

obstacles to the provision of timely medical, mental health, and supportive social services. Affected families have consequently had great difficulty accessing critical services. One specific and disheartening example of the gap between need and availability of services is that very few substance abuse programs will accept pregnant women or women with children. When services are available they are too often fragmented. For instance, though women with HIV infection have significant gynecological problems, these services may not be available in clinics where they receive their routine HIV follow-up care. (See Appendix H for a complete roster of family HIV-related services.)

LEGAL AND ETHICAL ISSUES

From the start of its deliberations, the Subcommittee agreed that its goal would be the development of policies that would maximize the number of HIV-infected women and HIV-positive and infected infants identified and placed into treatment. The Subcommittee tried to maintain a focus on HIV as an issue that affects entire families, rather than a matter of the rights of newborns or mothers.

However, HIV screening of pregnant women and newborns does raise important ethical and legal questions. Although in most issues related to medical care of a child, parental decisions are

respected, there are legal and ethical precedents for situations in which the interests of the child can and should limit parental discretion. For example, in New York State, all pregnant women are mandatorily screened for hepatitis B and syphilis. While, like HIV, these two diseases can be passed from mother to child, unlike HIV, they can be prevented or cured with currently available treatment. Screening is also done mandatorily on every newborn, except when parents refuse for religious reasons, for a variety of treatable congenital diseases, mostly metabolic disorders.

New York State Public Health Law, Article 27-F, requires that HIV testing be preceded by detailed counseling, administered with written informed consent, and followed by equally specific post-test counseling. Federal law does provide for HIV testing without informed consent for prisoners, military personnel, and Job Corps applicants.

Since mandatory HIV screening of newborns and/or pregnant women, that is, without informed consent or the specified counseling, would present potentially serious ethical and legal challenges to existing law, the Subcommittee considered legal principles concerning: confidentiality, disclosure, constitutional rights to equal protection, privacy, child neglect, the Americans with Disabilities Act (ADA), and applicable case law, that is, precedents.

Confidentiality is an ancient and venerated principle of medical ethics but is not absolute. It may be strengthened or undercut by case law and by legislation in the interest of protecting a patient, identifiable others, or the public health. The intent of the New York State HIV Confidentiality Law is to empower individuals, enlist their cooperation, and protect their privacy. Since mandatory newborn HIV testing with parental notification is viewed by many as tantamount to testing the mother and revealing her HIV status without consent, it may be inconsistent with the intent of the law.

Disclosure of medical information means making it available to the patient. Under current law, disclosure of HIV status may only follow an adequate informed consent process with pre- and post-test counseling. To be consistent with current law regarding counseling, expanded counseling services would have to be developed and provided under either a mandatory or more aggressive voluntary testing program.

~~Public health law provides national precedents for the view~~ that the police power of the state is sufficient to protect the public health and can do so as long as the intervention would be effective, as in the case of mandatory immunization of children. ~~The Supreme Court has specified that an intervention must be the~~ least restrictive alternative necessary to achieve the public

health goal, infringing as little as possible on protected rights. While individual states have been given broad latitude to respond to public health problems of local concern, mandatory newborn HIV testing would presumably have to meet the "least restrictive alternative" standard.

Ethically, a public health screening test must meet, at a minimum, two conditions: it should be accurate and effective. "Effective" means both that the test should be cost-effective and that an effective treatment should be available. HIV antibody testing is not an accurate indicator of infection in infants in that at least 70 percent of infants who test positive for HIV antibodies are not infected; PCR (polymerase chain reaction) testing is much more accurate, but much more expensive. Some argue that CD4+ cell counts could be used instead of testing to monitor children for immune suppression. Regarding the efficacy of therapy for HIV, it is currently clearest in relation to PCP prophylaxis.

The fifth and fourteenth amendments to the Constitution provide for equal protection under the law, meaning that any classification scheme for individuals must be fair and equitable. Escalating standards of fairness and equity depend on the importance of the right to be protected and the level of suspicion about the classification. For a racial classification, the state is subject to strict scrutiny and must show that a

compelling state purpose can only be achieved by means of this classification. Since neonatal HIV disproportionately affects minority communities, some have argued that mandatory HIV testing might be considered a de facto racial classification subject to strict scrutiny.

The right to privacy has been considered as both autonomy and solitude. Privacy as autonomy provides for the rights of couples to use contraceptive devices and for women to use abortion services. Privacy as solitude is the legal basis for restricting the state's powers of search and seizure. Some have argued that maternal autonomy is unacceptably compromised by mandatory newborn HIV testing, or that a mother's own HIV status is in effect being discovered through an unwarranted search and seizure.

Legally, a neglected child is one whose welfare is in danger. In medical ethics, beneficence (doing good for the patient) is an obligation of health care providers, though determining what is good for a minor is a parental right ~~abrogated only under highly defined circumstances.~~ The state can intervene if "necessary" medical care is withheld. The burden would be to show that available HIV treatment constitutes necessary medical care for an infant and that a parent who ~~withholds it has neglected the child.~~

Finally, the Americans with Disabilities Act specifically includes HIV infection as a disability and protects disabled persons against discrimination unless they present a direct threat to others. Multiple-drug resistant tuberculosis is arguably a direct threat that meets the ADA exception, but pregnancy in an HIV-infected woman might not be interpreted as a direct threat to the infant, especially since the infant will probably not be infected. On the other hand, some may argue that failure to diagnose and treat individuals in a class which qualifies under the provisions of the ADA is de facto discrimination. It is unclear how the ADA may affect a program of mandatory testing.

OPTIONS FOR PERINATAL HIV TESTING PROGRAMS

The Subcommittee considered a broad range of possible programs for identifying and bringing HIV-infected mothers and their exposed or infected children into care. These options can be arrayed on a continuum as follows:

1. Mandatory newborn testing with mandatory parental notification of results. This is the option proposed by the Mayersohn bill before the New York State Assembly. It does not include any pre- or post-test HIV counseling provisions.
2. Mandatory counseling of all pregnant women and mandatory newborn testing with mandatory parental notification.
3. Mandatory newborn testing with voluntary parental notification, but access to test results by care providers at a later date, by request, with parental consent.
4. Mandatory newborn testing with parental option to refuse testing.
5. Mandatory counseling of all pregnant and postpartum women with voluntary testing strongly encouraged.
6. Voluntary counseling of all pregnant and postpartum women with voluntary testing encouraged. This is a modification of current programs, which concentrate voluntary counseling and testing efforts in high risk areas and show high variability in acceptance rates for testing.

NOTE: All but option 1 could provide for pre- and post-test counseling.

The Subcommittee discussed the relative merits of various approaches, taking into account the option's likelihood of success, cost, and legal and ethical implications.

Success was defined, first, as the "capture" rate, that is, the percent of HIV-infected pregnant women and HIV exposed newborns who might be identified in any given period of time --

prenatally, within a day or two of birth, or within the first month. Each time period was discussed in terms of its potential for preventing perinatal transmission and its potential for beneficial medical intervention for those identified.

Secondly, success was defined as the rate at which infected and exposed children could be expected to enter treatment. Success in identifying affected women and children does not imply success in delivering HIV services, which is dependent on the variety, quantity, and integration of programs, their accessibility, and the ability of the family to come in for care. Yet, clearly, identification is necessary to target service programs.

In theory, mandatory newborn testing would capture all newborns who carry maternal HIV antibodies. However, there are a number of qualifications to this assessment. It has been suggested that some women may elect to avoid testing by delivering outside of New York State or by avoiding hospital delivery. Further, in any given period, some additional infants may be missed due to inadequate time for laboratory follow-up on insufficient or untestable blood specimens. For example, in the New York State congenital screening program, by the end of one month (although follow-up continues for a total of 13 weeks), four percent of specimens that are not testable or are missing have not been replaced despite repeated requests.

The rapidity with which test results can be reported is critical to earlier HIV treatment. A protocol to return standard antibody test results (ELISA with Western Blot confirmation) in about five days could be developed, but would cost more than current protocols. Even with an optimal five-day HIV test reporting protocol, some samples would be inadequate and HIV results not available before mother and child leave the hospital. Therefore, an appropriately funded, aggressive, and effective follow-up program would need to be established as a part of any program designed to increase identification and treatment of HIV-infected newborns and mothers.

Inaccurate test results, both positive and negative, are a further caveat in designing a program to identify all HIV-exposed infants. Expensive protocols requiring multiple tests of a newborn's blood still cannot eliminate the falsely negative test that occurs when there are not yet detectable levels of maternal HIV antibodies. Most test protocols will also yield a number of false positives and equivocal results. Moreover, distinguishing between those infants who are truly infected and those who carry ~~only maternal antibodies has been a major focus of research in~~ newborn testing technology. Newer tests, such as PCR, which can make this distinction, are considerably more expensive than standard antibody testing and are not yet widely available, ~~although sufficient resources could provide for statewide PCR~~ availability.

Just as testing inaccuracies and delayed results would occur whether testing was voluntary or mandatory, success in contacting parents with test results may depend on the same factors regardless of testing policy. In New York State's congenital disease screening program, physicians, hospitals, or disease specialty centers are required to contact parents following certain abnormal test results in a newborn. In the experience of this program, parental tracing after hospital discharge is in most cases a time and labor-intensive process that depends entirely on staff resources and commitment. Cost and rapid success in contacting parents varies widely by hospital, by geographic location, and by disease. Families who are homeless, highly dysfunctional, undocumented aliens, or who give false information or move often for any reason are, naturally, more difficult to find. It often takes longer than a 13-week tracing period to reach a parent and requires a variety of strategies.

Voluntary HIV counseling and testing programs, while well-intentioned in their aim of convincing pregnant women to have HIV tests, have had widely varying rates of success. Casual or ~~poorly-timed offers of counseling by busy or ill trained staff~~ fail to persuade many women to accept counseling, or testing, or to return for test results or post-test counseling. Although there is no data on the exact number of HIV-infected women who ~~know their status at the time of delivery, it is estimated that~~ through New York State's two main voluntary perinatal testing

programs -- the Obstetrical Initiative and the Prenatal Care Assistance Program -- about 46 percent of HIV-infected pregnant women have learned their status prior to delivery.

However, program directors report that mothers who receive clear explanations of the reasons for and importance of HIV testing rarely decline. Information provided in presentations and materials to the Subcommittee indicates that rates of test acceptance near or above 90 percent (such as those achieved at Harlem Hospital Center and at some neighborhood health centers and family planning facilities) are the result of highly coordinated, interdisciplinary efforts by dedicated personnel and a strong institutional commitment to this approach. With proper implementation of an aggressive voluntary program, it may be possible to achieve Statewide rates of test acceptance and post-test parental counseling that would equal rates postulated for mandatory testing and parental notification.

It is clear that significant improvements in quality and possibly length of life, especially as a result of PCP prevention, can be achieved once an infant is identified and under medical supervision. Once again, success in delivering HIV monitoring and treatment services to exposed and infected infants and their mothers poses similar problems under both mandatory and voluntary newborn testing options. Parental notification, under either a mandatory or voluntary testing policy, does not insure

subsequent care. Although many of the current voluntary programs assert that it is rare for a parent to neglect needed HIV care for a child, there is still the problem of inaccessible, fragmented, or overburdened programs.

The Subcommittee, in trying to insure that the maximum number of HIV-exposed infants and their infected mothers obtain the earliest treatment possible, has had to determine not only whether HIV testing should be mandatory or voluntary, but whether greater benefit would be derived from prepartum or postpartum testing, and how quality programs of any kind can be assured.

Evidence presented to the Subcommittee supports the view that testing to identify HIV infection during pregnancy has some distinct advantages over postpartum testing, such as the possibility of preventing perinatal transmission to the fetus and greater opportunity to preserve a strong family environment for the newborn. According to a presentation by the Centers for Disease Control and Prevention, prepartum interventions to reduce the risk of transmission are the emerging focus of perinatal HIV treatment. ~~Since breastfeeding begins at birth, preventing HIV transmission through this route also has the greatest chance of success if HIV-infected mothers are identified prior to delivery and counseled about the risk of breastfeeding their infants.~~ Regarding treatment for HIV-exposed infants, ~~while PCP~~ prophylaxis does not in any case begin before one month of age,

monitoring for opportunistic infections, timely modification of immunization regimens, institution of antiviral medication, and attention to the child's development would be enhanced by the earliest possible knowledge of HIV exposure.

Given that neither a mandatory nor a voluntary testing program would identify 100 percent of HIV-exposed infants, and that either would have some difficulties tracing parents and providing sufficient and accessible treatment services to every affected family, the advantages of prenatal HIV determination and availability of the mother for counseling would argue for an emphasis on expanded and more consistently successful prenatal testing. Those women who do not seek prenatal care, and may thus require HIV testing after delivery, may also need a revised HIV test protocol that made results available before the mother leaves the hospital.

Mandatory testing during pregnancy would be a legally and ethically questionable practice, involving possible invasion of individual rights. Some believe that mandatory testing of newborns may also be viewed as a violation of maternal rights. A significant expansion of HIV-treatment services for women and children, together with counseling to insure that mothers are referred to appropriate programs, may also be required by ethical and legal concerns, as well as by the practical problem of providing care for greater numbers of women and children

identified as HIV-affected.

Thus, the Subcommittee searched for an option that would avoid the potential legal and ethical concerns of mandatory testing without consent or counseling, but be more consistently successful than voluntary counseling and testing programs have been to date at identifying infected women, especially prenatally.

If it could be replicated statewide, mandatory HIV counseling of all pregnant women with voluntary but strongly encouraged testing in a program similar to the Harlem Hospital model seems, in the opinion of the Subcommittee, to offer the best chance for a high rate of success in testing, preventing HIV transmission, and bringing infected families into care. The Subcommittee is aware that this option poses problems of cost and implementation, but feels that with proper support from the Legislature and health care professionals, these problems are surmountable.

~~This option would require the active and informed~~ participation of all providers of care to pregnant women and newborns in New York State. But it is warranted by the intensity of the HIV epidemic and the consequences of HIV infection for women and children. ~~Counseling and testing during pregnancy~~ allows the widest range of maternal options for treatment and

planning, the greatest potential to prevent HIV transmission before, during, and after delivery, and the longest lead time to plan medical care for exposed infants. Making this counseling mandatory in well-run, well-supported programs will, in the opinion of the Subcommittee, convince the largest number of women to learn their HIV status. Convincing them to take an HIV test, rather than forcing them, will presumably lead to more cooperative, effective treatment for all affected family members.

The Subcommittee realizes that implementation of a policy of mandatory HIV counseling and strongly encouraged voluntary testing statewide is an ambitious undertaking. Although the Subcommittee believes this is the approach most likely to succeed, it also believes that its efficacy must be regularly analyzed to determine whether the goal of bringing nearly all HIV-infected women and HIV-exposed and infected children into treatment is in fact being met. To this end, the Subcommittee believes that the results of this policy, if adopted, should be reviewed in a timely and regular manner, and alternative strategies considered if it fails in achieving its goals.

The Subcommittee has agreed on the Principles and Recommendations below.

PRINCIPLES AND RECOMMENDATIONS

The Subcommittee's recommendations are based on the following principles:

Principles

1. The goal of New York State policies with regard to HIV-infected newborns and families must be to maximize the number of HIV-infected newborns and families identified and entered into treatment, and to provide them with optimal health care, psychosocial support, and other necessary services.
2. Given the importance of preventive therapy and early treatment for HIV-infected women and infants, all adults and sexually active adolescents, and especially all pregnant and postpartum women, should be informed of the benefits of knowing their own HIV status and that of infants.
3. Regardless of the policy on newborn and maternal HIV counseling and testing, identification of more women and infants with HIV and their subsequent entry into treatment will require that funds be allocated to expand comprehensive HIV treatment and support services for women and children.
4. All counseling, testing, treatment, and supportive service policies must acknowledge and focus on the needs of the family,

and be designed to support the ongoing involvement of the family in caring for HIV-positive newborns and young children.

5. Programs should be designed to maximize the likelihood that women will seek services for themselves and their children, emphasizing accessibility and confidentiality, as well as family-oriented service delivery.

6. The distinct needs of urban and rural communities should be considered in identifying services and costs to implement enhanced counseling, testing, and treatment programs.

7. The State must be prepared to move quickly to respond to innovations in testing and therapy for women and children. The latest HIV testing technology should be utilized to reduce test processing time and to distinguish as rapidly as possible between maternal antibodies and HIV infection in infants.

8. A new standard of care requiring HIV counseling for all pregnant and postpartum women and the provision of HIV services as early as possible to HIV-exposed and infected infants cannot be implemented without the commitment of all providers of health care to women and children. Appropriately trained health care professionals, paraprofessionals, and community leaders, as well as the administrators of health institutions and community health organizations, must firmly support this policy and work to make

it a success. An integrated (interdisciplinary) care model dedicated to optimal care for HIV-infected women and children, such as the Harlem Hospital Center program, is considered exemplary.

Recommendations

Guided by these principles, the Subcommittee on Newborn HIV Screening recommends that the following policies be adopted by order of the Commissioner of Health, by regulation, or by statute, as appropriate:

1. A policy of mandatory HIV counseling and strongly encouraged voluntary testing for all pregnant and postpartum women should be implemented as soon as possible.

Although the Subcommittee does not recommend mandatory HIV testing of newborns at this time, it is imperative that HIV testing should be presented as a standard medical recommendation by providers in all prenatal, obstetrical, postpartum, and pediatric settings.

2. All providers of health care services in New York State should provide HIV counseling to and strongly encourage HIV testing for all sexually active adults and adolescents (males and females).

This should be presented as a standard medical

recommendation and should become part of routine medical practice in all health care settings.

3. Women who have tested HIV-negative prior to their pregnancy must be provided with repeat counseling and strongly encouraged to repeat the test during pregnancy.

4. All providers of care to neonates and young infants must ensure during postpartum or ongoing pediatric care that appropriate HIV counseling has been given to the infant's mother.

If the mother has not been counseled or has been counseled but has not been tested prenatally, HIV counseling must be provided and testing for the mother and/or infant strongly encouraged.

5. Adequate funding must be provided to implement the new policy of expanded HIV counseling and testing programs and for comprehensive medical care and psychosocial support services for all HIV-positive women, infants, and children.

Funds for these services should not be diverted from other critical human service programs.

The AIDS Institute should identify the specific services that will be required to effectively implement enhanced counseling, testing, and access to care programs for women and their newborns, together with the costs of these programs, and report these assessments to the AIDS Advisory Council (See

Appendix I). This assessment may be done on a regular basis in response to changes in testing or clinical care options.

6. Evaluation of the effectiveness of a program of enhanced HIV counseling, testing, and access to services for women and their newborns must begin not later than one year after financing is made available to providers in order to determine whether the program has resulted in an appropriate increase in the number of HIV-infected women and infants who enter treatment.

The New York State AIDS Advisory Council or its designee should monitor the progress of these recommendations and oversee evaluation of the new policy on a regular basis.

Adequate resources and staffing must be provided to support the initial and ongoing evaluation. Performance standards should take into account hospital seroprevalence rates as well as the goal of maximizing the number of HIV-infected women and children in care.

7. Policies and procedures must be in place at all hospitals, clinics, and doctors' offices where pregnant women, postpartum women, and children are seen to:

- implement the new policy of expanded HIV counseling and testing programs,
- provide for the appropriate notation of maternal HIV status in the neonate's record,
- assist women in returning for their post-test counseling

visit and expedited access to care for themselves and their infants.

8. The AIDS Institute should review current regulations to streamline procedures for HIV counseling, testing, and informed consent within existing law.

9. Commercial health insurance carriers should be required to cover and Medicaid should be required to continue to cover the cost of prenatal and postpartum HIV counseling and testing.

HIV counseling and testing should be specifically excluded from co-payment requirements under Medicaid.

10. Literature on HIV counseling/testing, HIV medical care, and supportive services for HIV-infected persons should be readily available in all health care settings providing services to pregnant and postpartum women, other adults, adolescents, and children.

Such literature should be culturally sensitive and linguistically appropriate to the population served by the ~~specific providers~~. In particular, ~~the Department of Health~~ should prepare and distribute a new Guide for HIV Counseling and Testing in Women's Health Care Settings. This Guide would cover such issues as breastfeeding, immunization, the family's role in ~~caring for the child with or at risk for HIV, and care of the~~ mother to maintain her health and ability to care for her

children.

11. Institutions responsible for the education of health care professionals should include in their curricula instruction concerning the importance of integrating HIV counseling and testing into routine primary medical care, effective counseling methods, the importance of confidentiality, and information to be transmitted to patients.

12. The Medical Society of the State of New York, the New York State chapter of the American College of Obstetricians and Gynecologists, the New York State district of the American Academy of Pediatrics, the New York State Nurses Association, the New York State chapter of the American College of Nurse Midwives, and all other relevant organizations of health services and health education professionals should take an active role in expanding the availability of HIV counseling, testing, and treatment, especially for pregnant and postpartum women and children, and educating both the public and their members on this issue.

Dissenting Comments on the January 31, 1994 Report of the Subcommittee on Newborn Screening to the AIDS Advisory Council, February 4, 1994

Early identification and comprehensive health care now can lengthen and improve the quality of life for HIV infected infants. The Subcommittee on Newborn Screening was created because too many of the infants who need such care are not identified in time to receive these benefits. Resistance to testing newborn infants for HIV, a procedure that would guarantee the benefits of early, appropriate care has been based on fear that such routine testing, as is done for nine other diseases, could subject infants and their mothers to stigmatization, discrimination and even physical harm. In light of current experience that proper care is beneficial and can be provided to such infants and their families, that confidentiality can be maintained and that a well established methodology for testing is at hand, it is time for New York State to exercise its responsibility to vulnerable children by designating early identification of HIV infection as a necessary component of newborn care. The gap between the documented number of children and families who would benefit from appropriate care, 1800 per year, and the number being identified by current efforts at prenatal and postnatal counseling has provided the impetus for the Subcommittee to seek "a better way."

The central recommendation of the Subcommittee Report proposes mandatory prenatal and postnatal counseling which strongly encourages voluntary testing for HIV antibody (rather than routine testing). This recommendation is a valuable step toward reinforcing an accepted standard of care for women and children, but it is insufficient to offer the protection which every infant deserves, protection which has been guaranteed newborn infants in New York State for other serious diseases. Reliance on counseling and that encourages voluntary testing ignores the unacceptably high failure rate of such an approach. In addition, it siphons off resources which could be focused more effectively for needed care. The failure of our health system to identify many of the infants born each year in New York State to HIV infected mothers denies them access to life-saving and life-enhancing care. A substantial body of experience supports our concern that delay in diagnosis is literally a matter of life versus preventable, early death.

In making the case for its central recommendation, the Report contains much information that is

accurate, humane, constructive and practical. However, in our judgement, the Report is distorted by errors of omission, commission, logic and unlabeled speculation. The remarkable accuracy and economy of existing diagnostic tools for identifying infants who can benefit from special care is glossed over, as are the disappointing results of currently funded programs that focus on efforts to "counsel and encourage testing".

The Report does not address adequately the lessons learned from efforts to control perinatal morbidity and mortality from Rh Disease, rubella, syphilis, hepatitis B, sickle cell disease, congenital hypothyroidism, PKU and infectious conjunctivitis of the newborn. Although each of these diseases has its own special characteristics, as does HIV, a uniform message is clear. Infants were subject to preventable harm until an easily monitored requirement for routine testing was supported by Public Health Law and regulation, and in the case of newborn screening, was also accompanied by development of a proper public health infrastructure. In our judgement, the report falls short by not recommending such an approach.

The "Harlem Hospital Model" espoused by the Report as evidence that effective counseling will bring infants and their mothers into care is not described in detail, nor are its infrastructure, resource base and special characteristics analyzed with regard to its potential for replicability across the State. Based on the available details of that research-oriented and research-funded program and the low acceptance of testing rates achieved in pilot programs involving many thousands of women throughout the State, there is ample evidence for serious doubt that the "Harlem Hospital model" can be replicated on a state-wide basis.

The Report gives insufficient attention to society's responsibility "to act in the best interest of the child" and speculates in an unbalanced and unsubstantiated manner on how testing of newborn infants for HIV infection will be harmful to their mothers. The language of the Report is confusing with regard to issues of confidentiality and disclosure. It equates newborn testing with breach of confidentiality and any disclosure with improper disclosure. While reminding the reader that HIV infected persons are subject to discrimination and stigmatization in spite of existing statutes, the Report offers no evidence (in fact, does not even address) its implied conclusion that testing of infants as part of a voluntary program, rather than as a component of routine newborn care,

would reduce the potentially harmful consequences of improper disclosure and discrimination, both of which are illegal.

The Report gives scant attention to an option presented which is mindful both of parental rights and responsibilities and the hazard to the child of unrecognized HIV infection. That option adds HIV antibody testing to the existing routine Newborn Screening Program, with an "opt out" provision for mothers who, after proper counseling, object to having their infants tested for HIV

The Report recommends a program which fails to guarantee the protection of timely health services to infants and their families. Even if this were an era of unlimited resources, we would still favor the remarkably cost-effective, easily implemented and monitored alternative provided by the well-established NY State Newborn Screening Program. In addition, the Report is too vague on how additional funds should be allocated, or how the compelling needs of the children (and their families) for services will receive appropriate priority.

In attempting to summarize where we feel the Report falls short, we have tried to avoid the imbalance and inaccuracy which compromise the lengthy document. Given the complexity of the scientific, medical, legal, psycho-social, ethical and logistic issues involved in newborn HIV testing, we recognize that this brief response is also at risk of imbalance. On that basis, we stand ready to offer more detailed information and opinion as public discussion leads us, hopefully, to clarity about the issues involved. Such clarity should assist those who must make well-informed public decisions, decisions in which New Yorkers must act in the best interest of our vulnerable children and their families.

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