



Testimony of the New York Informed Consent Coalition Before the Joint Legislative Budget Hearing on Health

January 23, 2024

The Informed Consent Coalition is a coalition of people impacted by the family regulation system,¹ organizers, activists, doulas, physicians, nurses, social workers, public defenders, civil rights and reproductive rights organizations. For several years we have supported A109-B/S320-B (Informed Consent Act), which would promote trust between health care providers and pregnant and parenting patients, improve maternal and infant health outcomes, and support racial and reproductive justice by ensuring that no pregnant person or newborn is subjected to a drug test or screen without their informed consent. We were pleased that Governor Hochul included a proposal in this year's State of the State to require informed consent before drug testing a pregnant person or infant. Although the executive budget legislation did not include language to effectuate this proposal, we are hopeful that it will be added through the 30-day amendment process, and we urge the Legislature to include informed consent in their one-house budget proposals.

Non-consensual drug testing of pregnant people, new parents² and their newborns is a violation of individual bodily integrity, undermines maternal-fetal health, and unnecessarily exposes new families to the risk of traumatic family separation. A drug test is not a parenting test; a positive drug test says nothing about a parent's capacity to parent their child or a parent's love for their child. To create a world where the dignity and integrity of all families is valued and supported, we must put an end to punitive and criminalizing responses to drug use.

This is especially urgent as New York, and indeed the whole country, is grappling with the racial disparities rife in our healthcare system.³ We are seeing a collective reexamination of how certain healthcare practices erode patients' trust in the very system tasked with providing care and support. Among these practices is the targeting of pregnant people and new parents and their newborns—overwhelmingly Black and Latine—for non-consensual drug tests by hospitals and subsequent

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>

² Throughout this memo, “new parents” will refer to parents immediately before and after birth (perinatal people).

³ Jamila Perritt, M.D., M.P.H., *#WhiteCoatsForBlackLives — Addressing Physicians' Complicity in Criminalizing Communities*, *New England J. of Medicine* (Nov. 5, 2020), https://www.nejm.org/doi/full/10.1056/NEJMp2023305?query=recirc_inIssue_bottom_article.



reporting by healthcare providers to family regulation system authorities. In our experience, this “test and report practice” makes pregnant people fearful of engaging in critical prenatal care and puts new families at risk of traumatic family separation.

We urge the Governor and the Legislature to take steps toward reducing racial disparities and moving prenatal and postpartum healthcare toward support and away from surveillance by requiring that healthcare providers obtain written and verbal specific informed consent before drug testing pregnant people, new parents, and their newborns.

I. The Harmful Impact of Non-consensual Testing

A major way that pregnant people, new parents and their newborns come to the attention of family regulation system authorities is through obstetric and pediatric healthcare providers who routinely drug test pregnant people, new parents and their newborns without their consent.⁴ 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.⁵ 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.

A. Test and Report Disproportionately Impacts Black and Latine People

⁴ See Movement for Family Power, et al., *Whatever They Do, I'm Her Comfort, I'm Her Protector: How The Foster System Has Become Ground Zero for the U.S Drug War*, 24 (June 2020), <https://static1.squarespace.com/static/5be5ed0fd274cb7c8a5d0cba/t/5eead939ca509d4e36a89277/1592449422870/MFP+Drug+War+Foster+System+Report.pdf>.

⁵ 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.



Consistent with racial disparities that plague the family regulation system at large,⁶ 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 they meet hospital guidelines for testing.⁷ 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,⁸ and despite the well-documented fact that Black people use illicit substances at rates no higher than any other race.⁹ Similarly, studies have specifically found that Black and Latine pregnant people use illicit substances at virtually the same rate as white pregnant people,¹⁰ 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 ideologies¹¹ rather than medical imperatives.

B. The Harms Stemming from Hospitals’ “Test and Report” Practices Are Many and Long-lasting

The harms associated with forced family separation, especially among newborns, is unambiguously clear. Researchers have noted that, separating a child from their parents can cause a “monsoon of stress hormones” to “flood[] the brain and body,” and prolonged exposure to high levels of these hormones can “increase the risk of

⁶ 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/>.

⁷ 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>.

⁸ 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.

⁹ 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.

¹⁰ 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>.

¹¹ See *Movement for Family Power*, et al., *supra* note 4 at 24..



lasting, destructive complications.”¹² This is especially true with newborns, for whom the first stages of life impact infant-parent attachment, development, and the child’s ultimate sense of security.¹³

“Test and report” practices also undermine maternal-fetal health. When pregnant persons, new parents and their newborns are tested without informed consent and subsequently reported to the family regulation system, medical providers break the trust between patient and provider that is absolutely critical to good healthcare. Access to prenatal care is one of the most critical factors bearing on the health and well-being of mothers and their fetuses, yet the threat of family regulation system investigation and family separation often dissuades pregnant people from seeking the medical care and support they need.¹⁴ For this reason, several medical professional organizations have taken a firm stance against non-consensual drug testing and punitive responses to prenatal drug use.¹⁵

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

¹² See Allison Eck, *Psychological Damage Inflicted by parent-Child Separation is Deep, Long-Lasting*, NOVA (June 20, 2018), https://www.pbs.org/wgbh/nova/article/psychological-damage-inflicted-by-parent-child-separation-is-deep-long-lasting/?utm_source=FBPAGE&utm_medium=social&utm_term=20180620&utm_content=1603761016&linkId=53285432&utm_source=FBPAGE&utm_medium=social&utm_term; see also *Trauma Caused by Separation of Children From Parents*, American Bar Association (Last updated Jan. 2020), available at https://www.americanbar.org/content/dam/aba/publications/litigation_committees/childrights/child-separation-memo/parent-child-separation-trauma-memo.pdf.

¹³ See Emma Ketteringham et al., *Healthy Mothers Healthy Babies: A Reproductive Justice Response to the “Womb-to-Foster Care Pipeline,”* 20 CUNY L.R. 77, 100-101 (2016).

¹⁴ 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/>.

¹⁵ 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>.



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.

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, we know that the policy is not consistently implemented.¹⁶

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

¹⁶ 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=>.



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.”¹⁷ 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.

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 and verbal screen results 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 screening 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. The

¹⁷ American Medical Association, Code of Medical Ethics Opinion 2.1.1, <https://www.ama-assn.org/delivering-care/ethics/informed-consent>.



Informed Consent Coalition urges the Governor and the Legislature to advance informed consent protections in the FY 2024-2025 Budget.