Counting Stillbirths

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Stillbirths — pregnancy losses after 20 weeks of pregnancy but before birth — are interfering with the right to have and parent a child, a centerpiece of the reproductive justice movement. And this interference is disproportionately affecting marginalized persons, as Black women and poor women face double the risk of stillbirth compared to white women and those with higher socioeconomic status, respectively.

Hampering our ability to prevent stillbirths is our data systems. Currently, we count stillbirths in the United States via state-issued fetal death certificates ("FDCs"). Studies, however, demonstrate that FDCs are underreporting stillbirths, especially early stillbirths, which Black women face triple the risk of. Studies also show that FDCs commonly lack data and contain inaccurate data.

This Article argues for legal reforms to make stillbirths count. The first is to legally routinize fetal autopsies, modeled after state laws' routinization of autopsies after suspected Sudden Infant Death Syndrome deaths. The second reform is to create stillbirth public health surveillance registries. Surveillance registries, which commonly exist for illness and injuries, will better ensure complete and accurate data. Improved data and data collection means effective epidemiological studies and proper public health prioritization of stillbirth.

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The Article also necessarily addresses the increasing criminalization of stillbirth and the possibility that registries would contribute to this disturbing response pursued most often against marginalized women and persons. The answer is not to avoid research, but instead to legislatively protect the data and otherwise prevent the prosecutions. These prosecutions are counterproductive as they deter pregnant people from seeking prenatal care — which will increase stillbirths. They are also cruel. Stillbirth already involves the natural punishments of your child's death and childbirth of that child. Prosecutions will reinforce self-blame and further traumatize those prosecuted, who are also likely to lack access to mental health care.

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INTRODUCTION

In 2015, Ana Vick gave birth to her stillborn son, Owen Nathaniel, when she was thirty-one weeks pregnant.[1] The pregnancy had been normal; she had no reason to suspect any problem until that night when she noticed Owen wasn't moving in her womb and she went to the hospital.[2] Eventually, Ana was undergoing an emergency c-section. Owen showed no signs of life at birth and the doctor's efforts to resuscitate him were unsuccessful.[3]

The trauma did not end with Owen's birth. The next morning, the doctor asked whether they wanted an autopsy.[4] Fetal autopsies are the "gold standard" in determining the cause of death,[5] but the doctor neither explained that nor encouraged the Vicks to have one. Instead, he commented that Owen would likely not look the same after, sewn back up, and that many families decide against an autopsy because it may not determine the cause of death — meaning the baby's body would be cut open for nothing.[6] Not surprisingly, Ana and her husband declined an autopsy, a decision they now regret.[7]

Before they left the hospital without Owen, the Vicks were given a hospital birth certificate and instructions of how to later obtain an official one from the county.[8] Months later, when she felt strong enough to do so, Ana went to the county office to obtain Owen's birth certificate only to be told that he was not in the system.[9] After inquiring, the hospital told Ana it had made a mistake regarding a birth certificate. Instead, Owen's death, a stillbirth, would be registered only as a fetal death with issuance of a fetal death certificate ("FDC").[10] The only legal record issued would not acknowledge Owen's birth, only his death.

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[1] Telephone Interview with Ana Vick (Feb. 28, 2021) (notes on file with author).

[2] *Id.*

[3] *Id.*

[4] *Id.*

[5] *See infra* Part III.A.

[6] Telephone Interview with Ana Vick, *supra* note 1.

[7] *Id.* When they later visited a lawyer to inquire about legal options for Owen's death, they were told the lack of an autopsy would make their case more difficult. *Id.*

[8] *Id.*

[9] *Id.*

[10] *Id.*

Stillbirth is the death of the fetus in the womb after twenty weeks of pregnancy, but before birth.[11] Ana is one of at least 24,000 people[12] who give birth to their stillborn child every year in the United States.[13] About 1 in 160 childbirths is a stillbirth.[14] Black women face double the risk of stillbirth compared to white women, with 1 in 87 Black women's pregnancies ending in stillbirth.[15] Poor women similarly face double the risk of stillbirth compared to women with more economic means. The United States' current stillbirth rate is higher than the rate in most other high-income countries. Our rate has also been relatively stagnant for most of this century, whereas other high-income countries have decreased their rates by over 20% within the past decade.[16] Unfortunately, our stillbirth numbers are very likely to increase due to

[11] *What Is Stillbirth?*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/stillbirth/facts.html (last updated Nov. 16, 2020) [https://perma.cc/UHZ2-BBC5].

[12] Persons who do not identify as women are capable of pregnancy and childbirth. Trans men and gender nonbinary people also need reproductive healthcare and experience pregnancy loss. These people often struggle to access appropriate care due to stigma and marginalization. For instance, in 2019, hospital health care providers refused to entertain the possibility of pregnancy of a transgender man, a misdiagnosis that eventually led to his child's stillbirth. *See* Marilynn Marchione, *Blurred Lines: A Pregnant Man's Tragedy Tests Gender Notions*, ABC NEWS (May 15, 2019, 5:30 PM), https://abcnews.go.com/Health/wireStory/blurred-lines-pregnant-mans-tragedy-tests-gender-notions-63062856 [https://perma.cc/BZ25-QG28]. This Article uses the term pregnant person or birthing parent, an emphasis is needed to convey that stillbirth involves pregnancy, childbirth, and parenthood. At the same time, conversations about pregnancy loss have always been gendered, and laws and policy choices impact women as a class. Also, this Article relies heavily on stillbirth research of women, and that research can only be relied on for women. Due to these numerous needs, I will use both gender inclusive and gendered terms.

[13] *What Is Stillbirth?*, *supra* note 11. This 24,000 number is an undercount because it is based on FDCs filed, and numerous studies have shown that FDCs are undercounting stillbirths. *See infra* Part IV.B.

[14] *What Is Stillbirth?*, *supra* note 11.

[15] Sarah Muthler, *Stillbirth Is More Common than You Think — And We're Doing Little About It*, WASH. POST. (May 16, 2016, 6:00 AM EDT), https://www.washingtonpost.com/posteverything/wp/2016/05/16/stillbirth-is-more-common-than-you-think-and-were-doing-little-about-it/ [https://perma.cc/9ZLA-AVRU].

[16] *See* Vicki Flenady, Aleena M. Wojcieszek, Philippa Middleton, David Ellwood, Jan Jaap Erwich, Michael Coory, T. Yee Khong, Robert M. Silver, Gordon C.S. Smith & Frances M. Boyle et al., *Stillbirths: Recall to Action in High-Income Countries*, 387 LANCET 691, 693 (2016) (describing that the U.S.'s annual percentage stillbirth rate reduction from 2000-2015 was lower than all but one other high-income country).

COVID-19 infections in pregnant people,[17] and the reversal of *Roe v. Wade*.[18]

Stillbirth is interfering with the right to have a child and parent that child with dignity, especially for Black and poor women. Unlike the more narrow abortion-focused reproductive rights movement, the reproductive justice framework recognizes the right to have a child and parent with dignity as equally important to the right to abortion.[19] One cannot give birth to and raise a child, however, unless they are able to get pregnant and *stay* pregnant.[20] This Article builds on my prior work arguing for the integration of pregnancy loss into the reproductive justice movement, specifically focusing on legal reforms to improve stillbirth prevention.[21]

Crucial to getting the United States back on track in decreasing its stillbirth rate is reliable population-based data on stillbirth. Without this data, epidemiological studies — studies of how often and why diseases occur in populations — "of risk factors and causes of stillbirth are challenging" at best.[22] Further, without proper data, it is impossible to effectively educate the public and policymakers about possible prevention efforts. As a 2021 Comment published in the medical journal the Lancet explained, "[r]educing preventable stillbirths . . . must be a global priority. This goal . . . requires the data to track and guide public health action."[23]

In the United States, both data and data collection are currently lacking. A common refrain in the stillbirth community is "we count

[17] *See* Erika Edwards, *Delta Variant Linked to Increased Risk of Stillbirth, CDC Study Finds*, NBC NEWS, https://www.nbcnews.com/health/health-news/delta-variant-linked-increased-risk-stillbirth-cdc-study-finds-rcna6152 (last updated Nov. 22, 2021, 6:37 AM PST) [https://perma.cc/T9JU-4SLE].

[18] *See* Greer Donley & Jill Wieber Lens, *Second-Trimester Abortion Dangertalk*, 62 B.C. L. REV. 2145, 2171 n.183 (2021) [hereinafter *Second-Trimester Abortion*] (discussing the connection between abortion and stillbirth rates).

[19] *See infra* Part I.

[20] *See infra* Part I.

[21] *See* Jill Wieber Lens, *Miscarriage, Stillbirth, & Reproductive Justice*, 98 WASH. U. L. REV. 1059, 1111-14 (2021) [hereinafter *Reproductive Justice*].

[22] Wes Duke & Suzanne M. Gilboa, *The Utility of Using an Existing Birth Defects Surveillance Program to Enhance Surveillance Data on Stillbirths*, 41 J. REGISTRY MGMT. 13, 13 (2014); *see also id.* at 17 ("Complete and reliable surveillance data is needed if hypothesis-driven epidemiologic studies are to be conducted.").

[23] Caroline S.E. Homer, Susannah Hopkins Leisher, Neelam Aggarwal, Joseph Akuze, Delly Babona, Hannah Blencowe, John Bolgna, Richard Chawana, Aliki Christou & Miranda Davies-Tuck et al., *Counting Stillbirths and COVID 19 — There Has Never Been a More Urgent Time*, 9 LANCET e10, e11 (2021).

what matters."[24] And frankly, stillbirth does not matter. The fetus is front and center in American life — in pregnancy announcements and antiabortion billboards — but not the stillborn fetus. The reproductive justice framework, however, requires recognition that far too many pregnancies end in stillbirth.

The Article details two legal reforms to improve population-based data. The first is to improve data by legally standardizing fetal autopsies after stillbirth.[25] Fetal autopsies are the "gold standard" in determining the causes of stillbirth, yet they are rarely completed in the United States. Doctors either do not mention their possibility or do so in a discouraging way. The cost is also a major obstacle, with most parents having to pay out of pocket. This Article advocates for legal routinization of autopsies after stillbirth, the same as many states do for after suspected deaths due to Sudden Infant Death Syndrome ("SIDS") and other infant and child deaths.[26] States have identified SIDS prevention as a public health priority.[27] Stillbirth is *ten times* more likely than a SIDS death.[28] These already-existing state laws provide an easy blueprint for autopsies after stillbirth.

The Article's next suggested reform is to improve data collection.[29] Currently, stillbirths are recorded only with FDCs.[30] The process is decentralized, leaving states to define when a FDC is even issued, immediately creating nonuniformity. Studies demonstrate the woeful inadequacies of FDCs — they are underreporting stillbirths, missing important information, and full of inaccurate information. This Article advocates instead for the creation of stillbirth surveillance public health registries.[31] Registries enable active surveillance of stillbirths, getting information directly from hospitals and from medical records, allowing

[24] *See* J. Frederik Frøen, Sanne J. Gordijn, Hany Abdel-Aleem, Per Bergsjø, Ana Betran, Charles W. Duke, Vincent Fauveau, Vicki Flenady, Sven Gudmund Hinderaker & G. Justus Hofmeyr et al., *Making Stillbirth Count, Making Numbers Talk - Issues in Data Collection for Stillbirths*, 9 BIOMED CENT. 58 (2009); Homer et. al., *supra* note 23, at e11; Joy E. Lawn, Hannah Blencowe, Robert Pattinson, Simon Cousens, Rajesh Kumar, Ibinabo Ibiebele, Jason Gardosi, Louise T. Day & Cynthia Stanton, *Stillbirths: Where? When? Why? How to Make the Data Count?*, 377 LANCET 1448, 1449 (2011).

[25] *See infra* Part III.A.

[26] *See infra* Part III.B.

[27] *See infra* Part III.B.

[28] Joanne Cacciatore, *Effects of Support Groups on Post Traumatic Stress Responses in Women Experiencing Stillbirth*, 55 OMEGA 71, 72 (2007) [hereinafter *Effects of Support Groups*].

[29] *See infra* Part IV.

[30] *See infra* Part IV.B.

[31] *See infra* Part IV.C.

researchers to gather complete and accurate data. Registry abstractors can easily obtain any data that could be missing from a FDC and correct any inaccurate data. Clinicians also review the data to determine if the fetal death was a stillbirth. What results is much better public health data than what can be gathered from FDCs. The Stillbirth Health Improvement and Education for Autumn Act of 2021, which creates grants for states to create stillbirth registries, passed with broad bipartisan support in the U.S. House of Representatives in December 2021.[32]

The Article then addresses a very problematic possible unintended consequence of fetal autopsies and registries — blame and potential criminal consequences for birthing parents when stillbirth does occur.[33] Blame is not new, however. Studies confirm that women already both blame themselves and feel blamed by others. Notably, the lack of research into the causes of stillbirth perpetuates this blame, meaning research may help alleviate it.[34]

Blame can unfortunately also be more tangible. Despite the lack of evidence connecting drug use and stillbirth, prosecutions for drug use during pregnancy ending in stillbirths are on the rise.[35] Prosecutors have targeted marginalized women, the same marginalized persons who already face double the risk of stillbirth. These prosecutions are likely to increase after the Supreme Court's reversal of *Roe v. Wade*. This reversal will both cause an increase in stillbirths and suspicions when they do occur.

This Article advocates for stillbirth *surveillance* registries.[36] The word *surveillance* is especially concerning to those working to protect the right to abortion and the rights of pregnant people.

This Article acknowledges this danger. But the solution to these prosecutions is not to preclude research that could help reduce stillbirths in the first place. We do, however, need to protect this public health data. Legislation creating registries can and should protect privacy and preclude law enforcement use.[37]

The Article otherwise also joins the call to end these extremely counterproductive prosecutions.[38] Public health experts overwhelmingly agree that prosecutions will actually increase stillbirths

[32] *See* H.R. 5487, 117th Cong. (2021).
[33] *See infra* Part V.
[34] *See infra* Part V.A.
[35] *See infra* Part V.B.
[36] *See infra* Part IV.C.
[37] *See infra* Part IV.C.
[38] *See infra* Part V.B.

because pregnant people will not seek prenatal care.[39] A recent empirical study of Tennessee's fetal endangerment law affirms this result.[40]

What this Article specifically adds to this ongoing conversation about criminalization is an emphasis on its cruelty. Stillbirth already involves the natural punishments of self-blame for your child's death and giving birth to that dead child.[41] State reinforcement of that self-blame could be debilitating, especially for marginalized persons who likely lack access to mental health care.

The organization of the Article is as follows. Part I argues for the integration of stillbirth into the reproductive justice framework. Part II describes the commonality and purposes of public health surveillance registries. Part III describes how data on stillbirth is lacking in this country due to the lack of fetal autopsies and argues that states should pay for fetal autopsies after stillbirth the same as they do after suspected SIDS deaths. Part IV describes our inadequate data collection efforts and argues for the creation of stillbirth surveillance registries. Part V then addresses the concern that stillbirth registries could be used as part of efforts to criminalize stillbirth. The risk is real, although likely exaggerated. But the solution to criminalization is to prevent prosecutions, not to preclude research. Part VI briefly concludes.

I. STILLBIRTH PREVENTION AS A REPRODUCTIVE JUSTICE ISSUE

I have previously introduced the idea of integrating rights related to pregnancy loss into the reproductive justice movement. Briefly, the historical reproductive rights movement focused mostly on the right to *not* have a child through contraception and abortion.[42] Women of color were concerned that this focus was too narrow and failed to reflect the type of reproductive oppressive that marginalized women often faced — prevention of reproduction.[43] And thus, women of color introduced a more holistic focus, not just on the right to have a child, but also on the equally important rights to not have a child and to have one and parent that child with dignity.[44] This broader focus thus included emphases on sterilization initiatives aimed at marginalized women, and

[39] *See infra* notes 417–18 and accompanying text.

[40] *See infra* notes 424–32 and accompanying text.

[41] *See infra* Part V.A.

[42] Lens, *Reproductive Justice*, *supra* note 21, at 1065.

[43] *Id.* at 1066-67.

[44] *Id.* at 1067-68.

access to infertility treatments, given that this health care is normally unobtainable for marginalized persons due to extensive costs.[45]

But the ability to get pregnant does not guarantee the birth of a living baby nine months later. To the contrary, millions of pregnancies end in pregnancy loss, meaning miscarriage before 20 weeks and stillbirth after 20 weeks.[46]

Public awareness of stillbirth — that the baby can die in your womb even after 20 weeks of pregnancy — is extremely low.[47] Doctors do not talk about the possibility of stillbirth with pregnant patients,[48] and it's almost impossible to find any mention of stillbirth in pregnancy books.[49] Parents surveyed after stillbirth explain that before their own child was stillborn, they "believed that stillbirth [was] a very rare event."[50] They also were "surprised to learn of the actual rates of stillbirth worldwide, or that stillbirth occurs much at all in high-income countries like the U.S."[51] Even those in high-risk pregnancies report that they had little to no knowledge of the possibility of stillbirth before it happened.[52]

The ignorance about stillbirth also includes ignorance that stillbirth still involves childbirth — birth to a baby who has already died.[53] The medicalization of pregnancy and childbirth means that most will learn of the baby's death before birth and then will still give birth to the baby, a physiologically identical experience to live childbirth.[54]

Stillbirth fits especially well within the reproductive justice framework because of its disparate impact on marginalized persons. Since the United States started collecting data on stillbirths in the early 1900s, Black women have *always* experienced higher rates of stillbirth.[55]

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[45] *Id.* at 1067, 1099-1100.

[46] *Id.* at 1069-70.

[47] *See* Jill Wieber Lens, *Medical Paternalism, Stillbirth, & Blindsided Mothers*, 106 IOWA L. REV. 665, 672-73 (2021) [hereinafter *Medical Paternalism*].

[48] *Id.* at 686-87.

[49] *Id.* at 666-67.

[50] Maureen C. Kelley & Susan B. Trinidad, *Silent Loss and the Clinical Encounter: Parents' and Physicians' Experiences of Stillbirth — A Qualitative Analysis*, 12 BMC PREGNANCY & CHILDBIRTH 1, 3 (2012), http://www.biomedcentral.com/1471-2393/12/137 [https://perma.cc/R9NC-DPEY].

[51] *Id.*

[52] *See id.*

[53] *See id.* at 4.

[54] Joanne Cacciatore, *The Unique Experiences of Women and Their Families After the Death of a Baby*, 49 SOC. WORK HEALTH CARE 134, 135 (2010) [hereinafter *The Unique Experiences*].

[55] Lens, *Reproductive Justice*, *supra* note 21, at 1071.

As mentioned, currently, Black women face double the risk of stillbirth compared to white women.[56] Increased education lowers the risk of stillbirth, but much more so for white women than for Black women.[57] Poor women face the same discrepancy in the rate, facing double the risk of stillbirth compared to women with more economic means.[58]

Stillbirth also fits well within the reproductive justice framework because it is a significant life event and can have long-lasting health consequences, especially for marginalized persons. Frequently reported "[n]egative psychological symptoms" after stillbirth include "high rates of depressive symptoms, anxiety, post-traumatic stress, suicidal ideation, panic and phobias."[59] Symptoms lasted at least four years in about half of cases in one study.[60]

Studies also show that stillbirth can cause tension that "might lead to relationship breakdown, which some studies report as more frequent in parents who have a stillborn child compared with a livebirth."[61] These relationship failures can then easily lead "to hardship, ill health, low income and poor satisfaction with life."[62] The effects can have long-lasting and intergenerational effects for siblings. "Some report significant effects decades after their own mothers' stillbirths. They experience intense emotions, such as anxiety and guilt, and an intergenerational transmission of grief," affecting their interactions with and attachment to their own children.[63] One stillbirth "affects . . . the entire family system."[64]

Stillbirth can also easily affect parents' employment. "For many parents, stillbirth was associated with reduced earnings from employment or an inability to return to paid employment."[65] Even if the

[56] *Id.*

[57] *Id.* at 1073.

[58] *Id.* at 1072.

[59] Alexander E.P. Heazell, Dimitrios Siassakos, Hannah Blencowe, Christy Burden, Zulfiqar A. Bhutta, Joanne Cacciatore, Nghia Dang, Jai Das, Vicki Flenady & Katherine J. Gold et al., *Stillbirths: Economic and Psychosocial Consequences*, 387 LANCET 604, 606 (2016) [hereinafter *Stillbirths*].

[60] *See id.* at 606.

[61] *Id.*; *see also* Chidubem B. Ogwulu, Louise J. Jackson, Alexander E.P. Heazell & Tracy E. Roberts, *Exploring the Intangible Economic Costs of Stillbirth*, 15 BMC PREGNANCY & CHILDBIRTH 1, 8 (Sept. 1, 2015), https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-015-0617-x [https://perma.cc/4FGP-DM2S] ("[S]tillbirth could cause relationship issues among couples leading to separation and divorce.").

[62] Ogwulu et al., *supra* note 61, at 8.

[63] Cacciatore, *The Unique Experiences*, *supra* note 54, at 137.

[64] *Id.*

[65] Heazell et al., *Stillbirths*, *supra* note 59, at 605.

parent returned to work, "productivity was greatly reduced with estimates of 26% of normal work after 30 days, increasing to 63% after 6 months."[66] Especially in the United States where we lack any standard paid bereavement leave, parents will return to work but perform with reduced productivity, often referred to as "presenteeism."[67]

As a 2016 Lancet article summarized, stillbirth causes "substantial direct, indirect, psychological, and social costs to women, and to their families, society, and government."[68] The costs "include: medical care and investigations at the time of stillbirth and in subsequent pregnancies; funeral costs; grief and negative psychological effects; reduced social functioning; family and relationship disruption and breakdown; and negative effects on employment."[69] And these effects can last for years.[70]

Notably, much of this research on the effects and costs of stillbirth assumes pregnant people and families have the resources for these costs. Birthing parents "will require long-term therapy and treatment, either funded privately or by-state supported health services."[71] But far from all have access to these services, even in high-income countries. Marginalized women, who face double the risk of stillbirth in the first place, likely lack these resources. And the lack of resources means these parents are likely to experience "greater despair and higher levels of depression."[72] Pre-existing "economic hardship, racism and discrimination, [and] lack of social and professional support" will make stillbirth even more difficult and possibly exacerbate the intergenerational effects.[73]

Overall, "the burden of stillbirths is substantial yet greatly underappreciated."[74] Part of this underappreciation is a dismissal of the trauma — dismissed by cultural platitudes like "you can have another,"

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[66] *Id.*

[67] Ogwulu et al., *supra* note 61, at 8.

[68] Heazell et al., *Stillbirths*, *supra* note 59, at 611.

[69] *Id.* at 612.

[70] *Id.*

[71] Ogwulu et al., *supra* note 61, at 7.

[72] Jackelyn Y. Boyden, Karen Kavanaugh, L. Michele Issel, Kamal Eldeirawi & Kathleen L. Meert, *Experiences of African American Parents Following Perinatal or Pediatric Death: A Literature Review*, 38 DEATH STUD. 374, 376 (2014).

[73] *Id.* at 379.

[74] Heazell et al., *Stillbirths*, *supra* note 59, at 613. Also concludes that every though the costs of stillbirth prevention are likely large, "the combined direct, indirect, and intangible costs of stillbirth are almost certainly greater still." *Id.*

assuming a new pregnancy and baby will make the trauma of stillbirth magically disappear.[75]

This dismissal may be especially strong with marginalized women due to racial biases. When Representative Cori Bush, a Black woman, went into premature labor with her second child at 16 weeks, her doctor told her to go home and let her child "abort" as she "could get pregnant again because that's what you people do."[76] This sentiment relies on racist stereotypes of Black women as breeders and Welfare Queens.[77]

These (sometimes racist) sentiments mask the overall long-lasting effects stillbirth can have on the woman, her family, and society,[78] and the undervaluation of stillbirth is likely "contribut[ing] to the slow pace of change to address stillbirths on national and international platforms."[79]

Stillbirth support and prevention seems to fit very well within the reproductive justice framework, yet it is not currently emphasized.[80] One possible reason for the non-emphasis may be the strong cloud of fatalism and inevitability surrounding stillbirth — the belief that stillbirth is unpreventable.[81] This fatalism not only affects public awareness, but it also has likely stunted medical research and prevention efforts.[82]

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[75] Sarah Meaney, Claire M. Everard, Stephen Gallagher & Keelin O'Donoghue, *Parents' Concern About Future Pregnancy After Stillbirth: A Qualitative Study*, 20 HEALTH EXPECTATIONS 555, 558 (2017). These sentiments also appear in discussions of the damages awarded in tort cases after stillbirth. *See* Jill Wieber Lens, *Tort Law's Devaluation of Stillbirth*, 18 NEV. L.J. 955, 994 (2019) [hereinafter *Devaluation of Stillbirth*].

[76] Michele Munz, *U.S. Rep. Cori Bush Reveals How She Nearly Lost Her Two Babies*, ST. LOUIS POST-DISPATCH (May 6, 2021), https://www.stltoday.com/lifestyles/health-med-fit/health/u-s-rep-cori-bush-reveals-how-she-nearly-lost-her-two-babies/article_2925e2b3-6720-595c-ad22-edfa2103e69c.html [https://perma.cc/FS8P-BFXV].

[77] Colleen Campbell, *Medical Violence, Obstetric Racism, and the Limits of Informed Consent for Black Women*, 26 MICH. J. RACE & L. 47, 51 (2021); Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and Right to Privacy*, 104 HARV. L. REV. 1419, 1443 (1991).

[78] *See* Muthler, *supra* note 15 ("Stillbirth has not received the same interest [as infant death] because the public underestimates its devastating toll . . . .").

[79] Heazell et al., *Stillbirths*, *supra* note 59, at 613.

[80] *See* Lens, *Reproductive Justice*, *supra* note 21, at 1078-79.

[81] *See* Lens, *Medical Paternalism*, *supra* note 47, at 690-92.

[82] *See, e.g.*, Flenady et al., *supra* note 16, at 699 (explaining that fatalism must be reduced in order to prevent further stillbirths); Robert L. Goldenberg, Elizabeth M. McClure, Zulfiqar A. Bhutta, José M. Belizán, Uma M. Reddy, Craig E. Rubens, Hillary Mabeya, Vicki Flenady & Gary L. Darmstadt, *Stillbirths: The Vision for 2020*, 377 LANCET 1798, 1798 (2011) ("Inappropriate fatalism regarding stillbirths among caregivers and policy makers will virtually guarantee that no progress occurs."); Muthler, *supra* note

That belief of unpreventability, however, is inaccurate. Despite the pervasive myth, only about 7% of stillbirths globally (using the 28-week definition of stillbirth) are due to congenital abnormalities, and even some of those abnormalities can be prevented with folic acid.[83] Simply put, current research demonstrates that the overwhelming majority of stillbirths are not due to some unpreventable abnormality.

Most concretely demonstrating the preventability of some stillbirths is the great successes that other countries have had in reducing their stillbirth rates.[84] Successes in the Netherlands, England, Scotland, and Norway were based on multiple initiatives, including education on the importance of not smoking during pregnancy, sleeping on your side, and monitoring fetal movement.[85] These countries already had lower stillbirth rates to start with than the United States and successfully reduced their stillbirth rates by 20% or more.[86] The Netherlands even reduced its stillbirth rate by more than 50% between 2000 and 2020.[87]

Similarly, a recent study specific to the United States estimated that at least one fourth of stillbirths are potentially preventable.[88] The study also clarified that it used conservative criteria and that "compelling arguments exist that many of the stillbirths [the study] did not include as potentially preventable were, in fact, preventable."[89]

Still, the fatalism myth persists. One likely reason is due to the frequent conflation of miscarriage and stillbirth. In the United States, if the pregnancy loss occurs in the first 20 weeks of pregnancy, it is a miscarriage. After 20 weeks of pregnancy, it is a stillbirth. Despite the differing medical definition, stillbirths are often described as miscarriages.[90] Conflation contributes to stillbirth's fatalism myth

15 ("Stillbirth has not received the same interest [as infant death] because the public . . . tends to view it as inevitable . . . .").

[83] Lens, *Medical Paternalism*, *supra* note 47, at 675.

[84] *See id.* at 676.

[85] *See id.* at 704-05 (summarizing other countries' initiatives).

[86] *See id.* at 704.

[87] *Dutch Stillbirth Rate More than Halves, Unicef Says in New Report*, DUTCHNEWS.NL (Oct. 8, 2020), dutchnews.nl/news/2020/dutch-stillbirth-rate-more-than-halves-unicef-says-in-new-report [https://perma.cc/78BY-XY7A].

[88] Jessica M. Page, Vanessa Thorsten, Uma M. Reddy, Donald J. Dudley, Carol J. Rowland Hogue, George R. Saade, Halit Pinar, Corrette B. Parker, Deborah Conway & Barbara J. Stoll et al., *Potentially Preventable Stillbirth in a Diverse U.S. Cohort*, 131 OBSTETRICS & GYNECOLOGY 336, 337 (2018).

[89] *Id.*

[90] Joanne Cacciatore & Jill Wieber Lens, *The Ultimate in Women's Labor: Stillbirth and Grieving*, *in* ROUTLEDGE INTERNATIONAL HANDBOOK OF WOMEN'S SEXUAL AND REPRODUCTIVE HEALTH 308, 311 (Jane M. Ussher, Joan C. Chrisler & Janette Perz eds., 2019). One recent high-profile example of this conflation involved celebrity Chrissy

because most miscarriages are unpreventable (at least according to current research).[91] And if miscarriage and stillbirth are the same thing and miscarriages are unpreventable, stillbirths are similarly unpreventable.[92] That is simply not true, however.

The cloud of fatalism and inevitability surrounding stillbirth is strong, but it should not be insurmountable. The same exact cloud surrounded infant and child mortality not that long ago in this country. Infant and child mortality rates were very high in the nineteenth century,[93] and infant and child death were simply an accepted part of parental life.[94] Nineteenth-century mothers, and even doctors, were "resigned to inevitability and futility" and "just accepted that infants and children would die."[95]

But things changed. As people started to realize that diseases and death were related to sanitation and other controllable causes,[96] the "common reaction to infant and child death [then] changed from resignation to indignation."[97] And the United States was able to dramatically decrease its infant and child mortality rates in the

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Teigen. She shared the loss of her unborn child Jack over social media. She was just over 20 weeks, meaning he was stillborn if born not alive. Her loss, however, was widely reported as a miscarriage. *See, e.g.*, Greer Donley & Jill Wieber Lens, *Abortion, Pregnancy Loss, & Subjective Fetal Personhood*, 75 VAND. L. REV. 1649 (2022) [hereinafter *Subjective Fetal Personhood*] (discussing the media coverage of Teigen). In September 2022, Teigen shared that she had actually had an abortion and had not realized so until over a year later. Kimberly Nordyke & Ryan Gajewski, *Chrissy Teigen Reveals She Had an Abortion to "Save My Life for a Baby that Had Absolutely No Chance*, HOLLYWOOD REPORTER (Sept. 15, 2022, 6:31 PM), https://www.hollywoodreporter.com/news/general-news/chrissy-teigen-miscarriage-abortion-john-legend-baby-jack-1235221899/ [https://perma.cc/Q6NT-UWP6].

91 Lens, *Reproductive Justice*, *supra* note 21, at 1075-76.

92 *Id.*

93 Jill Wieber Lens, *Children, Wrongful Death, and Punitive Damages*, 100 B.U. L. REV. 437, 451 (2020) ("[A]n informed estimate would be that somewhere between 15 and 20 percent of all Americans infants born in the second half of the nineteenth century died before they could celebrate their first birthdays." (quoting RICHARD A. MECKEL, SAVE THE BABIES: AMERICAN PUBLIC HEALTH REFORM AND THE PREVENTION OF INFANT MORTALITY, 1850-1929, at 28 (1990))); *id.* at 452 ("Nearly two out of every ten children died before reaching their fifth birthday." (quoting SAMUEL H. PRESTON & MICHAEL R. HAINES, FATAL YEARS: CHILD MORTALITY IN LATE NINETEENTH-CENTURY AMERICA (1991))).

94 *Id.* at 455.

95 *Id.* at 453.

96 *See id.* at 456-57.

97 *Id.* at 456.

twentieth century.[98] The same can happen with stillbirth. Just as all infant and child deaths were not inevitable, neither are all stillbirths.

Reproductive justice's non-emphasis of stillbirth may also be based on the same reason that the reproductive rights movement has avoided the topic of pregnancy loss — because of the (supposed) tension with abortion rights.[99] That tension is based on fear that acknowledging the "loss" in pregnancy loss provides ammunition for the anti-abortion idea of fetal personhood.[100] Abortion rights advocates are afraid of this slippery slope to fetal personhood because the slippery slope was specifically part of antiabortion strategy. The plan was to "have fetuses declared 'children' or 'persons' in as many legal contexts as possible" and then argue that "Fourteenth Amendment jurisprudence should similarly recognize the reality of fetal personhood."[101]

In response, abortion rights advocates have historically opposed legal measures that would recognize stillbirth. This includes opposing applying wrongful death law, the same claim parents would have if a living child was tortiously killed, to stillbirth.[102] It even includes opposition to memorial birth certificates recognizing that a baby was still born even though he was stillborn.[103] More recently, opposition is no longer outright, but support also is often not present. In 2022, a bill in California to create an income tax credit for parents after stillbirth had only two sponsors, both Republicans.[104]

None of this is meant to imply that antiabortion advocates are actually doing anything to help reduce stillbirths. To the contrary, the interest in stillbirth is only about chipping away at abortion rights.[105] For instance, restrictions on abortion, especially in cases of fetal anomaly, means an increase in stillbirths and infant deaths[106] — an increase that

[98] *Id.* at 458 (quoting RICHARD A. MECKEL, SAVE THE BABIES: AMERICAN PUBLIC HEALTH REFORM AND THE PREVENTION OF INFANT MORTALITY, 1850-1929, at 28 (1990)).

[99] Professor Greer Donley and I introduce a way to resolve this tension in *Subjective Fetal Personhood*. *See* Donley & Lens, *Subjective Fetal Personhood*, *supra* note 90.

[100] Lens, *Reproductive Justice*, *supra* note 21, at 1077.

[101] Kenneth A. De Ville & Loretta M. Kopelman, *Fetal Protection in Wisconsin's Revised Child Abuse Law: Right Goal, Wrong Remedy*, 27 J.L. MED. & ETHICS 332, 335 (1999).

[102] Lens, *Reproductive Justice*, *supra* note 21, at 1110-11; *see also* Donley & Lens, *Subjective Fetal Personhood*, *supra* note 90, at 1659.

[103] Lens, *Reproductive Justice*, *supra* note 21, at 1109; *see also* Donley & Lens, *Subjective Fetal Personhood*, *supra* note 90, at 1659-60.

[104] *See* A.B. 1697, 2022 Cal. Leg., Reg. Sess. (Cal. 2022).

[105] Lens, *Reproductive Justice*, *supra* note 21, at 1076-77; *see also* Donley & Lens, *Subjective Fetal Personhood*, *supra* note 90, at 1659-60.

[106] *See* Donley & Lens, *Second-Trimester Abortion*, *supra* note 18, at 2170-71.

does not bother antiabortion leaders. As another example, numerous well-known anti-abortion members of the House of Representatives also just voted against the SHINE for Autumn Act,[107] which would provide grants to states to improve stillbirth research. Antiabortion advocates are also quick to emphasize the emotional distress one can feel after abortion yet support legal measures like noneconomic damage caps that undercut the compensation one can recover for emotional distress after pregnancy loss.[108] The antiabortion movement has great interest in protecting the fetus from termination, but little interest in preventing its possible stillbirth.

The reproductive rights movement has tiptoed around stillbirth due to the possible tension, but this tiptoeing really is not possible within the reproductive justice framework. As discussed, this framework recognizes that the right to have a child and parent him is equally important to the right to not have a baby. It is not possible to have a child and parent him unless one is able to get pregnant and *stay* pregnant. Avoidance of stillbirth because of its (supposed) tension with abortion rights is simply not possible within the reproductive justice framework.

And thus, stillbirth prevention should be part of the reproductive justice framework. The next Part explains the importance of public health data generally, setting the stage for the later discussion of legal reforms to improve the quality of data that we both gather and collect on stillbirths — data needed to help prevent stillbirth.

II. PURPOSES OF PUBLIC HEALTH DATA

Public health surveillance is "the ongoing systematic collection, analysis, and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know."[109] It also includes the "application of these data to prevention and control."[110] The purpose of surveillance then is to "prevent or control disease or injury and to improve health, or to

[107] This includes Representatives Lauren Boebert, Matt Gaetz, Louis Gohmert, and Marjorie Taylor Greene. *Roll Call 416: Bill Number: H.R. 5487*, CLERK (Dec. 8, 2021, 7:22 PM), https://clerk.house.gov/Votes/2021416?BillNum=5487 [https://perma.cc/46C6-MSNV].

[108] Lens, *Devaluation of Stillbirth*, *supra* note 75, at 1000.

[109] Stephen B. Thacker, *Historical Development*, *in* 3 PRINCIPLES & PRACTICE OF PUBLIC HEALTH SURVEILLANCE 1, 1 (Lisa M. Lee, Steven M. Teutsch, Stephen B. Thacker, and Michael E. St. Louis eds., 2010).

[110] *Id.*

improve a health program or service."[111] Said another way, data is "used to assess public health status, track conditions of public health importance, define public health priorities, evaluate programs, and develop public health research."[112]

The idea of public health surveillance dates back to 1300s, and existed in the United States in colonial times.[113] The historical focus was on infectious diseases,[114] which were still the leading causes of death in the United States at the beginning of the twentieth century.[115] And that focus re-emerged with the ongoing COVID-19 pandemic.[116] Throughout the twentieth century, deaths from infectious diseases decreased and instead chronic diseases were the causes of the majority of deaths in the United States.[117] Public health surveillance thus shifted to chronic diseases, and also to injuries and birth defects, both of which also cause a substantial number of deaths in the United States yearly.[118]

One long-time example of statistical surveillance data to measure the health of communities is the tracking of births and deaths with birth and death certificates. This is a "staple of health measurement dating back to the 17th century."[119] These certificates alone "continue[] to provide an important, albeit somewhat blunt, indicator of population health."[120]

The data from vital statistics can be limited, however, meaning other public health mechanisms have been developed to improve data and data collection. In modern day, many registries exist to surveil public health. A very common example is registries on cancer, which gather diagnostic, treatment, and outcome information.[121] Obviously, this can gather much more information than just the number of deaths due to

[111] Lisa M. Lee & Stephen B. Thacker, *Public Health Surveillance and Knowing About Health in the Context of Growing Sources of Health Data*, 41 AM. J. PREVENTIVE MED. 636, 637 (2011).

[112] Thacker, *supra* note 109, at 1.

[113] *Id.* at 1-2.

[114] *Id.* at 2.

[115] Ali H. Mokdad, Joseph L. Annest, Robin M. Ikeda & Cara T. Mai, *Public Health Surveillance for Chronic Diseases, Injuries, and Birth Defects*, *in* PRINCIPLES & PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 109, at 255.

[116] *See FAQ: COVID-19 Data & Surveillance*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/coronavirus/2019-ncov/covid-data/faq-surveillance.html (last visited Dec. 6, 2021) [https://perma.cc/4QME-EACX].

[117] Mokdad et al., *supra* note 115, at 255.

[118] *Id.*

[119] Lee & Thacker, *supra* note 111, at 636.

[120] *Id.*

[121] *See id.* at 637.

cancer. The overwhelming majority of states have cancer surveillance registries.[122] Other existing registries include those for "non-infectious chronic diseases like asthma, multiple sclerosis, and lupus," existing partly "in order to study whether they might be caused by environmental risks."[123] An example of a pregnancy-related registry that is also common is one for birth defects. Interest in public health surveillance of birth defects began in the 1960s after common prescription of thalidomide to pregnant women for nausea led to severe birth defects in thousands of children.[124] In 1967, the CDC created the Metropolitan Atlanta Congenital Defects Program ("MACDP") to create an active surveillance system.[125]

This public health data gathered is then used in numerous ways. It is used to "identify[] potential factors involved in disease occurrence, facilitate epidemiologic and laboratory research, and assess[] control and prevention activities."[126] Similarly, the data "is used to assess public health status, track conditions of public health importance, define public health priorities, evaluate programs, and develop public health research."[127]

Epidemiology is the study of diseases in populations, investigating how, when, and why they appear. Surveillance data is crucial for this research.[128] Surveillance data gathered in the MACDP has been used for numerous epidemiological studies exploring connections between maternal use of prescription drugs, obesity, vitamin A use, and febrile illnesses and birth defects.[129] Public health surveillance data has also been used in case-control studies. Again, data from MACDP was used to confirm that Vietnam veterans did not have any increased risk of

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[122] *See generally* Jorge N. Izquierdo & Victor J. Schoenbach, *The Potential and Limitations of Data from Population-Based State Cancer Registries*, 90 AM. J. PUB. HEALTH 695 (2000) (discussing the widespread practice of cancer surveillance registries).

[123] Wendy K. Mariner, *Reconsidering Constitutional Protection for Health Information Privacy*, 18 U. PA. J. CONST. L. 975, 991 (2016).

[124] Mokdad et al., *supra* note 115, at 257.

[125] *Id.*

[126] Stephen B. Thacker, Ruth L. Berkelman & Donna F. Stroup, *The Science of Public Health Surveillance*, 10 J. PUB. HEALTH POL'Y 187, 188 (1989).

[127] Thacker, *supra* note 109, at 6.

[128] *See id.* at 14.

[129] *See* Adolfo Correa-Villaseñor, Janet Cragan, James Kucik, Leslie O'Leary, Csaba Siffel & Laura Williams, *The Metropolitan Atlanta Congenital Defects Program: 35 Years of Birth Defects Surveillance at the Centers for Disease Control and Prevention*, 67 CLINICAL & MOLECULAR TETRALOGY 617, 624 (2003).

fathering children with birth defects.[130] Public health surveillance data was also used in studies connecting tampon use to toxic shock syndrome and long-time use of oral contraceptives to breast cancer.[131]

The public health surveillance field also has already recognized the importance of social determinants of health — "the range of personal, social, economic, and environmental factors that determine the health status of individuals or populations."[132] Numerous systems in the United States already gather this information.[133] And literature exists to help create and guide effective surveillance of health determinants. Much surveillance looks to health care records, meaning surveillance of health determinants would be improved if health care providers gathered additionally determinant-relevant information.[134]

Another important use and purpose of public surveillance data is to educate.[135] "Much communication in public health is for the purpose of persuading people to do, or not do, something."[136] This communication thus involves both informing the public about a health issue and also attempting to persuade them. "For example, surveillance information about a specific foodborne outbreak might be communicated to persuade individuals to not eat a potentially contaminated product."[137]

This also includes education of those in a place to formulate policy and prevention efforts. Specifically, the "data can be used to inform policymakers and the public about the nature and extent of health problems and to persuade these audiences to address particular issues."[138] For example, Congress looks to HIV surveillance data to determine how much money to allocate for care and treatment for those living with HIV/AIDS through the Ryan White Care Act.[139] Also, public health data gathered on child deaths led to the creation of a graduated driver's license program for teenagers in Arizona, an education

[130] Stephen B. Thacker & Ruth L. Berkelman, *Public Health Surveillance in the United States*, 10 EPIDEMIOLOGIC REVS. 164, 167-68 (1988).

[131] *Id.* at 168.

[132] Roy Gibson Parrish, II, Sharon M. McDonnell & Patrick L. Remington, *Surveillance for Determinants of Population Health*, *in* PRINCIPLES & PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 109, at 277.

[133] *Id.* at 292-98.

[134] *Id.* at 292.

[135] *See* Patrick L. Remington & David E. Nelson, *Communicating Public Health Surveillance Information for Action*, *in* PRINCIPLES & PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 109, at 154.

[136] *Id.*

[137] *Id.*

[138] Thacker & Berkelman, *supra* note 130, at 173.

[139] Thacker, *supra* note 109, at 12.

campaign on the dangers of infants bed-sharing with adults in Massachusetts, and improved motor vehicle child restraint laws in Georgia.[140]

Without quality data, stillbirth remains an underestimated if not invisible public health problem. The next Sections describe legal reforms that would improve both data and data collection — reforms that could help bring stillbirth out of the dark.

III. Improving Data

Even though at least 24,000 stillbirths occur in the United States every year, there is little to no standardization on what tests and procedures should be performed after stillbirth. Most problematically, fetal autopsies, the testing best able to determine the cause of the stillbirth, are rarely performed in the United States.[141] This Part describes the obvious need for autopsies — "[i]f we don't know why [stillbirths] happen, we won't be able to prevent them"[142] — and the reasons that they are rarely performed. This Part also contrasts the lack of standardized response to stillbirth to the very organized state response to other infant and child deaths, especially suspected SIDS deaths. Stillbirth is ten times more common than SIDS deaths, but only suspected SIDS deaths are routinely autopsied at state cost. These detailed statutory mechanisms provide a blueprint for mandatory, paid-for autopsies after stillbirth.

A. Lack of Fetal Autopsies

Experts agree what tests should be done after stillbirth — a placental pathology and a full fetal autopsy.[143] A fetal autopsy is often labeled as the "gold standard for determining the cause of death."[144] A 2016 study

[140] The Comm. on Child Abuse & Neglect, The Comm. on Injury, Violence, & Poison Prevention & The Council on Cmty. Pediatrics, Am. Acad. Of Pediatrics, *Policy Statement — Child Fatality Review*, 126 PEDIATRICS 592, 593 (2010). Surveillance data can also be used to evaluate implemented measures. Mokdad et al., *supra* note 115, at 267.

[141] *See infra* Part III.A.

[142] Muthler, *supra* note 15.

[143] Robert M. Silver, *Optimal "Work-up" of Stillbirth: Evidence!*, 206 AM. J. OBSTETRICS & GYNECOLOGY 1, 1 (2012); *see also* Fleurisca J. Korteweg, Jan Jaap H.M. Erwich, Albertus Timmer, Jan van der Meer, Joke M. Ravisé, Nic J.G.M. Veeger & Jozien P. Holm, *Evaluation of 1025 Fetal Deaths: Proposed Diagnostic Workup*, 206 AM. J. OBSTETRICS & GYNECOLOGY 53.e1, 53.e2 (2012).

[144] Linda M. Ernst, *A Pathologist's Perspective on the Perinatal Autopsy*, 39 SEMINARS PERINATOLOGY 55, 61 (2015); *see also* ROYAL COLL. OF OBSTETRICIANS & GYNAECOLOGISTS, LATE INTRAUTERINE FETAL DEATH AND STILLBIRTH 4, 10 (2010),

explained that a clinical evaluation alone left 76% of stillbirths with an undetermined cause.[145] Adding a gross and histological placental examination and pathology done by a pathologist reduced that number to only 49% of stillbirths with an undetermined caused, and then adding a fetal autopsy left only 26% of stillbirths completely unexplained.[146] Another study explained that the combination of a placenta examination and pathology and a full fetal autopsy leads identified a "possible or probable cause of death . . . in more than 75% of cases."[147]

Even though we know what tests are best at determining the causes of stillbirth, we lack "uniform protocols to evaluate and classify stillbirths."[148] The lack of uniformity means we have far too few fetal autopsies.[149] Although gross and histological placental examinations are relatively common, fetal autopsies are neither mandatory nor routine in the United States.

A study published in 2020 examined the rates of fetal autopsies in the United States[150] and concluded that fetal autopsy was performed in only 21% of stillbirths that occurred in 2014-16.[151] Autopsy was more likely with increased gestational age, but less likely with increased maternal age.[152] The study also found that stillborn children of Hispanic women had the lowest rates of fetal autopsies, with higher rates for stillborn children of Black and white women.[153] The study also found that autopsy was more likely with increased maternal education; women with a Doctorate degree had twice the fetal autopsy rate that women with an eighth grade level of education.[154] Women with at least one

https://www.rcog.org.uk/media/0fefdrk4/gtg_55.pdf [https://perma.cc/64PU-ZK9U] (describing that no other test is as effective as an autopsy in determining the cause of stillbirth); Am. Coll. of Obstetricians & Gynecologists & Soc'y for Maternal-Fetal Med., *Management of Stillbirth*, 135 AM. J. OBSTETRICS & GYNECOLOGY e110, e118 (2020) [hereinafter *Management of Stillbirth*] (describing fetal autopsy as "one of the most useful diagnostic tests in determining the cause of death").

145 Emily S. Miller, Lucy Minturn, Rebecca Linn, Debra E. Weese-Mayer & Linda M. Ernst, *Stillbirth Evaluation: A Stepwise Assessment of Placental Pathology and Autopsy*, 214 AM. J. OBSTETRICS & GYNECOLOGY 115.e1, 115.e3 (2016).

146 *Id.* at 115.e5.

147 Ernst, *supra* note 144, at 59.

148 *Management of Stillbirth*, *supra* note 144, at e115.

149 *See id.* (describing the lack of uniform protocols when evaluating stillbirths).

150 Emily A. Oliver, Kara M. Rood, Marwan Ma'ayeh, Vincenzo Berghella & Robert R. Silver, *Stillbirth and Fetal Autopsy Rates in the United States: Analysis of Fetal Death Certificates*, 135 OBSTETRICS & GYNECOLOGY 166S, 166S (2020).

151 *Id.*

152 *Id.*

153 *Id.*

154 *Id.*

living child were also less likely to have had an autopsy done.[155] The study concluded that the fetal autopsy rates are too low in the United States, especially when "[r]ates of perinatal autopsy approach 100% in countries with similar resources."[156] The study also encouraged the need for additional research to "inform strategies to increase availability and uptake."[157]

The decision whether to have an autopsy will likely occur still within the shock of stillbirth. Stillbirth is "among the most distressing experience an adult may face," and any discussion of autopsy occurs within that distress.[158] Parents are in an especially vulnerable position after stillbirth. The shock also means doctors are unprepared for this discussion. These doctors usually deliver living babies to happy parents, making it further difficult to transition to one who counsels parents after death.[159] "Parents also felt health care providers were unprepared for stillbirth and that this affected the management of their care."[160] The lack of preparation likely relates to a lack of education — doctors who

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155 *Id.*

156 *Id.*; *see also* Melissa Davey, *Australia Failing to Adequately Investigate Stillbirths, Research Finds*, GUARDIAN, www.theguardian.com/australia-news/2016/jan/19/australia-failing-to-adequately-investigate-stillbirths-researcher-finds (last updated Aug. 8, 2017, 2:52 PM EDT) [https://perma.cc/36DV-TF7U] (explaining Australia's similar issue regarding investigation of stillbirths in comparison to the United States); Muthler, *supra* note 15 (explaining the Netherlands's success in reducing its stillbirth rate based on measures including free autopsies and placental exams and a medical team reviewing each stillbirth).

157 Oliver et al., *supra* note 150, at 166S.

158 Dell Horey, Vicki Flenady, Liz Conway, Emma McLeod & Teck Yee Khong, *Decision Influences and Aftermath: Parents, Stillbirth and Autopsy*, 17 HEALTH EXPECTATIONS 534, 535 (2012) (describing stillbirth as "among the most distressing experiences an adult may face" and "also a time when parents are faced with the most difficult decision" of whether to have an autopsy on their infant); *see also* A.E.P. Heazell, M-J McLaughlin, E.B. Schmidt, P. Cox, V. Flenady, T.Y. Khong & S. Downe, *A Difficult Conversation? The Views and Experiences of Parents and Professionals on the Consent Process for Perinatal Postmortem After Stillbirth*, 119 BRIT. J. OBSTETRICS & GYNAECOLOGY 987, 991 (2012) [hereinafter *A Difficult Conversation?*] (noting "emotional distress as a barrier to discussing autopsy"); Kelley & Trinidad, *supra* note 50, at 5 (describing the difficulty of bringing up an autopsy "following the shock of losing the baby"); Anne Schirmann, Frances M. Boyle, Dell Horey, Dimitrios Siassakos, David Ellwood, Ingrid Rowlands & Vicki Flenady, *Understanding Mothers' Decision-Making Needs for Autopsy Consent After Stillbirth: Framework Analysis of a Large Survey*, 45 BIRTH 255, 256 (2018) (explaining that "agreeing to autopsy can be very difficult at any time, particularly at a time of intense shock and grief" like the trauma of stillbirth).

159 *See* Kelley & Trinidad, *supra* note 50, at 5 (explaining that "[s]tillbirth challenges familiar roles in Obstetrics" and that NICU doctors are much better prepared to deal with death than obstetricians).

160 Horey et al., *supra* note 158, at 539.

do not know the process of fetal autopsy, its benefits, and its financial cost cannot accurately educate parents.[161]

Also affecting the decision whether to have an autopsy after stillbirth is how the doctor brings up the issue. In one study, none of the physicians in the focus groups routinely offered an autopsy but would discuss it with the parents if the parents brought it up.[162] Obviously, if parents are not offered an autopsy, one does not occur. But even when doctors do bring up the possibility, there is little doubt that the way they do so affects whether parents' consent. "Health professionals . . . influenced decisions about autopsy in important ways, both to encourage and discourage autopsy as an option."[163] Unfortunately, some parents "felt actively discouraged to consider autopsy and expressed suspicion of their care providers' motives."[164]

The topic of autopsy may also be difficult for doctors because of fear of blame.[165] Fetal autopsies can (and should) serve as "an important quality assurance and education tool" for hospitals and clinicians.[166] Some even argue that it is an ethical obligation of clinicians to pursue perinatal autopsy.[167] Relatedly, in one study, "[s]everal physicians reported that they worry about being blamed for stillbirth."[168] And they worried about possible liability. "These parents described the information flow as restricted and health professional behaviour as self-protective. One couple went so far as to get their autopsy results from an independent source."[169]

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[161] Heazell et al., *A Difficult Conversation?*, *supra* note 158, at 994 (describing UK study results showing "[a] substantial proportion of midwives and obstetricians underestimated the value of autopsy," including underestimating the rate at which fetal autopsies can determine probable or possible causes of death).

[162] Kelley & Trinidad, *supra* note 50, at 5.

[163] Horey et al., *supra* note 158, at 538.

[164] *Id.*; *see also* Muthler, *supra* note 15 (explaining that her doctor "discouraged us from spending several thousand dollars on [an autopsy]").

[165] *See* Lens, *Medical Paternalism*, *supra* note 47, at 714-15 (discussing doctors' concerns about being blamed for stillbirth).

[166] Ernst, *supra* note 144, at 60.

[167] *Id.*

[168] Kelley & Trinidad, *supra* note 50, at 5.

[169] Horey et al., *supra* note 158, at 538-39; *see also* Heazell et al., *A Difficult Conversation?*, *supra* note 158, at 995 (discussing an earlier study where a small percentage of consultants stated they did not offer a postmortem examination to parents because of "concern that the result might question their professional judgment"). Interestingly, sentiments of self-blame also can make women hesitant to consent, with some women scared that the autopsy would reveal that the woman did something wrong. Schirmann et al., *supra* note 158, at 259; *see also infra* Part V.A (describing the blame women feel after stillbirth).

The difficulty of the situation may translate to why doctors sometimes use language that discourages fetal autopsy. Parents need to know that an autopsy may not reveal the cause of death, but this same notion can also be discouraging depending on how it is communicated.[170] Any discussion of possible bodily disfigurement can also be discouraging.[171] These two notions combined translate to a sentiment that the baby will be cut up for nothing. A clinician's confidence about a cause of death may also discourage by implying that an autopsy isn't necessary.[172]

Parents may also decline an autopsy because they do not understand the process, which relates back to the doctor's explanation of it.[173] Others decline because of religious or cultural beliefs.[174] More studies are needed to determine the best practices for presenting parents with the option of an autopsy.

Another reason parents may decline an autopsy is due to the cost and confusion over insurance coverage. It is difficult to answer these questions in the moment. Autopsies cost at least $1,000.[175] Some hospitals automatically cover the costs of an autopsy if performed there. If the baby must be sent to a specialty center for an autopsy, the hospital is less likely to pay for the autopsy. Perhaps the parents' insurance will cover the cost, but many do not.[176] Notably, almost half of pregnancies in the United States are covered by Medicaid.[177] This does not mean that Medicaid covers half of all stillbirths, but some overlap is likely as poor women face an increased risk of stillbirth.[178] Medicaid does not, however, cover the cost of autopsies after stillbirth.[179] This leaves the cost for parents to pay out of pocket.[180] And with the surprisingly

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[170] *See* Schirmann et al., *supra* note 158, at 259 (describing a patient's experience with a doctor's explanation of an autopsy).

[171] *Id.*

[172] *Id.* at 258 (explaining that many mothers who did not consent to an autopsy "believed the reason for death was already known").

[173] *Id.* at 260.

[174] *Id.* at 258.

[175] Lens, *Reproductive Justice*, *supra* note 21, at 1112; *see also* Muthler, *supra* note 15 (describing a complete evaluation of a stillbirth as "phenomenally expensive").

[176] *See* Lens, *Reproductive Justice*, *supra* note 21, at 1111-13 (explaining the overall coverages of medical insurance concerning autopsies); Muthler, *supra* note 15 (discussing the "lack of insurance coverage for autopsies and genetic tests after a stillbirth" is "preventing progress" because "[i]f we don't know more about why they happen, we won't be able to prevent them").

[177] Lens, *Reproductive Justice*, *supra* note 21, at 1112.

[178] *Id.*

[179] *Id.*

[180] *Id.*

expensive costs of stillbirth, an autopsy that may not reveal a cause of death quickly falls lower on the priority list.[181]

Unfortunately, even if parents desire an autopsy (and could afford it), a qualified perinatal pathologist is needed.[182] The nation faces a shortage of pathologists,[183] and perinatal pathology seems to be one of the least attractive specialties within pathology.[184]

The lack of an autopsy not only means passing up the best opportunity to determine the cause(s) of death, but it also means passing up the opportunity to help parents. Studies have also found that autopsies are beneficial for parents. Consistent with reproductive justice, having an autopsy performed "enables parents to parent their stillborn child by determining how he died."[185] In one study in Ireland, parents explained how they had an autopsy done for the baby's sake, so that they did everything they could to determine why he died.[186] Another study concluded that "the autopsy seems to allay guilt and anxiety in parents of stillborns. Even when no definite cause of death is found, emphasis on the baby's normality seems to alleviate a great deal of parental concern."[187] In one study, "no parent who consented to

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[181] *Id.*

[182] Ernst, *supra* note 144, at 55 ("[F]or maximal benefit for the patient and the health care system in general, the perinatal autopsy is best performed by a pathologist with special interest, experience, and skill in dissection of fetuses and neonates."); *see also id.* at 56 (describing that the vast majority of perinatal autopsies "can be considered complex"); *Management of Stillbirth*, *supra* note 144, at e119 ("It is preferable to use a pathologist who is experienced in perinatal autopsy and to have a physician who is experienced in genetics and dysmorphology examine the fetus.").

[183] Shivayogi Bhusnurmath, *Industry Voices — The Shortage of Invisible Doctors*, FIERCE HEALTHCARE (Oct. 25, 2019, 12:01 AM), https://www.fiercehealthcare.com/hospitals-health-systems/industry-voices-shortage-invisible-doctors [https://perma.cc/A2GM-ERZC].

[184] *See* Interview by Sanjita Ravishankar with Ray Redline, Dr., Univ. Hosps. Cleveland Med. Ctr., https://www.spponline.org/spotlight (last visited Aug. 31, 2022) [https://perma.cc/TQ9Q-95CY] (showcasing an interview with a pathologist who describes the desirability of their work within the profession).

[185] Lens, *Reproductive Justice*, *supra* note 21, at 1113.

[186] *Id.*; *see also* Heazell et al., *A Difficult Conversation?*, *supra* note 158, at 995 (describing that parents seek fetal autopsy to "find a reason for their child's death" and suggesting that the autopsy provides some emotional closure" by ensuring that parents "explored every potential cause"); Schirmann et al., *supra* note 158, at 259 (describing that parental responsibility drove many parents to consent to an autopsy because of "an obligation as parents to find out what had gone wrong and to obtain factual information for themselves, for their baby, and for future children," although parental instincts also pushed some parents to decline to protect the child's bodily integrity).

[187] Elizabeth Kirkley-Best & Kenneth R. Kellner, *The Forgotten Grief: A Review of the Psychology of Stillbirth*, 52 AM. J. ORTHOPSYCHIATRY 420, 426 (1982); *see also* Ernst, *supra* note 144, at 60 (describing that a "negative" autopsy that does not identify a cause of

autopsy expressed regret about their decision . . . ."[188] On the other hand, "some form or regret or uncertainty about the choice was common among those parents who did not have an autopsy, including realization of a missed opportunity to find a possible explanation for the baby's death."[189]

Another way that autopsies can help parents is to reveal possible issues that may come up in future pregnancies — consistent with reproductive justice's focus on enabling those who want to have children to do so. Specifically, studies show that a common secondary reason for consenting to an autopsy is the "desire to avoid a similar fate for future children,"[190] and to obtain "factual information . . . for future children."[191]

Parents may also regret the decision to forego an autopsy if they later attempt to pursue some legal action against someone who may have caused the child's stillbirth, including their doctor. The lack of autopsy may create too many doubts that the doctor's conduct actually caused their child's stillbirth. This is especially true given the widespread myth that stillbirth is inevitable — that something is wrong with these babies and that is why they die in the womb. This myth is widespread, but it is also inaccurate.[192] The lack of autopsies also, of course, contribute to that myth.

B. State-Provided Fetal Autopsies

The reproductive justice movement specifically seeks to highlight the experiences of marginalized persons. Access to an autopsy — to find out answers about why their child was stillborn and whether there could be an issue in a future pregnancy — should not depend on economic status.

The state should thus provide free access to a fetal autopsy just as most states do after suspected SIDS deaths. Many states have adopted formalized review in an attempt to reduce SIDS deaths — a review

death is still valuable "because oftentimes the family and clinicians can find answers to some of their questions by just knowing what was not present").

[188] Horey et al., *supra* note 158, at 539.

[189] *Id.* at 540; *see also* Heazell et al., *A Difficult Conversation?*, *supra* note 158, at 990, 995 (explaining that most participants in the study "remained satisfied with their decision to have or to decline an autopsy" but "parents who did not consent to a postmortem examination were approximately twice as likely to regret their decision compared with those who chose to have this investigation performed").

[190] Horey et al., *supra* note 158, at 538.

[191] Schirmann et al., *supra* note 158, at 259.

[192] *See supra* Part I.

including routine autopsies paid for by the government.[193] Thus, parents are able to find out answers after a suspected SIDS death regardless of their economic status. The same should be true of stillbirth, which, notably, is *ten times* more likely than infant death from SIDS.[194]

Formalized review of suspected SIDS deaths exists because states saw the public health concern and acted. As one example:

> The [California] legislature finds and declares that sudden infant death syndrome, also referred to as SIDS, is the leading cause of death for children under age one, striking one out of every 500 children. The Legislature finds and declares that sudden infant death syndrome is a serious problem within the State of California, and that the public interest is served by research and study of sudden infant death syndrome and its potential causes and indications.[195]

[193] *See, e.g.*, ARK. CODE ANN. § 20-15-503 (2022) (standardizing procedure for autopsy with parental consent); CAL. GOV'T CODE § 27491.41 (2022) (mandating autopsy "in any case where an infant has died suddenly and unexpectedly"); 55 ILL. COMP. STAT. 5/3-3016 (2022) (providing autopsy when infant dies "suddenly and unexpectedly and the circumstances concerning the death are unexplained following investigation"); IND. CODE § 36-2-14-6.7 (2022) (mandating autopsy of child "less than 3 years of age" who "dies suddenly and unexpectedly"); KY. REV. STAT. ANN. § 213.161 (2022) (providing autopsy "[i]n instances where an ostensibly healthy child dies suddenly and unexpectedly with no known or apparent cause . . . with the written approval of the parents"); MICH. COMP. LAWS § 52.205a (2022) (providing autopsy at no cost to parents if "a child under the age of 2 years dies within this state under circumstances of sudden death, cause unknown, or found dead, cause unknown"); MO. REV. STAT. § 194.117 (2022) (providing autopsies for suspected SIDS deaths "at the expense of the state"); N.J. STAT. ANN. § 26:6B-13 (2022) (providing autopsies for suspected SIDS infant deaths and any "sudden and unexpected" deaths of children between one and three years old); OHIO REV. CODE ANN. § 313.121 (2022) (providing autopsies for death of "a child under two years of age dies suddenly when in apparent good health"); VA. CODE ANN. § 32.1-285.1 (2022) (providing autopsies for any suspected SIDS infant deaths); WASH. REV. CODE § 43.103.100 (2022) ("The council shall develop a protocol for autopsies of children under the age of three whose deaths are sudden and unexplained."); W. VA. CODE § 61-12-10 (2022) (providing autopsy if advisable in chief medical examiner opinion and if "in the public interest"); WIS. STAT. § 979.03 (2022) (making autopsy mandatory for suspected SIDS death of child under 2 years at no cost to parents unless parents object); D.C. CODE § 5-1405 (2022) (mandating autopsy for suspected SIDS infant deaths).

[194] Cacciatore, *Effects of Support Groups*, *supra* note 28, at 72.

[195] GOV'T CODE § 27491.41(b).

A crucial part of that research and study, of course, is autopsies.[196] Without autopsies, we can't learn more about what causes SIDS deaths. This is why states mandate autopsies for suspected SIDS deaths.

If truly interested in preventing SIDS, however, states need to update their strategies to reflect newer research. Specifically, newer research has noted a possible connection between term stillbirths (after 37 weeks of pregnancy) and SIDS deaths, essentially characterizing these late term stillbirths as early SIDS deaths.[197] Thus, states wanting to end SIDS deaths should be funding not only just autopsies after unexplained infant deaths, but also autopsies after stillbirths, especially term stillbirths.

Notably, research into SIDS deaths was partly motivated because of blame on parents — parents were blamed, making their child's death even more traumatic. Advocates pushed for research, including autopsies, to help alleviate this blame.[198]

State mandated autopsies after unexpected child deaths are not limited to circumstances of SIDS suspicions. Louisiana law more broadly defines that "the unexpected death of infants and children is an important health concern that requires legislative action" and that "[c]ollecting data on the causes of unexpected deaths will better enable the state to protect some infants and children from preventable deaths and will help reduce the incidence of such deaths."[199] And the law mandates "death investigations," which may include autopsies, in order to help achieve this public health goal.[200]

The state paying for autopsies after stillbirth fixes the current cost deterrent — making marginalized persons also able to find out as much

[196] *Id.* (mandating autopsy "in any case where an infant has died suddenly and unexpectedly").

[197] *See* S. Walsh & G. Mortimer, *Unexplained Stillbirths and Sudden Infant Death Syndrome*, 45 MED. HYPOTHESES 73, 75 (1995).

[198] *See SIDS: Overcoming the Sense of Blame*, WASH. POST (Nov. 20, 1985), https://www.washingtonpost.com/archive/lifestyle/wellness/1985/11/20/sids-overcoming-the-sense-of-blame/cef48637-5247-43ce-a25b-0930541d6be0/ [https://perma.cc/2S6A-CMZ5]. More recently, some have questioned whether parental blame is in fact appropriate when parents fail to use safe sleeping practices and that a "SIDS diagnosis offers compassion in a moment of a distress, and a way to avoid blaming parents amid the tragedy." Andrea Hsu, *Rethinking SIDS: Many Deaths No Longer a Mystery*, NPR (July 15, 2011, 6:25 PM ET), https://www.npr.org/2011/07/15/137859024/rethinking-sids-many-deaths-no-longer-a-mystery [https://perma.cc/93HG-J7ZP].

[199] LA. STAT. ANN. § 40:2019(A)(1)(a)-(b) (2022); *see also* KAN. STAT. ANN. § 22a-242(a) (2022) (mandating autopsy if the coroner determines the cause of the child's death is unknown); NEB. REV. STAT. § 23-1824(1) (2022) (mandating autopsy for death of "any person less than nineteen years of age who dies a sudden death").

[200] LA. STAT. ANN. § 40:2019 (2022).

as possible about why their child was stillborn. Equally as important, however, is that state-paid-for autopsies communicate the value and importance of fetal autopsies after stillbirth. The state's emphasis of the importance of autopsies will likely encourage more parents to take have one done. Still, doctors also still need to be better educated on the value of an autopsy so as to not intentionally or accidentally discourage parents.

Paid-for autopsies may also help increase demand for and interest in perinatal pathology. Qualified perinatal pathologists are key to ensuring quality fetal autopsies. The SHINE for Autumn Act of 2021, which passed in the House of Representatives in December 2021, creates a perinatal pathology fellowship program to help address the problem of the lack of qualified pathologists to conduct fetal autopsies.[201]

We need fetal autopsies to improve our stagnant stillbirth rate — to help ensure that those who want to be pregnant will end that pregnancy with the birth of a living child. Fortunately, already-existing state laws on SIDS deaths provide a blueprint.

IV. IMPROVING DATA COLLECTION

Today, the only legally required record of stillbirth is a Fetal Death Record maintained within our vital statistics systems. Vital statistics "are collected and published through a decentralized, cooperative system"[202] dependent on federal-state cooperation with states maintaining records and providing them to the federal government so that it can produce national data.[203]

Fetal Death Records, more commonly referred to as Fetal Death Certificates ("FDCs"), have numerous data-quality issues. Inconsistencies in data are inevitable given state control of issuance and experts agree that FDCs are underreporting stillbirths, especially early stillbirths, which Black women face almost triple the risk of compared

[201] SHINE for Autumn Act of 2021, H.R. 5487, 117th Cong. (2021).

[202] G.C. Tolson, J.M. Barnes, G.A. Gay & J.L. Kowaleski, *The 1989 Revision of the U.S. Standard Certificates and Reports*, 4 VITAL & HEALTH STAT. 1, 1 (1991). The roots of this vital registration system started before independence, with some colonies keeping records of christenings, marriages, and burials. Anders S. Lunde, *The Organization of the Civil Registration System of the United States*, 8 TECH. PAPERS 1, 1 (1980), https://unstats.un.org/unsd/demographic-social/crvs/documents/IIVRS_papers/IIVRS_paper8.pdf [https://perma.cc/H9WL-WRK6]. Colonies became states and the United States became a federated rather than central government, and vital registration power remained with states. *Id.*

[203] Joyce A. Martin & Donna L. Hoyert, *The National Fetal Death File*, 26 SEMINARS PERINATOLOGY 3, 4 (2002).

to white women. Studies also show that data is incomplete; that various data on FDCs is just simply missing.[204] A third data quality issue is that the data that is included is often inaccurate.

This Part proposes a superior public health data collection mechanism — stillbirth surveillance registries. As discussed, public health surveillance registries are already very common, and stillbirth registries have the capacity to avoid all of the data quality issues that FDCs create. Registries are also easy to create from already-existing birth defect registries and would create something closer to a systemic review of stillbirths.

A. From Birth and Death Certificates to Fetal Death Certificates

States first started issuing birth and death certificates in the early 1900s. Those state laws required that stillbirths be registered with both birth and death certificates, the same as how infant deaths were and still are registered. For example, 1905 Pennsylvania law required that "[s]tillborn children, or those dead at birth, shall be registered as births and also deaths, and a certificate of both the birth and death shall be filed with the local registrar in the usual form and manner."[205]

In an effort to create much-needed uniformity,[206] a Model Vital Statistics Act was introduced in 1907, which similarly required the issuance of both birth and death certificates for stillborn children, using the same modern after "the fifth month of uterogestation" definition of stillbirth.[207] The U.S. Census Bureau also created standard birth

[204] *See infra* note 246 and accompanying text.

[205] GEORGE W. PEPPER & WILLIAM D. LEWIS, PEPPER & LEWIS'S DIGEST OF THE LAWS OF PENNSYLVANIA 1700 to 1907, at 2870 (2d ed. 1910).

[206] Lunde, *supra* note 202, at 2-3; *see also* ALICE M. HETZEL, NAT'L CTR. FOR HEALTH STAT., HISTORY AND ORGANIZATION OF THE VITAL STATISTICS SYSTEM app. 2, at 52 (1997), https://www.cdc.gov/nchs/data/misc/usvss.pdf [https://perma.cc/XUJ4-SUBG].

[207] CRESSY L. WILBUR, THE FEDERAL REGISTRATION SERVICE OF THE UNITED STATES: ITS DEVELOPMENT, PROBLEMS, AND DEFECTS app. 4, at 79 (1916) (reprinting the Model Law, section 6); *see also* ALA. CODE. § 1070 (1936); ARIZ. REV. STAT. § 2728 (1928); CAL. GEN. LAWS Act 879 tit. 125a, § 5 (1906); FLA. STAT. § 3274 (1927); GA. CODE § 88-1204 (1933); IOWA CODE § 2323 (1939); LA. STAT. ANN. § 3457 (1932); MICH. COMP. LAWS § 6587 (1929); MINN. STAT. § 2140(e) (1909); MO. REV. STAT. § 6669 (1909); MONT. CODE ANN. § 69-501 (1947); N.Y. GEN. LAW, ch. 13, art. 20, § 376 (1913); N.C. GEN. STAT. § 7093 (1927); OHIO GEN. CODE tit. 3, ch. 2, § 207 (1910); OKLA. STAT. ch. 79, art. 19, § 8988 (1921); OR. REV. STAT. § 59-1206 (1930); TEX. CRIM. STAT. tit. 12, art. 801, r. 45 (1915); UTAH CODE ANN. § 35-2-6 (1933); VA. CODE ANN. ch. 181(6) (1912); WASH. REV. CODE ch. 2, § 5427 (1910); W. VA. CODE § 28 (1923); WIS. STAT. ch. 47, §§ 1022-33 (1911). One exception is Illinois, which registered stillbirths with only a "certificate of stillbirth" already in 1915. S.B. 213, 49th Gen. Assemb., 1st Sess. (Ill. 1915).

certificates. The 1905, 1910, 1915, and 1930 standard birth certificates applied to both live births and stillbirths, with one part of the certificate asking if the baby was born alive or stillborn.[208]

Commentary at the time emphasizing the importance of birth and death certificates in no way distinguished stillbirths from live births or deaths or implied stillbirth's lesser status or importance.[209] Modern day, stillbirth is often conflated with miscarriages (pregnancy losses before 20 weeks),[210] but historically it was associated more closely with infant death.[211] A recent study of stillbirths between 1890 and 1940 in an Indiana county showed that many families mourned their stillborn infants publicly, both with burials in family plots in local cemeteries and birth announcements and/or obituaries of the often named child in the local newspapers.[212] Records also show specific government concern about the high number of stillbirths.[213] In 1916, Congress passed the Sheppard-Towner Maternity and Infancy Act, the first major legislation aimed at decreasing maternal and infant mortality. In discussions of the Act, New York legislators specifically noted that 10,000 babies were stillborn in New York every year.[214]

In 1939, the Census Bureau decided that stillbirths need only be registered with a stillbirth certificate.[215] Thus, in 1939, the first standard stillbirth certificate was introduced.[216] The 1941 Model Vital Statistics Act similarly clarified that stillbirths should be registered only with

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[208] Heather L. Brumberg, Donna Dozor & Sergio G. Golombek, *History of the Birth Certificate: From Inception to the Future of Electronic Data*, 32 J. PERINATOLOGY 407, 408-09 (2012).

[209] The preface to 1907 Model Vital Statistics Act explains that "the proper registration and preservation of records regarding births and deaths is one of the most important questions with which the state has to deal. On the accuracy of such records depends the value of conclusions drawn regarding longevity, births, effects of occupations., etc." WILBUR, *supra* note 207; Am. Med. Ass'n, *Report of the Committee on Uniform State Laws on Vital Statistics*, 4 AM. MED. ASS'N BULL. 141, 180 (1910); *see* P.I. Leonard, *The Prevention of Opthalmia Neonatorum*, 6 J. MO. STATE MED. ASS'N 102, 103 (1909).

[210] *See supra* Part II.

[211] LARA FREIDENFELDS, THE MYTH OF THE PERFECT PREGNANCY: A HISTORY OF MISCARRIAGE IN AMERICA 29 (2020) (describing that the emotional experience of stillbirth was closer to infant death than to miscarriage).

[212] Katherine Parkin, *"Joy Turned to Sorrow": Stillborns in Howard County, Indiana, 1890-1940*, 45 J. FAM. HIST. 64, 69-72 (2020).

[213] *Id.* at 67.

[214] *Considering Mother Aid: Legislators Say 10,000 Babies Are Stillborn in State Yearly*, N.Y. TIMES, Jan. 30, 1922, at 8.

[215] HETZEL, *supra* note 206, at 16.

[216] *See id.*

stillbirth certificates.[217] Many states changed their laws and started using this certificate, some immediately and some a few years later,[218] although some states continued issue birth and death certificates for even decades longer.[219]

Meanwhile, the federal government continued to revise the suggested registration. The 1955 federal standard certificate dropped the word stillbirth and was instead named a Certificate of Fetal Death.[220] The 1977 revision to the Model State Vital Statistics Regulations also clarified that such certificates are "statistical reports only and are not to be incorporated into the official records of the Office of Vital Records."[221] Stillbirth is "not a legal event" as it does not "create nor change a legal status."[222] In 1978, the federal government changed the title from certificate to report, Standard Report of Fetal Death, "to reflect the nature of the document as a statistical report rather than a certificate to be filed permanently,"[223] although the report is still more commonly referred to as a certificate.

This historical shift in vital records registration reflects a gradual shift in how stillbirth was viewed — from the birth of a baby who happened to be stillborn to a clinical, medical event distinct from live birth. The timing of the historical shift also coincides with the movement of childbirth from the home to the hospital,[224] and with successful decreases to the stillbirth rate.[225]

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[217] *Id.* at 5-6 ("The revision also included the first provision for a standard certificate of stillbirth, discarding the making of a birth and death certificate to cover a stillbirth.").

[218] *See, e.g.*, FLA. STAT. § 382.07 (1949); MONT. REV. CODE § 69-513 (1947); OHIO CODE ANN. § 1261-58 (1948); UTAH CODE ANN. § 32-2-6 (1943).

[219] *See, e.g.*, IOWA CODE § 144.20 (1946); KY. REV. STAT. § 213.070 (1953); MICH. COMP. LAWS § 326.15 (1948); N.D. REV. CODE § 23-0216 (1943) VA. CODE § 1566 (1942) W. VA. CODE § 1326 (1961).

[220] HETZEL, *supra* note 206, at 6-7.

[221] NAT'L CTR. FOR HEALTH STAT., DHEW PUB. NO. 78-1115, MODEL STATE VITAL STATISTICS ACT AND MODEL STATE VITAL STATISTICS REGULATIONS: 1977 REVISION 34 (1977), cdc.gov/nchs/data/misc/mvsact77.acc.pdf [https://perma.cc/58WE-LVKG] [hereinafter 1977 REVISION].

[222] *Id.* at 2.

[223] HETZEL, *supra* note 206, at 7.

[224] Elizabeth Kukura, *Giving Birth Under the ACA: Analyzing the Use of Law as a Tool to Improve Health Care*, 94 NEB. L. REV. 799, 812 (2016).

[225] Lens, *Medical Paternalism*, *supra* note 47, at 700-01 (discussing that the much-criticized medicalization of pregnancy and childbirth may also have helped reduce the stillbirth rate).

Much has been written about how the movement to the hospital changed the experience of childbirth,[226] but not also how it changed the experience of stillbirth. Once in hospitals, the standard of care was to take the stillborn baby away after birth, such that the mother would never see the baby,[227] reflecting the medical event recharacterization. It was not until the 1980s, after extensive organizing of parents, that that standard of care changed, allowing parents to see their stillborn baby and spend time with him.[228] Wide consensus exists that parents spending time with and holding their stillborn baby helps with grief.[229] The only vital record those parents who are now encouraged to hold their baby today after birth will receive, however, is a "fetal death record."[230]

B. Fetal Death Certificates' Data Quality Issues

FDCs are the only legal records of stillbirths maintained and the only source for population-based data. Epidemiologists overwhelmingly agree, however, that FDCs have numerous data quality issues[231] — underreporting, data incompleteness, and data inaccuracy.

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[226] Kukura, *supra* note 224, at 802 ("Typical twenty-first-century childbirth in the U.S. reflects a socially constructed understanding of birth as a medical event, fraught with risk and fear of complications, rather than a normal, physiologic process female bodies are well-constructed to perform.").

[227] Kirkley-Best & Kellner, *supra* note 187, at 425 ("Mothers were almost never allowed to see their infants for fear they would be unduly upset, as if they were not already."); Samantha Murphy & Joanne Cacciatore, *The Psychological, Social, and Economic Impact of Stillbirth on Families*, 22 SEMINARS FETAL & NEONATAL MED. 129, 130 (2017) ("Until the 1970s, mothers were not allowed to see or hold a baby who died.").

[228] Murphy & Cacciatore, *supra* note 227, at 130.

[229] Lens, *Devaluation of Stillbirth*, *supra* note 75, at 965-66.

[230] Jarred by the experience of only received a fetal death record after stillbirth, parents have pushed for the creation of stillbirth birth certificates, which now a large majority of states issue. *See* Lens, *Reproductive Justice*, *supra* note 21, at 1108-10. The certificates are not vital statistics.

[231] *See, e.g.*, Lauren Christiansen-Lindquist, Robert M. Silver, Corette B. Parker, Donald J. Dudley, Matthew A. Koch, Uma M. Reddy, George R. Saade, Robert L. Goldenberg & Carol J.R. Hogue, *Fetal Death Certificate Data Quality: A Tale of Two U.S. Counties*, 27 ANNALS EPIDEMIOLOGY 466 (2017) (finding that fetal death certificate data from two counties suffered from missing and inaccurate data); C. Wes Duke, C.J. Alverson & Adolfo Correa, *Fetal Death Certificates as a Source of Surveillance Data for Stillbirths with Birth Defects*, 122 PUB. HEALTH REPS. 664 (2007) (citing underreporting as one of numerous data quality issues threatening effective epidemiological studies); Anne E. Greb, Richard M. Pauli & Russell S. Kirby, *Accuracy of Fetal Death Reports: Comparison with Data from an Independent Stillbirth Assessment Program*, 77 AM. J. PUB. HEALTH 1202 (1987) (finding frequent inaccuracies and misdiagnoses in fetal death report forms); Edward J. Lammer, Lisa E. Brown, Marlene T. Anderka & Bernard Guyer,

First, experts agree that, under this current system, "the number of fetal deaths in the United States is undoubtedly under-reported,"[232] especially early stillbirths. The possibility of underreporting stems from the nonuniformity created by the fact that vital registration areas (50 states, New York City, District of Columbia, and five U.S. territories) control the issuance of FDCs. The CDC's National Center for Health Statistics attempts to create uniformity through the Model State Vital Statistics Act and standard certificates and reports.[233] But these are still recommendations, not law, leaving states free to do whatever they want. Fortunately, great variations no longer exist, but some variations still exist and continue to create problems for data quality.

Any requirement for issuance of FDC based on something other than the gestational weeks — the medical definition of stillbirth as 20 weeks or later — creates the potential for underreporting. And this is exactly what states do. According to the 2020 National Vital Statistics Report, South Dakota reports only stillbirths over 500 grams.[234] This weight is very likely to correspond to a gestational age greater than 20 weeks, instead closer to average fetal weight at 23 or 24 weeks.[235] Other states also used this 500-gram requirement until recently. Until 2011, Tennessee required the issuance of an FDC when the fetus weighed 500 grams or more, or if weight is not available, if the stillbirth occurred after 22 gestational weeks.[236] This requirement was inconsistent with both the average weight at 20 weeks' gestation and the weeks definition

Classification and Analysis of Fetal Deaths in Massachusetts, 261 J. AM. MED. ASS'N 1757 (1989) (finding disagreements between records for 55% of fetal deaths); Mona T. Lydon-Rochelle, Vicky Cárdenas, Jennifer L. Nelson, Kay M. Tomashek, Beth A. Mueller & Thomas R. Easterling, *Validity of Maternal and Perinatal Risk Factors Reported on Fetal Death Certificates*, 95 AM. J. PUB. HEALTH 1948 (2005) (finding fetal death certificate reports of placental cord conditions and other chromosomal abnormalities were inaccurate); Martin & Hoyert, *supra* note 203, at 3 (finding several data quality issues in a review of the National Vital Statistics System).

[232] Martin & Hoyert, *supra* note 203, at 3.

[233] *Id.*

[234] NAT'L CTR. FOR HEALTH STAT., *Fetal Mortality: United States, 2020*, 71 NAT'L VITAL STAT. REPS. 1, 16 n. 3 (2022) https://www.cdc.gov/nchs/data/nvsr/nvsr71/nvsr71-04.pdf [https://perma.cc/WKP4-K2LS]. South Dakota, however, changed its law from 500 grams to 20 weeks in 2007. S.D. CODIFIED LAWS § 34-25-32.1 (2022). It is unclear if South Dakota continues to only report stillbirths over 500 grams or if the report is incorrect.

[235] L.J. Salomon, J.P. Bernard & Y. Ville, *Estimation of Fetal Weight: Reference Range at 20-26 Weeks' Gestation and Comparison with Actual Birth-Weight Reference Range*, 29 ULTRASOUND OBSTETRICS & GYNECOLOGY 550, 552 (2007).

[236] TENN. CODE ANN. § 68-3-504(a)(1) (2010).

itself. New Mexico also had a 500 grams issuance requirement until 2014.[237]

Many states require issuance if fetal weight exceeds 350 grams, or, if weight unknown, if the pregnancy was at 20 weeks' gestation or later.[238] This is the issuance standard in the 1992 Model Vital Statistics Act.[239] This 350 grams weight at least better correlates with average weight at 20 weeks.[240] But it inexplicably does not follow the medical definition of stillbirth, and will miss certain stillbirths given that 350 grams is the average weight for all fetuses at 20 weeks. Some stillborn fetuses at 20 weeks will weigh less than 350 grams and thus not be issued an FDC. Many stillborn babies suffer from fetal growth restriction, increasing the possibility that the fetus will not meet that average weight issuance requirement.[241]

Fortunately, a majority of states base the issuance of an FDC on the 20-week stillbirth medical definition — either mandating issuance at (1) 20 weeks of pregnancy, or (2) 20 weeks of pregnancy, or if gestational age unknown, 350 grams.[242] This 20 weeks or if, unknown,

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237 N.M. STAT. ANN. § 24-14-22 (2013).

238 For examples of states making such requirements, see ARIZ. REV. STAT. ANN. § 36-329 (2022); DEL. CODE ANN. tit. 16, § 3124 (2022); MONT. CODE ANN. § 50-15-403 (2021); OR. REV. STAT. ANN. § 432.143 (2022); S.C. CODE ANN. § 61-19-801(A) (2022); TENN. CODE ANN. § 68-3-504 (2022); TEX. HEALTH & SAFETY CODE ANN. § 674.001(2) (2021).

239 NAT'L CTR. FOR HEALTH STAT., MODEL STATE VITAL STATISTICS ACT AND REGULATIONS: 1992 REVISION 8 (1994), https://www.cdc.gov/nchs/data/misc/mvsact92b.pdf [https://perma.cc/WJG8-PK9R] [hereinafter 1992 REVISION].

240 Salomon et al., *supra* note 235, at 552.

241 *See* Radek Bukowski, *Stillbirth and Fetal Growth Restriction*, 53 CLINICAL OBSTETRICS & GYNECOLOGY 673, 675 (2010).

242 *See, e.g.*, ALA. CODE § 22-9A-13(a) (2022) (20 weeks); ALASKA STAT. § 18-50-240(a) (2022) (20 weeks); CAL. HEALTH & SAFETY CODE § 102950 (2022) (20 weeks); COLO. REV. STAT. § 25-2-102 (2022); CONN. GEN. STAT. § 7-60 (2022) (20 weeks); FLA. STAT. ANN. § 382.002 (2022) (20 weeks); 410 ILL. COMP. STAT. ANN. 535/20(1) (2022) (20 weeks); IOWA CODE ANN. § 114.29 (2022) (20 weeks or, if unknown, 350 grams); KAN. STAT. ANN. § 54-2401 (2022); KY. REV. STAT. ANN. § 213.096 (2022) (20 weeks or, if unknown, 350 grams); LA. STAT. ANN. § 40:49(9) (2022) (20 weeks or, if unknown, 350 grams); ME. REV. STAT. ANN. tit. 22, § 2841 (2022) (20 weeks); MD. CODE ANN., HEALTH-GEN. § 4-213(a) (2022) (20 weeks); MASS. GEN. LAWS ANN. ch. 111, § 202 (2022) (20 weeks or, if unknown, 350 grams); MINN. STAT. ANN. § 144.222 (2022) (20 weeks); MO. ANN. STAT. § 193.165 (2022) (20 weeks or, if unknown 350 grams); NEB. REV. STAT. ANN. § 71-606 (2022) (20 weeks); N.J. STAT. ANN. § 26:6-11 (2022) (20 weeks or, if unknown, 350 grams); N.M. STAT. ANN. § 24-14-22 (2022) (20 weeks or, if unknown, 350 grams); N.Y. PUB. HEALTH LAW § 4160-a (2022) (20 weeks); N.C. GEN. STAT. ANN. § 130A-114 (2022) (20 weeks); N.D. CENT. CODE ANN. § 23-02.1-20 (2022) (20 weeks); OHIO REV. CODE ANN. § 3705.20(A) (2022) (20 weeks); 23 R.I. GEN. LAWS ANN. § 23-3-17 (2022) (20 weeks); UTAH CODE ANN. § 26-2-2 (2022) (20 weeks); VT.

350 grams, was the standard in the Model Vital Statistics before 1992[243]; no explanation accompanied the change. Some states require the issuance even at an earlier gestation,[244] increasing the chances that all stillbirths are captured (along with late miscarriages).[245] Either a 20-week standard or an earlier weeks-based standard provides the best opportunity to capture all stillbirths in this country.

Regardless, nonuniformity currently exists, meaning stillbirths are likely underreported in the U.S. simply because of how data is gathered. This underreporting is especially problematic because it leads to less data collected on early stillbirths, the exact same stillbirths that Black women are almost three times as likely to experience compared to white women.[246] Allowing state nonuniformity specifically means an undercounting of stillborn Black babies.

Decentralization also means more nonuniformity every time model law or federal entities suggest a change. A new standard FDC was introduced in 2003.[247] Only 16 registration areas had adopted it by 2007.[248] Different states using different definitions and systems means "extraordinarily difficult problem[s] for compilation of data files and for the analysis and dissemination of national birth and fetal death data."[249] Even if all reporting agencies used the same processes, staggered implementation of changes means a lack of comparable data for certain years.

STAT. ANN. tit. 18, § 5222 (2022) (20 weeks or, if unknown, 400 grams); WASH. REV. CODE ANN. § 70.58A.010(12) (2022) (20 weeks or, if unknown, 350 grams); WIS. STAT. ANN. § 69.18(1)(e) (2022) (20 weeks or, if unknown, 350 grams); WYO. STAT. ANN. § 35-1-419 (2022) (20 weeks). Michigan law mandates an FDC at 20 weeks or, if unknown, 400 grams. MICH. COMP. LAWS ANN. § 333.2834(3) (2022). Note that any estimates of gestational weeks will always be difficult. But it's a difficulty we look past within pregnancy generally and should do the same for stillbirth.

243 NAT'L CTR. FOR HEALTH STAT., 1977 REVISION, *supra* note 221, at 13.

244 *See* ARK. STAT. ANN. § 20-18-603(a)(1)(A)(i) (2022) (12 weeks); OKLA. STAT. ANN. tit. 63, § 1-301(8) (2022) (12 weeks); *see also* 35 PA. STAT. AND CONS. STAT. § 450.105(4) (2022) (16 weeks).

245 Donna L. Hoyert & Elizabeth C.W. Gregory, *Cause of Fetal Death: Data from the Fetal Death Report, 2014*, 65 NAT'L VITAL STAT. REPS. 1, 4 (2016).

246 Marian Willinger, Chia-Wen Ko & Uma M. Reddy, *Racial Disparities in Stillbirth Risk Across Gestation in the United States*, 201 AM. J. OBSTETRICS & GYNECOLOGY 469.e1, 469.e6-.e7 (2009).

247 Nat'l Ctr. for Health Stat., *The U.S. Vital Statistics System: A National Perspective*, *in* VITAL STATISTICS: SUMMARY OF A WORKSHOP 87, 97-98 (Michael J. Siri & Daniel L. Cork eds., 2009).

248 *Id.* at 98.

249 *Id.*

Nonuniformity is not the only thing skewing the data. Other problems exist causing an overreporting. Health care providers remain confused about deaths of premature or extremely low birth weight infants, or very short-lived live births.[250] No matter the gestational age, any signs of life mean a live birth certificate is filed, but some of these infant deaths are likely being reported as fetal deaths.[251] This confusion is potentially logical if one focuses on the gestational age. Under current laws, a premature baby born at 22 weeks who shows signs of life at birth is issued both birth and death certificates.[252] But a stillbirth at term (at 37 weeks or after), a fetus as fully developed as a newborn at term, is issued only a fetal death certificate.

Similar misclassification likely occurs with abortions after 20 weeks. An abortion is supposed to be recorded as an Induced Termination of Pregnancy, but some of these late abortions, especially if due to a life-limiting fetal condition, are issued an FDC.[253] Or, a pregnant person over twenty weeks pregnant may travel to a state where abortion is legal and obtain a digoxin injection causing fetal demise. She can then travel back home and present at the hospital as stillbirth and will be issued an FDC. At the same time, terminations due to life-limiting conditions perhaps should be counted with stillbirths. Due to the abnormality,

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[250] *See* Martin & Hoyert, *supra* note 203, at 8.

[251] Steven Schwartz, *The U.S. Vital Statistics System: The Role of State and Local Health Departments*, *in* VITAL STATISTICS: SUMMARY OF A WORKSHOP, *supra* note 247, at 77, 81; *see also* Martin & Hoyert, *supra* note 203, at 8.

[252] *See, e.g.*, ALA. CODE § 22-9A-1(7) (2022) (defining "live birth" as "[t]he complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy, which after the expulsion or extraction breathes or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles . . . ."); N.M. STAT. ANN. § 24-14-2(E) (2022) (defining "live birth" the same as the above Alabama law); *see also* NAT'L CTR. FOR HEALTH STAT., 1992 REVISION, *supra* note 239, at 2.

[253] *See* Duke & Gilboa, *supra* note 22, at 14. Another really interesting reporting issue can occur with induction abortions performed without fetal demise beforehand after 20 weeks. The model act defines induced terminations as the "purposeful interruption of an intrauterine pregnancy with the intention other than to produce a live-born infant and which does not result in a live birth." J. KOWALESKI, NAT'L CTR. FOR HEALTH STAT., STATE DEFINITIONS AND REPORTING REQUIREMENTS FOR LIVE BIRTHS, FETAL DEATHS, AND INDUCED TERMINATIONS OF PREGNANCY, 1997 REVISION 8 (1997), https://www.cdc.gov/nchs/data/misc/itop97.pdf [https://perma.cc/W7VB-CU44]. Not at all clear that that would apply to an induced termination without fetal demise beforehand if the induction results in a live birth. Presumably, a birth certificate would be issued because there is some sign of life and birth certificates apply at all lengths of gestation. *Id.* at 2. Notably, a birth certificate would entitle the parents to federal tax benefits.

these pregnancies may very well have ended in stillbirth. So perhaps these inaccurate recordings may actually be appropriate.

Even when FDCs are appropriately filed, they tend to be much more incomplete than live birth certificates.[254] Researchers label this issue "item completeness," meaning "a report of fetal death has been filed, but specific information on the report is missing."[255] FDCs asked for medical information regarding the causes and conditions contributing to fetal death, information on prenatal care, pregnancy history and outcomes of other pregnancies, history of cigarette smoking before and during pregnancy, the presence of defined risk factors (diabetes, hypertension, use of infertility treatment, specified infections), the method of delivery, and fetal congenital anomalies.[256] It also includes information on the mother's education, ethnicity, race, and marital status,[257] though it does not ask for any of the information regarding the other biological parent.

In 2013, over 9% of FDCs were missing the stillborn child's birthweight, compared to only .1% of live birth certificates missing the same data.[258] This study also found other important information also missing: "pregnancy weight gain (70% of records with missing values), gravidity (11%), alcohol and tobacco use during pregnancy (18%), paternal age (74%), and cause(s) of death (69%)."[259] The likelihood of missing information decreases with increased gestational age at the time of stillbirth, meaning early stillbirths — again those that Black women face almost triple the risk of compared to white women — are more likely to have missing FDC information than later stillbirths.[260]

Even when data is included, "there are concerns for its data accuracy."[261] Other studies have found inaccuracies in congenital anomaly, cause of death, birth weight, and gestational age information.[262] The cause of death on an FDC is frequently listed as "stillbirth," essentially stating that death is the cause of death.[263] Studies

[254] *See* Martin & Hoyert, *supra* note 203, at 7.

[255] *Id.*

[256] CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. STANDARD REPORT OF FETAL DEATH 1-2 (2003), https://www.cdc.gov/nchs/data/dvs/FDEATH11-03finalACC.pdf [https://perma.cc/2JWE-3H99] [hereinafter STANDARD REPORT].

[257] *Id.*

[258] Christiansen-Lindquist et al., *supra* note 231, at 466.

[259] *Id.*

[260] *See* Martin & Hoyert, *supra* note 203, at 7-8.

[261] *Id.* at 8.

[262] Christiansen-Lindquist et al., *supra* note 231, at 467.

[263] This was actually the directions in the early Model Vital Statistics Act.

have suggested that the extent of missing data differs according to geographic area, with some areas more likely to issue incomplete FDCs than others.[264]

Multiple reasons explain the missing and inaccurate information. Care is not taken simply because FDCs don't matter; they do not have nearly the same importance as a live birth certificate.[265] Families simply "do not have the same need for [fetal death] certificates,"[266] and health care providers also do not appreciate the importance of FDCs on a population level. If this purpose was more emphasized, it might "make[] the task of reporting more relevant and less of a paperwork burden."[267]

Inaccuracies are especially likely with cause-of-death information. The thought is that the physician or medical examiner would be the best able to determine the cause of death and complete the FDC, but circumstances make this difficult. A doctor's lack of familiarity with and training to complete FDCs can affect the quality of the cause-of-death information.[268] The lack of training and the lack of "know[ing] where to turn for assistance when faced with the task of completing the report" complicate reporting.[269]

Inaccuracies are also inevitable because state law usually requires the issuance of the FDC within days after the stillbirth[270]; medical tests, especially a fetal autopsy, cannot be completed within that timeframe.[271] The standard FDC actually has boxes to check asking whether an autopsy and an histological placental examination was performed with answer options including yes, no, or planned.[272] It also asks whether the results of those tests were used in determining the cause of fetal death

[264] *See* Christiansen-Lindquist et al., *supra* note 231, at 467.

[265] Schwartz, *supra* note 251, at 81.

[266] *Id.*

[267] Martin & Hoyert, *supra* note 203, at 9.

[268] *Id.*

[269] *Id.*

[270] *See, e.g.*, IOWA CODE ANN. § 144.29 (2022) (requiring filing of FDC within 3 days after delivery); OR. REV. STAT. ANN. § 432.143 (2022) (requiring filing of FDC within 5 days after delivery); W. VA. CODE ANN. § 16-5-21 (2022) (requiring filing of FDC within 5 days after delivery).

[271] *Management of Stillbirth*, *supra* note 144, at e115 ("In most cases, stillbirth certificates are filled out before a full postnatal investigation has been completed and amended death certificates are rarely filed when additional information from the stillbirth evaluation emerges."); Duke & Gilboa, *supra* note 22, at 17 ("[T]he majority of FDCs are completed before all postmortem evaluation information is available.").

[272] CTRS. FOR DISEASE CONTROL & PREVENTION, STANDARD REPORT, *supra* note 256.

indicated on the FDC.[273] If the tests are planned but not completed before the FDC is filed, researchers have no access to these test results unless the FDC is amended.

Amending an FDC, however, is a legal process and rarely done.[274] A parent is not even able to legally request a change to the cause of death since that change must be requested by the medical professional who initially filled out the medical information on the certificate.[275] If a parent receives new information on her child's cause of stillbirth from a specialist, the parent would still have go back to the initial doctor to start the process of amendment. But the doctor has much less interest in an amendment than a parent.

There's little emphasis in the FDC itself about the need to amend, in stark contrast to the emphasis on the need to amend a death certificate. Just like the FDC, the standard death certificate also includes questions whether an autopsy was performed and whether the autopsy findings were available to complete the cause of death.[276] The Standard Death Certificate contains strong language emphasizing the need to amend: "Should additional medical information or autopsy findings become available that would change the cause of death originally reported, the original death certificate should be amended by the certifying physician by **immediately** reporting the revised cause of death to the State Vital Records Office."[277] No similar language appears on the standard FDC.

FDCs have also proved an inept source for gathering data concerning COVID-19 infections and stillbirths. Very early in the pandemic, the CDC realized the need to gather information about COVID-19 infections and pregnancy.[278] The CDC thus asked states to add a field specifically asking about COVID-19 infections during pregnancy on live

[273] *Id.*

[274] *Management of Stillbirth*, *supra* note 144, at e115.

[275] *See, e.g.*, MO. CODE REGS. ANN. tit. 19, § 10-10.110(4)(B)(2) (2022) (allowing amendment of the information of the cause of death on an FDC by a "medical certifier, coroner, or medical examiner"); 28 PA. CODE § 1.37 (2022) (requiring a medical professional to request a change in a cause of death); 25 TEX. ADMIN. CODE § 181.30 (2022) (requiring a medical professional to request a change in a cause of death).

[276] CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. STANDARD CERTIFICATE OF DEATH (2003), https://www.cdc.gov/nchs/data/dvs/death11-03final-acc.pdf [https://perma.cc/2NA4-LBVD].

[277] *Id.*

[278] *See* Joyce A. Martin, Michelle J.K. Osterman & Claudia P. Valenzuela, *Maternal and Infant Characteristics and Outcomes Among Women with Confirmed or Presumed Covid-19 During Pregnancy: 14 States and the District of Columbia*, VITAL STAT. RAPID RELEASE, Dec. 29, 2021, at 6, https://www.cdc.gov/nchs/data/vsrr/vsrr-17.pdf [https://perma.cc/KVM2-CEUC].

birth certificates.[279] But the CDC did not do the same for FDCs. The CDC systematically excluded pregnancies that end in stillbirth.

The standard FDC does have a field for information on "Other (Specify) Infections present and/or treated during this pregnancy."[280] This would be the most obvious spot to include information on COVID-19 infection. And that information may very well be written on FDCs. But the CDC is not gathering that information. In 2014, in a well-intentioned attempt to simplify FDCs, the CDC stopped collecting certain FDC data, including the "other" maternal infections.[281] The CDC's official instructions for completing an FDC no longer request information on maternal infections.[282] The standard FDC has not changed so states may still be collecting the data. But we will never have national data.

This is not to say that the CDC is not doing some research on COVID-19 infections and stillbirth. It certainly is. It published a study in November 2021 showing the increased risk of stillbirth when an unvaccinated pregnant person has COVID-19 at the time of delivery.[283] The data source was not FDCs.[284] Similarly, the CDC is gathering information on stillbirth and COVID-19 infection through its Surveillance for Emerging Threats to Mothers and Babies ("SET-

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[279] CTRS. FOR DISEASE CONTROL & PREVENTION, RECOMMENDATIONS FOR WORDING AND PLACEMENT OF COVID-19 ITEMS ON THE BIRTH CERTIFICATE, https://www.cdc.gov/nchs/covid19/COVID-question-mock-up_4_22.pdf (last visited Sept. 1, 2022) [https://perma.cc/TG6W-AW2D].

[280] CTRS. FOR DISEASE CONTROL & PREVENTION, STANDARD REPORT, *supra* note 256.

[281] Nat'l Ctr. for Health Stat., *Deletion of Data Items from the Birth and Fetal Death National Files*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/nchs/nvss/deleted_items_from_birth_fetal_death_files.htm (last updated Sept. 25, 2015) [https://perma.cc/J529-A4GN].

[282] *See generally* CTRS. FOR DISEASE CONTROL & PREVENTION, FACILITY WORKSHEET FOR THE REPORT OF FETAL DEATH (2019), https://www.cdc.gov/nchs/data/dvs/fetal-death-facility-worksheet-2019-508.pdf [https://perma.cc/S99E-3X4X].

[283] *See* Carla L. DeSisto, Bailey Wallace, Regina M. Simeone, Kara Polen, Jean Y. Ko, Dana Meaney-Delman & Sascha R. Ellington, *Risk for Stillbirth Among Women with and Without Covid-19 at Delivery Hospitalization — United States, March 2020 –September 2021*, 70 MORBIDITY & MORTALITY WKLY. REP. 1640, 1641, 1645 (2021), https://www.cdc.gov/mmwr/volumes/70/wr/pdfs/mm7047e1-H.pdf [https://perma.cc/ENQ7-WARN].

[284] *See id.* at 1640.

NET").[285] FDCs are just one of many data sources for SET-NET.[286] FDCs are the only source of national data on stillbirths, yet the CDC cannot rely solely on them to learn more about how COVID-19 infection increases the risk of stillbirth.

We have relied on FDCs for over 80 years to collect data on stillbirths in this country. Yet, their numerous data quality issues are well documented, creating good reason to question both historical and current stillbirth data, and frustrating progress on prevention.

C. The Need for Stillbirth Public Health Surveillance Registries

Another option that exists for collecting data on stillbirths is a stillbirth public health surveillance registry, the same type of data collection system already existing for numerous chronic illnesses, injuries, and birth defects.[287] As previously discussed, the Stillbirth Heath Improvement and Education Act for Autumn Act of 2021 passed the United States House of Representatives in December 2021 with overwhelming bipartisan support.[288] The bill allows the Secretary of Health & Human Services to award grants to states enabling them to "conduct surveillance and collect data" on stillbirths and "collect[] and report[] data on stillbirth risk factors, including any quantifiable outcomes with respect to such risk factors."[289] The bill also requires the Secretary to issue guidelines on that data collection and to develop education to improve awareness of stillbirth.[290]

Although registries are quite common for illnesses, injuries, and birth defects, only a few stillbirth registries have ever existed or do exist. One is in Arkansas. In 1985, the Arkansas legislature created the Arkansas Reproductive Health Monitoring System. Its purpose "is to collect and analyze data from a number of sources to describe trends in the

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285 CTRS. FOR DISEASE CONTROL & PREVENTION, *Data on COVID-19 During Pregnancy: Birth and Infant Outcomes*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://covid.cdc.gov/covid-data-tracker/#pregnant-birth-infant (last visited Oct. 15, 2022) [https://perma.cc/Z99T-FF4M].

286 *See* Kate R. Woodworth, Emily O'Malley Olsen, Varsha Neelam, Elizabeth L. Lewis, Romeo R. Galang, Titilope Oduyebo, Kathryn Aveni, Mahsa M. Yazdy, Elizabeth Harvey & Nicole D. Longcore et al., *Birth and Infant Outcomes Following Laboratory-Confirmed SARS-CoV-2 Infection in Pregnancy — SET-NET, 16 Jurisdictions, March 29–October 14, 2020*, 69 MORBIDITY & MORTALITY WKLY. REP. 1635, 1638 (2020), https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6944e2-H.pdf [https://perma.cc/3C56-H7UN].

287 *See supra* Part II.

288 SHINE for Autumn Act of 2021, H.R. 5487, 117th Cong. (2021).

289 *Id.* § 2(a)(1)(A)-(C).

290 *Id.* § 2(b)(1)(A)-(B).

occurrence of reproductive endpoints, including without limitation congenital abnormalities, fetal deaths, stillbirths, and premature births, and to investigate the causes of unexpected reproductive endpoints."[291] The law creating the registry grants access to medical information,[292] and requires the periodic dissemination of anonymized reports to appropriate agencies and interested persons.[293]

New Jersey also created a stillbirth database in 2015. The legislative findings to the "Autumn Joy Stillbirth Research and Dignity Act" specifically note that the state already "collects some data related to fetal deaths, but full autopsy and laboratory data related to stillbirths could be more consistently collected and more effectively used to better understand risk factors and causes of stillbirth, and thus more effectively inform strategies for their prevention."[294] The law mandated that the State Department of Health establish a "fetal death evaluation protocol"[295] and create a database of all the data obtained through that protocol.[296] The law, however, lacked any funding. Similarly, with funding from the CDC, Iowa also maintained a stillbirth registry from 2005 to 2015 using its already-existing birth defect registry.[297] But the funding ran out in 2015, leaving the Department of Health unable to even do anything with the extensive data.

Registries have the capability to cure the data quality issues that FDCs create. First, registries will provide a more accurate count of how many stillbirths are actually occurring. In contrast to passive reliance on FDCs, a registry enables active surveillance of stillbirths. Active surveillance means"[t]rained abstractors visit area hospitals, locate medical records for potential cases, and record the relevant information."[298] The abstracted information is then "systematically reviewed" by clinicians "to ensure that inclusion criteria are met and to designate the appropriate outcome classification."[299] A 2014 study concluded that combining surveillance of FDCs and stillbirths identified within Metropolitan Atlanta Congenital Defects Program

[291] ARK. CODE ANN. § 20-16-201 (2022).

[292] *Id.* § 20-16-208.

[293] *Id.* § 20-16-212.

[294] N.J. STAT. ANN. § 26:8-40.27 (2022).

[295] *Id.* § 26:8-40.29.

[296] *Id.* § 26:8-40.30.

[297] Telephone Interview with Kim Piper, State Genetics Coordinator, Iowa Dep't of Pub. Health (Mar. 31, 2021) (notes on file with author).

[298] Duke & Gilboa, *supra* note 22, at 17.

[299] *Id.*

resulted in better data capture — using the two systems together "ascertained more stillbirths than either system independently."[300]

Second, registries will result in production of complete and accurate information because of access to medical records. If information is missing on an FDC, nothing can be done. A registry, on the other hand, can easily look to medical records to discover any missing information. Medical record access also means ensuring accurate data. Studies have shown that "active ascertainment and medical chart review improves upon the quantity and quality of the data collected" on stillbirth.[301]

One more specific example of improved accuracy is based on the perhaps common instance of issuing an FDC for an induction abortion after 20 weeks. A 2014 study found that "about 50% of the inductions performed for a fetus affected by a birth defect linked to a FDC, whereas about 75% of those inductions performed for other pregnancy complications were issued a FDC."[302] As the study explained, a registry with access to medical records, however, can easily distinguish induction abortions from stillbirths.[303] The authors of the study noted, however, that possible counterproductivity of excluding terminations for life-limiting fetal conditions from stillbirth records because "many of these birth defects can be considered lethal anomalies and should be considered when understanding fetal mortality rates."[304] Regardless, it is clear that a registry provides greater accuracy than reliance on FDC data alone.[305]

A registry also has improved accuracy due to its flexibility. Again, the only way to change data on an FDC is through formal legal amendment, including data learned from the results of a fetal autopsy, which is basically impossible to perform before an FDC must legally be issued. And amendments are not easy, meaning most parents do not bother. None of this is necessary with a registry. First, gathering information in a registry is usually delayed anyway, such that information would likely not be gathered until after an autopsy and other testing is completed. But even if not, the ability to review medical records means that the registry could collect and integrate autopsy results without any formal legal process.

Use of registries should also better enable researchers to connect stillbirth to social determinants of health, an especially important task

[300] *Id.*
[301] *Id.*
[302] *Id.*
[303] *Id.*
[304] *Id.* at 17-18.
[305] *Id.* at 18.

for the United States. Studies on the race and class disparities of stillbirth risk suggest that social determinants of health can help explain the disparities — environmental or product exposures, higher stress, a lack of social support, depression, a higher prevalence of chronic health conditions, and limited access to abortion.[306] Compared to FDCs, stillbirth registries have a much greater capacity to gather information relevant to the social determinants of stillbirth. This data could then lead to epidemiological studies explaining the social gradient in stillbirth,[307] and prevention efforts and policies to prevent that social gradient.

The SHINE for Autumn Act provides grants to states to create stillbirth registries and, fortunately, studies show that creating such registries is not difficult.[308] Specifically, stillbirth registries are easily adaptable from already commonly existing congenital birth defect registries.[309] The 2014 study concluded that the MACDP could be changed into a stillbirth registry with only a few modifications.[310] The modifications included adding access to emergency department records to capture any stillbirths that occurred without hospital admission and adding captured information from autopsies and placental examinations.[311] Notably, "[t]here was no additional staff required to implement stillbirth surveillance as sources for case finding overlapped with sources already used for birth defects surveillance and were already being reviewed by clinical abstractors."[312]

A stillbirth registry, combined with routine autopsies, would create something closer to systemic review of stillbirths in the state, similar to what most states already do for infant and child deaths. As already discussed, autopsies are often mandatory after infant and child deaths. States also do more, since most states have a formalized system of review after child death, known as a child fatality review.[313] Generally, child

306 Lens, *Reproductive Justice*, *supra* note 21, at 1083.

307 Anne-Marie Nybo Andersen, *Commentary: Social Inequalities in Risk of Stillbirth — The Price of Success?*, 30 INT'L J. EPIDEMIOLOGY 1301, 1302 (2001).

308 *See supra* notes 288–89 and accompanying text.

309 Duke & Gilboa, *supra* note 22, at 17.

310 *Id.*

311 *Id.*

312 *Id.*

313 *See, e.g.*, TEX. FAM. CODE ANN. § 264.503 (2022) (creating a Child Fatality Review committee to investigate child deaths to "develop an understanding of the causes and incidence of child deaths" in Texas, identify strategies "to reduce the number of preventable child deaths" and to "promote public awareness and make recommendations to the governor and the legislature for changes in law, policy, and practice to reduce the number of preventable child deaths"); VA. CODE ANN. § 32.1-

death review "is a multidisciplinary, multi-agency process designed to examine the causes and circumstances of child deaths."[314] The review team usually includes representatives from "public health, law enforcement, social services, and clinical medicine (usually a medical examiner, pediatrician, or general practitioners)."[315] As of 2016, more than 1350 state and local review teams exist, covering all 50 states.[316]

Child fatality review teams were originally established with a criminal law lens, intended to review suspicious deaths possibly involving abuse or neglect.[317] But the reviews "have expanded toward a public health model of prevention of child fatality through system review of child deaths from birth through adolescence,"[318] review either all child deaths or far more than just criminally suspicious ones.[319] Now, the purpose

283.1 (2022) (creating a State Child Fatality Review Team to develop procedures to ensure "that child deaths occurring in Virginia are analyzed in a systematic way" to "improve the identification, data collection, and record keeping of the causes of child death" and "recommend components for prevention and education programs").

[314] Romi A. Webster, Patricia G. Schnitzer, Carole Jenny, Bernard G. Ewigman & Anthony J. Alario, *Child Death Review: The State of the Nation*, 25 AM. J. PREVENTIVE MED. 58, 58 (2003).

[315] *Id.* at 60.

[316] Reade A. Quinton, *Child Death Review: Past, Present, and Future*, 7 ACAD. FORENSIC PATHOLOGY 527, 529 (2017). Some child death review exists because of legislation, some by executive order, and some are volunteer. Webster et al., *supra* note 314, at 60. Existing, however, doesn't mean functioning. In 2003 survey, 16 states said their child death review programs received no state funding. *Id.*

[317] *See* The Comm. on Child Abuse & Neglect et al., *supra* note 140, at 593; *see also* Webster et al., *supra* note 314, at 58-59 (discussing the initial motivations of CDR for abuse and neglect).

[318] The Comm. on Child Abuse & Neglect et al., *supra* note 140, at 592; *see also* Webster et al., *supra* note 314, at 58-59 (discussing the evolution of CDR's purpose). In a 2003 survey of state child death review systems, only 13 states noted providing assistance in "prosecution of maltreatment cases" as an important function of the review. Webster et al., *supra* note 314, at 62. 94% of responding states, on the other hand, noted that the purpose of child death review was to "identify circumstances of death" and noted another important purpose of "providing suggestions for prevention." *Id.* at 60. The majority of state review systems are retrospective (59%), with some states precluding review until post criminal investigation or prosecution. *Id.* at 62. This delay likely means loss of opportunity for improved data collection and secondary prevention. *Id.* at 63. "Rarely, teams and their reviews assist in prosecution of child abuse and neglect." Quinton, *supra* note 316, at 530. Some states do design CDR to be investigative, "occurring shortly after the death." *Id.* Some are retrospective (review post investigation, sometimes post prosecution), investigative (which causes problems that the team members may desire protection from subpoena or discovery), or parallel to investigative (with the two not working together). *Id.* at 530-31.

[319] The Comm. on Child Abuse & Neglect et al., *supra* note 140, at 593. In 2003 survey, six states review only maltreatment-related deaths, four of which review

of child death review teams are "1) identifying and collecting data pertaining to the cause and manner of child deaths, and 2) providing prevention recommendations to state or local agencies based on this data."[320]

The American Academic of Pediatrics describes that "the process of fatality review has identified effective local and state prevention strategies for reducing child deaths" and "can be a powerful tool in understanding the epidemiology and preventability of child death locally, regionally, and nationally; improving accuracy of vital statistics data; and identifying public health and legislative strategies for reducing preventable child fatalities."[321] And data collecting from child fatality reviews have motivated creation of numerous public health measures.[322]

Child and infant death reviews do not, however, apply to stillbirths.[323] Some localized Fetal Infant Mortality Review ("FIMR") does exist, sometimes with state assistance.[324] Texas has three local FIMR review teams, one in each of Dallas, San Antonio-Brexas, and Tarrant counties.[325] Missouri has two local teams, one in St. Louis and the other in Kansas City.[326] Local teams do a case review, including review of medical records if legally allowed (which not all are) and interviews with family.[327] Many local teams emphasize investigation of the social determinants of health — neighborhoods, violence, poverty, food access, health care access.[328] The local teams then make prevention

suspected and confirmed maltreatment and two review only confirmed maltreatment. Webster et al., *supra* note 314, at 60.

320 Quinton, *supra* note 316, at 529.

321 The Comm. on Child Abuse & Neglect et al., *supra* note 140, at 592.

322 *See supra* note 140 and accompanying text.

323 *See, e.g.*, TEX. STATE CHILD FATALITY REV. TEAM COMM., CHILD FATALITY REVIEW TEAM OPERATING PROCEDURES 12 (2011), https://www.dshs.state.tx.us/mch/pdf/Child-Fatality-Review-Team-Operating-Procedures/ [https://perma.cc/N93B-BJW6] (exemplifying a child death review that does not include stillbirths).

324 *See FIMR Map*, NAT'L CTR. FOR FATALITY REV. & PREVENTION, https://ncfrp.org/fimr-map/ (last visited Dec. 23, 2021) [https://perma.cc/N82Z-MXK4].

325 *FIMR Spotlight — Texas*, NAT'L CTR. FOR FATALITY REV. & PREVENTION, https://ncfrp.org/fimr-map/fimr-spotlight-texas/ (last visited Dec. 23, 2021) [https://perma.cc/73NF-KVQN].

326 *FIMR Spotlight — Missouri*, NAT'L CTR. FOR FATALITY REV. & PREVENTION, https://ncfrp.org/fimr-map/fimr-spotlight-missouri/ (last visited Dec. 23, 2021) [https://perma.cc/X45P-WAXN].

327 NAT'L CTR. FOR FATALITY REV. & PREVENTION, MORE FIRST BIRTHDAYS: A REPORT ON THE STATUS OF FETAL & INFANT MORTALITY REVIEW IN THE UNITED STATES, 2018, at 9, 21 (2020), https://ncfrp.org/wp-content/uploads/Status_FIMR_in_US_2018.pdf [https://perma.cc/2Q5Y-4YM2].

328 Telephone Interview with Abby Collier and Rosemary Fournier, Nat'l Ctr. for Fatality Rev. & Prevention (Feb. 25, 2021) (notes on file with author).

suggestions to local leaders.[329] Local FIMR teams are doing important work, but it is very limited geographically and certainly does not produce any population data like a registry would. Plus, when fetal death review is grouped with infant death review, fetal deaths are very likely to be a lesser priority.

Stillbirth registries are not investigative per se like death reviews, but they are a step forward and a systemic recognition of the need for better quality data on stillbirths. The existence of registries alone can help better frame stillbirth as a public health problem capable of mitigation and worth attempting to mitigate.

Last, it is important to address that creation of a registry does create potential privacy concerns. Threats to confidentiality within public health surveillance are historically low, but the perception exists.[330] Professor Wendy K. Mariner has written extensively about privacy issues within public health surveillance — expressing concern that individuals' data is gathered within registries for non-infectious chronic diseases.[331] Normally, medical research requires free and informed consent by prospective subjects.[332] But now common surveillance registries do not require individual consent. The interest in public health monitoring has trumped any individual privacy interest,[333] and "[a] patient seeking care often does not have the right to prevent personal information from being reported to the state for mandatory public health surveillance activities."[334]

But registries do not impede on privacy significantly more than FDCs already do. Whether birth and death certificates originally or the more modern fetal death certificates, states already gather otherwise private, identifying information. The included medical information is relatively extensive (although commonly missing and inaccurate).[335] Fetal death certificates are not available to the public, but each state already gathers this information.

What this Article advocates for is an official registry that would include this data and possibly more — specifically more medical information obtained from the birthing parent's medical records and from fetal autopsies. The increase in data would be in the extent, not

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[329] *Id.*

[330] Charles M. Heilig & Patricia Sweeney, *Ethics in Public Health Surveillance*, *in* PRINCIPLES & PRACTICE OF PUBLIC HEALTH SURVEILLANCE, *supra* note 109, at 202.

[331] Mariner, *supra* note 123, at 991-92.

[332] Heilig & Sweeney, *supra* note 330, at 202.

[333] *Id.*

[334] *Id.*

[335] *See supra* notes 258–64 and accompanying text.

the kind. Importantly, access to medical records would actually allow us to fill in or correct the often missing or incorrect information in FDCs.

Privacy can and should be protected within the legislation creating the stillbirth registry. For instance, legislation should mandate that any registry-created report or information shared from the registry be de-identified.[336] Again, the information is valuable as population data; identifying information is not necessary for that value.[337] Another important part of an ethical surveillance system includes a clear articulation of "the goal of the proposed data collection and the intended public health purpose."[338] Privacy concerns exist, but they are more palatable in light of the goals of educating and raising awareness, enabling epidemiological studies, and providing the data necessary to advocate for prevention initiatives.

Moreover, many stillbirth parents, the same parents whose data will be collected, are specifically frustrated with the United States' stillbirth rate and the lack of progress. In a 2016 study, many women contacted "expressed gratitude that research was underway to better understanding stillbirth in the United States."[339] Similarly, in a study about why parents choose to have fetal autopsies after their child's stillbirth, the second most common reason (after wanting to know the cause) was to "enable research to prevent stillbirth affecting other parents."[340] Maybe if data collection had not been lacking for decades now, we would know much more about stillbirth and maybe their

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[336] *See, e.g.*, N.J. STAT. ANN. § 26:8-40.30 (2022) (mandating that "data shall be made available to the public through the department website, except that no data shall identify any person to whom the data relate"). Arkansas's law could be stronger in its privacy protection. ARK. CODE ANN. § 20-16-207 (2022) (prohibiting "supplying any information by individual name or other personal identifier or in a form other than a statistical report . . . except to any state agency or department which originally supplied the information . . . unless both the originating agency and the system grant release of this information for a specific purpose").

[337] The Model State Public Health Privacy Act specifically describes ethical guidelines that "nonidentifiable data" be used "whenever possible," and that only nonidentifiable and nonconfidential data be disseminated or published. Heilig & Sweeney, *supra* note 330, at 206-07.

[338] *Id.* at 208.

[339] Lauren Christiansen-Lindquist, *Improving Surveillance for the Hidden Half of Fetal-Infant Mortality: A Pilot Study of the Expansion of the Pregnancy Risk Assessment Monitoring System to Include Stillbirth*, 26 ANNALS EPIDEMIOLOGY 401, 403 (2016).

[340] Heazell et al., *A Difficult Conversation?*, *supra* note 158, at 995; *see also* Schirmann et al., *supra* note 158, at 259 (explaining that one reason some parents consented to an autopsy was to "contribut[e] to wider knowledge about stillbirth and its causes and to help others avoid similar loss").

babies could have been saved. Much better than FDCs, registries at least create the prospect of progress in reducing the United States' stillbirth rate.

V. RESEARCH TO PREVENT, NOT TO BLAME

Even if legal initiative existed, however, another problem looms behind the creation of stillbirth surveillance registries. That problem is the concern that increased awareness and research of stillbirth may also cause an increase in blame of birthing parents when stillbirth does still occur. Problematically, this blame can also turn into criminal consequences, consistent with the now increasing (but still rare) prosecutions for drug use during pregnancies supposedly causing stillbirth. These prosecutions have targeted marginalized women and been successful despite the lack of scientific evidence connecting drug use and stillbirth. Although stillbirth generally has not been featured within the reproductive justice framework, this criminalization is addressed.[341]

Potential blame and criminalization, however, are not reasons to avoid research, as the research could actually help prevent stillbirth in the first place. Blame on pregnant people after stillbirth is already widespread. Increased awareness and research will likely not dramatically increase blame. As for prosecutions, the answer is that they must stop. Public health and legal scholars have written about their counterproductivity — the laws will deter people from seeking prenatal care, and instead actually increase the number of stillbirths. A recent empirical study of Tennessee law confirms this result.[342] This is not surprising as the prosecutions are much more about villainization than prevention. The villainization is consistent with their cruelty; using the power of the state to reinforce already-existing blame after the traumas of fetal death and childbirth.

This villainization of women can ultimately be traced back to the country's ever-present abortion debate, a debate that will continue even with the Court's overruling *Roe* as abortion is still legal in about half of the states. This debate creates a single-path narrative that all pregnancies end with the births of healthy babies and frames the woman and fetus in opposition. This abortion lens paints a picture that stillbirth

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[341] Lens, *Reproductive Justice*, *supra* note 21, at 1079.

[342] *See generally* Meghan Boone & Benjamin J. McMichael, *State-Created Fetal Harm*, 109 GEO. L.J. 475 (2021) (finding that Tennessee's 2014 fetal endangerment law "undermined the ability of mothers to access prenatal care, worsened birth outcomes, and increased both fetal and infant death rates").

does not happen and that it is the woman's fault when it does. This warped abortion lens should not be a reason to resist beginning efforts to reduce stillbirths in the country.

A. *Blame Is Already Widespread*

Concern exists that increased attention to stillbirth may also increase blame on pregnant people when stillbirth occurs. This same difficult balance exists within a debate whether to increase education about stillbirth for pregnant people. If we do so, and then stillbirth occurs (because not all stillbirths are preventable), would we then be more inclined to blame the pregnant person?[343] Similarly, the more we learn about stillbirth, the more we could learn about how conduct during pregnancy either contributes to or helps prevent stillbirth, also increasing possible blame.

The idea that we should not research stillbirth because it might lead to blame ignores the reality that blame — both internal and external — is already widespread. Studies show that mothers "meticulously [review] the events of [their] pregnancies" to try to determine what they did wrong.[344] A 2013 study showed "that nearly all mothers of stillborn babies report intense behavioral and characterological self-blame following the baby's death."[345]

Blame is not only self-imposed. In a 2020 study, participants "commonly reported that their family, friends, colleagues and even strangers suggested that they must have done something wrong to cause the death of their baby."[346] "One example of blame, was others

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[343] *See* Meghan Boone, *Considering the Risks of Medical Paternalism and Tort Liability for Reproductive Harms: A Conversation with Jill Wieber Lens*, 106 IOWA L. REV. ONLINE 37, 42 (2021) (explaining that mechanisms created for the benefit of pregnant women can "instead morph into additional mechanisms to *blame* or *punish* pregnant women").

[344] Kirkley-Best & Kellner, *supra* note 187, at 422; *see also* Cacciatore, *The Unique Experiences*, *supra* note 54, at 140 (explaining regret and guilt and agonizing over decisions made within pregnancy).

[345] Joanne Cacciatore, J. Frederik Frøen & Michael Killian, *Condemning Self, Condemning Other: Blame and Mental Health in Women Suffering Stillbirth*, 35 J. MENTAL HEALTH COUNSELING 342, 343 (2013).

[346] Danielle Pollock, Elissa Pearson, Megan Cooper, Tahereh Ziaian, Claire Foord & Jane Warland, *Voices of the Unheard: A Qualitative Survey Exploring Bereaved Parents Experiences of Stillbirth Stigma*, 33 WOMEN BIRTH 165, 169 (2019); *see also* Katherine J. Gold, Ananda Sen & Irving Leon, *Whose Fault Is It Anyway? Guilt, Blame, and Death Attribution by Mothers After Stillbirth or Infant Death*, 26 ILLNESS, CRISIS & LOSS 40, 46 (2018) (In the survey of bereaved moms in Michigan (which also include infant deaths within first month), 17% of participants "agreed that other people blamed them for the death even if it was not their fault" and some of those 17% reported that "someone had

questioning the bereaved parent about how they did not notice that there was a change in movement."[347] The partner may also even blame the birthing parent, causing strain in marital and familial relationships.[348]

Blame is closely related to the widespread guilt women report feeling because they didn't prevent their child's death. In a 2010 study, the words "*guilt, kill, regret, wish,* and *should have*" were common."[349] Women expressed guilt and regret and even "unrealistic expectations that they should have had a prescient experience forewarning them of the impending death. Many mothers blamed themselves for the baby's death, citing their 'body's failure' such as 'I have moments when I apologize for killing our daughter even though there was nothing I could do to stop it . . .'"[350] Similarly, a 2018 study explains that "guilt and shame may be particularly salient in reproductive losses" because of the "failure of [the woman's] body of which she is accustomed to feeling in control."[351]

This blame is also the result of broader cultural and legal forces. Even nineteenth century pregnancy advice literature emphasized to women "that they could produce healthy babies if they did the right things during pregnancy."[352] An 1890s ad for "Dr. Pierce's Favorite Prescription," which supposedly could prevent stillbirth, stated: "Thousands of babes are still-born every year because women innocently and ignorantly neglect, during the expectant period, to take proper care of the delicate and important organs that bear the burdens of maternity."[353] This focus on the woman's control continued and increased in the next century rejecting any fatalism and "suppress[ing] realistic warnings about what could go wrong."[354] Increased discoveries about the dangers of prenatal exposures to German measles, the drug thalidomide, the drug diethylstilbestrol, alcohol exposure, smoking exposure, and crack cocaine resulted in a public health emphasis on

told them to their face that they were at fault for the death," that someone sometimes including health care professionals and the participant's partner").

347 Pollock et al., *supra* note 346, at 170.

348 *See id.*

349 *See* Cacciatore, *The Unique Experiences*, *supra* note 54, at 140.

350 *Id.*; *see also* Gold et al., *supra* note 346, at 42 (explaining that guilt is common because "[p]arents feel it is their job to care for and protect their children, thus feeling they have failed if their child should die").

351 Gold et al., *supra* note 346, at 42.

352 FREIDENFELDS, *supra* note 211, at 84.

353 Parkin, *supra* note 212, at 74.

354 FREIDENFELDS, *supra* note 211, at 89-90.

"personal responsibility rather than communal solutions."[355] "Mother love and guilt harnessed to individual responsibility and initiative were supposed to produce better birth outcomes across the nation."[356]

The ever-present abortion debate is another force contributing to blame after stillbirth. For decades, the reproductive rights movement has focused on a woman's "choice."[357] Choice implies that reproductive decisions are within one's control.[358] This choice rhetoric has also always assumed a binary — that either the pregnancy ends in abortion or with the birth of a living, healthy baby.[359] This binary choice rhetoric and the resulting control imply that the pregnant person did something wrong causing the child's stillbirth.[360] Both sides "give a misleading picture of how much control anyone has over" pregnancy.[361]

The medicalization of pregnancy and childbirth also contributes to blame after stillbirth. The development of "new reproductive technologies appear to be changing . . . expectations regarding biomedicine's abilities to guarantee a live birth."[362] If medical advancements now demonstrate even a severely premature baby can survive, then assuredly medicine has also developed to the point where stillbirth, especially at term, must not occur anymore.[363] Stillbirth is thus widely believed to be something of the past — something that happened in a time when medical care was less advanced and happens currently only in lower-income countries without quality prenatal care.[364] And if it does still occur, surely it was not due to medicine's failure. But this is false. "[E]xpectations concerning reproductive outcomes are higher than the level of medical confidence."[365] Yet the

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[355] *Id.* at 104-05.

[356] *Id.* at 106.

[357] *See* Lens, *Reproductive Justice*, *supra* note 21, at 1078.

[358] *See id.* at 1081. The more recent and holistic reproductive justice movement has rejected the individualistic choice rhetoric because it does not fit marginalized women's lives; choice and access are two very different things. *See id.* at 1081-82. Still, the reproductive justice movement has not emphasized the danger of the choice rhetoric within miscarriage or stillbirth. *See id.* at 1066-67.

[359] *Id.* at 1062.

[360] *See id.* at 1081-83.

[361] FREIDENFELDS, *supra* note 211, at 192.

[362] LINDA LAYNE, MOTHERHOOD LOST: A FEMINIST ACCOUNT OF PREGNANCY LOSS IN AMERICA 93 (2003).

[363] *See id.* at 93-95.

[364] Lens, *Medical Paternalism*, *supra* note 47, at 672-73.

[365] LAYNE, *supra* note 362, at 95.

expectations exist and the increased sophistication of medical care means "even less excuse [exists] for reproductive failure."[366]

Ironically, more recent pushes against the medicalization of pregnancy and childbirth and to restore autonomy to the pregnant person also imply control and thus fault in cases of stillbirth.[367] "The primary agenda of the U.S. women's health movement has been to restore to women the autonomy and control that has been wrestled away from them by biomedicine."[368] Anthropologist Linda Layne powerfully argues that the natural childbirth movement's "ethic of individual responsibility" and even the idea that "women must wrest back control of their bodies from physicians, *especially* during pregnancy and birth, reinforces the notion that positive birth outcomes are something women can control."[369] If the baby is stillborn, "it is hard to imagine a woman who could not go back over that daunting list and find at least some areas in which she should have done more, could have tried harder."[370] There is little doubt that people will question their choices, whether it be to avoid "unnatural" medicine or interventions or to give birth in a birth center instead of a hospital.[371] "Challenging biomedicine's pathologization of pregnancy and birth . . . systematically minimizes and marginalizes negative reproductive outcomes."[372]

The fear that research will increase the potential for blame also ignores how the lack of research on stillbirth actually perpetuates self-blame.[373] Currently, the message is "we don't know what caused your child's stillbirth," but "it's not your fault." (At least, hopefully that second part of the message is communicated). How can one not question their possible causation when their child's death — in their womb — is unexplainable? Relatedly, a study released in May 2022, led

[366] Carol Sanger, *"The Birth of Death": Stillborn Birth Certificates and the Problem for Law*, 100 CALIF. L. REV. 269, 277 (2012).

[367] Linda L. Layne, *Unhappy Endings: A Feminist Reappraisal of the Women's Health Movement from the Vantage of Pregnancy Loss*, 56 SOC. SCI. & MED. 1881, 1889 (2003); *see also* LAYNE, *supra* note 362, at 241 ("Despite the women's-health movement's sustained critique of biomedical models of reproduction, it in fact shares with biomedicine a belief in the ability to control reproduction.").

[368] Layne, *supra* note 367, at 1886.

[369] *Id.* at 1888.

[370] *Id.*

[371] *See id.*

[372] *Id.* at 1886-87.

[373] Samantha Banerjee, *Stillbirth Continues to Happen. The Silence Around It Needs to End.*, WASH. POST (Dec. 11, 2021, 9:00 AM EST), https://www.washingtonpost.com/health/how-common-is-stillbirth/2021/12/10/58820b22-3282-11ec-93e2-dba2c2c11851_story.html [https://perma.cc/AB2R-VDPC] (explaining that a consequence of the lack of research is "that mothers in particular feel guilty, as if they did something wrong").

by an Australian doctor whose child died of SIDS, found a biochemical marker that may make a baby more inclined to die from SIDS.[374] The doctor in charge of the study explained its importance to alleviate the guilt many parents feel after their child died from SIDS — that this biochemical marker means the parents were not at fault for their child's death was not their fault.[375]

Resisting research because of possible increased blame is not only paternalistic, but it also ignores the reality that blame is historical, widespread, and reinforced by broader cultural and legal forces. Research has a much greater potential for alleviating the blame, rather than increasing it.

B. Criminalization Will Not Reduce Stillbirths

Unfortunately, society sometimes reinforces the blame women feel after stillbirth through criminal prosecution. For decades, some prosecutors have been eager to prosecute pregnant women, most commonly for drug use.[376] A large majority of these prosecutions do not involve any harm to the fetus because most babies born after prenatal drug use are perfectly healthy; the prosecution is then instead based on the alleged potential for harm to the unborn baby.[377] But just as some pregnancies that do not include drug use end in stillbirth, others that do involve drug use also end in stillbirth. And thus, some of these prosecutions against women for prenatal drug use are for murder or homicide — prosecution for causing her child's stillbirth. Little to no scientific evidence connects drug use and stillbirth,[378] and any epidemiological studies are population-based and therefore cannot show that any particular pregnant person's drug use caused stillbirth. Yet, prosecutors are pursuing these cases, seeking to prove *beyond a reasonable doubt* that a woman's drug use caused her child's stillbirth.

374 Rosemary Scott, *Researchers Pinpoint Important Biomarker for SIDS — Updated*, BIOSPACE (May 16, 2022), https://www.biospace.com/article/researchers-answer-how-and-why-infants-die-from-sids/?fbclid=IwAR0cbZ_jT46AdasGN7f1aD7oGGzb-eHK-RjiOYcRQvyvANNcvcirnSeOX_s [https://perma.cc/ASP2-H6AC].

375 *Id.*

376 There 413 documented prosecutions between 1973 and 2005, and an additional 200 between 2005 and 2014. Jessica Mason Pieklo, *Murder Charges Dismissed in Mississippi Stillbirth Case*, REWIRE NEWS GRP. (Apr. 4, 2014, 2:43 PM), https://rewirenewsgroup.com/article/2014/04/04/murder-charges-dismissed-mississippi-stillbirth-case/ [https://perma.cc/38EQ-MDPJ].

377 *See* Boone & McMichael, *supra* note 342, at 487 ("The majority of children born to women who use drugs while pregnancy have zero long-term negative effects as a result.").

378 *See id.*

Some higher-profile examples include the conviction of Regina McKnight in 2001 for "homicide by child abuse" after giving birth to her stillborn baby named Mercedes in 1999 and admitting to cocaine usage.[379] After spending eight years in prison, the South Carolina Supreme Court reversed her conviction ruling that she did not receive a fair trial.[380] In 2007, Rennie Gibbs, a Mississippi teenager, was charged with murder after her child's stillbirth.[381] The umbilical cord was wrapped around the baby's neck at birth, but charges were filed after the medical examiner found traces of cocaine byproduct in the baby's system (although no cocaine was found in the baby's blood).[382] The charges were dismissed in 2014. More recently, in May 2021, a California judge dismissed a murder charge against Chelsea Becker based on her child's stillbirth and her methamphetamine use.[383] The dismissal was due to the lack of evidence that Becker had the knowledge and intent to cause the stillbirth, a finding leaving open the possibility of prosecution when that knowledge and intent is present.[384] In June 2022, Adora Perez was released after four years in jail for allegedly causing her son's stillbirth with methamphetamine use.[385] She had accepted a plea deal and pled guilty to "manslaughter of a fetus," which a judge eventually vacated as no such crime exists under California law.[386]

Prosecutions are also likely to increase now that *Dobbs* has overruled *Roe*.[387] The illegality of abortion makes every pregnancy loss suspicious.[388] Even if abortion is no longer legal, abortion medication — the drugs mifepristone and misoprostol — are relatively accessible.[389] The FDA has approved these drugs to terminate pregnancy up to 10 weeks.[390] If used after, the drugs may cause

379 McKnight v. State, 661 S.E.2d 354, 357, 362 (S.C. 2008).

380 *See id.* at 356.

381 Pieklo, *supra* note 376.

382 *Id.*

383 Azi Paybarah, *Judge Dismissed Murder Charge Against California Mother After Stillbirth*, N.Y. TIMES (May 20, 2021), https://www.nytimes.com/2021/05/20/us/chelsea-becker-stillbirth-murder-charges-california.html [https://perma.cc/DHE7-HEGJ].

384 *Id.*

385 *See* Jessica Pishko, *California Prosecutions for Pregnancy Loss Spark Outrage, and a Bill to Stop Future Investigations*, BOLTS (June 6, 2022), https://boltsmag.org/california-pregnancy-prosecutions-kings-county/ [https://perma.cc/FFS8-QBEQ].

386 *Id.*

387 *See* Donley & Lens, *Subjective Fetal Personhood*, *supra* note 90, at 1711.

388 *See id.* at 1707-08.

389 *See id.* at 1705.

390 *See id.* at 1710.

premature birth or stillbirth.[391] There's no medical way to determine if a pregnancy loss is due to medication abortion or natural causes.[392]

Purvi Patel, an Indiana woman, showed up to the emergency room bleeding vaginally due to pregnancy loss.[393] Police later discovered text messages in which she said she obtained mifepristone and misoprostol.[394] In 2015, Patel was convicted of feticide and neglect of a dependent based on the theory that she had taken abortion medication.[395] *Dobbs* likely means more cases like this. At the same time, although the illegality of abortion will certainly increase suspicions surrounding miscarriages (pregnancy losses before 20 weeks), abortion was already illegal after 20 or 24 weeks in most states before *Dobbs*.[396] So suspicions surrounding stillbirth should have already existed. Still, the increased tension surrounding abortion post-*Dobbs* could be its own reason for increased suspicion.

As scholars have noted, racial and class disparities exist in prosecutions of conduct during pregnancy. Drug use, including in pregnancy, is "equally common among different racial and socioeconomic groups in the United States," yet [s]tates overwhelmingly target poor women and women of color" in their enforcement of the laws.[397] This disproportionate enforcement is "the result of deeply ingrained stereotypes regarding" the "good mother."[398] The racial disparity has always existed, while the class disparity is more recent. Poor white women are most often targeted for prosecution for use of opioids during pregnancy. "[S]ocioeconomic class has, in some cases, become as much of a determinant of who is prosecuted as race has historically."[399]

It's reasonable to expect this same sort of targeting of marginalized persons with suspicions of intentionally causing pregnancy loss via medication abortion.[400] Those most likely to be suspected are the ones who fit the "bad mother" stereotype — those who had failed to attend

[391] *See id.* at 1707.

[392] *See id.* at (PIN).

[393] Imani Gandy, *Purvi Patel and the Case of the Self-Managed Abortion*, REWIRE NEWS GRP. (Feb. 8, 2021, 8:46 AM), https://rewirenewsgroup.com/ablc/2021/02/08/purvi-patel-and-the-case-of-the-self-managed-abortion/ [https://perma.cc/W7TS-KH9Y].

[394] *Id.*

[395] *Id.*

[396] Donley & Lens, *Second-Trimester Abortion*, *supra* note 18, at 2155-56.

[397] Boone & McMichael, *supra* note 342, at 489.

[398] *Id.*

[399] *Id.* at 490.

[400] Donley & Lens, *Subjective Fetal Personhood*, *supra* note 90, at 1708-09.

prenatal care appointments, or those who fail to display the correct grief response.[401]

Not only do Black women and poor women already face double the risk of stillbirth,[402] but they are also disproportionately targeted for prosecutions for murder or homicide after stillbirth.[403] Thus, this population of women are at an increased risk for the trauma of stillbirth *and* the further traumatization resulting from a possible law enforcement investigation and prosecution.

A very valid concern exists that if stillbirth registries existed, prosecutors may want to access the information and possibly pursue criminal consequences for women after stillbirth.[404] This concern is especially acute given the "surveillance" label. This term has only a positive connotation in the public health field, but a very negative connotation within the reproductive rights and justice context. Reproductive justice, especially, emphasizes that women experience reproduction differently based on "race, class, gender, age, and sexual identity."[405] Part of that different experience is due to historical state policies aimed at curbing marginalized women's fertility and increased surveillance of marginalized pregnant women, including the possibility of prosecution.[406] This history reflects why Black women and Hispanic women may feel more stigma about miscarriage and stillbirth because their pregnancy losses can "quickly be subject to scrutiny."[407] Any concerns about the potential criminal law surveillance from stillbirth registries should be even more heightened given my analogy of stillbirth registries to child death fatality review systems. Even though the originating criminal law lens of child death review teams has faded, law enforcement and prosecutors are frequently still members of the review team.

The stillbirth surveillance registries that have existed or still do exist, however, have not encountered law enforcement desiring to use any

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[401] *Id.*

[402] Boone & McMichael, *supra* note 342, at 483; Olof Stephansson, Paul W. Dickman, Anna L.V. Johansson & Sven Cnattingius, *The Influence of Socioeconomic Status on Stillbirth Risk in Sweden*, 30 INT'L J. EPIDEMIOLOGY 1296, 1299 (2001).

[403] Boone & McMichael, *supra* note 342, at 489.

[404] *See* Boone, *supra* note 343, at 42 (explaining how mechanisms created "to protect, honor, or compensate mothers for harm have been perverted as additional ways to punish, criminalize, and stigmatize mothers themselves).

[405] Aalap Bommaraju, Megan L. Kavanaugh, Melody Y. Hou & Danielle Bessett, *Situating Stigma in Stratified Reproduction: Abortion Stigma and Miscarriage Stigma as Barriers to Reproductive Healthcare*, 10 SEXUAL & REPROD. HEALTHCARE 62, 63 (2016).

[406] *Id.*

[407] *Id.* at 68.

data. Iowa never ran into an issue with law enforcement wanting access to data within the ten years of its registry.[408] Arkansas has had a registry since 1985 and has similarly never encountered law enforcement involvement.[409]

Still, perhaps increased awareness of stillbirth simply due to creation of registries would pique prosecutors' interest. At the same time, it is unlikely that a registry would change things significantly. The current way that prosecutions start is with a doctor who either suspects or knows of drug use calling the police.[410] The doctor will likely run drug tests, often without particularized consent. The police will ensure an autopsy is completed (but likely not by a qualified perinatal pathologist) — despite the lack of standardization of autopsy after stillbirth. Then, the police can obtain medical records either through a warrant or subpoena, or possibly even without either. Police and prosecutors can already do all of this. They don't need registry data to prosecute for stillbirth. But, if registries did exist, it is theoretically possible that an eager prosecutor might attempt to use a registry to look up all stillbirths in the past 5 years in the county to fish for possible prosecutions. After all, some prosecutors have already shown their eagerness to prosecute arguing for application of inapplicable laws like child abuse to prosecute people for drug use during pregnancy.[411] These same prosecutors might be giddy at the idea of registry data.

The answer, however, is not to preclude stillbirth registries, but to protect the data via legislation. Public health ethics principles dictate this protection: "[s]urveillance data may be shared ethically only for non-public health purposes under extreme and compelling circumstances where the consequence of not doing so would result in significant harm to an individual or the public's health."[412] No such

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[408] Telephone Interview with Kim Piper, *supra* note 297.

[409] Telephone Interview with Dr. Wendy Nembhard (July 12, 2021) (notes on file with author).

[410] MICHELE GOODWIN, POLICING THE WOMB: INVISIBLE WOMEN AND THE CRIMINALIZATION OF MOTHERHOOD 86 (2020).

[411] Prosecutors are so eager that, if the baby is healthy, they have to essentially make up that those laws apply. Drug use is not illegal; laws criminalize the manufacture, sale, and possession of drugs, not the use. Boone & McMichael, *supra* note 342, at 482; *see also* Lynn M. Paltrow, *Pregnant Drug Users, Fetal Persons, and the Threat to* Roe v. Wade, 62 ALB. L. REV. 999, 1021 n.114 (1999) ("Most courts have concluded that evidence of use alone cannot be the basis for prosecution of drug possession — a crime that is distinguished by the presence of the substance rather than the status of being an addict."). Prosecutors have instead relied on child abuse laws to prosecute women for drug use during pregnancy. Boone & McMichael, *supra* note 342, at 481.

[412] Heilig & Sweeney, *supra* note 330, at 22.

extreme or compelling circumstance exists when the stillbirth has already occurred and little to no evidence connects drug use and stillbirth. One example of protective language is found in New Jersey's 2020 bill dictating that the work product and results of any Fetal Infant Death Review Committee "shall not be subject to public inspection, discovery, subpoena, or introduction into evidence in any civil, criminal, legislative, or other proceeding."[413] Just in September 2022, California Governor Gavin Newsom signed into law a prohibition on any criminal or civil liability for a pregnant person for miscarriage, stillbirth, or abortion. The law also provides a cause of action for anyone whose reproductive rights are violated.[414]

Moreover, as other scholars have noted, another solution is to prevent the prosecutions. Numerous states already preclude murder or homicide prosecutions against women after stillbirth,[415] though some antiabortion states may be inclined to eliminate these statutes post-*Dobbs* and/or states looking to protect abortion rights may pass something similar post-*Dobbs*. More states should explicitly exempt the pregnant person from potential homicide charges given that numerous expert entities oppose prosecutions for conduct during pregnancy including ACOG, American Academy of Pediatrics, American Psychiatric Association, and American Medical Association.[416] One reason for this widespread opposition was already discussed — that prosecutors are targeting marginalized women.

Another reason for the opposition is because criminalization will likely deter pregnant people from seeking prenatal care for fear of prosecution. This will worsen pregnancy outcomes. "[P]renatal care is not merely one factor in determine health outcomes for infants — it is perhaps the most important factor."[417]

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[413] S. 298, 220th Leg., Reg. Sess. (N.J. 2022).

[414] A.B. 2223, 2022 Cal. Legis. Serv., Reg. Sess. (Cal. 2022).

[415] *See, e.g.*, MONT. CODE ANN. § 45-5-116 (2021) (prosecution for death of a fetus may not be brought against "a woman with respect to her fetus"); N.H. REV. STAT. ANN. § 630:1-a (2022) (exempting "[a]ny act committed by the pregnant woman" from first degree murder); N.C. GEN. STAT. ANN. § 14-23.7 (2022) (exempting "acts committed by a pregnant women with respect to her own unborn child, including, but not limited to, acts which result in miscarriage or stillbirth by the woman" to crimes involving unborn victims); GA. CODE ANN. § 16-5-80 (2022) (exception in feticide statute that prosecution not permitted of "[a]ny woman with respect to her unborn child"); 720 ILL. COMP. STAT. 5/9-1.2 (2022) (exempting "the pregnant woman whose unborn child is killed" from intentional homicide of an unborn child crime).

[416] Boone & McMichael, *supra* note 342, at 512.

[417] *Id.* at 488.

This includes stillbirth. Numerous studies connect the risk of stillbirth to the receipt of quality prenatal care.[418] Improvements in prenatal care throughout the twentieth century likely help explain the significant reduction in high-income countries' stillbirth rates, a reduction preceded by the current stagnation of rates.[419] A 2012 study attempted to specify how few prenatal care appointments is too few and found that those who attended less than 50% of the recommended had an almost threefold increased risk of late stillbirth," defined as after 28 weeks.[420] The study concluded that "[i]t is the substantial under-utilization of care (rather than a relative reduction in the number of visits) that is associated with increased mortality."[421]

Again, marginalized women already face an increased risk of stillbirth compared to white women and women with economic means. It is incredibly important that marginalized women receive quality prenatal care.[422] But prosecutions for conduct during pregnancy will almost certainly deter marginalized women from seeking prenatal care.

A 2021 empirical study by Professors Meghan Boone and Benjamin J. McMichael confirmed this public health concern — that fetal endangerment laws would deter pregnant people from seeking prenatal

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[418] *See, e.g.*, Diana Y. Huang, Robert H. Usher, Michael S. Kramer, Hong Yang, Lucie Morin & Ruth C. Fretts, *Determinants of Unexplained Antepartum Fetal Deaths*, 95 OBSTETRICS & GYNECOLOGY 215, 220 (2000) (finding that a connection between unexplained fetal deaths and "fewer than four antenatal visits in women whose fetuses died at 37 weeks or later"); Kaisa Raatikainen, Nonna Heiskanen & Seppo Heinonen, *Under-Attending Free Antenatal Care Is Associated with Adverse Pregnancy Outcomes*, 7 BIOMED CENT. PUB. HEALTH 268, 271 (2007) (study linking a lack of prenatal care to poor pregnancy outcomes, including that the risk of stillbirth was "found to be statistically higher than in the general obstetric population who attended routine [prenatal] care"); Stacey Tomasina, John M.D. Thompson, Edwin A. Mitchell, Jane M. Zuccollo, Alec J. Ekeroma & Lesley M.E. McCowan, *Antenatal Care, Identification of Suboptimal Fetal Growth and the Risk of Late Stillbirth: Findings from the Auckland Stillbirth Study*, 52 AUSTL. & N.Z. J. OBSTETRICS & GYNAECOLOGY 242, 242 (2012) (finding that "during the 20th century, there was a significant reduction in the rate of stillbirths in high-income countries, in considerable part because of improvements in antenatal care"); *see also* Elizabeth M. McClure, Sarah Saleem, Omrana Pasha & Robert L. Goldenberg, *Stillbirth in Developing Countries: A Review of Causes, Risk Factors and Prevention Strategies*, 22 J. MATERNAL-FETAL NEONATAL MED. 183, 188 (2009) (linking stillbirths in developing countries to the lack of appropriate obstetric care).

[419] Lens, *Medical Paternalism*, *supra* note 47, at 701 ("Medicalization's possible effect of reducing the United States' stillbirth rate, however, appears complete.").

[420] Tomasina et al., *supra* note 418, at 243-44.

[421] *Id.* at 245.

[422] *See* Lens, *Reproductive Justice*, *supra* note 21, at 1085 (discussing study that expressed concern "that the quality of [medical] care may differ with social class" given the class disparity in stillbirth risk, especially at term, in Sweden despite universal access to prenatal care).

care and thus actually worsen fetal and infant health outcomes.[423] The study focused on the impact of Tennessee's 2014 fetal endangerment law, which specifically criminalized prenatal drug use, by examining birth data and fetal death data.[424] The law was in effect from April 2014 to June 2016.[425] The regression analysis concluded that Tennessee's law "reduced the probability of a mother receiving prenatal care by approximately 6.2 percentage points," translating to approximately 5,421 people skipping prenatal care just in 2015.[426] In fact, the authors found that "the chilling effect of such law on pregnant mothers" even deterred them from seeking prenatal care "past the time the law lapses,"[427] and that "foregone care translates into more fetal and infant deaths."[428] The study also revealed that fetal deaths increased when the law was effective and that the number decreased following lapse in the law.[429] Specifically, the study concluded that "[t]he fetal endangerment law increased fetal deaths by 0.225 for every 1,000 births."[430] Translated to the number of babies born in 2015 in Tennessee, this means that "Tennessee sponsored the deaths of approximately twenty fetuses in 2015."[431]

If the aim is to prevent stillbirth, the empirical evidence demonstrates that criminalization is not the solution. In fact, the experts and the evidence agree that criminalization will instead likely lead to more stillbirths.

That criminalizing stillbirth will likely not decrease stillbirths is not surprising as prevention really does not seem to be the point of criminalization. Why would the government only pay attention to whatever number of stillbirths a year allegedly caused by the drug use, but no attention to the others that happen each year? Similarly, if the lack of attention generally to all of the 24,000 stillbirths is due to the idea that stillbirth is a lesser death, then why is prosecution the answer

[423] *See generally* Boone & McMichael, *supra* note 342 (discussing how "states are actively creating conditions that result in poorer fetal health outcomes — including an increase in fetal and infant death").

[424] *Id.* at 491-92.

[425] *Id.* at 491.

[426] *Id.* at 504-05.

[427] *Id.* at 507. The stillbirth rate also hadn't rebounded, suggesting "that the fetal endangerment law had lingering deleterious effects on the unborn in Tennessee" with a chilling effect likely stemming from "decreased trust in the healthcare and criminal justice systems that began, but did not end, with the law." *Id.* at 506.

[428] *Id.* at 507.

[429] *Id.* at 501.

[430] *Id.* at 505.

[431] *Id.*

when the woman supposedly causes it? The prosecution seems to be much less about the baby's stillbirth and more about the villainization of the (likely marginalized) pregnant person.

Last, prosecution after stillbirth is simply cruel. Stillbirth already means the natural punishments of their child's death and also the physical and psychological trauma that accompanies birthing a dead baby.[432] The underlying "bad mother" marginalized woman stereotype may make some think that these women do not suffer from their child's stillbirth, despite literally giving birth to their dead baby. Grief can vary obviously, but

> the feelings of grief are not unique to any particular group or class of women. A woman who has been targeted for prosecution after a perinatal loss shares these same feelings of despair. Although the voices of women in these circumstances are obscured by societal reprobation, anecdotal reports confirm what is obvious: a woman, regardless of her circumstances, also and just as poignantly grieves her loss.[433]

As discussed, "high rates of depressive symptoms, anxiety, post-traumatic stress, suicidal ideation, panic and phobias"[434] are reported by women after stillbirth. These emotions already exist and could likely be crushing when reinforced by blame from the state (despite the lack of scientific evidence linking drug use and stillbirth).[435] Law enforcement interest and possible prosecution will only further traumatize marginalized women, who likely lack access to quality mental and emotional health care.[436]

Chelsea Becker's story provides a glimpse into that further traumatization. Becker was rushed to the hospital in an ambulance at

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[432] *See* Raff Donelson, *Natural Punishment*, 100 N.C. L. REV. 557, 557 (2022) (arguing that natural punishment, meaning punishment that "occurs when a wrongdoer faces serious harm that results from her wrongdoing and not from anyone seeking retribution against her" should be incorporated into U.S. criminal law).

[433] Brief of Legal Voice and Perinatal Loss Support Organizations and Experts as Amici Curiae Supporting Appellant at 15, Shuai v. Indiana, 966 N.E.2d 619 (Ind. Ct. App. 2012) (No. 49A02-1106-CR-00486), 2011 WL 3892889.

[434] Heazell et al., *Stillbirths*, *supra* note 59, at 606.

[435] *See* Murphy & Cacciatore, *supra* note 227, at 132 (describing that women after stillbirth "are keen to emphasize that they had behaved well in the pregnancy that ended with a stillbirth" to attempt to "maintain the identity of a 'good mother'").

[436] *See* Lens, *Reproductive Justice*, *supra* note 21, at 1096-99 (discussing how "culture can affect the effectiveness of support mechanisms after a parent's experience of stillbirth" and that "Black women are 'more likely to experience loss,' but 'have limited access to bereavement support'").

eight months pregnant because of uncontrollable bleeding.[437] Two hours after she arrived at the hospital, her son died while still in her womb.[438] The standard medical care for stillbirth is to give the birthing parent time with the baby. Becker held her son only briefly.[439] The medical personnel left her son on a table at the other end of her hospital room for hours.[440] In her words: "That image of me lying in the hospital bed with my deceased son left on a table, seemingly abandoned, is an image I will never forget."[441]

Two months after her son's stillbirth, Becker surrendered to a police officer pointing a large automatic weapon at her.[442] Becker was in jail 16 months before her charges were dismissed and during that time, she was unable to receive proper counseling, afraid that anything she said would be used against her in court.[443]

C. The Warped Effect of the Abortion Lens

Our country's pervasive abortion debate has changed how we think about pregnancy. First, it has created a single-path narrative that all pregnancies end with a healthy, live birth. The antiabortion aim of that narrative is to present abortion as an unnatural aberration. It also, however, poses miscarriage and stillbirth as unnatural aberrations. For instance, in the prosecution of Regina McKnight, the "prosecution advanced a seriously distressing proposition related to perfection in pregnancy" that assumed "all pregnancies produce healthy babies and that absent so-called depraved conduct on the part of pregnant women, stillbirths do not occur."[444]

That is obviously not true. It is also a very strange juxtaposition with the widespread belief that stillbirth is inevitable.[445] Apparently stillbirth is unpreventable, unless it is the bad mother's fault.

[437] Sam Levin, *She Was Jailed for Losing a Pregnancy. Her Nightmare Could Become More Common*, GUARDIAN, https://www.theguardian.com/us-news/2022/jun/03/california-stillborn-prosecution-roe-v-wade (last updated June 28, 2022, 12:56 PM EDT) [https://perma.cc/3JJF-EWFF].

[438] *Id.*

[439] *Id.*

[440] *Id.*

[441] *Id.*

[442] *Id.*

[443] *Id.*

[444] Michele Goodwin, *How the Criminalization of Pregnancy Robs Women of Reproductive Autonomy*, 47 HASTINGS CTR. REP. S19, S21 (2017).

[445] Muthler, *supra* note 15.

Second, the ever-present abortion debate has framed the woman and the fetus in opposition. This oppositional framing has created almost a presumption that the woman is acting in her interests and against fetal interests. This framing has leaked into other pregnancy contexts. For instance, one who desires a VBAC after a prior c-section delivery is selfishly neglecting the fetus. This VBAC example is just one of many "maternal-fetal" conflicts that supposedly require the doctor to step in and protect the fetus.

The oppositional framing, however, rarely makes sense within the abortion context and makes little to no sense outside of it. "[T]he mother wants the child to be born alive and healthy; her interest is much greater than the doctor's . . . ."[446] Legal scholars have properly labeled these as "maternal-doctor" conflicts, not maternal-fetal.[447]

Still, both the single-path narrative and the oppositional framing create suspicion and the supposed need to surveil pregnant people — especially those who fit within the racist and classist "bad mother" stereotype. They also put us in the position of weighing the benefits of further research that could help prevent preventable stillbirths versus the risk of increased, counterproductive prosecution of stillbirths. Notably, marginalized women are on both sides of the balancing. They are already at increased risk of stillbirth and could thus benefit from research, yet they also face increased risk of further traumatization via prosecution.

It is currently difficult to view stillbirth as the public health problem that it is because of this abortion lens. Even though *Roe* is gone, the abortion lens is likely not going anywhere. Suspicions will likely only increase, as will stillbirths.

Stillbirth and all pregnancy loss is more than just a pawn in the abortion debate. Other countries have dramatically reduced their stillbirth rates and studies suggest a similar decrease is possible in the United States. Improved data is the first step in improving prevention efforts.

Conclusion

Each year in the United States, at least 24,000 parents leave the hospital after giving birth with an empty car seat. Stillbirth denies these parents the reproductive justice rights to have a child and parent him — to bring him home from the hospital after birth.

[446] Lens, *Medical Paternalism*, *supra* note 47, at 697.

[447] Michelle Oberman, *Mothers and Doctors' Orders: Unmasking the Doctor's Fiduciary Role in Maternal-Fetal Conflicts*, 94 NW. U. L. REV. 451, 454 (2000).

This Article proposes legal reforms to improve public health data on stillbirth, to help reduce the United States' high and stagnant stillbirth rate. Those reforms are routinizing fetal autopsies after stillbirth and creating public health surveillance registries. Both reforms translate to much better data than the current FDC system. To ensure that data is used for research to help prevent stillbirth and not to blame pregnant people, legislation must prevent law enforcement usage of the data. These reforms are the first step in making stillbirths count[448] — helping ensure that stillborn babies still matter.

[448] *See, e.g.*, *#StillCounts Awareness Campaign*, PUSH FOR EMPOWERED PREGNANCY, https://www.pushpregnancy.org/stillcounts (last visited Dec. 18, 2021) [https://perma.cc/WQ54-6RGK] (arguing that the above reforms are the first step to empowering pregnant women).