LEGALMOMENTUM®

The Women's Legal Defense and Education Fund

Memorandum in Support of A.109B (Rosenthal)/S.320B (Salazar)
Relates to prohibiting drug or alcohol testing and screening of pregnant or postpartum individuals and newborns

Legal Momentum, The Women's Legal Defense and Education Fund, is the nation's first and longest-serving legal advocacy organization for women. Among our primary focus areas is reproductive justice and protecting women and their families from being penalized for their pregnancies and pregnancy outcomes by combating discrimination in the systems that serve them. Through our national Helpline, our impact litigation, and our policy advocacy, we have seen firsthand how nonconsensual drug testing negatively impacts pregnant persons and their families, particularly low-income families and families of color. We call on the Legislature to pass, and the Governor to sign, the Informed Consent Bill (A.109B/S.320B) which moves prenatal and postpartum health care away from surveillance and toward support by requiring that health care providers obtain written and verbal informed consent before drug testing pregnant people, new parents, and their newborns—a critical measure for ensuring bodily autonomy and reproductive freedom. It is essential that this legislation mandate informed consent for drug screens, which we regularly see used as the gateway to drug testing; require informed consent for testing of perinatal patients *and* newborns; and mandate *written* consent.

It is essential for pregnant and postpartum individuals to have the opportunity to consent to drug or alcohol testing and screening and that such testing is within the scope of medical necessity. Nonconsensual perinatal drug testing targets women[1] and constitutes unlawful sex and pregnancy discrimination. While other patients are afforded the opportunity to receive information as to the medical reason(s) for a treatment or procedure, including the possible benefits and risks associated with that treatment or procedure, pregnant patients are routinely denied this and thus deprived of their bodily autonomy. Denying pregnant and postpartum individuals informed consent leads to deep and long-lasting consequences, including erosion of trust in medical providers; deprivation of bonding and breastfeeding at a critical time in a newborn's life; stigmatizing medical notations that remain in prenatal and newborn medical records marking women as drug abusers and negatively impacting future care; lengthy and intrusive child protective services and/or law enforcement investigations and family separation; and records indicating a history of suspicion of child abuse remaining available to state authorities for years, if not decades, even where no evidence of child abuse or maltreatment is ever observed.

Based on reports and our direct client work, we have seen that across New York, women, particularly Black, Latina, Indigenous, and low-income pregnant and newly parenting people and newborns are drug tested in health care settings without their knowledge or consent.[2] Pregnant and newly parenting people should have a clear, accessible understanding of the potential risks and negative consequences associated with drug and alcohol testing and screening, only be tested or screened if there is a medical necessity, and have the right to refuse testing or screening and still receive equal access to medical treatment. Providing informed consent to pregnant and newly parenting people will preserve pregnant patient's privacy and bodily autonomy.

[1] We recognize that there are people of all genders who have the capacity to become pregnant. Throughout this letter we often refer to pregnant "women," as women are overwhelmingly represented in the pregnant patient population.
[2] Press Release, NYC Commission on Human Rights, New York City Commission on Human Rights Launches Investigations Into Three Major Private Hospital Systems' Practices of Drug Testing Newborns and Parents (Nov. 16, 2020), https://www1.nyc.gov/assets/cchr/downloads/pdf/press-releases/Hospitals_Press_Release_11-16-2020.pdf.

In our experience, nonconsensual drug tests are typically administered without a medical reason and positive results do not trigger any medical guidance or treatment. Rather, newly parenting people are met by a child protective services caseworker at their bedside, where they are interrogated, sometimes mere hours after giving birth setting off a cascade of unwarranted intrusion into the families' privacy. The practice of routinely testing patients and their newborns without their informed consent and then reporting them to the family regulation system has expanded the surveillance responsibilities of health care providers and has made health care providers de facto arms of the family regulation system—a system in which families of color are disproportionately reported, investigated, and separated.[3]

Sex and Race Disparities

In performing nonconsensual drug tests on pregnant patients, a practice which is rightfully not used on all patients, health care providers make a treatment distinction based on sex and pregnancy, a clear violation New York's nondiscrimination laws.[4] The consequences of this overtly discriminatory practice has a disproportionate impact on women,[5] particularly women of color. Those patients who have a positive toxicology result after nonconsensual drug testing, are most often not provided any medical counseling or treatment. Rather, they are exclusively reported to child protective services or law enforcement. Drug testing pregnant patients not for any medical necessity but for solely punitive purposes amounts to an unlawful search and seizure,[6] and undermines the health and wellbeing of the mother and the child. The absence of informed consent, combined with the secretive ways in which we have seen women coerced into providing their urine for drug testing purposes, makes clear that these practices are being used to "catch" pregnant women and report them to child protective services (CPS).

Numerous studies and investigative reports have found that Black parents are more likely to be screened, tested, and reported for illicit drugs than their white counterparts, even though race is not associated with a positive result, and despite similar rates of use across racial and ethnic groups,[7] and we have found that these practices are often more prevalent in hospitals serving lower-income Black and Brown communities. Because drug screening criteria are not standardized across hospitals, health care providers often have discretion in determining whether or not to screen a pregnant patient, making way for implicit bias and discriminatory practices. From our experience, these discretionary practices have, in fact, disproportionately targeted women of color.

The disproportionate impacts are compounded by the inequities in the family regulation system. Once a report of suspected child abuse or maltreatment is made, Black and Brown children are more likely to be subjected to a child protective investigation, with nonconsensual perinatal drug testing among the primary examples of disproportionate child welfare surveillance.[8] Based solely on reports of positive perinatal drug tests, child protective services agencies throughout New York State launch intrusive, multi-month investigations—some of which are purported to be New York's non-investigative Family Assessment Response (FAR) yet include all the

[3] Andy Newman, *Is N.Y.'s Child Welfare System Racist? Some of Its Own Workers Say Yes.*, N.Y. Times (Nov. 23, 2022), https://www.nytimes.com/2022/11/22/nyregion/nyc-acs-racism-abuse-neglect.html.
[4] 47 R.C.N.Y. § 2-09.
[5] We acknowledge people of all genders have the capacity to become pregnant but that women are disproportionately impacted and that these policies impact people of all genders.
[6] *Ferguson v. Charleston*, 532 U.S. 67, 86 (2001).
[7] Hillary Veda Kunnis et al., *The Effect of Race on Provider Decisions to Test for Illicit Drug Use in the Peripartum Setting*, 16 J. Women's Health 245, 245–255 (2007), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2859171/.
[8] N.Y. State Bar Ass'n, *Report and Recommendations of the Committee on Families and the Law Racial Justice and Child Welfare* 15 (2022), https://nysba.org/app/uploads/2022/03/Committee-on-Families-and-the-Law-April-2022-approved.pdf.

surveillance and intrusion of a traditional investigation. Regardless of whether the response is a formal or informal investigation, even where the result is of no finding of child abuse or maltreatment, records of the report and associated investigations are maintained and available for future use by child protective services for at least ten years thereafter.

Exacerbation of Health Disparities and Barriers to Health Care Access

This practice of drug testing pregnant patients without their knowledge or consent has eroded trust between women and their healthcare providers, discouraged women from seeking prenatal and other care and treatment, and instilled fear among many patients and families.[9] In the nation with the highest maternal mortality rate in the industrialized world, with Black women three times more likely to die from pregnancy than white women,[10] it is critical to eradicate the pernicious practices that give pregnant patients more reason to distrust health care providers and avoid seeking critical care. As one Legal Momentum client described, she "could not trust anybody," and felt like the health care providers assisting her while she was in labor were "trying to get [her]," and "wanted to see [her] baby get taken away." Health care providers reported our client for suspected child abuse or maltreatment based on a single unconfirmed toxicology result, taken without her knowledge or consent, and indicating a legal substance. Even though her medical providers had previously drug tested her months prior in her pregnancy without her knowledge and consent, they failed to inform her about her positive results or to provide any medical guidance or treatment during the course of her pregnancy. Instead her initial test was used as a basis to conduct yet another nonconsensual test during labor, with the sole purpose of reporting her to ACS. After a multi-month investigation despite no evidence of any child abuse or maltreatment, her son's medical records still list her as a drug abuser, and she has been left with a generalized fear and anxiety to seek medical treatment for herself and her young children.

Notwithstanding that New York law makes clear that a positive toxicology test alone does not in and of itself constitute child abuse or maltreatment.[11] Adding insult to injury, in many instances, including in our client's case, health care providers do not even order and wait for confirmatory toxicology results before reporting patients to child protective services—and the state central registry is accepting these reports. This has led to child protective services surveillance of families resulting from drug test results based on consumption of poppy seeds, women seeking drug treatment, and women who were prescribed lifesaving medication for pregnancy-induced symptoms. Among the lasting harms to patients affected by these nonconsensual drug tests, the pregnant patient's and newborn's medical records include notations indicating maternal drug use. These notations are seen by subsequent medical providers and lead to bias in the provision of medical care in perpetuity.

[9] National Advocates for Pregnant Women, *Fact Sheet: Clinical Drug Testing of Pregnant Women and Newborns* (March 2019), https://www.nationaladvocatesforpregnantwomen.org/wp-content/uploads/2019/10/NAPW202522Clinical20Drug20Testing20of20Pregnant20Women20and20Newborns252220March202019.pdf.

[10] Latoya Hill, Samantha Artiga & Usha Ranji, Kaiser Family Foundation, *Racial Disparities in Maternal and Infant Health: Current Status and Efforts to Address Them* (2022), https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-in-maternal-and-infant-health-current-status-and-efforts-to-address-them/

[11] David A. Hansell, Commissioner & Dr. Dave A. Chokshi, Commissioner, *Reporting and Planning Requirements for Newborns Prenatally Exposed to Substances and Their Caregivers*, City of N.Y. (Nov. 12, 2020), https://www1.nyc.gov/assets/acs/pdf/child_welfare/2020/PositiveToxicology.pdf.

Violation of Bodily Autonomy and Privacy

Subjecting pregnant individuals to drug testing without their informed consent is a clear violation of their bodily autonomy and privacy. Because pregnant patients are carrying a fetus, medical providers uniquely disregard their opinions, choices, and right to information regarding medical care, tests, and procedures to be conducted on their bodies in a way that deviates significantly from their treatment of non-pregnant patients. In doing so, health care providers are depriving women of the right to make their own informed decisions about their health care in a context where the testing is not even used to provide medical care to either the mother, the fetus, or to newborns. Moreover, these reports to child protective services of prenatal drug tests, if even reliable, relate to substance consumption before any child within the legal purview of child protective services in New York actually yet exists and absent any actual indication of abuse or maltreatment to a child. Prioritizing the rights of the fetus over the privacy and bodily autonomy of the mother creates a slippery slope and opens the door to surveil, critique, and penalize women for a range of choices made during the course of pregnancy, including eating foods suspected of causing developmental problems, lifting heavy boxes for work, or working in an environment with toxins. Drug testing pregnant patients without their knowledge or consent deprives them of the right to have information about the purpose, risks, and consequences of the testing and to make an informed decision to testing performed on their bodies and bodily fluids. The condition of being pregnant does not negate your rights as a medical patient to choose and be informed about what can be done to and taken from your body.

The Language of the Informed Consent Bill

It is crucial that patients be fully informed of the consequences of prenatal/postpartum and newborn drug testing and screening as well as the medical reason(s) for testing and screening, and that they be provided the opportunity to consent to the drug test and/or screen without fear they will not receive appropriate medical care as a result. Although New York Public Health Law and Civil Rights Laws set forth general informed consent requirements in the health care setting, pregnant persons, new parents, and their newborns are nevertheless drug tested without notice, much less specific informed consent, every day across New York State. Patients receive this type of informed consent for other routine procedures and testing.

The Informed Consent Bill will require health care providers to obtain oral and written consent from pregnant and postpartum individuals before drug testing them or their newborns and require that testing is within the scope of medical care. With respect to verbal drug screening, the bill requires health care providers to obtain oral and written consent from pregnant and postpartum individuals and their newborns in a hospital setting, and oral consent in a non-hospital setting. The bill is carefully crafted to ensure that in case of a medical emergency, health care providers may test or verbally screen individuals without their specific and informed consent. Obtaining specific and informed consent prior to administering a drug test is recommended by several leading medical associations, including the American College of Obstetricians and Gynecologists (ACOG), and the American Academy of Pediatrics.[12] ACOG has developed ethical standards around seeking informed consent and opposes nonconsensual drug testing as a response to parental drug use.[13]

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[12] *ACOG Committee Opinion: Informed Consent and Shared Decision Making in Obstetrics and Gynecology*, Am. Coll. of Obstetricians & Gynecologists e34–e39 (Feb. 2021), https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2021/02/informed-consent-and-shared-decision-making-in-obstetrics-and-gynecology.pdf; Aviva L. Katz & Sally A. Webb, *Informed Consent in Decision-Making in Pediatric Practice*, 138(2) Pediatrics e1–e4 (2016), https://publications.aap.org/pediatrics/article/138/2/e20161485/52519/Informed-Consent-in-Decision-Making-in-Pediatric.

[13] *ACOG Committee Opinion: Informed Consent and Shared Decision Making in Obstetrics and Gynecology*, Am. Coll.

While we are pleased to see informed consent in the Governor's 30-Day Amendments within the Executive Budget Health and Mental Hygiene Part N, significant critical elements are missing from the Governor's language that materially weaken the proposal. The language of the Informed Consent Bill (A.109B/S.320B) provides the most robust protections to pregnant and postpartum individuals. We urge the Assembly and Senate to include the Informed Consent Bill's language in their respective one-house budgets. The three most critical differences between the Governor's proposed language in the Executive Budget and the Informed Consent Bill are:

I. The Executive Budget language inconsistently fails to require parents' informed consent before drug testing their newborns.

Drug testing newborns is a covert way of testing pregnant patients. Namely, the pregnant patient will ultimately be penalized for the newborn's toxicology results for conduct that occurred in utero. This tactic demonstrates the acceptance of fetal personhood because hospitals regularly report in utero exposure, based on newborn drug testing, as child abuse. This sets a dangerous model and stand in stark contrast to New York State policies. Additionally, newborn testing without informed consent violates trust between the patient and health care provider and undermines the provider-patient relationship in the same way that testing pregnant patients themselves would.

II. The Executive Budget language requires either oral *or* written consent, instead of both oral *and* written consent, which are both necessary for pregnant patients to make an informed decision.

Informed consent for pregnant people, postpartum people, and their newborns must require both written and oral consent. Oral consent alone is insufficient. As one might expect, oral consent alone leaves pregnant patients in a vulnerable situation where they will not have means to establish that they did not consent and will be forced to contradict medical providers, who are often given more weight than pregnant patients. Both patients and medical providers are better protected when written consent is required. In fact, even written consent alone raises concerns about ensuring that people meaningfully understand what they agree to. Patients are routinely given large stacks of forms to sign when they receive health care, and they rarely read or fully understand them. Fundamentally, both oral and written consent are necessary to ensure that patients have the best opportunity to make an informed decision about whether or not to consent and that their response is documented. Requiring oral and written consent will safeguard against inconsistent implementation, particularly for Black and Brown patients whose voices are regularly disregarded, and promote trust between patients and health care providers.

III. The Executive Budget language improperly excludes informed consent for performing a *verbal screening* of drug/cannabis/alcohol on perinatal patients.

Before a verbal screening, obtaining oral and written consent is imperative because information patients share during a screening conversation can still trigger a report to CPS and be used against them in a family court proceeding. In fact, many of the women we have spoken to believe they were drug tested after responding honestly to questions during the drug screen, which they assumed was for their medical care but ultimately was for the purposes of flagging

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of Obstetricians & Gynecologists e34–e39 (Feb. 2021), https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2021/02/informed-consent-and-shared-decision-making-in-obstetrics-and-gynecology.pdf.

them for drug testing and reporting during labor. Studies show that even universal verbal screening protocols yield racial disparities, with Black women being four times more likely to be reported to CPS than white women, despite similar usage rates.[14] Before providing any private health information by way of a verbal substance use screening—especially about behavior that is routinely stigmatized and met with punitive responses rather than care—perinatal patients have a right to be informed of the purpose of the screening and the risks associated with divulging information about any substance use so that they can make well-considered decisions about their care and well-being. Furthermore, verbal substance use screening is ineffective at facilitating patients into care and often serves only as surveillance.[15]

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Recently New York State has made important steps to protect the bodily autonomy, privacy, and dignity of pregnant individuals.[16] Despite New York's demonstrated commitment to strengthening reproductive justice, perinatal patients and newborns across the state are regularly subjected to drug testing without their knowledge and consent—and often intrusive and unjustified governmental surveillance as a result. These practices amount to a clear violation of women's rights to bodily autonomy and reproductive freedom. We urge the Legislature, and Governor Hochul, to swiftly enact the Informed Consent Bill and end this unlawful surveillance scheme of pregnant women that is exacerbating discriminatory family separations and undermining reproductive justice.

[14] Sarah C. M. Roberts & Amani Nuru-Jeter, *Universal screening for alcohol and drug use and racial disparities in Child Protective Services reporting*, 39 J. Behavioral Health Serv. & Rsch. 3–16 (2012), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3297420/.

[15] "Studies have found low rates of clinician referral to treatment following positive screens, such as 16% for substance use disorder, 16% for any drug and/or heavy alcohol use, or between 14% and 36% for unhealthy alcohol use." Dominic Hodgkin et al., *Referral to Treatment Following Positive Screens for Unhealthy Drug Use in an Outpatient Veterans Administration Setting*, 14 J. Addiction Med. 236–43 (2020), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7075731/#:~:text=Studies%20have%20found%20low%20rates,2012%2C%20Larson%20et%20al. (internal citations omitted).

[16] *Governor Hochul Signs Nation-Leading Legislative Package to Protect Abortion and Reproductive Rights for All*, Governor Kathy Hochul (June 13, 2022), https://www.governor.ny.gov/news/governor-hochul-signs-nation-leading-legislative-package-protect-abortion-and-reproductive; *Governor Hochul Celebrates Passage of Resolution to Enshrine Equal Rights into the New York State Constitution*, Governor Kathy Hochul (July 1, 2022), https://www.governor.ny.gov/news/governor-hochul-celebrates-passage-resolution-enshrine-equal-rights-new-york-state.