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Beyond Parens Patriae: Assuring Timely, Informed, Compassionate Decisionmaking for HIV-Positive Children in Foster Care

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Beyond *Parens Patriae*: Assuring Timely, Informed, Compassionate Decisionmaking for HIV-Positive Children in Foster Care

DEBORAH WEIMER*

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I. INTRODUCTION

Tyrone's mother, a heroin addict, leaves him with a neighbor and does not return. Tyrone, age two, is placed in a temporary foster home, awaiting his mom's return. He appears healthy, but has frequent colds and severe bouts of diarrhea. His foster mother finally takes him to the hospital emergency room, where doctors determine that Tyrone is suffering from Human Immunodeficiency Virus ("HIV") disease, a precursor to the deadly Acquired Immune Deficiency Syndrome ("AIDS"). The hospital refers Tyrone to a pediatric AIDS clinic. The clinic is conducting a drug trial of IV-IG, which it believes could benefit Tyrone by strengthening his immune system. However, when the clinic contacts the local office of the Department of Social Services responsible for Tyrone's care, the office informs them that regulations prohibit enrolling a child in its care in experimental trials. Attempts to reach Tyrone's mother are unsuccessful. Meanwhile, the foster family caring for Tyrone asks that he be placed elsewhere, because they cannot cope with a child with such serious medical problems.

Tyrone's story is one that has occurred repeatedly across the

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country over the past several years. In 1990, 42% of children known to be HIV positive were not living with their parents; 26% had been placed in foster care, 9% were living with a relative, and 7% were living with someone other than a relative.¹ Most of the HIV-positive children in foster care cannot obtain access to new drug treatments, still in the experimental stage, which may be their best hope of delaying the impact of their HIV infection. In 1989, for example, of the 785 children in foster care identified as HIV positive (and there are many more unidentified), only fifteen were enrolled in new drug trials at a time when such trials were the only hope to treat their infection.² At the same time, under-enrollment has also delayed the progress of these drug trials.

The Centers for Disease Control estimates that there are nearly twenty thousand HIV-positive children in the United States today.³ It also estimates that each year, two thousand children will be born infected with the virus.⁴ By the end of 1990, almost three thousand children had been diagnosed with AIDS.⁵ Many of these children will end up in foster care.

Most of these children are from poor, Black, or Hispanic inner-city communities, hard hit by the AIDS epidemic. These communities, already overwhelmed by a multitude of problems, are not organized to combat the disease. Nor have these communities been involved in the decisionmaking process for combating AIDS. Black and Hispanic men and women have been vastly underenrolled in trials of new, promising drugs.⁶ Many at-risk children receive no medical

1. Telephone Interview with Margaret Oxtoby, M.D., of the U.S. Centers for Disease Control, in Atlanta, Ga. (Feb. 22, 1991) (discussing the Centers' survey of 14,049 HIV-positive children in Los Angeles, San Francisco, Massachusetts, New York, Washington, D.C., and Texas). In some urban areas, statistics are even more dramatic. The general breakdown of HIV-positive children seen at Albert Einstein College of Medicine in New York City is as follows: "(a) child lives with his or her natural family (20 to 25%); (b) child is in foster care (55 to 60%); (c) child lives with relative or other surrogate caretaker (20 to 25%). . . ." Karen M. Hopkins, *Emerging Patterns of Services and Case Finding for Children with HIV Infection*, 27 MENTAL RETARDATION 219, 221 (1989).

2. Judith M. Martin & Henry S. Sacks, *Do HIV Infected Children Have Access to Clinical Trials of New Treatments?*, 5 AIDS & PUB. POL'Y J. 3 (1990); see also U.S. DEP'T OF HEALTH AND HUMAN SERVICES, FINAL REPORT: SECRETARY'S WORK GROUP ON PEDIATRIC HIV INFECTION AND DISEASE (1988).

3. Cheryl P. Weinstock, *Children with AIDS*, FDA CONSUMER, Oct. 1990, at 8, 19.

4. Centers for Disease Control, *HIV Prevalence Estimates and AIDS Case Projections for the United States*, MORBIDITY & MORTALITY WKLY. REP., Nov. 30, 1990, at 7.

5. Judy Foreman, *Gain Cited in Curbing Youth AIDS Infections*, BOSTON GLOBE, Jan. 18, 1991, at 28. Fifty-two percent of these children are Black, and a quarter are Hispanic. Weinstock, *supra* note 3, at 9.

6. Government statistics reveal that as of August 1989, Blacks and Latinos accounted for 42% of adult AIDS patients in the United States, but only 20.4% of patients enrolled in

care because of the lack of community awareness and the failure of social services agencies to respond to the epidemic. Children and their caretakers are unaware of experimental protocols that may benefit them. This ignorance in turn impedes the progress of research to address their needs.

To ensure that critical medical care decisions are made for these children in a timely, informed, and compassionate manner, and to incorporate the interest of the community most affected by these decisions, we need a structure beyond the simple substitution of state for parental decisionmakers. The system should not permit legal constructs and distrust to obstruct the delivery of much needed medical care.

The United States Department of Health and Human Services ("HHS") regulations for enrollment of children in experimental trials recognize that where parental consent is unavailable, some "appropriate mechanism" must protect childrens' interests.⁷ However, the HHS regulations fail to provide much guidance on what form the "appropriate mechanism" should take. This Article proposes a mechanism to fill that gap.⁸ A committee composed of the child's foster parent, an HIV-positive person, a health care worker knowledgeable about HIV disease in children, and a lay advocate from the child's community should have the authority to make medical decisions in the child's best interest. HIV-positive children need advocates from their communities to protect their interests and ensure that they receive the best possible medical care. Involving members of the community in the drug trial process has the added benefit of enhancing communication between the affected community and medical researchers. It will reduce distrust and provide more oversight of clinical trials in children.

This Article describes the present foster care system, explains

National Institute of Allergy and Infectious Diseases AIDS trials. Intravenous drug users accounted for 27.5% of adult AIDS patients, but only 11.3% of the participants in federal studies. Robert Steinbrook, *AIDS Trials Shortchange Minorities and Drug Users*, L.A. TIMES, Sept. 25, 1989, at 1.

In March 1991, a panel of the Institute of Medicine, a branch of the National Academy of Sciences, noted that Blacks made up 28% of the population with AIDS (and a much larger percentage of the HIV-infected population), but only 16.9% of those enrolled in clinical trials. The report recommended that Medicaid and Medicare consider reimbursing AIDS patients for experimental drugs or associated medical care. INSTITUTE OF MEDICINE, THE AIDS RESEARCH PROGRAM NATIONAL INSTITUTES OF HEALTH 24-27 (1991).

7. 45 C.F.R. § 46.408(c) (1990).

8. This Article primarily addresses the problems facing those children who contracted HIV infection at birth. The question of medical decisionmaking for adolescents is a complex one, addressed elsewhere. See, e.g., Richard L. North, *Legal Authority for HIV Testing of Adolescents*, 11 J. ADOLESCENT HEALTH CARE 176 (1990).

why it has failed to provide HIV-positive children in foster care with access to medical trials, and offers an improved means of medical decisionmaking. Part II details why delegation of decisionmaking for HIV-positive children to courts or temporary foster families is an undesirable solution. Part III proposes an alternative model, the committee described above, to facilitate timely decisionmaking in the child's interest. This model preserves positive aspects of parental consent and adds other elements to facilitate informed and sensitive decisionmaking. Finally, Part IV addresses the limits and function of committee intervention.

II. FOSTER CARE, MEDICAL TREATMENT, AND THE OBSTACLES TO ENROLLING FOSTER CHILDREN IN DRUG TRIALS

A. *Foster Care and Medical Consent*

The state typically places HIV-positive children in foster care because of parental neglect.⁹ Neglect may stem from the parents' drug use, illness, poverty, or lack of resources and education. Most cases involve a combination of several of these factors. In some situations state agencies place a child in foster care because of a parent's death. Sometimes parents who are ill or without resources voluntarily place their child in foster care.

State agency regulations on parental consent for medical care of a child in foster care vary, but their general outlines are similar. For example, if a child has been committed to the Department of Social Services, or the parents have placed the child in foster care voluntarily, most state regulations do not deprive the parents of medical guardianship for their child. The Maryland system illustrates such parental consent regulations. The parents retain medical guardianship, but may be asked to sign a consent authorizing the state to obtain routine or immediate care for the child.¹⁰ If the parent does

9. See Phyllis Gurdin & Gary R. Anderson, *Quality Care for Ill Children: AIDS-Specialized Foster Family Homes*, 66 CHILD WELFARE 291, 291 (1987). The Child Welfare League, in its report on HIV infection and children in foster care, recognized the special problems faced by HIV-positive mothers:

Women, and especially mothers, frequently ignore their own health care while attending to their child's needs, particularly if the child is also infected with HIV. Consequently, women delay treatment until the disease has progressed to the point where they are no longer able to care for a chronically ill child alone. If this woman happens to be a mother without a critical support system, the child is often referred for foster placement.

Virginia Anderson, *Beyond Medical Intervention: The Power of Family Foster Care*, in MEETING THE CHALLENGE OF HIV INFECTION IN FAMILY FOSTER CARE, 2 (Constance M. Ryan & L. Jean Emery eds., 1991) [hereinafter RYAN & EMERY].

10. 17 Md. Reg. 1875 (1990).

not consent, the local department must seek medical guardianship from the committing court.¹¹ The local department must notify the parents of and encourage their involvement in medical decisionmaking and treatment for the child.¹² If a child remains in foster care for an extended period of time without parental contact, the state agency can commence proceedings to terminate parental rights, and the court may award guardianship to the state foster care agency.¹³ Upon termination of parental rights, the state agency has authority to consent to all medical care.¹⁴

B. *HIV-Positive Minority Children in the Foster Care System*

Unfortunately, there is a serious shortage of adoptive homes for Black and Hispanic children, especially those with HIV disease.¹⁵ Thus, even if a child has lost both parents or the state has terminated parental rights, the child is likely to remain in the foster care system. Children in foster care can rarely participate in drug trials.

A primary cause of the underenrollment of these children in drug trials is the inadequacy of the foster care system, which was overwhelmed even before the impact of HIV disease. Individual agencies are consistently underfunded and understaffed, and often poorly managed. Social workers have such large caseloads that they often do not make mandatory visits to children in their care, much less provide needed services.¹⁶ Foster care agencies have difficulty obtaining even routine medical attention for children in their care.¹⁷

11. *Id.*

12. *Id.*

13. MD. FAM. LAW CODE ANN. §§ 5-313 to -317 (1990).

14. *Id.*

15. Shirley Jenkins et al., *Ethnic Differentials in Foster Care Placements*, SOC. WORK RES. & ABSTRACTS, Winter 1983, at 41.

16. The evidence in *LaShawn A. v. Dixon*, Civ. Act. No. 89-1754 (D.D.C. Apr. 18, 1991), indicated that while agency policy mandated monthly "face to face" visits with each child in foster care, in 64% of the cases where the plan was to return a child to her home eventually, no social worker had ever visited the child. In cases where the goal was to place the child in an adoptive home eventually, there was no evidence of a social worker's visits in 52% of the cases. The defendant agency admitted that as of October 1990, 149 children in the foster care system had no social worker assigned to them. *Id.* at 39.

17. One study revealed that 40% of children in foster care had no immunization records. Edward L. Schor, *The Foster Care System and Health Status of Foster Children*, 69 PEDIATRICS 521, 525 (1982). Studies indicate that many preschool children had not been vaccinated. See Michael B. Mushlin, *Unsafe Havens: The Case for Constitutional Protection of Foster Children from Abuse and Neglect*, 23 HARV. C.R.-C.L. L. REV. 199, 208-09 (1988); Janet Weinstein & Jollie La Fleur, *Caring for Our Children: An Examination of Health Care Services for Foster Children*, 26 CAL. W. L. REV. 319, 324 (1990).

The failure of the foster care system to provide adequate medical care was challenged successfully in the leading case of *L.J. v. Massinga*, 699 F. Supp. 508 (D. Md. 1988), *aff'd*, 838 F.2d 118 (4th Cir. 1988). In *Massinga*, the court approved new procedures for the Department

Other, more specific reasons explain the underenrollment in drug trials of HIV-positive children in the foster care system. Many state agencies require parental consent before they enroll a child in a drug trial.¹⁸ Parental consent is sometimes difficult, if not impossible, to obtain because the agency often loses contact with the parents after a

of Social Services to improve delivery of medical care to foster children. These procedures included screening the child within 24 hours for treatment of any immediate medical problems, giving the child a comprehensive physical, developmental, and emotional evaluation within 60 days of placement, and using a medical passport for each child. *Id.* at 518. The court also ordered the agency to develop an integrated, quality system of health care. *Id.*

In *LaShawn A. v. Dixon*, Civ. Act. No. 89-1754 (D.D.C. Apr. 18, 1991), the United States District Court for the District of Columbia found that the D.C. Department of Human Services harmed the foster children in its care by failing to serve them. The court found, *inter alia*, that the agency failed to place children in appropriate foster homes, to monitor placements, and to make efforts to create permanent placements. Though agency policy mandated that all children entering foster care undergo a complete medical examination, the record showed that the agency did not have adequate medical screening facilities. In addition, 44% of the foster children had not had a medical examination since their entry into care. Slip op. at 39.

The problem of adequate health care for children in foster care is pervasive. See Edward L. Schor, *A Summary of a White Paper on the Health Care of Children in Foster Care: Report of Colloquium on Health Care for Children in Foster Homes*, CHILDREN'S LEGAL RTS. J., Summer 1987, at 16, 17. The Child Welfare League of America ("CWLA"), in "Meeting the Challenge of HIV Infection in Family Foster Care," recognized the tremendous challenge posed to the Child Welfare System by the HIV epidemic:

Serving children and families affected by HIV poses some of child welfare's greatest challenges. HIV infection does, however, throw a highly concentrated light on the deficits in the system. It also thrusts the child welfare system into what is perceived to be unfamiliar territory, where attention is focused on the disease and its medical complexities. HIV infection/AIDS is both a medical and a social problem. One cannot deal with it without dealing with the problems of poverty, homelessness, and substance abuse. Nowhere is this more evident than in the families served by child welfare agencies. For this reason, close collaboration between child welfare and health care professionals is imperative in all aspects of prevention, planning, policy development, intervention, and advocacy.

Constance M. Ryan, *Introduction to RYAN & EMERY*, *supra* note 9, at x.

18. Illinois, New York, Pennsylvania, and Wyoming have explicit policies that forbid enrollment of foster children in clinical trials without the consent of their natural parents. Martin & Sacks, *supra* note 2, at 3. Although this may be an appropriate response for clinical trials with no expected participant benefit, most HIV trials do hold out some potential benefit to participants. These protocols should be reviewed on a case-by-case basis to assess the pros and cons of participation for each HIV-positive child. The merits of the case-by-case approach are apparently being recognized in the State of New York, where the commissioner who oversees foster care may consent to enrollment in cases where an experimental protocol is essentially the equivalent of medical treatment.

The State of Massachusetts has taken the lead in creating a systematic response to enrolling foster children in HIV drug trials. The Massachusetts Department of Social Services created a central AIDS review board to make decisions regarding testing and treatment of at-risk children in its care. The Board reviews experimental protocols and determines whether it will permit enrollment of children in its care in each trial. The Board is composed of professionals, doctors, lawyers, and social workers, and does not provide for substantial community input. While it certainly is a step in the right direction to create a well-informed

child is placed in foster care. The parents may be ill, heavily involved with drugs, or unresponsive to attempts to contact them. They may have moved without informing the social worker. Whether or not they require parental consent, state agencies have expressed understandable reluctance to enter children into experimental treatment. Some agencies specifically object to enrolling children in placebo-controlled trials.¹⁹

In addition to inertia, lack of resources, and concerns about authority and liability, the shadow of the Tuskegee syphilis experiment²⁰ has caused agencies and social workers to distrust the idea of entering a child into an experimental treatment program. The Tuskegee study, which began in 1932 and continued until 1972, involved observation of the effects of untreated syphilis on a group of poor, illiterate, black men in rural Alabama.²¹ The Public Health Service, working with the Tuskegee Institute, enrolled these men in a study to observe the long-term effects of their disease.²² They neither offered the men treatment, nor informed them of the nature of their illness.²³ Even after penicillin became available, the Public Health Service did not treat the men, but continued to monitor their conditions for forty years.²⁴ As of 1969, at least twenty-nine and perhaps as many as 100 men had died as a direct result of complications caused by untreated syphilis. Others had developed serious syphilis-related heart conditions that may have contributed to their deaths.²⁵

The Tuskegee study has engendered distrust in the Black community for any experimental treatment program sponsored by the federal government.²⁶ As Dr. Wayne Greaves, an infectious disease expert at Howard University Medical School, has said, "Many [B]lacks and Hispanics see research at universities as ivory-tower experimentation that is more for the sake of advancing researchers' prestige than improving patients' care."²⁷ Patients often ask Dr. Greaves for advice when they are eligible for a study. "Particularly

Board to review protocols, the Massachusetts model does not provide alternative solutions to the difficult question of consent in the absence of parental involvement.

19. Martin & Sacks, *supra* note 2, at 6.

20. See JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1981).

21. See *id.*; ROBERT J. LEVINE, *ETHICS AND REGULATION OF CLINICAL RESEARCH* 69 (1986); Taunya L. Banks, *Women and AIDS—Racism, Sexism, and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 361-65 (1989-1990).

22. LEVINE, *supra* note 21, at 70.

23. *Id.*

24. *Id.*

25. JONES, *supra* note 19, at 2.

26. Gina Kolata, *In Medical Research Equal Opportunity Doesn't Always Apply*, N.Y. TIMES, Mar. 10, 1991, at 16.

27. *Id.*

when I have to refer them to the National Institutes of Health, they ask, 'What are they going to do to me? Is this going to be another Tuskegee?' ”²⁸

This history provides an understandable reason to proceed cautiously with enrolling HIV-infected minority children in drug trials. However, to reject all drug trials out of hand disservices children in great need of finding treatment for their illness. Drug trials hold the possibility of useful intervention that may delay the onset of disease. Still, the risks and potential benefits of each trial must be weighed individually.

In May 1990, the Food and Drug Administration (“FDA”) approved zidovudine, commonly called “AZT,” as the first treatment for HIV-infected children.²⁹ However, researchers across the country were already conducting trials which revealed the promise of drugs such as AZT.³⁰ In 1989, for example, three drug trials were in process. One treated HIV-positive children with intravenous immunoglobulin, which had already proved useful in treating children with other kinds of immune disorders. This trial, Protocol 045, enrolled children with relatively mild symptoms of infection. It was a placebo-controlled trial—that is, some children enrolled in the trial did not actually receive immunoglobulin.³¹ Another trial, Protocol 128,

28. *Id.*

29. See Weinstock, *supra* note 3, at 9. The FDA approved children’s treatment with AZT after drug trials conducted under the auspices of the National Institute of Allergy and Infectious Disease AIDS Clinical Trials Group. The FDA did not require full evaluation of the effectiveness of AZT in children prior to approving its use. It proceeded on the basis of the proven effectiveness of AZT for adults and data demonstrating its safe use for children. *Id.*

30. The Food and Drug Administration had approved AZT for adult AIDS patients in 1987. *Id.* Available data indicates that AZT slows the progression of AIDS in both children and adults. Centers for Disease Control, *supra* note 4, at 7. A recent multi-center study of 88 children with advanced HIV disease concluded that the efficacy of AZT in children is similar to that in adults. It also noted substantial weight gain and improvement in cognitive function primarily in children under three. Ross E. McKinney et al., *A Multicenter Trial of Oral Zidovudine in Children with Advanced Human Immunodeficiency Virus Disease*, 324 *NEW ENG. J. MED.* 1018, 1021-22 (1991). Another study conducted by the Department of Veterans Affairs found AZT less likely to delay the onset of symptoms in minority patients than in white patients. Gina Lolata, *Federal Study Questions Ability of AZT to Delay AIDS Symptoms*, *N.Y. TIMES*, Feb. 15, 1991, at A1. However, this study was not designed to determine whether people of different races would react differently to AZT, and it reached no clear conclusion on this point. This suggests the need for including more people of color in drug trials, so the collected data can enhance treatment for all.

31. The positive impact of IV-IG on the children in this study was so dramatic that the Data Safety Monitoring Board, an independent evaluator, recommended that the study end a year early. The Board found that the injections were so effective that it would have been unethical to continue the study, given that some children were receiving only a placebo. The study concluded that monthly injection of intravenous immunoglobulin dramatically decreased serious bacterial infections and reduced the number of hospitalizations for children, though it did not appear to prolong the lives of the children. Foreman, *supra* note 5. The drug

tested the efficacy of AZT in the treatment of children. The third trial, Protocol 103, compared continuous infusion of AZT, oral AZT, and dideoxyinosine ("DDI"). Slots available in these trials went unfilled. At the same time, there were at least 785 children in foster care identified as HIV positive, and only fifteen of these children were enrolled in any clinical trial, notwithstanding that it was the only hope for treatment at that time.³² An amended Protocol 103 continues to be open to enrollment. Only eleven out of seventy-five slots had been filled as of April 10, 1991.³³

Researchers opened another trial, ACTG 138, to enrollment on November 5, 1990, but as of April 10, 1991, only fifty-one of the 140 slots had been filled.³⁴ This trial, designed to evaluate the long-term safety, tolerance, and efficacy of dideoxycytidine, is open to children with symptomatic HIV infection who are intolerant to AZT,³⁵ or who experience disease progression while taking AZT.³⁶

Today, HIV-infected children can receive treatment with AZT without enrolling in an experimental drug trial.³⁷ IV-IG is now also available now outside of a drug trial.³⁸ AZT, however, has side effects that limit its use in some children.³⁹ Furthermore, its helpful aspects are limited; apparently AZT merely slows down the progression of HIV disease. But other, potentially more promising drugs are being tested.⁴⁰ In addition to possibly beneficial treatment, enrollment in a drug trial brings other potential benefits, including developmental screening every six months and state-of-the-art care and monitoring. As treatment options grow, HIV-infected children need advocates who are aware of new developments and can consider whether enrollment in a trial is in the child's best interests.

III. OPTIONS FOR CHANGING THE STATUS QUO

How can we ensure children's access to potentially beneficial

company involved, Miles, Inc., a unit of Bayer, agreed to provide the drug free of charge to all participants when the study ended. *Financial Section, Reuters*, Jan. 17, 1991, available in LEXIS, Nexis Library, Wires File.

32. Martin & Sacks, *supra* note 2, at 3.

33. Search of AIDS Trials Database, Clinical Trials Info. Serv., Rockville, Md. (Apr. 25, 1991) (search for pediatric trials ACTG 103 and ACTG 138).

34. *Id.*

35. *Id.*

36. *Id.*

37. See Weinstock, *supra* note 3, at 9.

38. See Foreman, *supra* note 5.

39. AZT can inhibit the production of red blood cells, which are necessary for oxygen transport. It also may reduce the number of white blood cells. Weinstock, *supra* note 3, at 10.

40. *Id.*

drug trials, while protecting them from harmful experimentation? Much progress has been made in addressing the abuses in medical research since the Tuskegee syphilis experiments. Today an institutional review board must review and approve research protocols funded by the federal government and every subject must provide detailed, informed written consent.⁴¹ HHS regulations provide guidelines that must be met before an institutional review board can approve a particular research plan.⁴² The regulations also mandate what researchers must disclose and explain in an informed consent form to be signed by the patient.⁴³ HHS regulations thus provide a two-pronged check on research studies, consisting of an institutional review board and informed consent. For those from whom it is impossible to obtain truly informed consent, the Department of Health and Human Services has promulgated additional guidelines to prevent injury or unethical exploitation.⁴⁴

The HHS regulations require parental permission before enrolling a child in an experimental protocol.⁴⁵ If appropriate, depending on the child's age and level of maturity, the regulations also require the child's assent.⁴⁶ If permission of the parent or guardian is not reasonable under the circumstances, the regulations authorize the institutional review board to develop an "appropriate mechanism" to protect the children involved.⁴⁷ However, the HHS regulations do not define the appropriate mechanism that they authorize.⁴⁸

The critical issue for children in foster care is who can provide informed consent for the child in the absence of the parent? A traditional option used in a few states is to ask a court to authorize the child's enrollment in a drug protocol.⁴⁹ However, several problems arise with this method. First, the agency responsible for the child's care must initiate the court proceeding. As previously noted, social services and foster care agencies are typically under-funded and over-worked, and hardly able to provide routine health care to many foster

41. 45 C.F.R. § 46.103 (1990).

42. *Id.* § 46.111.

43. *Id.*

44. *See, e.g., id.* § 46.205 (1990) (fetuses, pregnant women, in vitro fertilization); *id.* § 46.305 (prisoners); *id.* § 46.401-.409 (children).

45. *Id.* § 46.408(b).

46. *Id.* § 46.408(a).

47. *Id.* § 46.408.

48. *Id.* § 46.408(c). The only guidance the HHS regulations provide is that the choice of an appropriate mechanism depends on the nature and purpose of the activity described in the protocol, whether there is an anticipated benefit to the research subject, and the ages, maturity, status, and condition of the participants. *Id.*

49. Martin & Sacks, *supra* note 2, at 3.

children.⁵⁰ Having to prepare petitions and proceed to court for many HIV-positive children is an unnecessary and time-consuming drain on resources. Timeliness is imperative in medical decisionmaking. Given the likely lag time at social services and the crowded court dockets in most areas, timely decisions by the courts are unlikely.⁵¹ Besides, a judicial decision to enter a child into a drug trial does not end the matter. Someone must monitor the child's progress in the trial, and keep up with new options for the child's treatment as they become available. Courts are ill-suited for this role. Furthermore, resorting to court action in every such instance is expensive and resource-consuming for the judicial system.

Perhaps the biggest drawback to having courts decide whether to enroll a child in a drug trial is the increasing recognition that courts are not necessarily the best arbiters of discretionary moral judgments.⁵² There may not be a clear right or wrong answer to a question of whether to enroll a child in a drug trial. Rather, it is a personal decision, one that those who best know the child should make.

Another option is to delegate decisionmaking authority to the foster parent caring for the child. At least one state court has ordered this procedure.⁵³ A difficulty with this method is that the child may move frequently from foster home to foster home.⁵⁴ Though the fos-

50. See *supra* part II.B.

51. See Herman Mendez & Jose E. Jule, *Care of the Infant Born Exposed to Human Immunodeficiency Virus*, 17 *OBSTETRICS & GYNECOLOGY CLINICS N. AM.* 637 (1990).

52. Commentators have recognized limitations of court involvement in questions of withdrawal of life support from a terminally ill or permanently unconscious patient.

[T]he judicial process has limited value in handling bioethical conflicts, such as withholding life-sustaining treatment or allocating scarce medical resources. First, legal services are expensive, and the judicial system's bureaucratic, adversarial approach is not designed to address the emotional issues faced by patients and health care professionals struggling with life-threatening issues. Second, the legal system often is not responsive to the time pressures of ethical conflicts in medicine. Courts often announce decisions months after the patient has either died or left the hospital. Finally, retrospective court judgments do not fulfill health professionals' need for hospital policies to help resolve ethical problems before they reach an impasse.

Janet Fleetwood et al., *Giving Answers or Raising Questions?: The Problematic Role of Institutional Ethics Committees*, 15 *J. MED. ETHICS* 137, 138 (1989). The Supreme Court of Minnesota held that judicial approval was unnecessary where each ethics committee had reviewed and agreed with a family's decision to withdraw life prolonging treatment from a patient in a persistently vegetative state. *In re Torres*, 357 N.W.2d 332 (Minn. 1984).

53. In Maryland, foster parents have the authority to consent to a foster child's enrollment in a clinical trial by court order. Martin & Sacks, *supra* note 2, at 3.

54. One of the named plaintiffs in *LaShawn A. v. Dixon*, Civ. Act. No. 89-1754 (D. D.C. Apr. 18, 1991), had been in six different foster homes and one group home. *Id.* at 32. Another named plaintiff, Kevin, was a "special needs" child who had been placed in congregate care as

ter parents should have a say in the decision, it should not be their decision alone, except in a long-term care setting or where the family plans to adopt the child. The level of a foster parent's involvement with a child varies dramatically from family to family. Foster parents may also experience a conflict between their other children and responsibilities, and the demands of enrolling a child in a clinical trial, which frequently involves extended monthly clinical visits. Additionally, because of the difficulty of finding foster parents for HIV-positive children, ever increasing numbers of these children are in group homes awaiting placement.⁵⁵

We need an alternative decisionmaking mechanism. The present model relies heavily on parental consent. Is it possible or desirable to duplicate the parental role in this context? We must examine the rationale for deference to the parent in medical decisionmaking. Does informed consent by a parent really protect children? If so, how?

The history of deference to a parental decisionmaker is complex. It began with the notion that the child was an extension of, or property of, the parent. Under the common law doctrine, the parent had an absolute right to control the child and was financially responsible for the child.⁵⁶ An injury to the child was an injury to the parent.⁵⁷ This notion of the child as the parents' property has only recently changed.

Courts now justify giving parents the right to make decisions for their children by recognizing that "natural bonds of affection lead parents to act in the best interests of their children."⁵⁸ Courts acknowledge parents' continuing responsibility for their child and make assumptions about the parent-child relationship. They assume, for instance, that parents love their children and care about what happens to them. Courts also presume that parents and their children share a common family and ethnic history. Because of this, the courts

an infant, and then moved from three different foster homes that had indicated plans to adopt him. *Id.* at 32.

55. See *id.* at 33; Hopkins, *supra* note 1, at 221.

56. Linda S. Ewald, *Medical Decision-Making for Children: An Analysis of Competing Interests*, 25 ST. LOUIS U. L.J. 689, 689-95 (1982); Francis B. McCarthy, *The Confused Constitutional Status and Meaning of Parental Rights*, 22 GA. L. REV. 975, 975-80 (1988); Mason P. Thomas, Jr., *Child Abuse and Neglect Part I: Historical Overview, Legal Matrix and Social Perspectives*, 50 N.C. L. REV. 293, 293-95 (1972).

57. For example, a Michigan court held a surgeon who operated on a child without parental consent liable in an action for battery by the parent. *Zoski v. Gaines*, 260 N.W. 99 (Mich. 1935); *Rishworth v. Moss*, 159 S.W. 122 (Tex. Civ. App. 1913); see also Eric S. Engum, *Expanding the Minor's Right to Consent to Non-Emergency Health Care*, 3 J. LEGAL MED. 557 (1982); Ewald, *supra* note 55, at 689-95; McCarthy, *supra* note 55, at 293-95.

58. *Parham v. J.R.*, 442 U.S. 584, 602 (1979), quoted in Stanley N. Katz, *Legal History and Family History: The Child, the Family, and the State*, 21 B.C. L. REV. 1025, 1026 (1990).

reason that parents know the child best and will advocate the child's best interests. Deference to parents, however, is not due entirely to the assumption that parents love their children and act in their best interests. Courts also consider separate values of family privacy and parental autonomy, which may conflict with the child's best interests.⁵⁹

When parents are unavailable or have been disqualified from decisionmaking for their children, courts often apply a "substituted consent" or a "best interests" test. The concept of substituted consent is not particularly meaningful in the case of a very young child because it is difficult, if not impossible, to ascertain what the child would want if she were competent to make a medical decision. The disadvantage of the best interests test is its vagueness. The Hastings Center⁶⁰ has provided helpful guidelines for applying the "best interests of the child" test and for determining who should make treatment decisions for severely ill newborns:

1. Priority should be given to those most likely to advance the interest of the child.

59. The notion of parental autonomy has constitutional dimensions. In *Meyer v. Nebraska*, 262 U.S. 390, 400-01 (1923) and *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925), the Supreme Court stressed the importance of parental autonomy in decisions about education for their children. The Court, however, recognized that it must balance a countervailing state interest in the child's welfare. In *Prince v. Massachusetts*, 321 U.S. 158 (1944), for example, the Court held that a parent's religious principles could not overcome the state's interest in protecting a child's welfare where child labor was involved.

In the more recent case of *Wisconsin v. Yoder*, 406 U.S. 205 (1972), the Supreme Court upheld the right of Amish families to prevent their children from continuing with public education beyond eighth grade. Only the dissent in *Yoder* recognized that the child had a separate interest that the Court should recognize. *Id.* at 241 (Douglas, J., dissenting).

Recent cases involving minors and the right to an abortion have recognized a child's separate interest. In *Planned Parenthood v. Danforth*, 428 U.S. 52, 75 (1976), and *Bellotti v. Baird*, 443 U.S. 622 (1979), the Supreme Court recognized that a child has a privacy interest separate from her parents that must be considered in the abortion context. A "mature minor" is capable of making an informed decision about whether or not to have an abortion, and her privacy must be respected.

Another important concept in the Supreme Court abortion cases, including *Danforth* and *Bellotti*, is that a parent may not always make a decision in the child's best interests, and that this necessitates some review or involvement by some other authority figure. *Danforth*, 428 U.S. at 74; *Bellotti*, 443 U.S. at 647. In *Parham v. J.R.*, 442 U.S. at 606, 617, the Court found that Georgia's procedures for allowing a parent to commit a child to a psychiatric institute met due process standards, although the Court recognized the need for a check on parental authority. The Court found that review by the medical director to ascertain the necessity of committing a child to a psychiatric facility was sufficient review of parental decisionmaking. *Id.* at 613-17.

60. The Hastings Center, founded in 1969, is composed of individuals concerned with medical and professional ethics, including physicians, nurses, lawyers, administrators, public policymakers, and other academic and health care professionals. The Center conducts research and funds national and international fellowships. It publishes the *Hastings Center Report* and *IRB: A Review of Human Subjects Research* on a bi-monthly basis.

2. Those intimately involved in the day-to-day care of the child must have a major role in decision-making.

3. Someone knowledgeable about the child's medical problem and experienced in dealing with such problems should participate.

4. Finally, someone who is able to look at the facts comprehensively and impartially should also be involved in making the decision.⁶¹

The authors of the Hastings Report acknowledge that fulfilling all of these criteria will probably involve more than one or two persons. Although the authors recommend giving the child's parents primary decisionmaking authority, they recognize that parents often need the support of medical professionals when making difficult decisions.⁶²

IV. AN ALTERNATIVE MODEL OF DECISIONMAKING FOR HIV-POSITIVE CHILDREN IN FOSTER CARE

Alternative decisionmakers should attempt to replicate the positive aspects of parental consent and incorporate the criteria identified as essential by the Hastings Center. They should know the child well and act out of concern for the child. They should know about HIV and medical treatment options and review the child's progress frequently. They should maintain objectivity in determining what action is in the child's best interests. To properly consider experimental treatment for HIV-positive children without parents to advocate for them, decisionmakers also should be sensitive to the historic role of race and class bias in medical experimentation, a lesson learned from the Tuskegee syphilis study.

Finding any one person who embodies all these qualities may be impossible. Thus, I propose an alternative model: granting medical

61. *Imperiled Newborns*, HASTINGS CENTER REPORT, Dec. 1987, at 5, 17. The CWLA Task Force on Children and HIV Infection recognized the importance of multidisciplinary involvement with HIV-infected children. Coordination of social services and medical services is imperative for successful family foster care placement of HIV-infected children. Pediatric HIV infection is a complex disease that requires ongoing partnerships among the child welfare agencies, the health care system, the child, the foster family, and, ideally, the biological family to provide support and continuity of care. Agencies and foster parents, including kinship caregivers, need access to knowledgeable health care providers who can deliver quality care and answer their medical and health questions. The best interests of the child dictate that the goals and functions of the social service and health effort be congruent.

62. *Id.* at 17-19. Where the benefits of treatment for seriously ill newborns are unclear, the President's Commission for the Study of Ethical Problems in Medicine and the American Academy of Pediatrics recommends that infant ethics committees review treatment decisions. Many hospitals across the country use these committees to review treatment decisions for severely ill or disabled infants. *Id.* at 21.

guardianship of foster children to a small committee that combines all of these attributes. This group would include the foster parent caring for the child (if any),⁶³ a health care worker (pediatrician, nurse practitioner, physician's assistant) familiar with HIV infection in children, an HIV-infected individual, and a lay advocate from the child's community.⁶⁴

The foster parent would be intimately involved in caring for the child and could bring day-to-day familiarity with the child to the decisionmaking process. The foster parent would also be in the best position to monitor the child's health and well-being and to observe the impact on the child if the committee decided to enroll the child in a medical trial.

The health care worker would be knowledgeable about the child's medical problems and have experience in dealing with HIV disease. Because of a potential conflict of interest, the health care worker selected could not be involved in the medical research. Including a health care worker in the decisionmaking process is particularly important because many HIV-positive children do not have regular contact with a primary care physician, much less one who is knowledgeable about HIV.

An HIV-positive person could provide an important perspective for the committee on the experience of living with HIV disease and the acceptable level of risk when one is faced with a terminal illness. As the authors of the Hastings Report noted, the best interests of the child standard should not be based on the sensibilities of an unimpaired adult.⁶⁵ Rather, it should be based on the sensibilities of an HIV-positive person.

Finally, the lay advocate on the committee would be an individual from the child's community—ideally of a similar racial, class, and religious background—who could bring the values and concerns of the child's community to the decisionmaking process. The lay advocate would be someone experienced with young children, such as a parent, teacher, or day care worker. Involving a community member in decisionmaking would provide additional oversight of the clinical trials process, and would enhance communication and reduce distrust between the community and the medical researchers.

Although it may be controversial, involving the community in

63. If a child is living in a group home, a care provider from that home would take the place of a foster parent on the committee.

64. The lay advocate and the HIV-positive individual could be the same person in some instances.

65. *Imperiled Newborns*, *supra* note 61, at 15.

decisionmaking for HIV-positive children is a critically important part of this proposal. Almost half of all HIV-positive children do not live with their parents.⁶⁶ In many of these cases the parents are dead, in prison, or struggling with drug habits that make it impossible for them to care for their children. The state has already shown itself to be a poor parental substitute. Members of the child's community can help fill the parental role. They can bring the values of the child's community to the decisionmaking process, as the child's parents might have done. In addition to advocating for the individual child, these representatives could help alleviate race and class bias in drug trials with these children.

Poor, predominantly Black and Hispanic inner-city communities have a great interest in finding successful treatment for HIV infection. To date, these communities have not been sufficiently involved in the treatment research. Their informed involvement is essential to the success of this research. These communities and their children need vigorous advocates to keep them abreast of medical and research developments and make informed choices about the avenues to pursue. The gay community has successfully forced changes in research on terminal illnesses.⁶⁷ Similar community advocacy and involve-

66. In some cases, members of the child's extended family offer support when the parent dies or becomes incapacitated. Where an extended family member is caring for a child, the intervention by a committee as proposed here may be unwarranted. The strength of the extended family has long been an important feature of Black and Hispanic communities. The role of the neighborhood and community has also been an important feature, though one eroded in recent times. All of these structures should be supported and encouraged. Unfortunately, the extended family is often unable to help the child. Grandparents and other relatives frequently have difficulty obtaining the financial support they need to assist them in caring for an HIV-infected child. Their authority to make medical decisions for the child in the parent's absence is often unclear.

A study of a poor urban Black community in the late 1960's describes kinship networks typically involved in raising a child. Though these relationships are not legally authorized or recognized, they nevertheless play an important role in the child's life and well-being. CAROL B. STACK, *ALL OUR KIN: STRATEGIES FOR SURVIVAL IN A BLACK COMMUNITY* (1974). A similar kind of kinship network exists in the Native American community, which state authorities have not typically respected. Social workers would consider a child neglected or abandoned when a parent left a child with a relative outside of the nuclear family. H.R. REP. NO. 1386, 95th Cong., 2d Sess. 10 (1978), *reprinted in* 1978 U.S.C.A.N. 7530, 7532. However, in a Native American community, "there is no such thing as an abandoned child because when a child does have a need for parents for one reason or another, a relative or a friend will take that child in. It's the extended family concept." *Problems that American Indian Families Face in Raising Their Children and How These Problems Are Affected by Federal Action or Inaction: Hearings Before the Subcommittee on Indian Affairs of the Senate Committee on Interior and Insular Affairs*, 93d Cong., 2d Sess. 5, 473 (1974) (statement of Sen. Abovrezk).

67. Harold Edgar & David J. Rothman, *New Rules for New Drugs, the Challenge of AIDS to the Regulatory Process*, 68 *MILBANK Q.* 111, 122-24 (Supp. 1 1990). Gay advocates reacted with fury to the slow pace at which new therapies for HIV disease were being tested. They

ment would allow comparable progress for HIV-infected children.

Substantial authority exists for recognizing a community's interest in decisions affecting its children and appointing someone other than a parent to serve as a child's advocate.⁶⁸ The Indian Child Welfare Act of 1978 ("ICWA"), for example, provides that tribal courts have the ultimate authority to decide where to place Indian children domiciled on their reservations if they are removed from their parents or voluntarily relinquished for adoption.⁶⁹ Congress enacted the ICWA because of concerns that state authorities who were ignorant, or even contemptuous, of Native American culture and values were removing Native American children from their homes and placing them in white environments. The removal of these children threatened their tribal integrity and welfare.⁷⁰ In response, the Act placed authority for decisionmaking with tribal courts.⁷¹

In *Mississippi Band of Choctaw Indians v. Holyfield*,⁷² the United States Supreme Court reversed a Mississippi court decision permitting Native American parents to place their child for adoption with a white family off the reservation. Interpreting the ICWA, the Court stressed the Native American community's interest in deciding where to place children of the tribe.⁷³ The Court found that the parents' decisionmaking in this circumstance gives way to the statutory pro-

argued for a less paternalistic system where informed consumers could make their own choices. The FDA responded by taking steps to allow more widespread use and testing of new drugs. See Michael Specter, *Pressure from AIDS Activists Has Transformed Drug Testing*, WASH. POST, July 2, 1989, at A1.

68. 20 U.S.C. § 1415(b)(1)(B) (1988). The Individuals with Disabilities Education Act explicitly recognizes that situations will arise where a parent cannot act as an advocate for her child. The Act authorizes the appointment of a parent surrogate who can act on the child's behalf for educational decisions. This system has been criticized because the surrogate parent, appointed by the school board, may not be sufficiently independent to be a good advocate for the child. This suggests that creating committees to represent the interests of HIV-positive children is probably best done under the umbrella of an agency other than the foster care system or U.S. Department of Social Services, such as the states' department of health.

69. 25 U.S.C. 1911(a) (1988).

70. See H.R. REP. No. 1386, 95th Cong., 2d. Sess. 8-11 (1978), reprinted in 1978 U.S.C.C.A.N. 7530, 7530-33.

71. 25 U.S.C. § 1911 (1988).

72. 490 U.S. 30 (1988).

73. The Court quoted at length from *In re Adoption of Holloway*, 732 P.2d 962 (Utah 1986):

To the extent that [state] abandonment law operates to permit [the child's] mother to change [the child's] domicile as part of a scheme to facilitate his adoption by non-Indians while she remains a domiciliary of the reservations, it . . . weakens considerably the tribe's ability to assert its interest in its children. The protection of this tribal interest is at the core of the ICWA, which recognizes that the tribe has an interest in the child which is distinct from but on a parity with the interest of the parents.

Id. at 969, quoted in *Holyfield*, 490 U.S. at 52.

tection vesting these decisions with the tribal court.⁷⁴

The ICWA and *Holyfield* reflect several important concepts. They recognize the importance of a child's racial and cultural ties; decisions made by even a well-meaning white, middle class person rely on a different value system and may ultimately harm a child of a different background. They also acknowledge that sometimes a community's interest in its own survival overrides the birth parents' rights to determine their children's future. Finally, both the ICWA and *Holyfield* reflect an understanding by Congress and the Supreme Court that at times the community can make a decision more in harmony with the child's best interests than a parent would make.

My proposal to include community members in the decisionmaking process for HIV-positive children addresses concerns similar to those underlying the ICWA and *Holyfield*. The involvement of a community representative will help insure that racism and class bias, however subtle or inadvertent, do not negatively effect decisionmaking for the HIV-positive child. It is true here as well that the community has an interest in the welfare of its children and that it may act to protect that interest.

Admittedly, the analogy between this situation of HIV-infected children and Native Americans is imperfect. Native Americans, at least those living on reservations and subject to the jurisdiction of tribal courts, are a truly separate community in a way that Black and Hispanic communities are not. Yet concerns about the impact of racial and cultural bias on the vitality of a community are equally pressing in both settings. In addition, the notion that a community has the right and the responsibility to advocate on behalf of its least powerful members is valid in each context. However, in light of the differences between Black and Hispanic communities and the Native American tribes, I do not propose that the community could override a parent's decision, as the ICWA authorizes. Rather, the community should step in only when the parent consistently has failed to act.

In other situations, courts have recognized that parents may not always be in a position to protect their children's welfare. In *Ad Hoc Committee of Concerned Teachers v. Greenburgh #11 Union Free School District*,⁷⁵ the United States Court of Appeals for the Second Circuit allowed a teachers' committee to represent the interests of Black and Hispanic students in a challenge to the discriminatory hiring policy of their school. The case involved a residential public school with a majority of Black and Hispanic children. Their teach-

74. *Holyfield*, 490 U.S. at 51-53.

75. 873 F.2d 25 (1989).

ers, who were white, Black, and Hispanic, alleged that the school discriminated against people of color in hiring teachers and that this practice harmed the children.⁷⁶ Many of the children were in foster care placements, though three-fourths of them eventually returned to their families.⁷⁷ The court granted "next friend" status to this ad hoc teachers committee under Federal Rule of Civil Procedure 17,⁷⁸ finding that the teachers were best suited to represent the children's interest. The teachers had first-hand knowledge of the children's needs, their interest in representing the children apparently arose out of a good faith concern about the children's welfare, and they had no apparent conflict of interest with the children's concerns.⁷⁹ Finally, and perhaps most important, the court found that the teachers were the only group likely to attempt to vindicate the children's rights.⁸⁰

An analogy exists between the teachers committee in *Greenburg* and the committee proposed in this Article. A committee composed of the foster parent, an HIV-positive person, a health care worker, and a community representative would have first-hand knowledge of the child's needs, a good faith concern for the child's welfare, and also would be the only group likely to vindicate the child's right to seek medical care.

The role of the committee I propose differs from the teachers' committee in *Greenburgh*. The proposed committee would make medical decisions for individual children that would have a direct impact on their welfare. However, there are similar reasons for authorizing the committees. *Greenburgh* supports the notion that community members other than parents may play a role in asserting rights on behalf of children otherwise powerless to assert these rights themselves. The ultimate goal, both in *Greenburgh* and the committee proposed here, is to have a positive impact on the climate in which the children receive care.

Theoretically, a conflict of interest could arise between the community's welfare and the welfare of an individual HIV-positive child. The community arguably has an interest in getting as many children as possible into clinical trials to increase the pace of research, although it may not be in each child's best interests to be enrolled in a drug trial. There are three responses to this potential conflict. First, the community representative is only one of four people charged with

76. *Id.* at 27.

77. *Id.*

78. *Id.* at 30.

79. *Id.*

80. *Id.*

making this decision. Second, the committee's charge is to make a decision in the interest of an individual child only. Finally, HHS regulations provide children with some protection. The regulations allow foster children to be enrolled only in protocols with prospects of personal benefit to the child.⁸¹ Under the HHS regulations, a child can be enrolled in a study with no prospect of personal benefit only if the risk of the study is minor and an independent advocate, in addition to another individual acting as a guardian or in loco parentis, is appointed to protect the child's interest.⁸²

The committee's decisionmaking authority will increase as parental involvement decreases. In the situation where a child's placement in foster care is due to temporary inability of a parent to care for the child, and the parent maintains frequent and consistent contact with the child, there probably will be no need or justification for committee intervention. However, even in such a circumstance, the committee may be a valuable resource to assist the parent in decisionmaking. The child's parent could receive information from the foster parent on the committee about the child's day-to-day health and well-being, and could receive medical advice on HIV disease and the available treatment and protocol options from the health care worker on the committee. At the opposite end of the spectrum, where both parents have died or abandoned the child, the committee would have full authority and responsibility to act.⁸³

The most difficult situation arises where the state places a child in foster care because of neglect or abuse, and parental involvement is unpredictable and inconsistent. In this situation, the committee must still respect the parents' right to make decisions for the child.⁸⁴ However, when the parents' inaction deprives the child of potentially bene-

81. 45 C.F.R. 46.401-.409 (1990).

82. *Id.* § 46.409.

83. *See, e.g.*, MD. FAM. LAW CODE ANN. §§ 5-313 to -317 (1990).

84. Parents have an interest in their child distinct from consideration of the child's best interests. A court cannot terminate parental rights absent a showing of unfitness or abandonment. As the Supreme Court held in *Santosky v. Kramer*, 455 U.S. 745 (1982), natural parents do not lose their fundamental liberty interest in the care, custody, and management of their children because they have not been model parents or have temporarily lost custody to the state.

Nevertheless, parents cannot exercise their rights in a manner that would endanger the lives of their children. In cases where a parent's religious beliefs would prevent a life saving blood transfusion to a minor, courts have ordered the transfusion for the child. *Jehovah's Witnesses in the Washington v. Kings County Hosp.*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd*, 390 U.S. 598 (1968). The state can also override a parent's wishes when public health is at issue. For example, most states require that children be immunized before attending public schools. In *Jacobson v. Massachusetts*, 197 U.S. 11 (1905), the Supreme Court recognized the police power of the state to require immunizations, though it noted that exemptions for medical reasons might be appropriate.

ficial medical treatment, the committee would have the right to act. One of the primary justifications for deferring to the parents in medical decisionmaking is the assumption that they are in close contact with the child and know the situation well. Where parents no longer have consistent contact with the child, they may not have the knowledge to make appropriate decisions for the child. Though courts typically defer to parental decisions on medical issues, where the child's life is endangered, courts have intervened.⁸⁵

In situations where parents' failure to respond to attempts to contact them would result in an inability to deliver appropriate medical care to the child, the committee would be authorized to act.⁸⁶ Such action could include consenting to enrollment in a clinical trial, but only when this option holds the best hope for treatment for the child, and the risks and potential side effects do not outweigh the potential benefit to the child. The goal is not to create an adversarial situation between the parent and the committee, or to override parental decisionmaking, but simply to ensure that someone makes timely decisions about the child's medical treatment.⁸⁷

85. In one case, the parents of a child suffering from leukemia refused to continue the child's chemotherapy treatment, opting instead for an experimental treatment of questionable value. The court intervened and ordered continued chemotherapy. *Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978), *aff'd on reh'g*, 393 N.E.2d 396 (1979). The court found that chemotherapy had a 50% chance of prolonging the child's life for at least five years. *Id.* at 1057. In a New York case around the same time, the parents presented medical testimony supporting their use of alternative treatments. *In re Hofbauer*, 411 N.Y.S.2d 416 (App. Div. 1978), *aff'd*, 393 N.E.2d 1009 (N.Y. 1979). The court allowed the parents to continue this alternative treatment with the caveat that if the child's condition worsened, they must use traditional treatment. *Id.* These cases appear to depend substantially on the parent's ability to bring a persuasive medical expert to support their treatment choices. See Karen H. Rothenberg, *Medical Decisionmaking for Children*, 1 BIOLAW § 8-2.4(d), at 155 (James F. Childress et al. eds., 1989).

86. A question could be raised as to whether the state can simply outline by regulation when committee decisionmaking is authorized or whether a court must authorize such intervention on a case by case basis. I would argue that regulations could authorize the committee to act after it has made substantial efforts to contact the parent (including phone calls, letters and visits to the parent's last known address) without success over a period of three months (or a shorter period if mandated by the child's health status). The committee would notify the parent in writing of its intention to assert decisionmaking authority and the parents would have the right to a hearing to challenge this assertion. However, the burden should be on the parent to initiate this proceeding.

87. As someone who often represents HIV-positive parents in proceedings where the state seeks to remove their children for alleged neglect, I do not intend to advocate further erosion of these parents' rights and involvement in decisionmaking for their children. I am also concerned that the alleged neglect becomes a self-fulfilling prophecy once the child is removed from his parent. The United States Department of Social Services often does little to encourage parental visits, and may inadvertently frustrate these visits. For example, HIV-positive children in Baltimore, Maryland, are sometimes placed in a group home in Harford County, making visits with the parent difficult if not impossible. In addition, some social workers appear to believe that where a parent is HIV-positive, death is imminent, and

The proposed committee would consist of volunteers⁸⁸ appointed and trained by the state health department. A committee independent of the Department of Social Services is more likely to develop a trusting relationship with family members who wish to be involved.⁸⁹ The committee would meet as often as needed, depending on the child's status. Each committee could make decisions for more than one child.

The committee's objective would be to keep informed about the options available to the child and to make medical decisions in the child's interest, including enrollment in experimental drug trials, when appropriate. The committee would weigh the potential benefits of a drug trial against the burdens, including possible side effects, additional doctor visits, and possible discomfort resulting from medical procedures. The committee would consider the impact of all these factors on the particular child and would consult with the child to the degree possible, given the child's age and maturity. The committee also would compare the relative benefits and burdens of a clinical trial to any established treatment available to the child. The committee might also consider, just as a parent might, the potential benefit of the child's participation in a drug trial to the progress of medical research. Of course, the committee's primary concern at all times would be the best interests of the child.⁹⁰

reunification or consistent contact is unimportant. In fact, a person who is simply HIV-positive has a substantial life expectancy. Even where the parent is ill, perhaps dying, it is in the child's interest to maintain as much contact with the parent as possible.

To address these concerns, I suggest that when the state places an HIV-positive child in foster care, it should immediately appoint a committee to work with the parent in medical decisionmaking. The parent would not have to accept the committee's input. But the parent would be informed of the committee's right to step in and make decisions in the event that a parent fails to maintain contact with the child, and the committee, after reasonable attempts, cannot reach the parent.

88. The provision of some compensation to committee members obviously would make recruiting volunteers easier. At the least, the state should provide reimbursement of expenses and provisions for day care for committee members' children.

89. The best time to assign a committee to an HIV-positive child is upon the family's first contact with local child protective services. The committee could work with parents to help them understand HIV disease and the range of treatment available. The committee would not override the parent's decisions, but would make decisions with the parent or in the parent's absence.

Families with HIV infection often come to the attention of Protective Services because of a report by a medical provider concerned that an HIV-positive child is not getting appropriate care due to missed medical appointments. Appointing a committee to work with the parent could prevent the child's removal in the first instance, which would be the most desirable result.

90. It would not be appropriate for the proposed committee to authorize a child's enrollment in a trial which held no potential benefit to the individual child. At least one commentator has questioned whether even a parent has the right to make this decision for his

In promulgating regulations to protect research subjects, the Department of Health and Human Services has recognized that where a child is a ward of the state, simply allowing the child's guardian to make decisions may not sufficiently protect the child. In particular, when enrolling a child in an experimental trial that involves a substantial risk or does not hold out the prospect of direct benefit to the individual child, HHS regulations require appointment of an advocate for each child, in addition to another person acting as guardian or in loco parentis.⁹¹ The advocate must be someone who has the background and experience to act in the child's best interests. This person also must agree to act in the child's best interests for the duration of the child's participation in the research and must not be associated with the research of the guardian organization.⁹²

V. CONCLUSION

HIV-positive children in foster care need advocates who will work to see that they receive the best medical care available. In many cases this may involve consenting to enroll a child in an experimental drug trial, which will have the added benefit of enhancing the search for effective treatment of HIV disease in all children. Because many HIV-positive children are without families to effectively advocate for them, we must create a new structure for advocacy and decisionmak-

child, despite authorization by HHS regulations. See, e.g., Robert E. Cooke, *Clinical Research on Children*, in ISSUES IN RESEARCH WITH HUMAN SUBJECTS 109 (1980).

The ethical issues raised by the use of prisoners and the poor seem simple when compared to the problems involved in the use of children and other non-competents. In order to develop certain kinds of drugs or procedures we can do all the animal and adult testing we want and still we must finally test on children—i.e., a test group who by definition cannot give informed consent. Paul Ramsey has argued that no one, parent or guardian, even with the best intentions has the moral status to consent for a child to be made the subject of medical investigation solely for the accumulation of knowledge (except when epidemic conditions prevail). To quote: "Where there is no possible relation to the child's recovery, a child is not to be made a mere object in medical experimentation for the good to come." If it is objected that this severely restricts possible advances in childhood medicine, Ramsey argues that the moral progress of the race is more important than the scientific. Thus, testing of children is the paradigm instance that at times it may be necessary to choose between morality and knowledge even though we normally assume that we do not have to choose between them.

Id. at 109 (quoting Stanley Hauerwas, *Must a Patient Be a "Person" to Be a Patient: Or My Uncle Charlie Is Not Much of a Person but He is Still My Uncle Charlie*, 39 CONN. MED. 815, 815-17 (1975)).

91. 45 C.F.R. § 46.409 (1990).

92. *Id.*

ing. Involving members of the child's community as advocates is the alternative most likely to result in responsible and sensitive decisionmaking.