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**Title:** The Case of Louisiana's "Medically Futile" Unborn Child List: Ethical Lessons at the post-Dobbs Intersection of Reproductive and Disability Justice

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**Abstract:** Ableist attitudes and structures regarding disability are increasingly recognized across all sectors of healthcare delivery. After Dobbs, novel questions arose in the USA concerning how to protect reproductive autonomy while avoiding discrimination against and devaluation of disabled persons. As a case study, we examine the Louisiana's Department of Public Health August 1st Emergency Declaration, "List of Conditions that shall deem an Unborn Child 'Medically Futile.'" We raise a number of medical, ethical, and public health concerns that lead us to argue the declaration should be rescinded. The ethically objectionable declaration provides valuable lessons concerning how to uphold both reproductive and disability justice in a post-Dobbs landscape.

**Keywords:** Dobbs; reproductive justice; disability justice; ableism, medical futility

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Following the Supreme Court’s *Dobbs* decision, state agencies and healthcare systems rushed to determine its implications for reproductive healthcare delivery, including qualifications for emergency conditions and other exceptions under strict state-level anti-abortion laws. Louisiana updated its sweeping abortion restrictions with Senate Bill 342, effective as a “trigger law” days before *Dobbs*. One of its few exceptions is the “removal of an unborn child who is deemed to be medically futile.”<sup>1</sup> To further clarify this exception, on August 1, 2022, the Louisiana Department of Health issued a declaration of emergency: “List of Conditions that shall deem an Unborn Child ‘Medically Futile.’” This list provides physicians with several diagnoses that would permit abortion “due to the unborn child having a profound and irremediable congenital or chromosomal anomaly that is incompatible with sustaining life after birth.”<sup>2</sup>

We find Louisiana’s emergency declaration (LED hereafter) to be objectionable for at least three reasons: (1) its mistaken use of the concept of “medical futility,” (2) its factually erroneous descriptions of some of the diagnoses in question and mistaken assumptions about disability in general, and (3) the multiple unethical implications it harbors for perpetuating ableism. These critiques are interwoven and reinforce each other. Although the authors of this piece support reproductive autonomy and the goal of urgently and capaciously expanding protected options for pregnant persons, we argue that LED is a misguided response to the post-*Dobbs* reproductive landscape and that states seeking to uphold evidence-based healthcare delivery should learn from its lessons. Our critique of LED exists within a much larger body of work that calls upon medical professionals to better understand the social, legal, and political dimensions of disability.<sup>3</sup>

### **Avoiding Regression and Error with the Term ‘Medical Futility’**

The LED blanket labels any fetus with one of the listed diagnoses as “medically futile.” The concept of futility has a fraught history in medicine that is evidenced by decades of debate among medical ethicists

and practitioners, but current consensus is that ‘futility’ is an evaluation of treatments in particular circumstances, not a label applied to certain diagnoses or to certain patients. As Griffin Trotter describes the issue as far back as 1999, for a treatment to be considered futile, there must be: (1) a goal, (2) a treatment aimed at achieving that goal, and (3) virtual certainty that treatment will fail. We can certainly debate about (1) and (3)—what goals are worthwhile and how low the probability needs to be that the treatment will fail—but one cannot categorically stipulate that a fetus with a given diagnosis is futile, for care decisions should depend on what our goals are as well as further particular determinates of the fetus and pregnant person in question.<sup>4</sup> Treatments can be futile or not, but conditions and the patients with them cannot be.

Moreover, clinicians commonly say that it is *unethical* to offer a futile treatment and that doing so would violate professional standards. Labeling everything in the LED list as “futile conditions” suggests that it is not ethically justifiable to offer treatment to anyone with these conditions. Given this, the LED doesn’t just give pregnant people legal permissions with respect to abortion in the context of certain fetal diagnoses; it implicitly *prohibits* attempts to treat or maintain support for certain conditions.

At first blush, the LED increases reproductive choice by expanding the availability of abortion to women who carry fetuses with certain genetic markers. As it is written, however, the LED also limits reproductive choice by leading to a situation where pregnant people who wish to bring a fetus to term with one of the listed conditions may be encouraged not to do so. That contravenes even the most basic understandings of patient autonomy, a foundational bioethical value, which might be undermined when pregnant people are nudged or otherwise encouraged not to have significantly disabled children in the first place.<sup>5</sup> Disability bioethicists have long argued that selective termination based on disability risk can be discriminatory and perpetuate ableism, especially insofar as such decisions are based in mistaken assumptions concerning the links between disability and quality of life.<sup>6</sup> This is in part because qualitative social scientific research suggests that

neonatal healthcare workers often believe that severe disability is worse than death.<sup>7</sup> Lastly, the implications of futility language as deployed in the LED may undermine efforts at perinatal palliative care and hospice, which many states will need to ramp up in light of post-*Dobbs* legislative restrictions.

### **Avoiding Factual Errors and Mistaken Assumptions about Disability**

To be charitable, the authors of LED seem to mean “lethal condition” when they invoke “futility” (though this is still a misuse of the term, as we described in the previous section). Yet, even within the category of a “lethal condition,” there is considerable variation and debate. Some conditions that were once considered lethal are now being treated, and the result is that many children are living longer than expected. For example, it is inappropriate to call trisomy 13 or 18 (both on the LED list) a “lethal chromosomal anomaly.” Over 12 years ago, *The Textbook of Neonatal Resuscitation* of the American Heart Association and the American Academy of Pediatrics removed trisomy 18 from the list of diagnoses for which it is considered ethical not to initiate resuscitation at birth.<sup>8</sup> A 2012 multi-year cross-sectional assessment of hospitalization data for American children with trisomies 13 and 18 revealed that when more medical interventions are performed than was done previously, the overall morbidity and mortality numbers for these conditions decrease and that the term “lethal” is thus unjustified.<sup>9</sup> There is not space here to unpack the evidence with all 24 conditions in the LED, but it is notable that hydrops fetalis and mosaic trisomy 22 have for many years now also been understood as potentially survivable conditions with treatment.

A central mistaken assumption underlying the LED is that the listed genetic conditions preclude a life worth living. This is an error fundamental to ableism. Unfortunately, ableism remains an entrenched moral challenge in medicine. By “ableism,” we mean interpersonal and structural discrimination against and oppression of persons with disabilities.<sup>10</sup> Bias against as well as lowered expectations for disabled people by the nondisabled results in the underestimation of the quality of

life of disabled people by the general public and in medical practice. For example, in a 2021 survey of practicing physicians in the USA, 82.4 percent of 714 physicians report that people with significant disability have worse quality of life than nondisabled people.<sup>11</sup> This survey is just one of many done by Iezzoni and colleagues that shows how pervasive ableism is among clinicians, for the judgment that disabled people have lower quality of life is demonstrably false.<sup>12</sup> It directly conflicts with a large, decades-long body of social scientific research suggesting that people with significant disability, just as with non-significant disability, experience similar, not lower levels of quality of life (QOL) as non-disabled people.<sup>13</sup> In related research, physicians reported feeling unaware of or overwhelmed by disability accommodation needs, leading to their discharging patients with disabilities from their practice and thus limiting these patients' healthcare access. These studies demonstrate how ableism operates at multiple levels of providers' attitudes, knowledge gaps, and discriminatory practices.

As the 2019 report *Medical Futility and Disability Bias* by The National Council of Disability argues, judgments concerning quality of life with disability are often inconsistent and misguided among medical practitioners and institutions. These determinations can be significantly affected by ableist biases about what lives are worth living, ethically fraught diagnostic and prognostic standards, communication challenges in clinical settings, and physical and programmatic access barriers to providing equal care to patients with a range of disabilities.<sup>14</sup> Real moral harm occurs when individual biases and barriers to care result in systemic and structural discrimination against disabled people. Structural ableism, along with a general misunderstanding and mischaracterization of the experiences of disabled people, can result in clinicians predicting a much lower quality of life and higher chance of mortality of infants than bear out in reality. In practice, false futurity narratives combined with uncertain prognoses can create an unjustified case for termination.<sup>15</sup> The ethically questionable assumptions and patent errors evident in the LED exacerbate these false narratives.

## **Avoiding the Perpetuation of Ableism and Disability Discrimination Post-*Dobbs***

The LED perpetuates disability discrimination and ableism in an especially egregious way by framing the “list of conditions that shall deem an unborn child ‘medically futile’” as necessary due to the “potential imminent peril to public health, safety or welfare” that would result without this list.<sup>16</sup> Whatever the intent, this opening statement does not seem to be a call to protect pregnant persons in medically unsafe situations (as that is a separate exception under SB 342 altogether); instead, the language and framing suggest that the listed conditions are themselves threats to the public. The LED thus goes beyond considerations of individual reproductive decision-making to a justification based in public welfare, which tragically echoes explicitly eugenic reasoning concerning people with significant disability that healthcare has stridently tried to move away from for decades. Public health values do not—and should not—include judging certain forms of disabled life as a threat to the public welfare.

The moral failings of LED are due in no small part to cultural misconceptions about disability. Health care professionals as well as public policy officials and law makers need to be educated on the latest evidence regarding life expectancy and quality of life for disabled persons as well on the social model of disability and disability rights. As disability bioethicists have suggested, there is great need for disability cultural competency that focuses on “how social and cultural structures influence health outcomes and shape personhood.”<sup>17</sup> Healthcare leaders and policymakers should acknowledge and compensate expertise where they lack it, including and especially regarding disability justice. We find it right to use the institutional power of medicine and professional power of clinicians to protect reproductive autonomy but using the concept of medical futility as the LED does fails both to protect reproductive autonomy and also to avoid ableism. Policy-makers need to do more to ensure that disability discrimination is avoided in the efforts to establish best practices in a post-*Dobbs* world.

To be clear, we do not wish to suggest a solution that involves increased prenatal testing, whether invasive or noninvasive, in order to gain clarity on the diagnostic or prognostic considerations of a given fetus. The ethical stakes of the LED are not ultimately about testing or diagnostic clarity—they are about understanding the most recent evidence regarding life expectancy and quality of life for severely disabled newborns, as well as protecting genuine reproductive autonomy. Upholding both reproductive justice and disability justice requires that we attend to evidence and work hard to avoid discrimination on the basis of *any* of the ways we group people, including in terms of disability.

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<sup>1</sup> Louisiana Senate. *Act No. 545*. Senate Bill 342. 17 June 2022, sect. 87.1, (19)(a). <https://legis.la.gov/legis/ViewDocument.aspx?d=1289698>.

<sup>2</sup> Louisiana Department of Health. Office of Public Health. *List of Conditions that shall deem an unborn child "Medically Futile."* LAC 48:I:Chapter 4.101. 1 August 2022. [https://ldh.la.gov/assets/oph/Rulemaking/er/LDH\\_ER\\_List\\_of\\_Conditions\\_that\\_Shall\\_Deem\\_an\\_Unborn\\_Child\\_Medically\\_Futile\\_CLV\\_Signed\\_and\\_Dated\\_1\\_August\\_2022.pdf](https://ldh.la.gov/assets/oph/Rulemaking/er/LDH_ER_List_of_Conditions_that_Shall_Deem_an_Unborn_Child_Medically_Futile_CLV_Signed_and_Dated_1_August_2022.pdf).

<sup>3</sup> D. Mukherjee, P.S. Tarsney, and K.L. Kirschner. "If Not Now, Then When? Taking Disability Seriously in Bioethics," *Hastings Center Report* 52, no. 3 (2022): 37–48. R. Garland-Thomson. "Evaluating the Lives of Others." *American Journal of Bioethics* 22, no. 9 (2022) :30-33. R. Garland-Thomson and J.M. Reynolds. "Rethinking Fetal Personhood in Conceptualizing Roe." *American Journal of Bioethics* 22, no. 8 (2022): 64-68. J.M. Reynolds, *The Life Worth Living: Disability, Pain, and Morality* (Minneapolis: University of Minnesota Press, 2022).

<sup>4</sup> G. Trotter. "Response to 'Bringing Clarity to the Futility Debate: Don't Use the Wrong Cases' by Howard Brody and 'Commentary: Bringing Clarity to the Futility Debate: Are the Cases Wrong?' by L.J. Schneiderman (CQ Vol 7, No 3). *Cambridge Quarterly of Healthcare Ethics* 8, no. 4 (1999): 527 - 537. Doi: 10.1017/S0963180199004156.

<sup>5</sup> J. 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." *American Journal of Medical Genetics Part A* 164, no. 2 (2014): 308-318.

<sup>6</sup> This body of work has been developed since at least the mid-1990s. For example, see: E. Parens and A. Asch, "Special Supplement: The Disability Rights Critique of Prenatal Genetic Testing Reflections and Recommendations." *The Hastings Center Report* 29, no. 5 (1999): S1–22; A. Asch and D. Wasserman. "Where Is the Sin in Synecdoche? Prenatal Testing and the Parent-Child Relationship," in *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, ed. D. Wasserman, J. Bickenbach, and R. Wachbroit (Cambridge: Cambridge University Press, 2005), 172–216; E. Dietz. "Abortion, Disability

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<sup>7</sup> H.S. Lam et al. “Attitudes toward Neonatal Intensive Care Treatment of Preterm Infants with a High Risk of Developing Long-Term Disabilities.” *Pediatrics* 123, no. 6 (2009): 1501–1508.

<sup>8</sup> American Academy of Pediatrics and American Heart Association. *Textbook of Neonatal Resuscitation* (Elk Grove Village, IL: American Academy of Pediatrics, 2010).

<sup>9</sup> K.E. Nelson, K. R. Hexem, and C. Feudtner. “Inpatient Hospital Care of Children with Trisomy 13 and Trisomy 18 in the United States.” *Pediatrics* 129, no. 5 (2012): 869-876; J.D. Lantos. “Trisomy 13 and 18—Treatment Decisions in a Stable Gray Zone,” *JAMA* 316, no. 4 (2016): 396-98.

<sup>10</sup> There is a very large body of work on the concept of ableism. As an entry point, see: M.R. Nario-Redmond, *Ableism: The Causes and Consequences of Disability Prejudice* (New York: Wiley-Blackwell, 2019).

<sup>11</sup> L.I. Iezzoni et al. “Physicians’ Perceptions of People with Disability and Their Health Care.” *Health Affairs* 40, no. 2 (2021): 297–306; National Council on Disability. *Quality-Adjusted Life Years and the Devaluation of Life with a Disability* (Washington, DC: National Council on Disabilities, 2019):  
[https://ncd.gov/sites/default/files/NCD\\_Quality\\_Adjusted\\_Life\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf).

<sup>12</sup> N. Agaronnik et al. “Communicating with Patients with Disability: Perspectives of Practicing Physicians.” *Journal of General Internal Medicine* 34, no. 7 (2019): 1139-1145; L.I. Iezzoni et al. “US Physicians’ Knowledge About the Americans With Disabilities Act And Accommodation Of Patients With Disability.” *Health Affairs* 41, no. 1 (2022): 96-104. N.D. Agaronnik et al. “Knowledge of Practicing Physicians About Their Legal Obligations When Caring For Patients With Disability.” *Health Affairs* 28, no. 4 (2019): 545-553.

<sup>13</sup> This has been studied since at least the 1990s and is a phenomenon so well-known that it has its own name, though controversial: “the disability paradox.” G.L. Albrecht and P.J. Devlieger. “The Disability Paradox: High Quality of Life Against All Odds.” *Social Science & Medicine* 48, no. 9 (1999): 977-88.

<sup>14</sup> National Council on Disability, *Medical Futility and Disability Bias* (Washington, DC: National Council on Disability, 2019):  
[https://ncd.gov/sites/default/files/NCD\\_Medical\\_Futility\\_Report\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf).

<sup>15</sup> J.A. Stramondo. “Disability and the Damaging Master Narrative of an Open Future.” *Hastings Center Report* 50, suppl. 1 (2020): S30-S36.

<sup>16</sup> Louisiana Department of Health. Office of Public Health. *List of Conditions that shall deem an unborn child “Medically Futile.”*

<sup>17</sup> R. Garland-Thomson and L.I. Iezzoni. “Disability Cultural Competence for All as a Model.” *American Journal of Bioethics* 21, no. 9 (2021) 26-28.