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## **Mandatory HIV Testing During Pregnancy: A Review of Its Considerations, Ethics & Precedents**

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# Mandatory HIV Testing During Pregnancy: A Review of Its Considerations, Ethics & Precedents

Project Submitted in Partial Fulfillment of the  
Requirements of the Renée Crown University  
Honors Program at Syracuse University

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And Renée Crown University Honors

May 2011

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## Table of Contents:

Abstract/Acknowledgments.....	3
Introduction.....	4
Arguments Against Mandatory Testing.....	7
Arguments For Mandatory Testing .....	11
The Impact of the Abortion Debate on HIV Testing .....	16
The Connecticut Case Study .....	18
Discussion.....	20
Conclusion.....	21
References.....	22
Summary .....	25

# Mandatory HIV Testing During Pregnancy: A Review of Its Considerations, Ethics & Precedents

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## Abstract:

Every year, in the United States, between 100-200 babies are infected prenatally with HIV. With the use of antiretroviral medications, elective cesarean section and formula feeding, the risk of vertical transmission can be reduced to less than 2%. In this paper I analyzed whether or not state governments should mandate HIV testing for all pregnant women in order to reduce vertical transmission of HIV. By looking at the cases for and against mandatory testing, as well as looking at states such as Connecticut who have implemented mandatory testing, I will present the case for why the benefit of mandatory testing outweighs the potential harm that could be inflicted as a result.

Keywords: HIV, mandatory testing, vertical transmission of HIV

## Acknowledgements:

In writing this paper, and throughout my time as a student at Syracuse University I have gained invaluable wisdom from my advisor Dr. Sandra D. Lane, a Professor in the Department of Health and Wellness at Syracuse University as well as a Research Professor in the Department of Obstetrics and Gynecology at SUNY Upstate Medical University. Dr. Lane has also led me to finding my passion in not only public health but also maternal and child health as well as global health by opening my eyes to the different issues that face these populations. I would also like to thank my family, friends and professors, all of whom have shaped me into a person who is excited to help others. My sincerest thanks to all who have had a hand in creating the person I have become.

## Introduction

Today in America one of the largest social issues that we struggle with is distinguishing whose rights should ethically, morally and legally come first-- that of the woman or that of the fetus. While most people only think of this argument in the terms of abortion rights, in this paper I will be looking at the issue from the standpoint of preventing the vertical transmission of HIV.

According to the Centers for Disease Control and Prevention (CDC), as of 2007 AIDS has been diagnosed for an estimated 8,460 children who were infected perinatally. Of those, an estimated 4,800 have died and every year between 100 and 200 children are infected with HIV. Of these cases 91% are due to perinatal transmission (CDC 2007). One third of babies born with HIV will die after one year if they do not receive any form of antiretroviral treatment. After the second year of life, almost 50% of infants not receiving treatment will die (World Health Organization, 2006). With numbers like these, it is imperative that we not only treat infants with HIV as soon as possible, but also that we prevent the transmission of HIV in the first place.

In 1994, the AIDS Clinical Trials Group (ACTG) released a breakthrough study, protocol 076, which showed that the use of zidovudine started after the first trimester, continuing during childbirth and administered to infants for six weeks post-partum could substantially reduce the vertical transmission of HIV from HIV positive mothers to their newborn children (CDC 1994). Prior to the implementation of protocol 076 in the United States when HIV positive women who were pregnant did not receive any form of antiretroviral treatment during pregnancy or labor, newborns of HIV positive

mothers had a 25% chance of acquiring HIV infection (CDC 1994). Since the adoption of the prophylactic protocol for HIV positive pregnant women, along with increased cesarean sections and increased testing of HIV during pregnancy, the risk of mother-to-child transmission has been reduced to less than 2% in the United States (Simpson & Forsyth 2007). For an infant whose antiretroviral therapy began while in utero, but no other precautions were taken, the risk of HIV transmission is 8.3% (CDC 1994). This breakthrough gave HIV positive women the choice to become pregnant knowing that such treatment could greatly decrease their infants' risk of potential HIV infection.

Yet one of the biggest barriers to the near elimination of mother-to-child transmission of HIV is that screening and prophylactic treatment is not always implemented. A key reason for this lack of implementation of such life saving treatment is that HIV testing of pregnant women is not universal.

Before the 2006 revision by the Center for Disease Control and Prevention of its recommendation regarding HIV testing during pregnancy, the standard of care was for health care providers to counsel pregnant women and offer women an HIV test with the women's written informed consent (Schuklenk & Kleinsmidt 2007). This method is known as opt-in testing. Opt-in testing included target testing, in which health care providers would offer an HIV test only to women who they saw as 'at risk' for HIV. Since it is the physician's decision whether to offer an HIV test, opt-in and target testing are weak preventive measures in which women who do not fit the HIV 'profile' fall through the cracks. The current recommendation from the CDC now states, "All pregnant women in the United States should be screened for HIV

infection. Screening should occur after a women is notified that HIV screening is recommended for all pregnant patients and that she will receive an HIV test as part of the routine panel of prenatal tests unless she declines (opt-out screening)” (Branson, 2006). By making HIV testing part of routine prenatal testing, the CDC sought to “normalize” HIV testing and take away some of the stigma associated with getting tested for HIV. The overall goal of this new recommendation was to increase the number of women who would get tested during pregnancy in the hope that the number of newborns each year who acquire HIV infection as a result of mother-to-child transmission would be greatly reduced.

Even with opt-out testing, some HIV positive women refuse to take the test. This has prompted some states, such as New York and Connecticut to institute mandatory HIV testing of infants at the time of birth in order to start antiretroviral therapy as soon as possible. There have been some concerns expressed over such laws, stating that they are a roundabout way of testing the mother. At the same time, ethicists and others have raised questions of whether or not we should go even further than the CDC recommendations or if we have already gone to far. One such question is whether or not state governments should make HIV testing during pregnancy mandatory. But what are the ramifications of such a law and what legal precedent would the states be able to use in supporting their decision? It is questions such as these that I will be focusing on in this paper in order to find a middle ground that will stand up against the contentions of people on the extreme end of the spectrum, the law and ethics.

In order to address the issues and questions above I will be reviewing the arguments for and against mandatory testing during pregnancy. I will also consider the impact that the abortion debate in America has on HIV testing. Finally, I will be looking at other cases and precedents for mandatory testing such as Connecticut Public Act 99-2 and routine syphilis testing during prenatal visits.

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### **Arguments Against Mandatory HIV Testing**

Since the start of the AIDS epidemic, activists have held the gold standard that the only acceptable type of HIV testing is voluntary and confidential. It is important to note the difference between confidential testing and anonymous testing. When a person is tested anonymously, no information that can be linked to that person, such as name, address or phone number, is recorded, and only that person keeps the results of their test. In contrast, confidential testing keeps a record of each individual's results, their demographic information and how to contact them. Early in the HIV/AIDS epidemic such protections as confidential testing were put into place for two reasons. The first reason for this policy is that early on there was no adequate treatment for HIV that could delay the onset of AIDS. Protections such as these allowed for the choice of when and how to get tested for HIV in a time when being HIV positive was a death sentence. Secondly, the stigma associated with HIV was, and still is, great. If test results were not confidential during the early years of the epidemic, HIV positive people could have experienced even more significant discrimination.



Concerns regarding stigma, discrimination and prejudice are the rationale driving the argument against mandatory HIV testing during pregnancy. “HIV/AIDS has characteristics that account for why it is so highly stigmatized. First it is a disease that is perceived as the bearer’s responsibility because the primary modes of transmission of the infection are behaviors that are considered voluntary and avoidable and the subsequent perceptions of people living with HIV/AIDS as people with no moral values” (Thomas *et al*, 2005, p. 795). These characteristics have created a social environment in which “people identified as HIV-positive may be rejected by their families or suffer discrimination in employment, access to health care, and housing if the confidentiality of their test results is breached. Domestic violence against HIV-infected women was identified as a particular risk.” (Lo *et al*, 2000, p. S137) It is these potential results of having HIV that deter many women from seeking out an HIV test in the first place. The potential of facing stigma, discrimination and prejudice because of being HIV positive is still a very likely possibility and one that plays a huge role in the spread of the epidemic (Pisani, 2008).

Another ethical argument against making HIV testing mandatory is autonomy. As of one the principles of bioethics (United States National Commissions For The Protection Of Human Subjects Of Biomedical and Behavioral Research, 1978), as well as an important value in American culture, the right to autonomy is not something that can be easily overlooked. Russell Armstrong, in his paper *Mandatory HIV Testing In Pregnancy: Is There Ever A Time?* stated that “mandatory HIV testing in any situation is

most problematic of any testing strategy... it involves very significant limitation of individual autonomy and deep incursions into the domain of individual privacy... In the absence of the ability to freely consent to an HIV test, an individual loses the full power to determine under what circumstances he or she chooses to learn this important life-altering fact” (Armstrong, 2008, p. 3). He goes on further to say that this inability to choose in such a situation could potentially instill distrust for the health care system.

It is this distrust that poses another potentially significant risk of implementing mandatory HIV testing during pregnancy. As said by Armstrong, “A woman who may already feel the most vulnerable in the medical care environment, may feel even less respect or trust in a system that refuses to let her be in charge of the decision of whether or not to have an HIV test” (Armstrong, 2008, p. 3). This in turn could deter women from seeking prenatal care in the first place by “making the receipt of prenatal care contingent upon forced consent to an HIV test” (McMillion, 1998, p. 230). This fear and distrust of mandatory testing could therefore have the potential indirectly and unintentionally to cause even further harm. If women were discouraged from seeking prenatal care due to being tested, they would not benefit from prenatal health care that could prevent pre-mature labor or low birth weight infants, a situation that would be counterproductive to the goals that mandatory testing hopes to achieve.

Finally, a large concern of proponents against mandatory HIV testing during pregnancy is how it would be enforced. If a woman declines to be tested, is she subsequently able to receive care? Or would her prenatal care be

dependant upon her cooperation and compliance with taking an HIV test? And if the woman were found to be HIV positive, would she then be required to receive prophylactic antiretroviral treatment? Or would she still have the option to refuse such treatment? Since the main purpose of mandatory HIV testing would be to start AZT treatment as early as possible, if women are allowed to refuse treatment then would implementing a mandatory protocol actually result in the increased acceptance of treatment? In a letter to the editor of the *American Journal of Public Health* Alison K. Groves, MHS, Matthew W. Pierce, JD, MPH, and Suzanne Maman, PhD, MHS said that “knowing one’s HIV status does not necessarily lead women to engage in treatment nor does it necessarily lead to change in risk behaviors” (Groves *et al.*, 2008, p. 196-197). The question is ultimately how far are the government and health care providers willing to go in order to enforce such a law? Are they willing to implement fines for refusing testing and treatment? Or are they willing to go so far as to place pregnant women in the custody of the police in order to achieve the maximum advantages that the policy has to offer? This has been done before in the case of tuberculosis. Admittedly, the spread of tuberculosis differs from vertical transmission of HIV. Tuberculosis has the potential to spread via respiratory droplets in the air to others who may have no connection to the person with active tuberculosis, whereas the vertical transmission of HIV occurs within the most intimate contact of birth. Nevertheless, in both cases a vulnerable person or persons could become infected and prophylactic medication taken by the infected person can potentially reduce such transmission.

## Arguments For Mandatory HIV Testing

It is hard to deny the science that compels people to consider implementing mandatory HIV testing during pregnancy. Vertical transmission rates since the application of protocol 076 have been dramatically reduced when compared to the pre-protocol rates of the 1980's and 1990's. Numbers such as these essentially speak for themselves. In addition to the prevention of mother-to-child transmission of HIV is the fact that those protected by prenatal and/or newborn HIV testing are infants, a population that in almost every culture is seen as free of blame and one that should be protected from harm at all costs. With all of the breakthroughs that have been made in the prevention of vertical transmission, however, they would not be nearly as effective if testing protocols did not diagnosis infected pregnant women because women were not being tested. Without the knowledge of a woman's HIV status, health care providers would be unable to implement any of the precautions that science has proven to reduce the risk of mother-to-child transmission. Duo Schuklenk, PhD, and Anita Kliensmidt, LLB, LLM in their paper *Rethinking Mandatory HIV Testing During Pregnancy in Areas With High HIV Prevalence Rates: Ethical and Policy Issues* state "It is significant that making it more difficult to avoid testing translates into larger numbers of pregnant women finding out about their HIV state. In turn, they and their health care providers are able to make informed choices about appropriate courses of action" (Schuklenk & Kleinsmidt, 2007, p. 1179). It could be argued that testing is the most important element in the fight against

HIV/AIDS because testing not only allows people to become aware of their status, but can also motivate people to reduce risky behaviors and begin treatment.

By making HIV testing mandatory during pregnancy, a woman is able to learn about her status earlier than she would if she never became pregnant. This in turn allows her to begin antiretroviral therapy sooner, which benefits not only her yet-to-be-born child but also herself. It is important to note that “... the reasonable objective of any intervention must be to improve the health of pregnant women and to prevent HIV transmission to newly born children,” (Armstrong, 2008, p. 6) which mandatory testing has the ability to do if done under the right circumstances. As for the health of the child, knowing a child’s HIV status as soon as possible in order to start treatment is “particularly important for children aged under 12 months as the probability of death in untreated HIV-infected children is high: mortality rates of up to 40% by the age of 1 year have been reported” (World Health Organization Department of HIV/AIDS, 2006).

As stated earlier, the fear of stigma and discrimination are huge factors for a woman when questioning whether or not she wants to ask for an HIV test. Women are often afraid that their status will become public knowledge, either because of a state or medical agency making it public or people discovering it on their own. Yet in her book *The Wisdom of Whores: Bureaucrats, Brothels and Business of AIDS* epidemiologist Elizabeth Pisani argues the idea of people refusing an HIV test due to fear of stigma. Pisani states that eventually an HIV positive person will begin to develop symptoms

and eventually die, earlier than necessary. So she asks, what is worse? Refusing an HIV test in order to avoid potential discrimination and in turn die earlier because they were unable to receive treatment? Or taking an HIV test and risking people discovering their status, yet still being able to start treatment and living a longer and healthier life in which symptoms are kept at bay (Pisani 2008)?

Although fear is a strong deterrent to getting tested, the potential to live a longer and healthier life would seem to outweigh the fear of stigma. Getting tested and subsequently receiving treatment, it could be argued, allows people to live for a longer time without anyone else discovering their status. One study suggests that fear of stigma is often much greater than experienced stigma. “Thirty three percent of women and 20% of men experienced actual stigma. However perceived stigma among women and men was 97% and 96% respectively, disclosure concerns 85% and 86% and internalized stigma, 63% and 62% respectively” (Thomas *et al*, 2005, p. 797).

What makes Pisani’s argument even more potent for pregnant women is that in many cases the time frame that they are able to live without knowing their HIV status is considerably shorter. Today, some states, such as New York and Connecticut, have implemented mandatory HIV screening of newborns in order to allow for the best chance to the infants to avoid HIV transmission. Some people argue that newborn screenings have all of the same ethical dilemmas as mandatory HIV testing during pregnancy, but seeing as at the point of birth, the newborn is its own entity, it is easy to say that the

newborn has the right to testing and treatment without interference from what the mother feels is best for herself.

The United States is currently in an important transition between treatment-based care and prevention-based care. In 2004 the United States spent \$1.9 trillion on health care. A majority of the spending went to treating diseases such as diabetes, obesity, hypertension and chronic heart disease that with the right type of care could have potentially been prevented (Agency for Healthcare Research & Quality, 2006). HIV/AIDS is a preventable disease that lasts a lifetime and comes with large associated costs. Treating HIV includes continuous medications that are very costly as well as treatment for any hospitalizations that occur due to opportunistic infections. According to a study by Bruce R. Stickman, the monthly cost of HIV treatment (including medications and hospitalizations) can range from \$2,100 to \$4,700 and the annual cost for the United States on the whole could reach as high as \$12.1 billion in the coming future (Shackman *et al*, 2006). Yet in comparison, the prevention and testing of mother-to-child transmission of HIV is considerably lower. It is “estimated that, compared with current practices, enhanced prenatal screening would avert 150 infection in infants annually at a cost of \$8,900 per life-year gained. Routine HIV screening of newborns nationwide would avert 266 infections in infants annually at a cost of \$7,000 per life-year gained. When enhanced prenatal screening is already in place, routine screening of newborns would have a net cost of \$10,600 per life-year gained... Our analysis indicated that both newborn routine screening and enhanced prenatal screening are cost effective” (Zaric *et al*, 2000, p. 410).

Although this study did not specifically measure the cost effectiveness of mandatory HIV testing during pregnancy, it is presumable that even stricter protocols such as mandatory testing would provide even further health care savings.

Finally, mandatory HIV testing has the potential to reduce stigma, racial/ethnic and socioeconomic profiling as well as fear by making an HIV test something that every woman does. This was the hope that the CDC has for their revised recommendations that were published in 2006, but I believe that mandatory testing could go even further. By making testing mandatory, women who are not aware of themselves as being at risk of HIV would no longer fall through the cracks that remain with opt-in and opt-out testing. There is also a hope that by making HIV testing mandatory women who would have been targeted would feel more comfortable getting tested knowing that they were not being asked because they looked like a “stereotypical” person with HIV/AIDS. The most important argument for mandatory testing is that the United States has the potential to eradicate almost entirely the perinatal transmission of HIV.

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### **The Impact of the Abortion Debate on HIV Testing**

The question of whether or not a state government has the legal and ethical right to mandate HIV testing during pregnancy has many of the same concerns as the abortion debate in America. The conflict is based on the competing rights of the mother and the fetus. Following English Common Law, legal personhood begins at birth. *Rowe v. Wade*, the historic Supreme



Court decision allowing abortion was based on the right of the pregnant woman to privacy taking precedence over the right of the fetus. Several subsequent state-level laws instituted restrictions on pregnant women's access to abortion, once the fetus has developed to the point of "viability," at about 23 weeks gestation (Tierney 2004). Viability, at about the fifth month of pregnancy, means that the fetus could potentially survive outside of its mother. Thus, once a fetus reaches the gestational age of viability, those state laws granted it legal protection.

The conflict in regard to mandatory HIV testing during pregnancy draws on such legal precedents in that it pits the mother's right to autonomy (and privacy) against the fetal right to be born without HIV infection. The possibility of granting fetal rights is strongly opposed by those who fear that such rights would be used to prohibit women's access to abortion. But while a fetus has few rights that are protected by law, a newborn certainly does. At the time of birth, the time when a fetus becomes a newborn, rights are gained and it is this small distinction that I argue in this paper.

Once a woman has made the decision to carry her baby to term, without coercion and upon her own free will, she can be seen as taking on the responsibility of protecting the rights of her not-yet-born child or newborn. Since in most states abortion is no longer legally available past the gestational age of fetal viability, after 23 weeks gestation it can be assumed that the woman has made such a decision. This point is crucial to the argument for mandatory HIV testing during pregnancy, as argued by Thomas H. Murray in his book *The Worth of a Child*, "... parents of not-yet-born children, are

obliged morally to act responsibly toward their charges, take reasonable steps to advance their welfare, and avoid unnecessary risks of serious harm to them.” (Murray, 1996, p. 102) Murray further argues that just as a woman has the responsibility to stop smoking and drinking during a pregnancy in order to prevent Fetal Alcohol Syndrome and other birth defects that could have been prevented, a mother also has the responsibility to take all steps possible to prevent her not-yet-born child from contracting a fatal disease such as HIV. At the very least this should include an HIV test. Murray seeks to find a “middle way” that acknowledges the rights and concerns of both the pregnant women and her fetus. “A woman who becomes pregnant and that chooses to carry that fetus to birth, does not become a moral hermit, stripped of all other relationships, forbidden to consider even her own welfare except as it concerns the fetus she carries. She remains a full-fledged moral agent, with a complex variety of moral relationships, and with the right to consider her own well-being” (Murray, 1996, p. 105). It is the hope that upon taking her own well being into consideration, the woman would realize that taking an HIV test and subsequently beginning anti-retroviral therapy she would be improving not only the health of her not-yet-born child but also that of herself.

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### **Connecticut Case Study**

In October of 1999 Connecticut passed a law that mandated HIV testing for the mother and if she refused a HIV test for the infant at the time of birth. Five years after the implementation of this law, researchers B. Joyce Simpson, ACRN, MPH and Brian W. Forsyth, MB ChB, FRCP(C) performed

a study at Yale New Haven Hospital, in order to evaluate the personal perspectives of the women who had discovered that they were HIV positive during their pregnancy concerning Connecticut Public Act [CT P.A.] 99-2. Between 1999 and 2005, 30 women (26.6% of all pregnant women tested at the Yale New Haven Hospital) tested HIV positive and 11 of these women agreed to take part in the study in addition to 11 women who had tested negative. Each woman took part in an in-depth interview and were asked: “Did you ever feel that you were being ‘pressured’ or ‘forced’ into taking the test when you were pregnant?” “Did you ask for an HIV test?” and “Did you ever suspect or have reason to believe that you might be positive?” Some example questions for HIV positive women only were: “Did you ever consider terminating your pregnancy?” “Did you accept antiretroviral treatment during your pregnancy?” “Have you lost friends when they learned that you have HIV infection? Did your having a positive HIV test lead to others getting tested?” “What is your opinion of the Connecticut law that says that if you do not get an HIV test when you are pregnant, that your baby will be tested?” and “Do you wish there was no such law?” (Simpson & Forsyth 2007).

Some of the most important data to come out of this study was that of the women who tested HIV positive, 7 out of 11 said that if they had not lived in Connecticut where the test was mandatory they would not have been tested at all. Also, of the 11 HIV positive women 9 said that they were “stunned” to find out that they were HIV positive. This shows that the law in effect is doing exactly what it was designed for: to identify the HIV positive pregnant women

who would have otherwise fallen through the cracks, either because they did not want to take the test or they felt they had no reason to take it. All 11 HIV positive women, after hearing their diagnosis started antiretroviral therapy and all 12 children (including one set of twins) ended up being HIV negative at 6 months of age (Simpson & Forsyth 2007).

Many of the women expressed feelings such as guilt, shame, sadness, denial, isolation and loss of hope, in other words feelings that are considered common for someone receiving a life-threatening diagnosis. In regards to the women's feelings about the Connecticut law, they were for the most part very positive. Responses included: "I'm so glad; my baby would have been infected. How can you deny it?" "I'm glad we have this law." "I'm just glad I got pregnant because I got to know about my HIV." Women also stated that they thought the law was: "beneficial," and "common sense," and that the law should be "tougher," and "stronger." Only two women who tested positive believed that their lives had been affected in a negative way by having to take an HIV test.

Overall, what this study shows is that, in general, even among women who at first do not want to take an HIV test, upon learning their status, they were grateful that the law was in place, for both their own health and their baby's. Also, this study shows that laws such as the one in place in Connecticut have the potential to diagnosis and treat women who otherwise would not have been tested.

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## Discussion

Although there are strong arguments against making HIV testing during pregnancy mandatory, ultimately I believe that prenatal mandatory testing has many potential benefits that outweigh the potential risks, the largest being that both the mother and child can receive treatment. Yet it is important to note that mandatory testing cannot be implemented without certain conditions being met. First and foremost, pre and post-test counseling must still be in place. It is imperative that the women understand what an HIV test entails and what an HIV positive test result means for herself and her baby. If necessary, health care providers should be able to refer women to counseling, just as they would for any other patient receiving life changing news. Secondly, the mother must have the right to and access to an abortion. If a woman feels that even with the treatment options available to prevent vertical transmission of HIV, she does not wish to take such a risk, she must have the option to terminate the pregnancy, if the test has occurred within the legal time frame in which termination is possible. Another condition that must be met is that of treatment. Both the woman and her baby must have access to antiretroviral treatment. If for any reason, whether financial or other reasons, the woman does not have access to such treatment, for at least the period of her pregnancy, then it would be unethical to force a fatal diagnosis upon her and her infant if said knowledge was not desired by the woman. Finally, and possibly most importantly is the matter of confidentiality. Confidentiality must be maintained. I believe that women would be wary of mandatory HIV testing and would therefore be deterred from prenatal care. Women would feel more comfortable and confident in having a law that mandated an HIV test during

pregnancy if they were assured that their HIV status was to be kept confidential (Schuklenk & Kleinsmidt 2007). Further, if for any reason, one or more of these conditions are not able to be met, I find that the next option for testing should be opt-out testing for pregnant women and mandatory HIV screenings for newborns.

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## Conclusion

HIV testing would not be the first test to be made mandatory for pregnant women. When a woman goes in for prenatal care, she and her baby go through a battery of tests including but not limited to the Rh antigen, phenylketonuria (PKU) and syphilis. All of these diseases have the potential to be passed on to the newborn and dramatically affect the quality of life of the baby. It is for this reason that these tests have become routine for every women. For the most part many mandatory tests over the years have become routine. They are something that every woman receives without questions and without the need to get written or even verbal consent, other than her written consent for her prenatal care. That is the hope that the CDC had when they revised the recommendations to opt-out testing for HIV. Every test needs to start somewhere on its way to becoming routine and for HIV I believe that mandatory testing is the best place to begin.

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## Resources

- AGENCY FOR HEALTHCARE RESEARCH AND QUALITY. (2006). *The high concentration of U.S. healthcare expenditures*. Issue 19. [Online]. Available from <http://www.ahrq.gov/research/ria19/expendria.htm>. [Accessed: 2 May 2011].
- ARMSTRONG, R. 2008. Mandatory HIV testing in pregnancy: is there ever a time? *Dev World Bioeth*, 8, 1-10.
- BRANSON, B.M., HANDSFIELD, H.H., LAMPE, M.A., JANSSEN, R.S., TAYLOR, A.W., LYSS, S.B., CLARK, J.E. (2006). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *Morbidity & Mortality Weekly Report*, 55 (RR14) P. 1-17. Available from - <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>. [Accessed: 12 April 2011].

- CENTER FOR DISEASE CONTROL AND PREVENTION. (2007). *Mother-to-child (perinatal) HIV transmission and prevention*. [Online]. Available from <http://www.cdc.gov/hiv/topics/perinatal/resources/factsheets/perinatal.htm>. [Accessed 1 May 2011].
- CENTER FOR DISEASE CONTROL AND PREVENTION. (1994). Zidovudine for the Prevention of HIV Transmission from Mother to Infant. *Morbidity and Mortality Weekly Report*. 43 (16) p. 285-287.
- GROVES, A. K., PIERCE, M. W. & MAMAN, S. 2008. Questioning mandatory HIV testing during pregnancy. *Am J Public Health*, 98, 196-7; author reply 197.
- LO, B., WOLF, L. & SENGUPTA, S. 2000. Ethical issues in early detection of HIV infection to reduce vertical transmission. *J Acquire Immune Deific Snyder*, 25 Suppl 2, S136-43.
- MCMILLION, E. (1998). The case against mandatory HIV testing of pregnant women: the legal and public policy implications. *Duke Journal of Gender Law & Policy*. 5 (spring). Available from <http://www.law.duke.edu/shell/cite.pl?5+Duke+J.+Gender+L.+&+Pol'y+227>. [Accessed 2 May 2011]
- MURRAY, T. H. 1996. *The worth of a child*, Berkeley, University of California Press.
- PISANI, E. 2008. *The wisdom of whores : bureaucrats, brothels, and the business of AIDS*, New York, W.W. Norton & Co.
- SCHACKMAN, B. R., GEBO, K. A., WALENSKY, R. P., LOSINA, E., MUCCIO, T., SAX, P. E., WEINSTEIN, M. C., SEAGE, G. R., MOORE, R. D. & FREEDBERG, K. A. 2006. The lifetime cost of current human immunodeficiency virus care in the United States. *Med Care*, 44, 990-7.
- SCHUKLENK, U. & KLEINSMIDT, A. 2007. Rethinking mandatory HIV testing during pregnancy in areas with high HIV prevalence rates: ethical and policy issues. *Am J Public Health*, 97, 1179-83.
- SIMPSON, B. J. & FORSYTH, B. W. 2007. State-mandated HIV testing in Connecticut: personal perspectives of women found to be infected during pregnancy. *J Assoc Nurses AIDS Care*, 18, 34-46.
- THOMAS, B. E., REHMAN, F., SURYANARAYANAN, D., JOSEPHINE, K., DILIP, M., DORAIRAJ, V. S. & SWAMINATHAN, S. 2005. How stigmatizing is stigma in the life of people living with HIV: a study on HIV positive individuals from Chennai, South India. *AIDS Care*, 17, 795-801.
- TIERNEY, M.J. (2004) Post-viability abortion bans and the limits of the health



exception. *The Notre Dame Law Review*. 80 (1) p. 465-479.

UNITED STATES. NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH. 1978. *The Belmont report : ethical principles and guidelines for the protection of human subjects of research : appendix*, Washington, The Commission : for sale by the Supt. of Docs., U.S. Govt. Print. Off.

WORLD HEALTH ORGANIZATION DEPARTMENT OF HIV/AIDS. (2006). *Antiretroviral therapy of HIV infection in infant and children in resource-limited settings: towards universal access*. [Online]. Available from <http://www.who.int/hiv/pub/guidelines/WHOPaediatric.pdf>. [Accessed: 4 May 2011].

ZARIC, G. S., BAYOUMI, A. M., BRANDEAU, M. L. & OWENS, D. K. 2000. The cost effectiveness of voluntary prenatal and routine newborn HIV screening in the United States. *J Acquire Immune Defic Snyder*, 25, 403-16.

## Summary

Today in America one of the largest social issues that we struggle with is distinguishing whose rights should ethically, morally and legally come first, that of the woman or that of the fetus. While most people only think of this argument in the terms of abortion rights, in this paper I will be looking at the issue from the standpoint of preventing the further spread of HIV. Currently in the United States if a pregnant woman is HIV positive and does not receive treatment for the disease, her newborn has a 35% chance of being born HIV positive. Luckily there is treatment that if done throughout the pregnancy that reduces risk to less a than 2% chance of contracting HIV. Yet, one of the biggest barriers preventing the total elimination of mother-to-child transmission of HIV is that some women are unaware of their HIV status during pregnancy and therefore these precautions are not always taken. The question that I address in my thesis is whether or not state governments should go so far as to make HIV testing during pregnancy a routine and mandatory issue. I believe that the answer is yes, but what are the ramifications and the legal precedent in doing so?

In any such ethical dilemma, it is important to look at both sides of the argument. In the case of mandatory HIV testing during pregnancy, the main concerns for the group against it are stigma and discrimination related to or caused by taking an HIV test and the loss of autonomy or the right to make their own medical decisions and have them respected by a

health care provider. Other concerns include how the law or protocol would be enforced if a woman does not wish to have an HIV test and that mandatory HIV testing may deter women who already distrust the health system from seeking any prenatal care, not just HIV testing.

On the other hand the arguments used by proponents for mandatory HIV testing during pregnancy include that the health benefits of HIV testing during pregnancy outweigh the harm that is created by stigma and discrimination. For example, the ability of the women to start antiretroviral therapy is beneficial not only for herself but also for her baby. Eradicating mother-to-child transmission (PMTCT) in the United States is a very realistic goal. Another argument that once a woman has committed to carry her baby to term, or has reached the age of viability for the fetus (23 weeks), she has gained the responsibility to prevent any unnecessary harm to the child. This includes doing all that is possible to prevent the vertical transmission of HIV. Other arguments used by the pro mandatory testing front include the cost effectiveness of prevention in comparison to the life-long treatment of an HIV infected infant, as well as a possible reduction of stigma as a result of making an HIV test something that every woman takes as part her prenatal care.

In this paper I look also look at case studies and precedents for mandatory testing of HIV during pregnancy. One such example is an in-depth look at a study done at the Yale New Haven Hospital in Connecticut in order to evaluate the personal feelings of pregnant women of the law

that was enacted in 1999. I also look at cases such as syphilis testing during pregnancy and the impact that the abortion debate in the United States has on this issue.

As you may be able to see, the issue of mandatory HIV testing during pregnancy is fraught with turbulence. Yet it is an important issue to discuss because it has the potential to reduce the number of infants born each year with a fatal disease. Although this paper is mainly concerned with mandatory HIV testing during pregnancy in the United States, I hope that other countries where mother-to-child transmission of HIV is much more significant would be able to look at this paper and see that mandatory HIV testing has the potential to lower not only the vertical transmission of HIV in their country but also their infant mortality rates. I believe that mandatory HIV testing during pregnancy has many benefits that outweigh any downsides, the main one being that both the mother and child may have the ability to live longer and healthier lives.