

# AN INTRODUCTION TO “MANDATORY HIV SCREENING OF NEWBORNS: A CHILD’S WELFARE IN CONFLICT WITH ITS MOTHER’S CONSTITUTIONAL RIGHTS?” — FALSE DICHOTOMIES MAKE BAD LAW.

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The issue raised by the articles collected in this edition of the *Cardozo Women’s Law Journal*<sup>1</sup> is one of great importance and moment — the mandatory unblinded HIV screening of newborns and notification to their mothers of their newborns’ HIV status.<sup>2</sup> This issue has generated intense and understandably emotional responses in all who have grappled with it,<sup>3</sup> no doubt especially in HIV-infected mothers who would face the consequences of the proposed legislative schemes enacting such mandatory screening.<sup>4</sup>

Although many had thought that public policy issues concerning voluntary versus mandatory HIV testing and treatment, and related confidentiality questions, had been settled in New York State

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<sup>1</sup> The papers included here by Colin Crawford, Esq., Professor Elizabeth B. Cooper, and Nina Loewenstein were originally presented at a symposium sponsored by the *Cardozo Women’s Law Journal* at Cardozo School of Law on November 2, 1994, entitled “Mandatory HIV Screening of Newborns: A Child’s Welfare in Conflict with its Mother’s Constitutional Rights?” They have been edited for publication in this volume of the *Journal*. See Elizabeth B. Cooper, *Why Mandatory HIV Testing of Pregnant Women and Newborns Must Fail: A Legal, Historical and Public Policy Analysis*, 3 *CARDOZO WOMEN’S L.J.* 13 (1996); Colin Crawford, *An Argument for Universal Pediatric HIV Testing, Counseling and Treatment*, 3 *CARDOZO WOMEN’S L.J.* 31 (1996); Nina Loewenstein, *Mandatory Screening of Newborns for HIV: An Idea Whose Time Has Not Yet Come*, 3 *CARDOZO WOMEN’S L.J.* 43 (1996). Notes by Jennifer Cooper and Julie D. Levinson are also included in this volume of the *Journal*. Jennifer Cooper, *The Politics of Pediatric AIDS*, 3 *CARDOZO WOMEN’S L.J.* 53 (1996); Julie D. Levinson, *While Ignorance May Not Be Bliss, It is a Mother’s Right: Constitutional Implications of Testing Newborn Babies for HIV*, 3 *CARDOZO WOMEN’S L.J.* 69 (1996).

<sup>2</sup> For a description of the current “blind” seroprevalence testing of newborns, in which test results are not identifiably traceable to an individual infant and, thus, are not available to its mother, see Crawford, *supra* note 1, at 33-34.

<sup>3</sup> See, e.g., newspaper articles cited by J. Cooper, *supra* note 1, at n. 4; See also Helen Mathews Smith, *The Deadly Politics of AIDS*, *N. Y. TIMES*, Oct. 25, 1995, at 14.

<sup>4</sup> Since the only way the newborn can become HIV-infected is by vertical transmission from the mother, HIV-testing of the newborn necessarily reveals the seropositive status of the mother. See REPORT OF THE SUBCOMMITTEE ON NEWBORN HIV SCREENING OF THE NEW YORK STATE AIDS ADVISORY COUNCIL, at 6 - 7 (Feb. 10, 1994); Taunya Lovell Banks, *Reproduction and Parenting, in AIDS Law Today. A New Guide for the Public* 216, 222 - 23 (The Yale AIDS Law Project 1993).

by New York's comprehensive statutory scheme,<sup>5</sup> new medical developments regarding early detection and treatment of HIV-infected newborns have required a second look at these issues as they apply to unblinded HIV testing of newborns. As the report of the Bar Association of the City of New York<sup>6</sup> noted:

governmental proposals to alter the law regarding HIV testing of pregnant women and newborns<sup>7</sup> stem from recent developments indicating that: 1) prophylactic treatment with antibiotics helps prevent the development of pneumocystis carinii pneumonia (PCP) in HIV-infected newborns, 2) HIV can be transmitted from a mother to her infant by breast-feedings, and 3) provision of AZT (anti-viral therapy) to some HIV-infected women during pregnancy and labor, and then to their infants, significantly reduced HIV transmission from mother to infant.<sup>8</sup>

The papers presented here make a significant contribution in guiding the public debate on this important and complex issue.

Colin Crawford, Counsel to the Association to Benefit Children, which sued New York State to compel unblinded HIV testing of newborns,<sup>9</sup> cogently argues that the increasing numbers of HIV-infected newborns constitutes a "medical emergency that overrides the most serious constitutional concerns,"<sup>10</sup> including privacy rights (whether analyzed in terms of confidentiality or autonomy), fourth amendment unlawful search protections, and equal protection concerns.<sup>11</sup> He submits that the overriding "medical emergency" supports the mandatory, unblinded HIV testing of newborns especially in light of "increasing evidence that newborns [can] be successfully treated for HIV [with AZT], but only if the

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<sup>5</sup> New York State's public health policy regarding testing for HIV infection is embodied in Article 27-F (§§ 2780-2787) of the Public Health law and related statutes and regulations. New York's system stands on two basic premises: first, that there should be no compulsory testing except in very limited circumstances, and second, that there should be vigilant protection of the confidentiality of those who seek testing and treatment. Article 27-F establishes a comprehensive statutory scheme aimed at encouraging those at risk for HIV infection to learn their HIV status, to seek treatment and to engage in appropriate behaviors to prevent them from spreading the disease to others. Ass'n of the Bar of the City of N.Y., *Prenatal/Newborn HIV Testing*, 49 RECORD OF THE ASS'N OF THE BAR OF THE CITY OF N.Y. 420, 432 (1994).

<sup>6</sup> *Id.* at 432.

<sup>7</sup> For descriptions of these proposals for mandatory HIV screening of newborns and release of the information to mothers, see Ass'n of the Bar of the City of N.Y., *supra* note 5; see also Levinson, *supra* note 1, at 71-72.

<sup>8</sup> See Ass'n of the Bar of the City of N.Y., *supra* note 5, at n. 7; for a discussion of possible limits regarding the actual prophylactic or curative potential of such anti-biotic and AZT treatments of newborns and potential harmful long-term effects of the AZT treatment, see E.B. Cooper, *supra* note 1, at 18-20; Loewenstein, *supra* note 1, at 48-50.

<sup>9</sup> Baby Girl Doe et al. v. Pataki, Index No. 10661/95 (Sup. Ct. N.Y. Co.).

<sup>10</sup> Crawford, *supra* note 1, at 31.

<sup>11</sup> *Id.* at 37-40.

virus [is] detected early enough.”<sup>12</sup> He concludes that only mandatory, unblinded testing of newborns will guarantee the availability of such information in a sufficiently timely manner and, presumably, result in early AZT treatment of newborns.<sup>13</sup>

In response to this argument, Professor Cooper poses disturbing questions regarding why individuals become invested in the principle that mandatory testing of pregnant women and newborns is the only way to achieve these goals (i.e., early diagnosis and treatment of HIV-infected newborns).<sup>14</sup> Professor Cooper argues that mandatory HIV screening programs not only frighten away the intended beneficiaries from treatment and necessary follow-up, but they also run afoul of basic constitutional protections, including the right to privacy, equal protection, the right to make health care decisions for ones children, and the right to informed consent.<sup>15</sup>

Nina Loewenstein, a research fellow funded by the Aaron Diamond Foundation and a member of the New York State Task Force on Women & AIDS, similarly argues that the harms of mandatory testing outweigh the putative benefits. She particularly emphasizes the “chilling effect that mandatory testing would have on [mothers’] participating in [health services treatment programs], and because testing programs must be voluntary in order to foster cooperation with prevention measures.”<sup>16</sup> Ms. Loewenstein implicitly counters Colin Crawford’s assertion that the existence of a “medical emergency” overrides constitutional concerns by relying on cases which hold that a parent’s right to refuse medical treatment for her child can be overridden only where the refused treatment is curative or where refusal constitutes a demonstrably imminent harm to the child.<sup>17</sup> She argues that the relatively moderate risk that an HIV-infected mother may transfer infection to her child, coupled with the uncertain “curative” effects and unknown and possibly deleterious long-term effects of proposed AZT treatment on newborns, is thus insufficient medically and legally to override a mother’s constitutional right to make informed voluntary choices regarding her child’s HIV testing and treatment.<sup>18</sup>

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<sup>12</sup> *Id.* at 34.

<sup>13</sup> *Id.* at 41. Indeed, although not part of the topic for the symposium, Crawford argues not only for mandatory testing, but also mandatory treatment. *Id.*

<sup>14</sup> E.B. Cooper, *supra* note 1, at 34.

<sup>15</sup> *Id.* at 23-25.

<sup>16</sup> Loewenstein, *supra* note 1, at 45; *See also* Loewenstein at 41; E.B. Cooper, *supra* note 1, at 24.

<sup>17</sup> Loewenstein, *supra* note 1, at 47-48.

<sup>18</sup> *Id.* at 47-50.

The student Notes included in this issue of the *Cardozo Women's Law Journal* reflect the same dichotomous arguments represented in the symposium articles. Jennifer Cooper argues that the clear benefits of early detection of HIV support regular mandatory HIV counselling of pregnant women and mandatory HIV-screening of newborns, which, she claims, has been blocked by "powerful special interest groups."<sup>19</sup> She submits that although questions of confidentiality and potential HIV-based discrimination are important, they should not prevent the mandatory HIV testing of newborns.<sup>20</sup> Finally, she summarily dismisses each of the constitutional arguments against mandatory testing raised by opponents.<sup>21</sup> Julie D. Levinson starkly counters that "While Ignorance May Not Be Bliss, It Is A Mother's Right."<sup>22</sup> Accordingly, she argues that not only mandatory HIV-screening, but also mandatory counselling may violate a woman's constitutional rights to equal protection, under either a strict scrutiny or intermediate scrutiny analysis, and her rights to privacy and to make her own medical decisions.<sup>23</sup> Finally, she argues that mandatory HIV counselling, if directive rather than non-directive, may impermissibly interfere with a woman's right to procreate by pressuring her to abort or to be sterilized.<sup>24</sup>

Most of the papers presented here recognize at their core that this issue is too complex to be reduced to the simple bipolarities and presumed dichotomies of children's health versus their mothers' constitutional rights or, indeed, reduced to other polarities such as counselling versus testing, voluntary versus mandatory, women's perspective versus male perspective, liberal versus conservative, etc.<sup>25</sup> Nevertheless, as these papers also demonstrate, the

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<sup>19</sup> J. Cooper, *supra* note 1, at 54.

<sup>20</sup> *Id.* at 66.

<sup>21</sup> *Id.* at 64-68.

<sup>22</sup> Levinson, *supra* note 1, at 69.

<sup>23</sup> *Id.* at 85.

<sup>24</sup> *Id.* at 88-91.

<sup>25</sup> *See, e.g.,*

This is not a matter of babies' rights versus women's rights: we cannot forget that perhaps the most important factor in a baby's health care is the mother. By building policy on the borne-out societal assumptions that a pregnant woman, including an HIV-positive pregnant woman, is interested in giving birth to a healthy baby, we foster, rather than undermine, the critical provider-patient trust relationship. This more comprehensive approach both respects individual autonomy and protects the public health — benefiting both mother and child.

E.B. Cooper, *supra* note 1, at 27-28 (emphasis in original; footnotes omitted). Cf. Crawford, *supra* note 1, at 41: "The failure to adjust one's notion of the disease and break free of outdated political rhetoric in favor of the best current medical science is clear: continued pitched political battles and more needless litigation."

discussion of the legal, political, medical, and public health policy implications of recent medical developments regarding HIV treatment of newborns is, indeed, all too frequently articulated in terms of a necessary and inevitable conflict between the child's medical welfare and his or her mother's constitutional rights of privacy and autonomous informed choice regarding medical testing and treatment.<sup>26</sup> Where this reductionistic, dichotomous approach controls, the resulting public policy questions and the range of possible responses is unnecessarily restricted, as we have seen, to two apparently conflicting and irreconcilable choices.<sup>27</sup>

As is also evident from the papers presented here, such a narrow Hobson's choice, resulting from a distortingly narrow and dichotomous posing of the foundational questions, fails to address not only the broader public policy issues regarding the diagnosis and treatment of HIV and AIDS, but also fails to effectively advance the more limited goal of providing appropriate prophylactic care for newborns of HIV-infected mothers. Indeed, the legislative proposals for mandatory testing of newborns do not provide or call for the necessary funding, access to appropriate health care or support services which would assure that treatment or care for newborns — mandatory or voluntary — would in fact be available upon the unblinding of the newborn's HIV status. Nor does the mere championing of women's constitutional rights to privacy and autonomous informed choice provide care or treatment to even a single child, let alone to its mother.

Perhaps such an unnecessarily limiting, distorting, and arguably futile exercise could be avoided if we were to ask the foundational policy questions in a more holistic and inclusive fashion. First, we must cease merely responding to each apparent medical discovery regarding HIV or AIDS or to each shift in public opinion or frustration by some hastily devised legal mandate or prohibition. Second, we should pose the foundational public policy questions in a manner that gives voice to the complex lived experiences and composite real concerns and needs of mothers and their infants faced with the prospect of HIV infection and, given the current

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<sup>26</sup> Such a presumption of "conflict of rights" informs the otherwise excellent essays published by the Yale AIDS Law Project; *see, e.g.*, Banks, *supra* note 4, at 219 - 24.

<sup>27</sup> Indeed, the rhetorical results of such a dichotomous approach are even more disturbing. Those who call for mandated testing are heard, at best, to implicitly mistrust HIV-infected mothers to make caring and appropriate decisions for their newborns' health care, and, at worst, to desire to punish and further victimize women already victimized and marginalized by poverty, racism, sexism or heterosexism. Those who oppose mandatory testing because of constitutional reasons are heard to devalue the worth of the life of even one infant for the sake of abstract principles or political agendas.

efficacy of medical care regimens, the inevitable development of AIDS and eventual death. That inquiry, holistically and expansively articulated, will include, minimally, compelling narratives of disempowerment, marginalization and victimization, and anguished cries for supportive, humane, effective care and treatment which is appropriate and responsive to the situations in which these women and children find themselves.<sup>28</sup>

In response to those real human beings' lives and their identified concerns and needs, we should then attempt to identify appropriate methodologies for meeting the complex intersecting of those concerns and needs — both in terms of minimizing HIV infection and in terms of extending the lives and maximizing the quality of the lives of those who, nevertheless, do become infected. Finally, with the methodologies of prevention, treatment, and care identified, are we not, then, mandated — ethically, morally, as a civilized society — to provide adequate funding, training, education, outreach, and care to effect these methodologies? Surely, the inevitable political limits on available funding for any public health problem may require that the recognized methodologies of care and treatment be implemented incrementally. However, we must be clear in our own analyses that it is that failure of resources, and possibly of political will, that prevents implementing what we know to be the optimal approach to prevention and care, rather than such limitations inevitably resulting from our having posed the initial public policy questions in a distortingly reductionist and dichotomous manner.

Such a holistic and clear-headed approach is particularly necessary when addressing the issue of HIV/AIDS. Why? As most of the papers presented here recognize, the profile of AIDS is different from that of other diseases, such as cancer, the diseases for which newborns are currently routinely tested,<sup>29</sup> and even venereal disease. Indeed, considering the writing of Colin Crawford and Susan Sontag,<sup>30</sup> it may always be so because of the intersection of at least four unsettling variables perhaps unique to AIDS. First, the

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<sup>28</sup> For a suggestive attempt at articulating such foundational questions in a nondichotomous and nonadversarial manner in the context of competing social values and demands affecting scientific research on AIDS, see Joni N. Gray, Phillip M. Lyons, Jr., and Gary B. Melton, *ETHICAL AND LEGAL ISSUES IN AIDS RESEARCH* (1995).

<sup>29</sup> For a description of these diseases, see Crawford, *supra* note 1, at n. 9; but see Loewenstein, *supra* note 1, at 47-48 ("A treatment or intervention that is curative or controls the diagnosed condition must be available before a disease may be included in the neonatal screening panel.").

<sup>30</sup> Crawford, *supra* note 1, at 32, cites approvingly Sontag's position that "it is highly desirable for a specific dreaded illness [including AIDS] to come to seem ordinary," SUSAN SONTAG, *AIDS AND ITS METAPHORS* 94 (1989), he apparently gives lesser weight to her more

primary means of HIV transmission are sex (usually extramarital, often same-sex, and, in many people's minds, promiscuous and immoral) and intravenous drug use (always illegal and generally associated in the public's mind with illegal actions in pursuit of such drugs, coupled with personal and social disintegration).<sup>31</sup> Thus, one's response to the disease — both on the part of some persons living with AIDS and many non-HIV infected people — is often informed by moral judgments regarding such underlying behavior and notions of self-infliction or "just deserts," even of divine retribution. Second, the populations most associated with the disease are gay men and racial minorities, who are generally poor.<sup>32</sup> Thus, majoritarian prejudice, and race and class bias also infect one's understanding of and response to the disease. Third, the stakes for those infected are high. The potential for discrimination and ostracization is well-documented.<sup>33</sup> In addition, even with optimal treatment and the growing body of evidence of extended periods of infection without illness, AIDS is still terminal and frequently accompanied by serious, painful illness.<sup>34</sup> Finally, although it is clear that transmission is essentially limited to the intimate exchange of semen, vaginal secretions and blood, primarily through sexual contact or intravenous drug use, the public fears this disease as essentially unknown and, perhaps, unknowable.<sup>35</sup> The reactions to the unknown are all too well-known: fear, panic, revulsion, attempts to control or at least quarantine at whatever cost, etc.<sup>36</sup>

Thus, since the reaction of the public and policy makers to this disease and those suffering from it is often informed and infected by fears and biases rather than sound science and public policy,<sup>37</sup> it has been recognized since the beginning of this epi-

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nued understanding that this normalization of AIDS will happen only "when the illness is much better understood and, *above all, treatable.*" *Id.* (emphasis added).

<sup>31</sup> Brett-Smith, M.D., and Gerald H. Friedland, M.D., *Transmission and Treatment, in AIDS LAW TODAY. A NEW GUIDE FOR THE PUBLIC* 18, 23 - 27 (1993); NATIONAL COMMISSION ON AIDS, AIDS: AN EXPANDING TRAGEDY. THE FINAL REPORT OF THE NATIONAL COMMISSION ON AIDS 6 - 7 (1993).

<sup>32</sup> NATIONAL COMMISSION ON AIDS, *supra* note 31, at 6 - 7.

<sup>33</sup> Arthur S. Leonard, *Discrimination, in AIDS LAW TODAY. A NEW GUIDE FOR THE PUBLIC* 297 - 316 (1993); *See also* Loewenstein, *supra* note 1, at 46-47.

<sup>34</sup> Brett-Smith and Friedland, *supra* note 31, at 31 - 38.

<sup>35</sup> Gray, Lyons, and Melton, *supra* note 28, at 163: "The psychological reality of AIDS is that it evokes fear. AIDS is not logical; it is hard to believe that a contagious disease so deadly can be transmitted in such limited ways."

<sup>36</sup> "[F]earful, mistaken, and sometimes mean-spirited attitudes persist in a substantial segment of the population. . . . There can be no doubt that hysteria about AIDS has led many policy-makers to support measures that have little, if any, rational basis." *Id.* at 163 - 64.

<sup>37</sup> *See, e.g.,* E.B. Cooper, *supra* note 1, at 28: "Perhaps boldly, . . . I suggest that [calls for compulsory testing of newborns] may well adhere to the demographics of the epidemic."

demical that this disease must be addressed in ways different than other diseases. Accordingly, in New York State, there has been put in place a comprehensive scheme which places primary emphasis on voluntary testing and treatment as the most effective and humane means by which this disease can be treated, and a correlative scheme which protects persons with HIV-infection or AIDS from public scrutiny, approbation, and discrimination.<sup>38</sup> The inevitable revisiting of some of these public policy choices in light of recent medical developments regarding treatment of HIV-infected newborns has threatened to unravel this comprehensive scheme.

I have attempted to sketch the broader framework in which, I submit, such a reevaluation should be articulated. The limitation of that suggested approach, of course, is that one can always claim that a particular proposal or opposition to that proposal, no matter how distortingly or dichotomously articulated, is directed towards meeting some aspect of the epidemic. As the papers presented here demonstrate, opposing sides in the current controversy have made just such claims.<sup>39</sup> However, as the papers also reflect, it is questionable whether either side has adequately explored or demonstrated whether its own position is really effective in its goal of comprehensive care for HIV-infected newborns or their mothers and whether the advancement of that position actually requires state sanctioned (by statute or court order) nullification of the adversary's position and concerns. Certainly it is clear that this adversarial modality of discourse has contributed little to the broader, integrated policy discussion suggested here. Rather, the dominant legal discourse in this area, perhaps in the context of the mandatory terms of the proposed legislation<sup>40</sup> and the mandatory relief sought in the *Baby Girl Doe* case,<sup>41</sup> has been, as indicated above, articulated in stark either/or categories.

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<sup>38</sup> See *supra* note 5.

<sup>39</sup> See generally the sources relied on in the papers presented here.

<sup>40</sup> See *supra* note 7; for a detailed description of the legislative schemes, see Levinson, *supra* note 1, at 71-73; the proposed New York State legislation would mandate notifying the mother, prospective adoptive parents and others of the results of any HIV tests on newborns; proposed federal legislation would mandate not only such notification, but also the testing of newborns.

<sup>41</sup> Plaintiffs sought a judgment:

Granting preliminary and permanent injunctions compelling the defendants (i) to provide for routine HIV diagnostic testing for all newborns in New York and, where appropriate, provide treatment and counseling for HIV positive infants, their mothers and other family members and caregivers, and (ii) to authorize immediate HIV diagnostic testing, and where necessary, appropriate counseling and medical treatment of all children who have not reached the age of consent in the foster care system.

*Baby Girl Doe et al. v. Pataki et al.*, Index No. 10661/95 (Sup. Ct. N.Y. Co.), First Amended Complaint, Prayer for Relief. By a Stipulation of Settlement so-ordered October 10, 1995,

Unfortunately, this reductionist, dichotomous, adversarial approach is all too frequently the sole or primary contribution lawyers and legal scholars bring to such wrenching human problems. We articulate emotionally complex issues in terms of allegedly absolute objective principles and rights,<sup>42</sup> which are often presented as being in necessary conflict with each other. The usual result of our articulation and advocacy is a mandate or prohibition, by statute or court, which enforces one of the claimed principles or rights and devalues the human values and insights articulated within ones adversary's position.<sup>43</sup> As a result, as we have seen in the current

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the parties agreed that New York State would propose regulations which would not only provide for mandatory counselling of pregnant women seeking prenatal services, but also for the counselling of post-partum mothers regarding HIV testing of their newborns and, if consent for such testing is refused, providing for mandatory testing of newborns where any of an expansive list of "risk factors" are present, as defined in N.Y. COMP. CODES R. & REGS. tit. 18, § 441.22(b) (1993).

<sup>42</sup> See, e.g., Peter Gabel, *Reification in Legal Reasoning*, 3 RES. IN L. & SOC. 25, 26 (1980):

The character of this repressive thought is accurately described by the word "reification," which is properly understood as a certain sort of distortion of meaning that occurs within communication. . . . [It] is descriptively accurate, but lays insufficient emphasis on the intersubjective and paradoxical meaning of reified communication. . . . [R]eification is not simply a form of distortion, but also a form of coercion which, on the one hand, separates the *communicated or socially apparent* reality from the reality of experience and, on the other hand, denies that this separation is taking place. [emphasis in original; footnote omitted].

<sup>43</sup> Indeed, the adversarial system often seems to sabotage opportunities for dialogue and principled compromise. For example, in the *Baby Girl Doe* case, see *supra* note 41, a number of AIDS and health groups, and individual women intervened. However, they were excluded from negotiations between the plaintiffs and defendant State of New York regarding the settlement of the case, even though they did not oppose mandatory counselling of pregnant women regarding the benefits of finding out their children's, and by extension their own, HIV status. Indeed, even the court was unreceptive to the intervenors' having an opportunity to participate in the settlement negotiations prior to entry of the Stipulation of Settlement and approved the settlement over the intervenors' objections. Thus prevented from participating in developing the terms of the settlement, see *supra* note 41, the intervenors felt compelled to move to vacate the settlement on the grounds that they had been excluded from the negotiations and that the settlement violated State law. In response to intervenors' motion to vacate the settlement, the other parties argued that since the intervenors would have an opportunity to comment on the implementing regulations provided for in the settlement, the intervenors were not harmed by the mere terms of the settlement prior to their codification in State law. However, when the regulations were published for comment shortly thereafter, the operative "risk factors" under which compelled rather than voluntary HIV testing of the newborn and notification of the results to the mother would be permitted were not specified and, thus, were in fact not subject to comment. N.Y. ST. REG., December 13, 1995, at 21. Rather, the proposed regulations would authorize non-consensual HIV-testing of a newborn where a doctor determines the existence of a life-threatening "emergency," the terms of which are unspecified. *Id.* at 22. The Stipulation, on the other hand, had specified that the "risk factors" under which such non-consensual testing would be permitted would be the same as those currently used to mandate testing of children in foster care, N.Y. COMP. CODES R. & REGS. tit. 18, 441.22(b) (1993), regarding whose appropriateness — even in the foster care setting — intervenors have serious reservations. Intervenors' motion to vacate the settlement is still pending before the Court. Telephone interviews with Theresa McGovern, Esq., Director of The HIV Law Project, and Virginia Shubert, Esq., of Housing Works, Inc., co-

controversy regarding mandatory HIV-testing of newborns, the human reality of this issue, with its messy complexity, is lost: HIV-infected mothers who will ultimately die, often alone, without adequate health care and social support; children who may become HIV-infected and die, often without mother or family, and without adequate health care and social support — all of whom are already marginalized and disempowered by the intersecting conditions of poverty, race, gender or sexual orientation.

To these members of our human, social, and political community, lawyers and legal scholars, politicians and policy makers, appear to offer only two choices with the same result: constitutional rights of privacy and autonomy — and death; or mandatory testing of newborns — and death. We do not speak to these mothers and their children about our commitment to provide the counselling, support, care, and financing that is necessary if the information revealed by testing is to result in any beneficial care for mother and child at all. We do not speak to them of our commitment to safeguard their privacy and confidentiality, and to protect them from discrimination and ostracization. We do not speak to them of our commitment to assist them in getting through the lengthy anti-bi-otic or AZT treatment of the newborns that a mother may choose? We do not speak to them of the limits or risks of such care regimens. We do not offer them other care options. We do not support and lobby for the funding and political will necessary to develop other modalities of care. With our assurance of those commitments and safeguards demonstrated, we do not speak to them of the moral imperative to seek out all available information, including their children's and their own HIV status as early as possible, in order to maximize treatment and care options. We do not bring the lawsuits necessary to force government and others to provide all of those necessary supports. Rather, we bring lawsuits whose effect, with all of the best intentions, is to further victimize, marginalize, and disempower the lives of HIV-infected mothers and their children; or which merely toll the ringing phrases of constitutional rights.

Colin Crawford urges that “people yearn for honest, unashamed discussion of known medical science about HIV and AIDS”<sup>44</sup> and concludes that “a regime of mandatory testing, counselling and treatment for newborns and their families” must be

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counsel for the intervenors, on January 2, 1996, and January 18, 1996, respectively. Thus, an opportunity to coordinate opposing positions was lost and divisive litigation continues.

<sup>44</sup> Crawford, *supra* note 1, at 41.

adopted.<sup>45</sup> Professor Cooper observes that “[i]n almost every other context, as a society, we support the provision of information to the patient and we support patient and familial decision-making autonomy”<sup>46</sup> and concludes that “mandatory testing [would] carve out an exception to these well-founded presumptions.”<sup>47</sup> But is it not more accurate to say that people, including HIV-infected mothers, “yearn for” and would “support” a comprehensive approach which will maximize the numbers of healthy mothers and babies even in the face of HIV-infection; which provides for informed choices regarding such a life-threatening medical condition and its available treatments; and which makes readily available appropriate, adequate, and affordable health care and support services to meet comprehensively the desperate needs of these mothers and their children?<sup>48</sup> Indeed, all nod approvingly at the success of the Harlem Hospital program in providing just such a comprehensive-approach model,<sup>49</sup> but then return to what appear to be their more “central” concerns: mandatory testing versus constitutional rights. And mothers and babies continue to die.

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<sup>45</sup> *Id.*

<sup>46</sup> E.B. Cooper, *supra* note 1, at 29.

<sup>47</sup> *Id.*

<sup>48</sup> Indeed, as noted above, *supra* note 25, the adversaries in this issue recognize the need for this more comprehensive approach.

<sup>49</sup> At Harlem Hospital in New York City, more than 90% of pregnant women and postpartum mothers consent to testing, where “HIV-related counselling is offered universally in pre-natal and delivery settings, and testing is voluntary, confidential, and linked to available care and services. . .” E.B. Cooper, *supra* note 1, at 22. Similar results have been achieved under similar conditions at Cook County Hospital in Chicago, Johns Hopkins in Baltimore, and Grady Hospital in Atlanta. *Id.* But see J. Cooper, *supra* note 1, at 64, who dismisses the significance and applicability of the Harlem Hospital success solely because there is not the political will to fully fund and fully staff other such treatment and care centers.

