Fordham Urban Law Journal

Volume 24 | Number 4 Article 9

1997

Mandatory Testing of Pregnant Women and Newborns: HIV, Drug Use, and Welfare Policy

Wendy Chavkin
MD, MPH, Associate Professor of Clinical Public Health, Columbia University, Center for Population and Family Health.

Deborah Elman
MPH, MIA, Columbia University, Center for Population and Family Health.

Paul H. Wise
MD, MPH, Associate Professor of Pediatrics, Boston University School of Medicine.

MANDATORY TESTING OF PREGNANT WOMEN AND NEWBORNS: HIV, DRUG USE, AND WELFARE POLICY

*Wendy Chavkin**
*Deborah Elman***
*Paul H. Wise****

Fallout from the abortion debate includes changes in the public conversation about pregnant women. An emerging strand of thought depicts them as so self centered that their selfish indifference, even hostility to the fetus, must be constrained by outside intervention. Thus, in the 1980s, debate focused on the legality of imposing medical interventions, such as blood transfusions or cesarean sections, on competent, dissenting pregnant women.[1] Towards the latter part of the decade, the focus shifted away from these cases and concentrated on women with stigmatized conditions, such as drug addiction and HIV infection. Such deviant status was construed to be willful hostility towards the fetus. The majority of imposed interventions involved identification through testing, and reporting the women to state authorities. Child protective and criminal justice sanctions sometimes followed such identification.[2]

I. Substance Abuse

The author's research team conducted surveys in 1992 and 1995 of all of the State Directors of Substance Abuse, HIV and Child Protective Services regarding policies and programs for affected mothers.[3] Our first survey revealed a tension between interdiction

* Please address all correspondence to: Wendy Chavkin, MD, MPH, Associate Professor of Clinical Public Health, Columbia University, Center for Population and Family Health, 60 Haven Ave., B3, New York, NY 10032, phone:(212) 304-5220, fax:(212) 305-7024.

** MPH, MIA, Columbia University, Center for Population and Family Health.

*** MD, MPH, Associate Professor of Pediatrics, Boston University School of Medicine.

1. V.E.B. Kolder et al., *Court-Ordered Obstetrical Interventions*, 316 NEW ENG. J. MED. 1192, 1192-96 (1987).

2. Wendy Chavkin et al., *Finding Common Ground: Necessity of an Integrated Agenda for Women's and Children's Health*, 22 J.L. MED. & ETHICS 262, 266-67 (1994).

3. Wendy Chavkin et al., *Efforts to Reduce Perinatal Mortality, HIV, and Drug Addiction: Survey of the States*, 50 JAMA 164, 165 (1995); Wendy Chavkin et al.,

and treatment efforts as well as a lack of coordination with other public health initiatives directed at reproductive and infant health.[4] The first survey came after efforts to improve services for women had begun. Such efforts included the 1988 Congressional mandate requiring that states (1) increase the portion of the budget "set-aside" for the treatment of pregnant women and women with children, from 5% to 10%, (2) give pregnant women priority enrollment in treatment, as well as specific services such as prenatal care and child care, and (3) establish demonstration programs for drug-using women.[5] These efforts reflected a public health approach to the problem, and promised improved access and availability of substance-abuse treatment for addicted pregnant women and mothers. This hope was followed, however, by the Congressional elections of 1994, the ensuing budget cuts, the devolution of budgetary and regulatory authority to the states, and the shift to Medicaid managed care.

In 1995, our second survey demonstrated a conflicting trend in funding and oversight. Federal funding for substance abuse services which had initially increased, (largely through block grants), in eighteen of the states, was in the process of being replaced by local control of services and reduced local funding.[6] At the same time, respondents from thirty-four states reported that cases of criminal prosecution had transpired in their states, a significant increase from the twenty-two states that had reported such cases in 1992.[7] Moreover, reporting of positive newborn urine toxicology results had increased significantly; about two thirds of states report such cases to Child Protective authorities, and ten states mandated that positive newborn toxicology results be reported to the Criminal Justice system (significantly more than the three which did so in 1992).[8] Approximately a quarter of the states reported that pregnant drug users and mothers were mandated to treatment.[9]

National Survey of the States: Policies and Practices Regarding Drug-Using Pregnant Women, AM. J. PUB. HEALTH (in press for 1998) (on file with author) [hereinafter *National Survey*].

4. *See National Survey*, *supra* note 3.

5. UNITED STATES GENERAL ACCOUNTING OFFICE, ADMS BLOCK GRANT: DRUG TREATMENT SERVICES COULD BE IMPROVED BY NEW ACCOUNTABILITY PROGRAM, REPORT TO THE CHAIRMAN OF THE HOUSE SELECT COMMITTEE ON NARCOTICS ABUSE AND CONTROL (1991) [hereinafter GAO REPORT].

6. *Id.*, n.3.

7. *Id.*

8. *Id.*

9. *Id.*

A similar pattern of increased governmental intervention and decreased resources prevails in New York City. Mayor Rudolph Giuliani closed the fifteen treatment programs established by the previous administration for drug using mothers, called for widespread testing, and for presumptive removals of newborns with positive toxicology results.[10] The following is a table of our rough estimate of the costs involved in universal testing (based on tests alone, not counting costs of personnel and other operational expenses).

Estimates of New York State and New York City Universal Toxicology Testing Costs[11]

TEST	NEW YORK STATE	NEW YORK CITY
Urine Drug Screen[12]	$26.1 million	$12 million
Urine Drug and Alcohol Screens	$47.1 million	$21.6 million
Meconium Drug Screen	$26.6 million	$12.2 million
Blood Alcohol Screen	$22.2 million	$10.2 million
Urine, Blood and Meconium Alcohol/ Drug Screens	$95.9 million	$44 million

Interestingly, according to birth certificate data, the prevalence of maternal drug use actually declined during this period, by about 20% from 1994-95.[13]

II. HIV

In 1987 the Centers for Disease Control and Prevention (CDC) began the National HIV Survey of Childbearing Women, to track HIV infection among women of childbearing age. This was part of a group of blinded serosurveys, which took advantage of blood

10. Jonathan Hicks, *A Wide Impact, From Soup Kitchens to Recycling; Social Services*, N.Y. TIMES, Oct. 26, 1994, at B4.

11. Based on vital statistics from the New York State Bureau of Biometrics, personal communications with New York City hospital labs, and test prices from Corning Clinical Laboratories, New Jersey. Using the lower estimate for a urine drug/ alcohol screening of $166.85 per screen (range of up to $280). The estimates here are based on the following costs: $74.20 for a urine alcohol screen, $78.80 for a blood alcohol screen, $92.65 for a urine drug screen, and $94.50 for a meconium drug screen.

12. Drug screens here refer to a 10-drug panel confirmed with immunoassay including tests for opiates, PCP, THC, barbiturates, methadone, cocaine and amphetamines. Alcohol screening requires a separate test.

13. Written Communication from the Bureau of Vital Statistics, New York City Department of Health, February 26, 1997.

samples collected for other purposes, to conduct population level surveillance.[14] This was economically and logistically efficient, because the blood had already been collected. Additionally, there was no need for informed consent because the serosurvey was anonymous. These discarded blood samples, together with minimal demographic information, were sent to a separate laboratory for HIV testing. Specific protections were devised to prevent inadvertent linkage of test results to identifiable individuals.[15] As a result, these serosurveillance data cannot provide information about a particular individual's infection status.

Many sectors of the public did not understand anonymous population surveillance and equated the surveys with withholding knowledge from individuals. Debate centered on whether there was an ethical obligation to inform individuals, their partners, or healthcare providers of infected status. In fact, both confidential and anonymous testing and counseling were available to individuals while anonymous seroprevalence studies provided critical epidemiologic data and guiding the allocation of resources for prevention and treatment.

The newborn heelstick survey particularly disturbed some opponents of the anonymous surveys.[16] These opponents argued as if a dichotomy existed between maternal and infant interests, claiming that the interests of innocent babies were being sacrificed to selfish maternal privacy concerns. Congressional bills were introduced to unblind the National Survey of Childbearing Women.[17] The CDC then announced the suspension of the survey.[18] New York, however, continued to operate the New York State Blinded Survey of Childbearing Women with its own funds. In 1996, the New York State legislature passed a law mandating that the results of the newborn heelstick survey be unblinded.[19] The law required an

14. *See* CENTERS FOR DISEASE CONTROL AND PREVENTION, National HIV Serosurveillance Summary: Results Through 1992 1-5 (1994).

15. George M. Pappaioanou, Jr. et al., *HIV Seroprevalence Surveys of Childbearing Women—-Objectives, Methods, and Uses of the Data.* 105 PUB. HEALTH REP. 147, 147-52 (1990).

16. *See* Nettie Mayersohn, Letter to the Editor, *Don't Abandon Infected Babies*, WALL ST. J., Apr. 24, 1996, at A15; K. Krasinski et al., *Failure of Voluntary Testing for HIV to Identify Infected Partutient Women in a High Risk Population*, 318 NEW ENG. J. MED. 185, 185-89 (1988).

17. H.R. 1289, 104th Cong., 1st Sess. (1995).

18. N. Touchette, *CDC and Congress at Odds Over Mandatory HIV Testing*, 1 NATURE MED. 723, 723-24 (1995).

19. NEW YORK COMP. CODES R. & REGS. tit. 10 § 69 (1997).

amendment to the State's Confidentiality Law exempting newborn HIV testing from the informed consent requirements.[20]

Many argue against unblinding the newborn heelstick serosurvey in terms of maternal autonomy, gender discrimination, bodily integrity, and the right to privacy in medical information.[21] Conversely, advocates of unblinding emphasize the independence of the newborn and the infant's right to medical care.[22] An assessment of public health efficacy adds another dimension. Such an assessment reveals a mismatch between the goals and interventions. The goals of the New York State law are unclear, the intervention will be difficult to implement and unrelated to the goal of preventing vertical transmission. Moreover, we are likely to lose an important public health tool.

Retroactive unblinding without advanced notification or opportunity to consent violates the ethical premises under which the survey was initiated, and more specifically violates study protocols granted at the beginning of the project.[23] In fact, New York State had to amend its confidentiality in HIV testing statute to exempt pregnant women from the universal protections. Recent developments, however, cast doubt on the relevance and efficacy of so doing. The findings of AIDS Clinical Trial Group protocol 076 make clear that for the purpose of preventing vertical transmission, the most useful time for maternal identification and treatment is prior to delivery.[24] This finding also underscores the need to inform and obtain consent from affected women, as they will have to comply with an onerous medical regime if they elect to take zidovudine [ZDV].[25]

---

20. *Id.*

21. *See* Howard Minkoff & Anne Willoughby, *Pediatric HIV Disease, Zidovudine in Pregnancy, and Unblinding Heelstick Surveys: Reframing the Debate on Prenatal HIV Testing*, 274 JAMA, 1165, 1167-68 (Oct. 11, 1995); Ana O. Dumois, *The Case Against Mandatory Newborn Screening for HIV Antibodies*, 20 J. OF COMMUNITY HEALTH 143, 143-159 (Apr. 1, 1995); Fleischman, *Mandatory Newborn Screening for HIV: The Wrong Answer to the Wrong Question*, 4 THE AIDS READER 172, 172-174 (1995).

22. Arthur J. Ammann, *Unrestricted Routine Prenatal HIV Testing: The Standard of Care*, 50 J. OF THE AM. MED. WOMEN'S ASS'N 83, 83-84 (1995).

23. *See* Touchette, *supra* note 18, at 723-24.

24. Edward M. Connor & Rhoda S. Sperling, *Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment*, 331 NEW ENG. J. MED. 1173, 1173-80 (1994).

25. Ronald Bayer, *Ethical Challenges Posed by Zidovudine Treatment to Reduce Vertical Transmission of HIV*, 31 NEW ENG. J. MED. 1223, 1223-25 (1994).

The unblinding of the newborn serosurvey transpired against the backdrop of stable HIV prevalence among women delivering, and a 27% decrease in vertical transmission rates since 1988.[26] Furthermore, voluntary testing by pregnant women in New York had risen significantly from 48% in 1993 to approximately 97% in 1996.[27]

Data from the author's 1993 survey indicated that only three-fourths of publicly funded prenatal care clinics and half of such gynecologic facilities provided both HIV counseling and testing.[28] These respective proportions did not change by 1995.[29] Yet both public health and ethical principles specify that voluntary measures should be widely available before mandatory ones are instituted. Outreach and education regarding HIV were even less likely to be offered at these obstetric and gynecology sites. Implementation of the new policy is both difficult and expensive. Counseling newly delivered women places an additional burden on obstetric services, which already struggle to condense care into forty-eight hours. Since test results will become available after women go home, funds and personnel are needed to trace and notify mothers. In some New York City hospitals as many as two-thirds of HIV-positive women could not be found to receive their results.[30]

This retroactive identification of infected mothers without consent is likely to adversely affect the public trust, and to undermine the credibility of both public health measures and professionals. We have failed to learn from earlier experiences with newborn metabolic screening. For example, Baltimore's Jewish community was successfully, voluntarily engaged in Tay-Sachs screening, in contrast to the manner in which newborn sickle cell testing was implemented.[31] In the latter case, insensitivity and coercion led to long term distrust.[32]

---

26. CENTERS FOR DISEASE CONTROL AND PREVENTION, *AIDS among Children—United States*, 276 JAMA 1791, 1791-92 (1996).

27. NEW YORK STATE DEPARTMENT OF HEALTH, AIDS IN NEW YORK STATE THROUGH 1994 (1995); K. Pass, HIV Testing of Newborns in New York State (Presented at the Conference of the American Public Health Association, New York, November 1996).

28. Wendy Chavkin et al., *Integrated Reproductive Health Services*, 87 AM. J. PUB. HEALTH 691, 691-92 (1997).

29. *Id.*

30. Deborah Sontag, *HIV Testing for Newborns Debated Anew*, N.Y. Times, Feb. 10, 1997, at A1, B6.

31. R.R. FADEN ET AL., AIDS, WOMEN AND THE NEXT GENERATION: TOWARDS A MORALLY ACCEPTABLE PUBLIC POLICY FOR HIV TESTING OF PREGNANT WOMEN AND NEWBORNS (1991).

32. *Id.*, n.30.

What does all this mean in the era of welfare reform and managed care?

There are a host of operational and policy questions that have not yet been analyzed. Do child protective, drug treatment, Temporary Assistance for Needy Families ("TANF") and Medicaid managed care authorities synchronize plans, especially on an individual case basis? If not, what happens to a woman mandated to drug treatment if the Medicaid managed care provider will not cover it? Will women receiving TANF be sanctioned and lose benefits if they have positive toxicology tests at delivery?

Conclusion

We are thus confronted with decreased funding for services, increased sanctions and many policy and logistical conundra. The symbolic function of depicting the mother in need as a vector of harm to her children is to obscure the dwindling resources available to her. The rhetoric of rage and blame towards "deviant" mothers has escalated to embrace poor mothers in general. The focus on her diverts our attention from the end-of-the-New-Deal concept of governmental obligation to the citizenry. In an expedient effort to cushion the harshness of these cuts, many will limit their arguments to the plight of children. We can remind them that babies need their parents, and we can help infants most by supporting their mothers.