Joint Written Testimony of The Bronx Defenders, Drug Policy Alliance, New York Civil Liberties Union, and Pregnancy Justice, on behalf of the New York Informed Consent Coalition

to

New York State Senate Standing Committees on Women's Issues, Health, Social Services, and Mental Health

regarding

Examination of Maternal Mortality and Morbidity Rates in New York State

February 24, 2025

The Bronx Defenders, Drug Policy Alliance, New York Civil Liberties Union, and Pregnancy Justice submit this collective testimony on behalf of the New York Informed Consent Coalition to lend our strong support to your work to improve maternal and infant health outcomes and better the lives of families and communities across New York State.

The Informed Consent Coalition is comprised of people impacted by the family regulation system,[1] organizers, activists, doulas, physicians, nurses, social workers, public defenders, and civil rights and reproductive rights organizations. Together, we work collaboratively to improve maternal and infant health by advocating for shifts away from discriminatory and punitive practices that serve as barriers to prenatal and postpartum care and towards policies that better support families' health and wellbeing. Specifically, we urge the Legislature to pass the Maternal Health, Dignity, and Consent Act (A.860/S.845), a reproductive and racial justice measure that would promote transparency and trust between pregnant and postpartum people and their health care providers, affirm pregnant people's bodily

[1] Many, including scholar Professor Dorothy Roberts, have come to refer to the so-called "child welfare" system as the family regulation system, given the harms historically and currently perpetuated by the system. *See e.g.*, Dorothy Roberts, "Abolishing Policing Also Means Abolishing Family Regulation," The Imprint (June 16, 2020), https://imprintnews.org/child-welfare-2/abolishing-policing-also-means-abolishing-family-regulation/44480

autonomy, and break down a key barrier to care by helping ensure that it doesn't expose pregnant people and their families to punitive systems.

I. Maternal Mortality and Morbidity is a Crisis in New York State, particularly for Black Women

As the Committees are aware, New York State faces a maternal mortality crisis that disproportionately impacts Black women. From 2018 to 2020, New York had a maternal mortality rate of 19.3 deaths per 100,000 live births.[2] Black women are dying at a rate over four times higher than white women.[3] In its most recent report, the New York State Maternal Mortality and Morbidity Advisory Council (MMMAC) highlighted the urgent need to reduce racial disparities in maternal health outcomes, including by recognizing and addressing the impacts of systemic discrimination and supporting maternal mental health.[4]

Reducing barriers to prenatal care--especially those that disproportionately affect Black pregnant people--is essential to this goal. Central to reducing racial disparities in New York State, and improving maternal mortality and morbidity, is ensuring that all people can access–and feel comfortable accessing–medical care during pregnancy and childbirth.[5] Presently, the practice by which New York hospitals test pregnant patients and their newborns without their consent, and then report positive drug or alcohol results to the Office of Children and Family Services (OCFS), deters pregnant and birthing people from seeking care. This in turn has devastating impacts for pregnant patients and their newborns. To address racial disparities by encouraging prenatal care, New York must invest in building collaborative and trusting relationships between healthcare providers and pregnant patients. A first step toward this goal is to ensure that pregnant and postpartum people have a clear opportunity to consent at each step of their, and their newborn's, health care journey—including with respect to drug testing and screening. That is why we urge the Senate to pass the Maternal Health, Dignity and Consent Act (A.860/S.845).

I. Hospitals' "Test and Report" Practices Undermine Maternal-Fetal Health and Contribute to the Maternal Mortality Crisis in New York State

[2] Office of the New York State Comptroller: Division of State Government Accountability Audit Highlights (July 2024), https://www.osc.ny.gov/files/state-agencies/audits/pdf/sga-2024-22s25.pdf.
[3] *Id.*
[4] *Id.*
[5] World Health Organization, Maternal Mortality (April 26, 2024) https://www.who.int/news-room/fact-sheets/detail/maternal-mortality

To address the maternal mortality crisis in New York State, hospitals must end their practices of testing pregnant people, birthing people, and their newborns without their consent.

A. Non-consensual Drug Testing Is Harmful and Disproportionately Impacts Black and Latine People

Obstetric and pediatric healthcare providers routinely drug test pregnant people, new parents and their newborns without their consent. Although New York Public Health Law and Civil Rights Laws set forth general informed consent requirements in the healthcare setting, pregnant people, new parents and their newborns are nevertheless drug tested without notice, much less specific informed consent. There is often no explanation given as to the medical necessity of the test, and in many circumstances, there is no treatment provided in response to a positive drug test. Even though positive drug tests often do not lead to any medical intervention, hospitals routinely report positive drug tests to family regulation system agencies. This is so even though New York law makes clear that a positive toxicology test alone does not in and of itself suggest that an infant is harmed or is at risk of harm.[6]

The result of this "test and report" practice is that newborns who test positive for an illegal drug are frequently held at the hospital and separated from their parents during a critical time of maternal-infant bonding, which is traumatic and has long-lasting consequences. The other result is that patients who once sought out medical care–or may have been inclined to do so–are reluctant to engage with health care institutions.

Consistent with racial disparities that plague the family regulation system at large,[7] there are extreme racial disparities in hospitals' "test and report" practices. Low-income Black and Latine people and their newborns are dramatically and disproportionately targeted by hospitals for surreptitious drug tests, whether or not

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[6] New York law does not require reporting to the State SCR a positive drug test of a mother or newborn at birth. Still, nearly 27,000 new reports are added to the SCR each year, many of those related to drug use and positive tests at birth.

[7] In New York State in 2019, Black children make up 15% of the population, but nearly 40% of the foster system population. *See Child Population by Race in New York*, Kids Count Data Center (Last Updated September 2020), https://datacenter.kidscount.org/data/tables/103-child-population-by-race#detailed/2/34/false/1729/68,69,67,12,70,66,71,72/423,424; and 2019 Monitoring an Analysis Profiles with Selected Trend Data: 2015-2019, New York State, Office of Children and Families (2019) 7, *available at* https://ocfs.ny.gov/main/reports/maps/counties/New%20York%20State.pdf. White children, on the other hand, make up 48% of the population, yet only 25% of New York's foster population. *Id. See also* Dorothy Roberts & Lisa Sangoi, *Black Families Matter: How the Child Welfare System Punishes Poor Families of Color*, The Appeal (Mar. 26, 2018), https://theappeal.org/black-families-matter-how-the-child-welfare-system-punishes-poor-families-of-color-33ad20e2882e/.

they meet hospital guidelines for testing.[8] A 2010 study of a hospital in Rochester revealed that despite race-blind testing guidelines, the hospital tested and reported greater numbers of women of color regardless of whether they met guidelines,[9] and despite the well-documented fact that Black people use illicit substances at rates no higher than any other race.[10] Similarly, studies have specifically found that Black and Latine pregnant people use illicit substances at virtually the same rate as white pregnant people,[11] suggesting that hospitals' decisions to target Black, Latine, and low-income people for non-consensual drug tests is motivated by racism, classism, ableism, and drug war ideologies[12] rather than medical imperatives.

B. Non-consensual Drug Testing Deters Pregnant and Birthing People from Accessing Health Care

When a pregnant person or new parent discovers that they or their infant have been secretly tested for drugs by their health care provider, they often experience this as a betrayal of trust and confidence–especially if the test results are subsequently reported to Child Protective Services (CPS) agencies. For other pregnant people, the threat of family regulation system investigation and family separation often dissuades them from seeking the medical care and support they need in the first place.[13]

This has devastating outcomes. Access to prenatal care is one of the most critical factors bearing on the health and well-being of mothers and their fetuses. According to the United States Department of Health and Human Services' Office of Women's Health, newborns whose parents do not receive prenatal care are three times more likely to have a low birth weight and five times more likely to die than

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[8] *See* Oren Yaniv, *Cannabis and pregnancy: Maternal child health implications during a period of drug policy liberations*, 104 Preventative Medicine 46, Abstract (2017). https://www.nydailynews.com/new-york/weed-dozen-city-maternity-wards-regularly-test-new-mothers-marijuana-drugs-article-1.1227292#ixzz31hXS2sUE.

[9] *See* Ellsworth MA, Stevens TP, D'Angio CT. Infant race affects application of clinical guidelines when screening for drugs of abuse in newborns. Pediatrics. 2010;125(6):e1379–e1385.

[10] *See* Rates of Drug Use and Sales, by Race; Rates of Drug Related Criminal Justice Measures, by Race, The Hamilton Project (Oct. 21, 2016), https://www.hamiltonproject.org/charts/rates_of_drug_use_and_sales_by_race_rates_of_drug_related_criminal_justice.

[11] *See* e.g., The Guttmacher Report on Public Policy, State Responses to Substance Abuse Among Pregnant Women, (Dec. 1 2000, Vol. 3, No. 6), https://www.guttmacher.org/gpr/2000/12/state-responses-substance-abuse-among-pregnant-women.

[12] *See* Movement for Family Power, et al., *supra* note 4 at 24..

[13] *See* Sarah C. Roberts, et al., State Policies Targeting Alcohol Use During Pregnancy and Alcohol Use Among Pregnant Women 1985-2016: Evidence from the Behavioral Risk Factor Surveillance System, 29 Women's Health Issues 213-221 (May 2019); *see also* Melissa Healy, *When Pregnant People Are Treated Like Criminals, Their Babies Suffer*, L.A. Times (Nov. 14, 2019 5:00 AM), https://www.latimes.com/science/story/2019-11-14/when-pregnant-women-who-abuse-opioids-are-treated-like-criminals-their-babies-suffer; Dinah Ortiz, *We Need More Focus on How the Drug War Attacks Parents of Color,* Filter Magazine (Mar. 28, 2019), https://filtermag.org/we-need-more-focus-on-how-the-drug-war-attacks-parents-of-color/.

newborns whose parents do get care.[14] And in New York City, overdose is the leading cause of death for pregnant people.[15] For this reason, several medical professional organizations have taken a firm stance against non-consensual drug testing and punitive responses to prenatal drug use.[16] And New York's own Department of Health published clinical guidelines to encourage medical providers to obtain written and verbal informed consent before drug testing and screening both pregnant person and newborn. However, our Legislature has yet to codify these guidelines–limiting their effectiveness. And while doulas and other advocates can help mitigate the harms of "test and report" practices, this care is not accessible to all New Yorkers evenly.

II. An Informed Consent Requirement Would Improve Maternal-Fetal Health, Respect Pregnant People's Equality and Bodily Autonomy, Help Reduce Racial Disparities, and Protect New York Families

As noted above, New York's Public Health and Civil Rights law addresses informed consent generally throughout. While New York Law has set forth specific informed consent requirements in some settings (e.g. genetic testing and HIV testing), it has not explicitly protected the rights of pregnant and postpartum people who are drug tested while seeking prenatal, labor and delivery, or postpartum healthcare.

In order to meaningfully support pregnant people's dignity and autonomy, New York law must explicitly require that health care providers obtain: (1) written and verbal specific informed consent before performing a drug test on pregnant people, new parents and their newborns; (2) written and verbal specific informed consent before performing a verbal drug screen in a hospital on pregnant people, new parents and their newborns; and (3) verbal specific informed consent before performing a verbal drug screen outside of a hospital on pregnant people, new parents and their newborns.

In New York, hospitals lack standard practices, oversight, and accountability mechanisms with respect to drug testing. As a result, drug testing and screening has become an arbitrary and discretionary practice that negatively impacts countless pregnant people, new parents and their newborns.

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[14] Womenshealth.gov. (2009, March 6). Publications: Prenatal care fact sheet. Retrieved April 12, 2012, from http://www.womenshealth.gov/publications/our-publications/fact-sheet/prenatal-care.html

[15] NYC Department of Health and Mental Hygiene, 2024 Health Advisory #31 (December 13, 2024). https://www.nyc.gov/assets/doh/downloads/pdf/han/advisory/2024/han-advisory-31.pdf

[16] *See e.g.*, American College of Obstetricians and Gynecologists Committee on Health Care for Underserved Women, Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period, Statement of Policy (Dec. 2020), https://www.acog.org/clinical-information/policy-and-position-statements/statements-of-policy/2020/opposition-criminalization-of-individuals-pregnancy-and-postpartum-period.

Although some hospital systems have adopted drug testing policies that require providers to obtain written and verbal informed consent from the pregnant person, such policies that do not extend to newborns are insufficient. Moreover, a patchwork approach to maternal-fetal care does not work. New Yorkers deserve a state-wide solution to a state-wide problem. This will create a standard practice in New York that respects the decision making of pregnant people over their bodies and their children's bodies, and helps guard against creating a relationship of distrust between medical providers and their patients.

A. Consent to a drug test or screen must be given verbally and in writing

Pregnant people, new parents and their newborns are often drug tested by obstetric and pediatric healthcare providers without even being told that the test is occurring. Even in the one hospital network in New York with a public uniform policy for drug testing during pregnancy, that the policy is not consistently implemented.[17]

Requiring verbal and written authorization for drug tests and verbal screens (done in hospitals), and verbal consent for verbal drug screens done outside of hospitals will serve as a bulwark against inconsistent implementation and document compliance. It will also create greater transparency—a cornerstone of trust—between the patient and provider, and enhance New York hospital systems' abilities to exercise oversight and accountability.

B. Healthcare providers must give specific information about the medical basis for a drug test or screen, a general description of the test or screen, a warning that a positive test or screen could have certain legal consequences, and notice about the confidentiality of the test results or screen responses, at the time of testing, in a language understandable to the patient/person authorized to consent for the newborn and under circumstances that minimize the possibility of coercion or undue influence.

The American Academy of Medicine makes clear that "[i]nformed consent to medical treatment is fundamental in both ethics and law."[18] The purpose of informed consent is to uphold the patient's right to receive information about recommended diagnostic tests, treatments and procedures so that they can make medical decisions for themselves and their family.

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[17] *See* Oversight: Prenatal Care in New York City Hospitals, New York City Council, Committee on Hospitals (Jan. 21, 2020), *available at* https://legistar.council.nyc.gov/LegislationDetail.aspx?ID=4296306&GUID=75241933-0E50-49C2-A17A-A9799F4D64EB&Options=&Search=; Cite to City Council Hearing on Marijuana Policing April 10, 2019; *Oversight: Impact of Marijuana Policies on Child Welfare*, New York City Council, Committee on General Welfare and Hospitals, *available at* https://legistar.council.nyc.gov/LegislationDetail.aspx?ID=3865489&GUID=5D4E94EE-45CB-4880-BED6-878037E8184F&Options=&Search=.

[18] American Medical Association, Code of Medical Ethics Opinion 2.1.1, https://www.ama-assn.org/delivering-care/ethics/informed-consent.

To ensure that people are able to make well-considered decisions about care, it is critical that the consenting person understands the nature of the procedure and its medical basis. Since positive drug tests are often reported to family regulation system agencies, it is imperative that the patient be fully informed of the consequences and benefits of prenatal/postpartum drug and testing.

C. *Under certain emergency circumstances, healthcare providers need not obtain specific informed consent before performing a drug test.*

We recognize that there are certain emergency circumstances in which drug testing may be medically necessary, yet the provider cannot obtain written and verbal information without putting the patient's health or life at risk. Informed consent legislation should allow for healthcare providers to perform a drug test without written and verbal consent in those limited circumstances.

III. Conclusion

Ensuring that pregnant people, new parents and their newborns are informed of their rights with respect to drug testing and provided a meaningful opportunity to accept or decline medical treatment protects pregnant New Yorkers, new parents, children, and families. Testing without consent undermines maternal-fetal health and puts new families at grave risk of traumatic family separation.

In order to reduce maternal mortality and morbidity, the Informed Consent Coalition urges the New York Senate to pass The Maternal Health, Dignity, and Consent Act (A.860/S.845). This legislation will help to preserve the necessary trust between pregnant and postpartum people and their health care providers, remove disincentives to accessing prenatal care and support, and protect pregnant and postpartum people's bodily autonomy and dignity. It is an essential step towards supporting healthy pregnancies, infants, and families.

APPENDIX: US Commission on Civil Rights – NY Advisory Committee Report Highlights

Following a yearlong investigation and public hearings, in May 2024 the US Commission on Civil Rights – NY Advisory Committee issued the report "Examining the New York Child Welfare System and Its Impact on Black Children and Families," which contains important findings and recommendations regarding

the need for informed consent for pregnant and perinatal people. Important highlights below:

The Maternal Health, Dignity, and Consent Act (new biennial bill numbers A.860/S.845; formerly known as the Informed Consent Act) is highlighted in the recommendations specific to the NYS Governor, Legislature, and Committee on Children & families on page 116:

- "g. Enact, fund, and implement The Informed Consent Act 2023-S320B / 2023- A109 which prohibits non-consensual drug and alcohol screening and reporting of pregnant and prenatal people and their newborns and requires health care providers to obtain written and verbal informed consent before drug testing or screening new parents and their newborns and that a drug test or screen be given only if it falls within the scope of medical care."

Informed consent is also included in the recommendations that the U.S. Commission on Civil Rights should issue to U.S. Congress and the President on page 110:

- "v. Enact legislation to prohibit drug testing of parents and pregnant people without prior written, voluntary, and informed consent or pursuant to court order and create a right to decline a drug test unless ordered by a court. Prohibit caseworkers or courts from drawing any adverse inferences from the exercise of the right."

Informed Consent is included under the recommendations to local Child Protective Services offices throughout New York State and New York City's Administration for Children's Services on page 128:

- "iii. Prohibit drug testing of parents and pregnant people without prior written, voluntary, and informed consent or pursuant to court order. Legislatively create a right to decline a drug test unless ordered by a court. Prohibit caseworkers or courts from drawing any adverse inferences from the exercise of the right."

The findings section on page 48 states:

"Finding VIII: Black families are reported to the hotline by healthcare professionals for abuse and neglect at higher rates than White families experiencing the same issues, raising concerns about racial bias in healthcare settings. When interacting with the healthcare system, Black families are disproportionately reported to the hotline for child abuse and neglect compared to white families, even when the injuries are sustained by Black

and white children are similar.[310] Emergency rooms continuously screen Black children for child abuse compared to white children with similar injuries.[311] The Committee received testimony noting that being Black and low-income increases the level of suspected culpability.[312] Pregnancy Justice, a nonpartisan, legal advocacy group, noted that drug testing and subsequent reporting are major contributors to racial disparities in the family regulation system.[313] Although the New York State Department of Health notes that evidence of substance use alone should not be used for making a report to the hotline, [314] Black people who are pregnant are drug tested and reported to CPS at higher rates than White people who are pregnant, despite higher rates of drug use among White people who are pregnant.[315] Disproportionate drug screening of Black mothers and newborns, without consent, adds to the excessive surveillance of Black families, [316] and leads to an increase in foster care placements.[317] Because of mandated reporting, 165,000 families in NYS are involved in investigations per year, yet in May 2022, 75% of the investigations ended up not being indicated for abuse or neglect. [318] Extensive reporting does not necessarily protect children from actual abuse, [319] as evidenced by the highest number of reports coinciding with the highest number of child fatalities.[320] Mandated reporters will also overreport concerns due to the threat of penalty for failing to report suspected abuse or neglect, [321] while those who do make a report are shielded from liability, which incentivizes overreporting.[322] Mr. Richter explained,

> *With penalties for failure to report, the system is set up to incentivize erring on the side of calling without providing adequate information to reporters about the consequences of reporting, not to mention resources that may address the basis of the report in the first place.*[323]

Commissioner Dannhauser shared that efforts are being made to address issues around mandated reporting, such as providing education and training to mandated reporters on how to provide support to families without making unnecessary reports.[324] Yet, Ms. Ketteringham stated that anti-bias training will not mitigate the harm and trauma associated with the mandated reporting laws.[325]

The New York Civil Liberties Union cautioned the Committee: Compelling professionals to initiate government intervention against their clients and patients promotes a rigid and adversarial approach to family well-being that undermines more holistic and collaborative solutions. Rather than keeping

children safe, mandated reporting laws deter families from seeking professionals' support and lead to a glut of unjustified reports.[326]

References

[302] NY State Bar Association. Dec. 7, 2022 Statement, at 10; Naveed Testimony, Feb. 15, 2023 Briefing, p. 5; Richter Testimony, May 19, 2023 Briefing, p. 13; Brady-Stepien Council of Family and Child Caring Agencies August 15, 2023 Statement, at 5.
[303] Brettschneider Nov. 18, 2022 Statement, at 5; Brettschneider Testimony, Nov. 18, 2022 Briefing pp. 20, 22.
[304] Naveed Testimony, Feb. 15, 2023 Briefing, p. 5; Roberts Testimony, Feb. 17, 2023 Briefing, p. 5; Hevesi Testimony, July 21, 2023 Briefing, p. 6.
[305] Richter Testimony, May 19, 2023 Briefing, p. 13.
[306] Roberts Testimony, Feb. 17, 2023 Briefing, p. 5.
[307] Harris Testimony, Apr. 19, 2023 Briefing, p. 17.
[308] McMillan Testimony, Nov. 18, 2022 Briefing p. 12; McMillan Nov. 18, 2022 Written Statement, at 3; Ketteringham Testimony, Apr. 21, 2023 Briefing, p. 11.
[309] Roberts Testimony, Feb. 17, 2023 Briefing, p. 5.
[310] NY State Bar Association Dec. 7, 2022 Statement, at 16; Naveed Testimony, Feb. 15, 2023 Briefing, p. 5; Roberts Testimony, Feb. 17, 2023 Briefing, p. 5; Ketteringham Testimony, Apr. 21, 2023 Briefing, p. 11; Charles Testimony, July 21, 2023 Briefing, p. 13; Naveed Testimony, Feb. 15, 2023 Briefing, p. 5.
[311] Ketteringham Testimony, Apr. 21, 2023 Briefing, p. 11.
[312] Day Testimony, Apr. 21, 2023 Briefing, p. 13.
[313] Pregnancy Justice August 19, 2023 Statement, at 4
[314] New York Civil Liberties Union, ACLU of New York August 18, 2023 Statement, at 6, referring to Marilyn Kacica, MD, MPH and Stephanie Shulman, DrPH, MS, CAPTA CARA Dear Colleague (Provider) Letter, New York Department of Health (Nov. 23, 2021) at 4, https://health.ny.gov/prevention/captacara/docs/dear_provider_letter.pdf.
[315] Ketteringham Testimony, Apr. 21, 2023 Briefing, pp. 11, 18.
[316] Brewington Testimony, Apr. 19, 2023 Briefing, p. 24; NY State Bar Association Dec. 7, 2022 Statement, at 16.
[317] Pregnancy Justice August 19, 2023 Statement, at 2.
[318] Ketteringham Testimony, Apr. 21, 2023 Briefing, p. 11.
[319] Ibid.
[320] Ibid., p. 11.
[321] Brettschneider Testimony, Nov. 18, 2022 Briefing, p. 15; Ketteringham Testimony, Apr. 21, 2023 Briefing, p. 11; Richter Testimony, May 19, 2023 Briefing, p. 14; Wexler Testimony, July 21, 2023 Briefing, p. 20.
[322] New York Civil Liberties Union, ACLU of New York August 18, 2023 Statement, at 8.
[323] Richter Testimony, May 19, 2023 Briefing, p. 14.
[324] Dannhauser Testimony, May 19, 2023 Briefing, p. 11.
[325] Ketteringham Testimony, Apr. 21, 2023 Briefing, p. 11.
[326] New York Civil Liberties Union, ACLU of New York August 18, 2023 Statement, at 8, see Kelley Fong, Concealment and Constraint: Child Protective Services Fears and Poor Mothers' Institutional Engagement, 97 Social Forces 1785 (2019), https://doi.org/10.1093/sf/soy093 (finding that low-income mothers concealed hardships from potential institutional reporters, such as healthcare, educational, and social service systems, potentially precluding opportunities for assistance).