDDP_NzX1vYRhUXxNCVGvWLYCTedcdnRJY (“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.”).


307 Allison Chang, Our Child Received A Devastating Diagnosis Before She Was Born. We Decided to Protect Her, STAT NEWS, https://www.statnews.com/2019/01/07/devastating-diagnosis-before-birth-trisomy-18/.


309 Sara Ahmed, This Story of One Woman’s Late-Term Abortion is a Powerful Reminder of Why Reproductive Rights Matter, BABBLE (2016), https://www.babble.com/parenting/late-term-abortion-story-reproductive-rights-matter. See also Hundredmark, supra note 305 (“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.”).


Parents are also extremely motivated to avoid the death, and corresponding grief, that comes with the loss of a wanted child. Those who choose termination grieve their children in the same way parents grieve natural fetal death. 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.” 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.

Just as parents are presumed to be acting in their child’s best interest when they choose to withhold life-sustaining treatment, 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. 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 shouldn’t 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. To the extent this is true, it is also true when parents are making end-

312 See, e.g., VICE News, supra note 304 (“I wasn’t recovering from an abortion, I was recovering from a loss of a child.”).

313 See, e.g., (“A part of me died that day, but there is not one ounce of me that regrets that decision.”); Triploidy—The Story of Zachary, Terminations Remembered (July 15, 2019), https://billmoyers.com/story/no-choice-valerie-peterson/?fbclid=IwAR2htrPIzO23mySuY2XfyR_5ttoyAWeK6TlH_c_pZxmU NW5LO3YxCFgQs (“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.”). Many parents experience intense grief for months, with 17% reporting post-traumatic stress disorder two to seven years post-procedure. Maguire et al., supra note 16, at 235.

314 Kurzweil, supra note 311.

315 No Choice, Moyers, https://billmoyers.com/story/no-choice-valerie-peterson/?fbclid=IwAR2htrPIzO23mySuY2XfyR_5ttoyAWeK6TlH_c_pZxmU NW5LO3YxCFgQs (last visited Aug. 31, 2019).
of-life choices for their children after birth, when the emotional and financial strains are real. 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 is to involve the state. At that point, the question for the court is 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.

If expectant parents are be 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. As a result, parents should have the right to terminate pregnancies after a Category I or II diagnosis, just as they have the right to withhold treatment on the basis of a Category I or II diagnosis after birth. Moreover, in the context of potential children, we actually know empirically that there is “no societal consensus about the ‘rightness’ of always deciding for ‘life.’” For Category I and II diagnoses, the majority of parents choose to terminate these pregnancies. And more than 70% of Americans support legal abortion “[i]f there is strong chance of a serious defect in the baby.” This reality makes it very difficult to prove that abortion is the wrong choice.

By excluding Category III diagnoses from the post-viability abortion right, I am not intending to vilify women who choose to

316 Field, supra note 126, at 95 (noting that after birth, parents are influenced by personal motives when deciding whether to withdraw or withhold life-sustaining treatment).
317 See Section II.
318 See Section II.C.
319 Goldstein, supra note 95, at 654–55.
320 See Section I.
321 Political Report, AEI (July/Aug. 2018), https://www.aei.org/wp-content/uploads/2018/07/Political-Report-July-August-2018.pdf. Though the survey responses likely reflect some ablest bias, the numbers have held steady for decades even as the disability rights movement has helped increase the rights and visibility of those living with disabilities. Id.
terminate in this situation. They too often abort out of love for their child and fears 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. 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, which may offend the disability-rights community.

2. **Same Action**

One could argue that abortion is fundamentally different from the withdrawal of life-sustaining treatment. But the reality is that the 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.\(^{322}\) The umbilical cord therefore acts as a feeding tube and ventilator to the potential child. In fact, many D&E abortion procedures 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.\(^{323}\) Fetal demise typically occurs within a few minutes after the cord is cut.\(^{324}\) 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.\(^{325}\) 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.\(^{326}\) Thus, abortions using either D&E or labor and delivery can act as a withdrawal of life-support.

\(^{322}\) Stephanie A. Schuette et al., *Perspectives from Patients and Healthcare Providers on the Practice of Maternal Placentaphagy*, 23 J. ALTERNATIVE & COMPLEMENTARY MED. 60, 60 (2017).


\(^{324}\) *Id.* at 714 (concluding that fetal death occurred an average of 3.35 minutes plus or minus 2.11 minutes).


\(^{326}\) See Fact Checking Rhetoric on Infants Surviving Abortions: Babies are Rarely Born Alive and When They are Doctors Don’t Kill Them, KHN Morning Briefing
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. 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* that citizens enjoy a “constitutionally protected right to refuse lifesaving hydration and nutrition” and other life-sustaining treatment, the Court later held in *Glucksberg* that citizens do not enjoy a constitutionally protected right to physician-assisted suicide. 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. By contrast, suicide was traditionally condemned. The Court determined that “the two acts are widely and reasonably regarded as quite distinct.” Though bioethicists have long debated whether there is any ethically relevant difference between killing versus letting die, physicians and courts do adhere to this distinction in practice.

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.


327 Tocce, *supra* note 323, at 712 (discussing fetal injection to induce demise).

328 *Cruzan*, 497 U.S. at 279.

329 *Glucksberg*, 521 at 728.

330 *Id.* at 725.

331 *Id.* at 728–30.

332 *Id.* at 725.


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. In fact, many doctors think this is a preferable approach clinically—it eliminates an unnecessary step that delays the abortion, adds expense, and creates additional maternal pain.\(^{335}\) The answer is a little more complicated starting in the third trimester when a D&E may be less safe than induction abortion.\(^ {336}\) Third trimester labor and delivery abortions often rely on the shot described above so that doctors do not have an ethical duty to treat the baby if he or she is born alive.\(^ {337}\) Though this is a very important step in third-trimester abortions of healthy babies—for whom doctors would have an ethical duty to treat—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.\(^ {338}\) 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.\(^ {339}\) This solution, however, does depend on doctors properly following the standard of care.\(^ {340}\)

\(^{335}\) Tocce, *supra* note 323, at 712. However, it is worth noting that it may be challenging for doctors to learn a new technique, and requiring them to change procedures could put make abortion riskier, at least in the short term.


\(^{338}\) See Section II.C.


\(^{340}\) It is worth noting that ideological 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 CENTER REPORT 22, 23-24 (1995); R. Alta Charo, *Physicians and the (Woman's) Body Politic*, NEW ENG. J. MED. (2014), http://www.nejm.org/doi/pdf/10.1056/NEJMp1313499. 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; the child survived, but with “severe physical and mental impairments and will never be able to care for herself.” 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 court dismissed the parents’ claim on the ground that the 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

Electronic copy available at: https://ssrn.com/abstract=3555943
It is also worth noting that the country as a whole is moving towards a recognition of the right to physician aid in dying. Ten states now permit physician-assisted suicide for terminally-ill individuals.\textsuperscript{341} While the analogy is not perfect,\textsuperscript{342} 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 decision to withdraw life-sustaining medical treatment on their critically ill infant or child. The right would simply extend existing parental rights to before birth.

3. \textit{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. One is that parents are making decisions for a child, while expectant parents are making decisions for potential child. Potential children are not people. \textit{Roe} made clear that fetuses are not persons under the Constitution,\textsuperscript{343} and that a state’s interest in regulating abortion rests in its interest in protecting “potential life,” not life.\textsuperscript{344} This distinction should suggest that the state has less of an interest in protecting potential children than living children. Some courts have been unwilling to find in the context of the Hyde Amendment that

\begin{footnotesize}
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\item of the child. \textit{Id.} at 768-69. Though this is a serious concern, third-trimester labor and delivery abortions are so uncommon that it would not be a pervasive problem.
\item Death with Dignity, \url{https://www.deathwithdignity.org/learn/death-with-dignity-acts/}.
\item 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). \textit{Id.} 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. \textit{Id.} Only fetuses with Category I diagnoses would likely qualify.
\item \textit{Roe}, 410 U.S. at 158.
\item \textit{Id.} at 150.
\end{itemize}
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the state has less of an interest in the potential life of a severely ill fetus than a healthy fetus.  However, this Article assumes that the state has some interest in the potential life of all fetuses (regardless of any fetal anomaly), but argues that this interest should be less than its interest in living children. If this were true, expectant parents should have even stronger rights against state intrusion into their parental health decisions as the state’s interests are weaker.

Some may worry that the argument advanced in this Article actually creates a slippery slope to personhood, thereby harming abortion rights in the long run. The concern is that encouraging the use of a standard developed for children in the context of fetuses would problematically equate the two. 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.”  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 this right 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.” 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 parental autonomy rights imagined children not as people, but as the property of their parents. The doctrinal hook of this argument, which is based the rights parenthood bestows, should therefore not create a slippery slope to personhood, which is based

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345 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, 1063 (9th Cir. 2005) with Karlin v. Foust, 188 F.3d 446, 489 (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.”).

346 Id. at 39–40.


on the inherent rights of people. And given the myriad of practical consequences that would result from giving fetuses personhood under the law—including the possibility that certain kinds of contraception and infertility treatments could be banned—

attempts to create personhood have been largely ineffective.\textsuperscript{349}

Second, the right would sit on top of pre-existing abortion rights, such as the right to abortion for any reason prior to viability under \textit{Casey}. The right would therefore be triggered only after a state’s post-“viability” abortion ban takes effect. After viability, the Supreme Court has already found that the state’s interest in protecting potential life can outweigh the mother’s interests.\textsuperscript{350} Fundamentally, my argument is simply that \textit{even assuming} 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 than living children, which is anomalous. As explained above, one would actually expect that the state would have a weaker interest in protecting potential children than living children.

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, therefore, not only forces both expectant parents to delay decisions they are entitled to make, but also forces the expectant mother 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.\textsuperscript{351}

\textsuperscript{349} Maya Manian, \textit{Lessons from Personhood’s Defeat: Abortion Restrictions and Side Effects on Women’s Health}, 74 OHIO ST. L. J. 1, 13-20 (2013).

\textsuperscript{350} Roe, 410 U.S. at 163, 93; \textit{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.”).

\textsuperscript{351} Claire Cullen-Delsol, \textit{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 (“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
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. 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. Again, this difference between end-of-life decision-making for children and potential children supports even stronger parental rights for expectant parents—in particular, expectant mothers—over parents of living children. Thus, the differences between parents and expectant parents demonstrate that the state interests are arguably weaker while the parental rights are greater.

* * *

In all legally 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 on 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 or women, who in the midst of a great trauma, must travel at significant expense to obtain an abortion. Second, the anti-abortion movement has spent decades chipping away slowly at abortion rights. This Article flips that strategy on its head and lays

352 See Field, supra note 126, at 94.
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 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.\(^{353}\) Stories of parents who discovered on an ultrasound that their child could not survive or would have to fight to survive, only to live with serious disabilities, engendered compassion from other parents and softened the American public to the concept of medically-necessary abortion.\(^{354}\) Starting in the eighties with the Baby Doe controversy, however, the anti-choice movement started changing the narrative surrounding these abortions.\(^{355}\) It wanted to shape its image as a defender of civil rights, and disability rights became a convenient and natural avenue to do so.\(^{356}\) Pro-life activists started to “present[] pro-choice organizations as heartless and indifferent to the struggles of weak, vulnerable, and handicapped persons.”\(^{357}\) The anti-choice community lobbied for the CAA and participated greatly in the litigation surrounding Baby Jane Doe and the regulatory efforts that preceded the CAA.\(^{358}\)

Tensions between the reproductive rights and disability rights communities were again strained when the federal government banned a particular type of abortion procedure (the D&X), dubbed by conservatives as a partial birth abortion.\(^{359}\) Pro-choice activists defended the D&X by arguing that the procedure was often the safest technique for women terminating on the basis

\(^{353}\) Ziegler, supra note 253, 604–05.

\(^{354}\) Id. at 594–95.

\(^{355}\) Id. at 603–05.

\(^{356}\) Id.

\(^{357}\) Id. at 603.


\(^{359}\) Ziegler, supra note 253, at 608
of fetal anomaly.\textsuperscript{360} The frequent defense of abortion by reference to fetal anomaly frustrated the disabled community, who “questioned the ease with which many turned to abortion in fetal-defect cases.”\textsuperscript{361} And many disability rights activists felt that leaders in the reproductive rights movement could acknowledge “no room for solutions that acknowledged the moral ambiguity of disability-based abortion.”\textsuperscript{362}

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 \textit{Planned Parenthood v. Casey}\textsuperscript{363}—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 the fetus’ 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.\textsuperscript{364}

\textsuperscript{360} Id.
\textsuperscript{361} Id.
\textsuperscript{362} Id. at 611.
\textsuperscript{363} Donley, supra note 278, at 326–27.
By changing the framing, the pro-choice community can avoid any claims 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.365

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.”366 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 collectively, and so parents should be empowered to play a lead in decision making throughout the process.”367

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.368 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

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365 Ziegler, *supra* note 253, at 625.
367 *Id.*
368 *Id.* at 627.
in question” without pressuring any particular choice. 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 online 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.”

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.

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.

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.”

This Article also fits nicely into recent attempts to view abortion as a parenting decision. For example, Jamie Abrams criticizes the stereotypes that paint women as selfish decision makers when it comes to abortion decisions, but selfless decision

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370 Id.
372 Jesudason & Epstein, supra note 370, at 542.
373 Ziegler, supra note 253, at 628.
makers when it comes to parenting decisions—i.e., by presuming that mothers are always acting in their child’s best interests. She notes that neither perception is perfectly accurate. Rather, women make abortion and parenting decisions after considering the interests of both themselves and their families. 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. Those abortion decisions are also parenting decisions based on the needs of a family.

 Abrams advocates for “a unified framing of reproductive and parenting decision-making.” She argues that “[p]ositioning abortion decision-making in a unified frame with parental decision-making would powerfully debunk troublesome and demonizing myths about why women terminate pregnancies.” It would also “challenge[] the monopoly on morality that the pro-life movement currently holds.” She suggests that “crossing longstanding boundaries [between abortion and parenting] may be necessary to move the movement forward.”

 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 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, and even when parents make the choice to withhold or withdraw life-saving treatment for a dying child, courts will respect that decision unless

375 Id.
376 Id. at 22–29.
377 Id.
378 Id. at 22–24.
379 Id. at 48.
380 Id. at 49.
381 Id.
382 Id. at 39.
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 any pregnancy, even after viability, if the termination is based on a severe, 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.