

## AN HIV ADVOCATE'S VIEW OF FAMILY COURT: LESSONS FROM A BROKEN SYSTEM

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### I. INTRODUCTION

Around the time I began working with HIV-positive clients,<sup>1</sup> a discussion was brewing about the potential for HIV-based discrimination in child custody and visitation cases. Several courts recently had evaluated the role of a parent's HIV status in custody and visitation cases and had held that HIV should not be the sole basis for a custody or visitation determination.<sup>2</sup> A number of law review articles also had been written on the topic<sup>3</sup> reviewing existing case law that had held that it is impermissible for a court to rely on a parent's disability as *prima facie* evidence of parental unfitness or harm to the child.<sup>4</sup> One article called upon courts to refrain from following a per se rule that a parent is unfit on the basis of HIV alone and to ensure that the paramount concern is the child's welfare.<sup>5</sup> Af-

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1. In 1989, South Brooklyn Legal Services founded the HIV Project ("the Project"), one of the first programs in the country dedicated to providing HIV-specific legal services to the low income community. The author founded the project and was the director until October 1996.

2. See, e.g., *Stewart v. Stewart*, 521 N.E.2d 956, 965 (Ind. Ct. App. 1988) (reversing the lower court's determination, which had found that a father's HIV infection was a sufficient reason to deny visits, as "extreme and unwarranted"); *Anne D. v. Raymond D.*, 528 N.Y.S.2d 775 (N.Y. Sup. Ct. 1988) (denying a motion for involuntary HIV testing on grounds that an unsubstantiated allegation of extra-marital affairs is not sufficiently egregious under equitable distribution to constitute an exception to the discovery rule); *Doe v. Roe*, 526 N.Y.S.2d 718 (N.Y. Sup. Ct. 1988) (denying motion for involuntary HIV testing of a father on the grounds that the plaintiffs failed to show compelling need for disclosure and because the father's HIV status would not determine visitation rights); *Jane W. v. John W.*, 519 N.Y.S.2d 603 (N.Y. Sup. Ct. 1987) (granting a father's motion for visitation even though he had AIDS because he was able to care for the child).

3. See, e.g., Aline Cole Barrett & Michelle Flint, *The Effect of AIDS on Child Custody Determinations*, 23 GONZ. L. REV. 167 (1987); Amy R. Pearce, *Visitation Rights of an AIDS Infected Parent*, 27 J. FAM. L. 715 (1988); Nancy B. Mahon, Note, *Public Hysteria, Private Conflict: Child Custody and Visitation Disputes Involving an HIV Infected Parent*, 63 N.Y.U. L. REV. 1092 (1988).

4. See, e.g., *In re Marriage of Carney*, 598 P.2d 36, 42 (Cal. App.1979) (holding that denial of custody on the basis of a parent's disability went against public policy embodied in state law protecting the disabled). For additional cases following *Carney*, see JOHN P. MCCAHEY ET AL., *CHILD CUSTODY VISITATION LAW AND PRACTICE* §§ 10-2[01]-10-2[11] (1997); Mahon, *supra* note 3, at 1125-28.

5. See Mahon, *supra* note 3, at 1138-41.

ter reviewing these cases and articles, I felt optimistic about representing HIV-positive parents in Family Court—until I entered the court room.

Denise,<sup>6</sup> the first HIV-positive woman I represented in Family Court, came to my office trying to regain custody of her daughter, Michelle, who was thirteen years old. While Denise had been hospitalized for many months with severe pneumonia, her daughter had been living with her paternal grandmother. Denise also had suffered from a psychotic episode due to HIV-related dementia,<sup>7</sup> which now was under control. It took Denise several months after being discharged from the hospital to regain the strength to get her daughter back. Unfortunately, the grandmother then refused to return Michelle to Denise and was allowing Denise to see her only a few hours a week.

We immediately filed a custody proceeding against the paternal grandmother. I felt confident about the merits of Denise's case, as biological parents have the presumptive right to custody of their children over non-parents.<sup>8</sup> We also had compelling facts on our side. Denise's HIV illness, although advanced, did not interfere with her ability to care for her daughter. She had a case manager and a home attendant twelve hours a day, and she was entitled to "homemaking" services.<sup>9</sup> Denise was seeing a therapist weekly to help her cope with her illness. She lived in the same apartment building as her sister, who had children of her own and was very involved in Denise's care. Denise's sister came to every court date, and reiterated her willingness to help care for Michelle.

I was sure these facts would help Denise in court; instead, they were used against her. The fact that she had a home attendant, case manager, and therapist were relied on by the opposing counsel as proof that she was too sick to care for her daughter. The reality that Denise was becoming increasingly ill meant that Michelle should be kept away from, and not permitted to spend more time with, her mother. When I argued in court that no judge would remove a child from a mother dying of cancer, the judge told me that AIDS is not like cancer. The judge ordered mental health examinations of the parties, which is a common court practice before making a final determination. The judge, however, refused to increase visitation before these exams were completed, even though Denise was visiting her daughter for only a couple of hours each week. I represented

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6. The first name of the client has been changed to protect her and her family's confidentiality. Each of the clients discussed in this Article are clients who were represented by South Brooklyn Legal Service's HIV Project.

7. AIDS dementia is believed to be caused by HIV attacking the brain and usually occurs at later stages of illness, causing changes in a person's mental ability, attitude, and muscle control. See JOHN G. BARTLETT ET AL., *LIVING WITH HIV INFECTION* 154 (1991).

8. The majority of jurisdictions employ the "parental preference" standard in evaluating the claims of non-parents against parents. See MCCAHEY ET AL., *supra* note 4, § 11.3-4. A biological parent has a right to custody of the children over all other parties except in "extraordinary circumstances," such as abandonment, unfitness, persistent neglect, or extended disruption of custody. See *Bennett v. Jeffries*, 356 N.E.2d 277, 280 (N.Y. 1970); see also *Petition of Doe*, 638 N.E.2d 181 (Ill. 1994); *Stuhr v. Stuhr*, 481 N.W.2d 212 (Neb. 1992).

9. A "homemaker" helps a parent care for the child. HIV-infected parents are eligible for preventive services if their condition impairs their ability to care for their children and places the children at risk of foster care placement. See N.Y. COMP. CODES R. & REGS. tit. 18, § 430.9(c)(4) (1997). Preventive services include homemaking services. See N.Y. COMP. CODES R. & REGS. tit. 18, §§ 423.2, .4 (1997).

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Denise in court for almost a year. The stress of the ongoing court proceeding and the constant setbacks we encountered were more than she could bear. She began to give up and stopped taking care of herself; her health deteriorated gradually. Before her death, she and her daughter never visited for more than a couple of hours each week.

Years later, I have a better understanding of the factors at work in Denise's case. The judicial response we witnessed was more than a fear of illness and death. It also reflected the judge's belief that she somehow could protect Michelle from these certainties. The judge also was struggling with an arduous task—how to evaluate the impact of a parent's fluctuating and unpredictable illness on a child. I have learned that many of the obstacles we faced are very much a part of the Family Court process in New York City. The judge's reluctance to deal with an emotionally-charged issue, her failure to examine the facts of the case in light of the appropriate legal standard, and the endless delays are all endemic to the system. These factors are the product of a court handling an extremely high volume of cases in overcrowded and stressful conditions. The Family Court is burdened further because it handles cases primarily of poor people who have few resources and many needs.<sup>10</sup> These elements create enormous barriers to HIV-positive litigants seeking resolution of their disputes.

Since representing Denise, I have advocated for hundreds of HIV-positive parents in Family Court. Most of these clients were women of color, and all of them were poor. Since then, several additional Family Court decisions have held that HIV should not be the sole basis for custody or visitation determinations.<sup>11</sup> While these cases are helpful, they do little to alleviate the real obstacles that HIV litigants face in the courtroom. In reviewing the published court decisions concerning HIV and parental relationships,<sup>12</sup> there is a great disparity between what the law says and what often occurs in the courtroom. There are powerful fears and assumptions at work in court that obliterate the effectiveness of laws prohibiting discrimination on the basis of disability. Fears include exposing children to illness and death, as well as intense prejudice against both individuals

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10. See THE FUND FOR MODERN COURTS, THE GOOD, THE BAD, AND THE UGLY OF NEW YORK CITY FAMILY COURT: A CITIZEN COURT MONITORS' ASSESSMENT OF THE COURT AND RECOMMENDATIONS FOR IMPROVEMENT 1 (1997) [hereinafter THE FUND FOR MODERN COURTS].

11. See, e.g., *Newton v. Riley*, 899 S.W.2d 509 (Ky. Ct. App. 1995) (upholding the lower court's denial of a motion to modify custody order based on mother living with HIV-positive husband); *Sherman v. Sherman*, No. 01-A-01-9304-CH00188, 1994 WL 649148 (Tenn. Ct. App. Nov. 18, 1994) (upholding the lower court's denial of a mother's motion to restrict visits of a father who lived with an HIV-positive brother, and overturning the lower court's decision that required the father to submit to periodic HIV testing and that restricted his children from sleeping in his home); *Steven L. v. Dawn J.*, 561 N.Y.S.2d 322 (N.Y. Fam. Ct. 1990) (denying a motion to modify a custody order on the grounds that HIV status is not a "material change in circumstances"); see also *DSCYF/DFS v. Bryant*, No. 95-08-07T, 1996 WL 436439 (Del. Fam. Ct. May 30, 1996) (holding that a mother and child's HIV status do not justify termination of parental rights). *But cf. H.J.B. v. P.W.*, 628 So. 2d 753 (Ala. Civ. App. 1993) (upholding the lower court's ruling that an HIV-positive father's health and lifestyle, coupled with two recent moves, constituted a material changed circumstance warranting a change in custody).

12. See *supra* notes 2 and 11.

with substance abuse histories and those who are gay or lesbian.<sup>13</sup> Most legal scholarship on HIV and custody determinations is based primarily on reported cases. Since most Family Court cases do not result in written decisions, the reported cases are not an accurate indicator of how custody disputes actually are resolved. Moreover, neither the published cases nor the law review articles consider HIV-related issues in court cases that involve foster care.<sup>14</sup> In this setting, the prejudices and assumptions about HIV, poverty, and substance abuse are even more powerful, and, as a result, parents and their children often are treated unfairly.

This Article examines the difficulties that HIV-positive litigants, most of whom are poor women of color, face in the court process, how laws prohibiting HIV-related discrimination fail to help them, and how the court process often obstructs their relationships with their children. Part II discusses the demographics of the current HIV epidemic and the impact of these changed demographics on HIV-related custody determinations. The significance of the increasing impact of the epidemic on women and children is highlighted because women tend to be the caretakers of children when the children are raised by a single parent.<sup>15</sup> Part III examines the laws prohibiting disability-based discrimination. Part IV looks briefly at the cases that address disability in the context of custody and visitation determinations and focuses on cases involving an HIV-infected parent. Part V explores the barriers that HIV-infected parents face in the Family Court process in New York. Part VI discusses how a court's consideration of seemingly neutral factors often results in discriminatory rulings. Part VII considers the improvements in the health status of people with HIV in the context of HIV-related custody cases, and Part VIII concludes by making recommendations for HIV legal advocates in light of these health advances.

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13. The stigma associated with HIV is based on the perception that those most affected by the disease are gay men and individuals with a history of intravenous drug use. Since this Article derives from the author's experience as a practitioner, it addresses only discrimination against individuals with substance abuse histories. Although some of the author's clients were gay or lesbian, this fact rarely was raised in court. While this Article does not explore this issue in detail, there is a strong connection between HIV-related discrimination and prejudice against gays and lesbians. In fact, in the reported decisions, prejudices against individuals based on their sexual orientation or their substance use histories is much more candid and vociferous than is the articulated discrimination based on HIV status. See Taunya Lovell Bank, *Reproduction and Parenting*, in AIDS LAW TODAY: A NEW GUIDE FOR THE PUBLIC 216, 229 (Scott Burris et al. eds., 1993) (discussing the influence drug use has in labeling a mother a "bad mother," a sentiment that often is reflected in judicial decisions about custody); Donna I. Dennis, *HIV Screening & Discrimination: The Federal Example*, in AIDS LAW TODAY, *supra*, at 187, 206-08 (reporting that discrimination against gay people has influenced federal court decisions in a variety of arenas).

14. There is only one reported case examining HIV in the context of foster care. See *John T. v. Carraher*, 538 N.W.2d 761, 772-73 (Neb. Ct. App. 1995) (holding that the Department of Social Services could not remove a child from his foster home because his foster mother was HIV-positive). As of January 1998, there are no reported cases discussing the HIV status of a biological parent seeking the return of a child from foster care.

15. The HIV Project, however, assists many HIV-infected fathers seeking custody or visitation of their children in Family Court, many of whom have overcome histories of substance abuse.

## II. OVERVIEW OF HIV AND FAMILY LAW ISSUES

The HIV epidemic has shifted dramatically in the past ten years as a result of the marked increase in HIV infection rates among women, people of color, and IV drug users. Women now represent almost one-fifth of the AIDS cases in the United States,<sup>16</sup> a proportion that has doubled since 1990.<sup>17</sup> AIDS is the third leading cause of death for women between twenty-five and forty-four years of age, and is the leading cause of death for African-American women between the ages of fifteen and forty-four.<sup>18</sup>

The borough of Brooklyn has the highest concentration of women with HIV infection in New York City; as of March 1997, 6335 women in Brooklyn had been diagnosed with AIDS, more than one-third of the total number of women diagnosed in New York City.<sup>19</sup> The HIV Project at South Brooklyn Legal Services ("the Project") represents almost 1000 people each year who reflect the cultural diversity of Brooklyn. The majority of the clients are women who come from many different ethnic backgrounds, including Latinas, African-Americans, recent African immigrants, Haitians, and other Caribbean-Americans.

In examining the impact of the shifting HIV epidemic on families, the powerful relationship between HIV and drug use cannot be ignored.<sup>20</sup> Intravenous ("IV") drug use, through the sharing of infected or "dirty" needles, is one of the primary modes of HIV transmission; nationwide, more than one-third of all diagnosed AIDS cases are related to injection drug use.<sup>21</sup> Many women who do not use drugs themselves contract HIV through sexual contact with an IV drug user.<sup>22</sup> In addition, many HIV-positive women who contracted HIV hetero-

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16. See Centers for Disease Control & Prevention, U.S. Dep't of Health & Human Servs., *Update: Trends in AIDS Incidence—United States, 1996*, 46 MORBIDITY & MORTALITY WKLY. REP. 861, 865 tbl.3 (1997) (noting that women account for 44,440 of the 235,470 people living with AIDS in the United States).

17. In 1990, less than one-tenth of the reported adult AIDS cases were women. See Tedd V. Ellerbrock et al., *Epidemiology of Women with AIDS in the United States, 1981 through 1990*, 265 JAMA 2972 (1991).

18. See Leslie Hanna, *Recent News About Women & HIV*, BETA, Mar. 1997, at 18, 18.

19. See NEW YORK CITY DEP'T OF HEALTH, AIDS NEW YORK CITY, AIDS SURVEILLANCE UPDATE: FIRST QUARTER 1997 12 tbl.16 (1997) [hereinafter AIDS SURVEILLANCE UPDATE—NEW YORK CITY]. The number of women who are HIV-infected is much larger. See CENTERS FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T OF HEALTH & HUMAN SERVS., NO. 2, HIV/AIDS SURVEILLANCE REPORT 5, 35 tbl.27 (1996). HIV infection data is not kept presently by New York or the Centers for Disease Control and Prevention, except for the 29 states that require HIV case surveillance of adults and children. See *id.* at 35 tbl.27; see also CENTERS FOR DISEASE CONTROL & PREVENTION (CDC) & COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS (CSTE), CONSULTATION ON THE FUTURE OF HIV/AIDS SURVEILLANCE, Attachment III (1997) (on file with the *Duke Journal of Gender Law & Policy*).

20. See J. F. Havens et al., *Mental Health Issues in HIV-Affected Women and Children*, 8 INT'L REV. PSYCHIATRY 217, 217-25 (1996) (discussing the prevalence of HIV illness in families struggling with substance abuse); Ann B. Williams & Patrick G. O'Connor, *Substance Abuse Issues, in PRIMARY CARE OF WOMEN AND CHILDREN WITH HIV INFECTION: A MULTIDISCIPLINARY APPROACH* 217, 217-38 (Patricia Kelly et al. eds., 1995).

21. See Centers for Disease Control & Prevention, *supra* note 16, at 865 tbl.3.

22. See Havens et al., *supra* note 20, at 217-18.

sexually also have current or past histories of crack or other substance abuse.<sup>23</sup> The impact of substance abuse on family relationships is profound,<sup>24</sup> and is at the heart of many of the custody and visitation disputes described in this Article.

As a result of this expanding HIV epidemic, more children and family relationships have been affected than could have been imagined fifteen years ago.<sup>25</sup> Not only are the numbers of HIV-infected women rising, but seventy percent of these women are in their reproductive years.<sup>26</sup> At least one study has attempted to demonstrate the profound impact on families by projecting the number of children who may be orphaned by AIDS;<sup>27</sup> it has been estimated that between 72,000 and 125,000 children will lose their mothers to AIDS by the year 2000.<sup>28</sup> In New York City, the number of children expected to be orphaned as a result of AIDS is expected to reach between 29,000 and 34,000 by the year 2000.<sup>29</sup>

The increasing number of HIV-positive women with children, the connection between HIV transmission and drug abuse, and the powerful role of Family Court and child welfare agencies in the lives of poor people have all led to the increased presence of HIV-related issues, either directly or indirectly, in the context of custody and foster-care cases. Since the mid-1980s there have been numerous articles published addressing these issues,<sup>30</sup> and legal services offices in high incidence areas, like Brooklyn, have been inundated with requests for representation by HIV-positive individuals.

This Article focuses on the types of cases most prevalent in the Project's practice, including custody, guardianship, visitation, and foster care cases, which are litigated primarily in Family Court. New York State Family Court was cre-

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23. See Williams & O'Connor, *supra* note 20, at 218; cf. Brian R. Edlin, *Intersecting Epidemics—Crack Cocaine Use and HIV Infection Among Inner-City Young Adults*, 331 NEW ENG. J. MED. 1422, 1425-27 (1994) (finding that poor urban youths who smoke crack cocaine are at high risk for contracting HIV).

24. See Havens et al., *supra* note 20, at 218-19.

25. See generally David Michaels & Carol Levine, *The Youngest Survivors: Estimates of the Number of Motherless Youth Orphaned by AIDS in New York City*, in A DEATH IN THE FAMILY: ORPHANS OF THE HIV EPIDEMIC 3, 3-12 (Carol Levine ed., 1993) (finding that American children increasingly are being orphaned by the epidemic); Wendy Nehring, *Family and Living Issues for HIV-Infected Children*, in WOMEN, CHILDREN, & HIV/AIDS 211, 211-27 (Felissa L. Cohen & Jerry D. Durham eds., 1993).

26. See COMMISSION ON WOMEN'S HEALTH, SELECTED FACTS ON U.S. WOMEN'S HEALTH: A CHARTBOOK 22, 27 (Mar. 1997).

27. See Michaels & Levine, *supra* note 25, at 6-11.

28. See *id.* at 9.

29. See *id.* In New York City, 9300 children were orphaned as a result of AIDS through 1992, and it is estimated that 30,000 will be orphaned by 2000. See *id.* at 6.

30. See Lenette Azzi-Lessing & Lenore J. Olsen, *Substance Abuse—Affected Families in the Child Welfare System: New Challenges, New Alliances*, 41 SOCIAL WORK 15, 17 (1996); Elizabeth B. Cooper, *HIV-Infected Parents and the Law: Issues of Custody, Visitation and Guardianship*, in AIDS AGENDA: EMERGING ISSUES IN CIVIL RIGHTS 69, 69-117 (Nan D. Hunter & William B. Rubenstein eds., 1992) (discussing the challenges HIV-positive parents face with respect to custody, visitation, and planning for their children); Abigail English, *The HIV-AIDS Epidemic and the Child Welfare System: Protecting the Rights of Infants, Young Children, and Adolescents*, 77 IOWA L. REV. 1509, 1509-60 (1992) (examining discrimination issues in child welfare context for children and adolescents with HIV infection); Robert D. Zaslow, *Child Custody, Visitation, and the HIV Virus: Revisiting the Best Interests Doctrine to Ensure Impartial Parental Rights Determinations for HIV-Infected Parents*, 3 J. PHARMACY & L. 58 (1994) (offering an historical view of child custody law and the impact that a parent's HIV status has on custody decisions made by courts).

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ated to integrate the handling of the most pressing family problems. The court has jurisdiction over, *inter alia*, the following proceedings: child custody and visitation, child protection, family offense (domestic violence), juvenile delinquency, paternity, and child support. In 1996, there were 228,921 cases filed in Family Court in New York City alone.<sup>31</sup>

The majority of the reported cases involving HIV concern custody disputes between two parents.<sup>32</sup> The legal standard that governs these disputes is the "best interests of the child" standard,<sup>33</sup> under which the judge weighs a variety of factors to determine which outcome is in the child's best interests.<sup>34</sup> The Project's general policy is to decline representation of a parent in a custody dispute against another parent.<sup>35</sup> One exception to this policy is a case in which a party's HIV infection is raised by the opposing party as a basis for custody or denial of visitation. In such cases, the Project's HIV-related expertise and affiliations with HIV social service agencies can make a difference by ensuring that the court has the appropriate information about HIV and that the client has access to needed services. The Project also is more likely to take the case of a parent where the parent has had custody for a long period of time and HIV is the primary motivation for the other parent to seek a change of custody.

As a result of the policy against representing parents against parents, the Project generally represents parents against non-parents in custody cases. In these cases, the court is supposed to use a standard favoring the parent.<sup>36</sup> The

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31. See Joe Sexton, *Opening the Doors on Family Court's Secrets*, N.Y. TIMES, Sept. 13, 1997, at A1.

32. See *supra* note 11 and accompanying text.

33. In general, custody disputes between two parents involve the "best interests" standard. See MCCAHEY ET AL., *supra* note 4, § 10.02. When a parent seeks to change a custody determination, most states place the burden upon the parent seeking to change custody to show that there has been a material change of circumstances that affects the best interests of the child. See Mahon, *supra* note 3, at 1116. In *Steven L. v. Dawn J.*, the court found that to modify custody, the movant must show that the mother's HIV status "poses a danger to the child." 561 N.Y.S.2d 322, 324 (N.Y. Fam. Ct. 1990). This Article will not describe in detail the legal standards used in custody and visitation disputes since they are described elsewhere. See Mahon, *supra* note 3, at 1109-20 (summarizing the legal standards for original custody and visitation decrees, as well as for the modifications of these orders); Barrett & Flint, *supra* note 3, at 171-74.

34. Every jurisdiction provides some statutory directive about which factors courts should consider in disputed custody cases. See MCCAHEY ET AL., *supra* note 4, § 10.02. The Uniform Marriage and Divorce Act identifies several factors for courts to consider: 1) the wishes of the parents; 2) the wishes of the child; 3) the relationship between the child and his or her parent or parents, siblings, and any other person who may significantly affect the child's best interest; 4) the child's adjustment to home, school, and community; and 5) the mental and physical health of all individuals involved. See Uniform Marriage and Divorce Act § 402, 9A U.L.A. 561 (1987).

35. The rationale for declining representation in cases involving a parent against another parent is that each parent has equal rights to the child. These cases leave the most room for discretion and require extensive litigation involving a wide range of factors. Like most Legal Services offices, the HIV Project has extremely limited resources and rarely can meet the demand for services. See Charles R. Coregs, *Who will Offer Legal Services to County's Poor?*, HOUSTON CHRON., Apr. 30, 1996, at 19A; *Legal Services Survives, Barely*, N.Y. TIMES, May 6, 1996, at A14; Kathy Rohatson, *Legal Aid Feels Pain of Budget Cuts*, BUS. J., Apr. 8, 1996, at 19. As a result of inadequate resources, these offices are forced to make very difficult choices about whom to represent.

36. See Mahon, *supra* note 3, at 1116-19. As this Article explains, however, the appropriate legal standard in a particular case often makes little difference in the outcome of the case. See discussion *infra* Part V.

Project also represents many HIV-positive parents against parents or other custodians seeking visitation rights with their children.<sup>37</sup>

The Project's representation in foster care cases usually involves helping a parent who is seeking the return of a child from foster care. The Project either will defend the parent against the city's petition to extend foster care placement or will file a petition to terminate placement. The Project also helps parents obtain increased visitation while their children are in foster care. More rarely, the Project helps clients to defend petitions to terminate their parental rights, or to vacate orders terminating, or agreements surrendering, parental rights. The Project also assists clients in custody planning.<sup>38</sup> Although this Article will not discuss custody planning in detail, developing a plan for the future of the children is very much a part of each Family Court case.

### III. USING DISABILITY ANTI-DISCRIMINATION LAW IN FAMILY COURT

The paramount challenge in Family Court is to ensure that judges do not act on the basis of presumption or bias, but rather make decisions based upon the appropriate facts. The public policy behind disability anti-discrimination laws can aid attorneys in educating judges about the importance of making decisions based on individual assessments instead of on general assumptions about disabilities. This Part does not try to argue that Family Court judges are bound by these laws. Rather, these laws should serve as the underpinning for evolving legal standards concerning HIV-related custody disputes. As this Part concludes, the use of anti-discrimination law in Family Court is circumscribed by established legal standards that exist in family law,<sup>39</sup> and because anti-discrimination laws were not intended for use in Family Court.<sup>40</sup> Even in the face of these limitations, however, these laws serve as important tools for lawyers to confront biases based on disability in Family Court.

Since the beginning of the HIV epidemic in the early 1980s, HIV-infected persons have suffered from discrimination because of the stigma associated with HIV.<sup>41</sup> In an effort to fight such discrimination, HIV-infected individuals and

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37. A non-custodial parent is entitled to reasonable visitation rights unless a court finds that visitation would seriously endanger the child's physical, mental, moral, or emotional health. See Uniform Marriage and Divorce Act § 407, 9A U.L.A. 612 (1987).

38. Permanency planning programs help parents to consider their available options, discuss plans with family members, record their decisions in legal documents, and do everything possible to ensure that the plans are implemented after their death or incapacity. See Cooper, *supra* note 30, at 81-95.

39. See *supra* notes 8, 33, and 37 and accompanying text.

40. For an overview of disability-based discrimination laws, see Arthur S. Leonard, *Discrimination*, in AIDS LAW TODAY, *supra* note 13, at 297, 297-318 (Scott Burris et al. eds., 1993). As discussed in this Part, federal and state anti-discrimination laws were designed to combat discrimination in employment, housing, and public accommodations, and by public entities.

41. Because of the stigma associated with HIV, some states, including New York, have passed statutes providing for strong confidentiality protections of HIV-related information. See, e.g., N.Y. PUB. HEALTH LAW § 2782 (McKinney 1993 & Supp. 1997-1998); see also Sallie Perryman, *Family Concerns About Confidentiality and Disclosure*, in A DEATH IN THE FAMILY, *supra* note 25, at 69, 70, 73 ("Conflicts still exist between the benefits of disclosure and the potential for stigma and discrimination.").



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their advocates have long relied on federal<sup>42</sup> and state laws<sup>43</sup> prohibiting discrimination on the basis of an individual's disability.<sup>44</sup> These anti-discrimination laws have served as powerful tools in achieving equal access to education,<sup>45</sup> employment,<sup>46</sup> health care,<sup>47</sup> and housing<sup>48</sup> for people with HIV. Likewise, advocates for HIV-positive parents should use these laws as tools for fighting HIV-related discrimination in Family Court.

Prior to the enactment of the Americans with Disabilities Act of 1990 ("ADA"),<sup>49</sup> the principle federal law prohibiting discrimination on the basis of disability was the Rehabilitation Act of 1973 ("Rehabilitation Act").<sup>50</sup> The Rehabilitation Act prohibits discrimination by any entity receiving federal funds, including most state and local government agencies.<sup>51</sup> Although the Rehabilitation Act is limited in scope to federally-funded entities, at least one decision has relied on the Rehabilitation Act to uphold an HIV-positive parent's right to custody or visitation with their children.<sup>52</sup> Other courts have held that the Rehabili-

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42. See, e.g., Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (1994); Rehabilitation Act of 1973, 29 U.S.C. § 794 (1994).

43. All states have statutes with anti-discrimination protections for people with disabilities. See, e.g., MASS. GEN. LAWS ch. 272, § 98 (1992); N.C. GEN. STAT. § 168A (1995). For a national overview of HIV-related discrimination and the statutes that protect against such discrimination, see NAN D. HUNTER, ACLU AIDS PROJECT, EPIDEMIC OF FEAR: A SURVEY OF AIDS DISCRIMINATION IN THE 1980S AND POLICY RECOMMENDATIONS FOR THE 1990S 83-133 (1990) [hereinafter ACLU AIDS PROJECT].

44. The Americans with Disabilities Act ("ADA") defines disability broadly as "impairment that substantially limits one or more of the major life activities . . . a record of such impairment, or being regarded as having such an impairment." 42 U.S.C. § 12102(2) (1994).

45. See 45 C.F.R. § 84.31 (1973) (stating that § 504 of the Rehabilitation Act "applies to pre-school, elementary, secondary, and adult education programs and activities that receive or benefit from Federal financial assistance."); see also Lynn E. Sudbeck, *Students with AIDS: Protecting an Infected Child's Right to a Classroom Education and Developing a School's AIDS Policy*, 40 S.D. L. REV. 72, 74 (1995) (examining statutes protecting students with AIDS, the treatment of school children with AIDS in the courts, and the response of medicine to AIDS in educational environments); see generally DAVID L. KIRP ET AL., LEARNING BY HEART: AIDS AND SCHOOLCHILDREN IN AMERICA'S COMMUNITIES 1-301 (1989) (relating and discussing the challenges faced by school children with AIDS and their specific communities).

46. See generally Chai R. Feldblum, *Workplace Issues: HIV and Discrimination*, in AIDS AGENDA, supra note 30, at 271, 271-300.

47. See Mark Jackson & Nan D. Hunter, "The Very Fabric of Health Care": *The Duty of Health Care Providers to Treat People Infected with HIV*, in AIDS AGENDA, supra note 30, at 123, 128-38; Lawrence O. Gostin, *Public Health Powers: The Imminence of Radical Change*, 69 MILBANK Q. 268, 270 (Supp. 1991).

48. The Federal Fair Housing Amendments of 1988 address housing discrimination against persons with disabilities. See 42 U.S.C. § 3604 (1994); see, e.g., *Baxter v. City of Belleville*, 720 F. Supp. 720, 734-35 (S.D. Ill. 1989) (granting an injunction under the Fair Housing Act to compel an issuance of use permit to allow a former office building to be remodeled for persons with AIDS).

49. See 42 U.S.C. §§ 12101-12213 (1994).

50. See 29 U.S.C. § 794 (1994).

51. See *id.*

52. See *Doe v. Roe*, 526 N.Y.S.2d 718, 726 (N.Y. Sup. Ct. 1988) (denying maternal grandparents' motion to compel a father to test for HIV, because, in part, the children would not be in danger of contracting HIV from living with the father if he were HIV-positive). The court's holding relied on cases prohibiting school authorities from excluding children with AIDS from school. See *id.*

tation Act protects HIV-positive children and have affirmed their right to attend public schools.<sup>53</sup>

Prior to the passage of the ADA, commentators on HIV and custody issues relied on *School Board of Nassau County v. Arline*<sup>54</sup> to argue that HIV should not presumptively limit an award of custody.<sup>55</sup> In *Arline*, the Supreme Court held that the Rehabilitation Act prohibited a school board from dismissing a teacher with tuberculosis, a contagious disease, if the teacher was "otherwise qualified" to perform her job.<sup>56</sup> Although the Rehabilitation Act is not the applicable law in an individual custody determination, the legal analysis can be used to ensure that a parent's disability does not result in a per se denial of custody. As in employment discrimination cases such as *Arline*, Family Court judges should conduct individual assessments based on the facts of the case to determine whether a parent is "otherwise qualified" to care for the child.

When the ADA was signed into law,<sup>57</sup> the HIV community had a renewed sense of hope about their ability to use federal law to combat discrimination.<sup>58</sup> The ADA significantly broadened the entities that are subject to its anti-discrimination rules,<sup>59</sup> and prohibited discrimination in public and private employment, public services, transportation, communications technology, and pub-

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53. See *Ray v. School Dist. of DeSoto County*, 666 F. Supp. 1524, 1530-32 (M.D. Fla. 1987) (granting a preliminary injunction prohibiting HIV testing of hemophiliac children); *Thomas v. Atascadero Unified Sch. Dist.*, 662 F. Supp. 376, 380 (C.D. Cal. 1987) (permitting kindergarten children who were HIV-positive to attend regular classes).

54. 480 U.S. 273 (1987).

55. See Barrett & Flint, *supra* note 3, at 188-90; Mahon, *supra* note 3, at 1130-31;.

56. See *Arline*, 480 U.S. at 285-87.

57. For a comprehensive overview of the ADA, see Leonard, *supra* note 40, at 301-03, 305-13.

58. See *id.* at 298; Gostin, *supra* note 47, at 269.

59. The Rehabilitation Act only applies to entities that receive federal funding. See 29 U.S.C. § 794 (1994). The ADA, by contrast, prohibits discrimination by employers with fifteen or more employees, see 42 U.S.C. §§ 12111-12112 (1994), by all public entities, see 42 U.S.C. §§ 12131-12132, and by public accommodations and services operated by private entities, see 42 U.S.C. §§ 12181-12182. The ADA, however, did not broaden who is protected by the ADA, i.e., who is considered disabled. Rather, the definition of disability appears to be very similar to that under the Rehabilitation Act. Compare 29 U.S.C. § 706(8) (1994), with 42 U.S.C. § 12111(8) (1994). At least one commentator has argued, rather, that recent litigation under the ADA and the resulting court interpretations have begun to narrow the scope of who is disabled. See Steven S. Locke, *The Incredible Shrinking Protected Class: Redefining the Scope of Disability Under the Americans with Disabilities Act*, 68 U. COLO. L. REV. 107, 110-15 (1997).

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lic accommodations.<sup>60</sup> Regulations clarified the legislative intent that all HIV-positive people are protected under this definition.<sup>61</sup>

In the family law setting, the ADA serves as an important backdrop for protecting the rights of HIV-positive persons. HIV advocates should rely on the ADA to argue that judges should make case-by-case assessments of an HIV-positive parent's ability to care for a child. In *In re Carney*,<sup>62</sup> California's highest court concluded that a physical disability limiting a parent's ability to participate with his children in physical activities is not a changed circumstance sufficient to warrant a change custody.<sup>63</sup> The court referred to state and federal anti-discrimination laws aimed at integrating disabled persons into the mainstream, and stated that "[n]o less important to this policy is the integration of the handicapped into the responsibilities and satisfactions of family life, cornerstone of our social system. . . . [T]rial courts must avoid impairing or defeating [this] public policy."<sup>64</sup> The *Carney* decision is significant precedent for relying on disability-based anti-discrimination laws in custody and visitation cases.

In Family Court, the prejudice against individuals with substance abuse also can be challenged using anti-discrimination laws.<sup>65</sup> Unfortunately, individuals who have substance abuse problems, or histories of such problems, do not have the same protections under the law as individuals with other disabilities.<sup>66</sup> The coverage of substance abusers in the Rehabilitation Act regulations was based in part on the medical and psychological literature treating substance abuse as a disease.<sup>67</sup> The use of anti-discrimination law in the family law context

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60. See 42 U.S.C. § 12101 (1994); see generally ACLU AIDS PROJECT, *supra* note 43, at 83-133.

61. See 28 C.F.R. § 35.104 (1991). The issue of whether HIV-infected individuals are protected by the ADA has prompted much discussion. Equal Employment Opportunity Commission regulations state that all HIV-infected individuals, even those who are asymptomatic, are covered by the ADA. See 29 C.F.R. pt. 1630 app. (1997) ("Impairments . . . such as HIV are inherently substantially limiting."). Many courts have agreed. See, e.g., *Abbott v. Bragdon*, 108 F.3d 328 (1st Cir. 1997); *Doe v. Montgomery Hosp.*, No. CIV. A. 95-3168, 1996 WL 745524 (E.D. Pa. Dec. 23, 1996); *Doe v. Kohn, Nast & Graf*, 866 F. Supp. 190 (E.D. Pa. 1994). Other courts, however, have held that HIV-infected individuals are not per se disabled and that disability should be determined on a case-by-case basis. See *Runnebaum v. NationsBank of Md.*, 123 F.3d 156 (4th Cir. 1997); *Cortes v. McDonald's Corp.*, 955 F. Supp. 541 (E.D.N.C. 1996). Ironically, considering HIV as "inherently limiting" and thus a disability under the ADA has the opposite effect of what parties generally are trying to argue in Family Court, namely that the disability will not have an impact on the child. See *In re Carney*, 598 P.2d 36, 42-43 (Cal. 1979).

62. 598 P.2d 36 (Cal. 1979).

63. See *id.* at 44; see also discussion *infra* Part IV.A.

64. *Carney*, 598 P.2d at 45.

65. See discussion *infra* Part V.

66. For a thorough review of how the Rehabilitation Act and the ADA treat addicted individuals, see Anne Robbins, *Employment Discrimination Against Substance Abusers: The Federal Response*, 33 B.C. L. REV. 155, 167-90, 197-208 (1991). While the Rehabilitation Act does not specifically cover addicted individuals, the implementing regulations state that "individuals with handicaps" includes substance users for the purpose of general hospital outpatient treatment. See 45 C.F.R. § 84.53 (1994). The Act later was amended to exclude any alcohol or drug abuser "whose current use of alcohol or drugs prevents such individual from performing the duties of the job in question or whose employment, by reason of such current alcohol or drug abuse, would constitute a direct threat to the property or the safety of others." 29 U.S.C. 706(8)(B) (1994); see also H.R. CONF. REP. NO. 95-1780, at 102 (1978), reprinted in 1978 U.S.C.C.A.N. 7375, 7413.

67. See Robbins, *supra* note 66, at 173.

to protect individuals with substance abuse problems is extremely limited because of the direct relationship between substance abuse and the ability to parent. Yet these laws may be helpful in cases where a litigant has been a substance abuser in the *past* and is far along in the recovery process.<sup>68</sup> In these cases, attorneys representing HIV-positive individuals with drug histories should educate judges about substance abuse by relying on the public policy prohibiting discrimination against substance users and on the literature establishing addiction as an illness.

Although disability-based anti-discrimination law provides some ammunition with which to fight improper and arbitrary decisions in Family Court, its use is limited in practice. Family law has well-established legal standards on which Family Court judges are accustomed to relying. These standards include the "best interests of the child," preventing harm to the child, and "material change of circumstances."<sup>69</sup> It is very difficult to convince judges making custody or visitation determinations to rely on different legal standards, such as anti-discrimination law, which they may not find relevant. In *Sherman v. Sherman*,<sup>70</sup> the Tennessee Court of Appeals confronted this tension, noting that

[d]espite the specter of AIDS, this appeal is essentially a dispute between divorced parents concerning visitation. While the courts must be concerned when the question of AIDS is raised in the context of child custody and visitation . . . we should continue to apply the settled principles and precedents normally brought to bear in [these] proceedings. Existing law provides sufficient direction for dealing with AIDS in the context of domestic relations proceedings. Accordingly, the possibility of exposure to [HIV] does not require us to fashion new legal principles or to depart from existing law.<sup>71</sup>

This passage from the *Sherman* decision embodies the inclination of Family Court judges to rely on well-settled family law principles. While such reliance is appropriate, Family Court judges should be prepared to evaluate these standards in light of contemporary public policy considerations, as the court did in *Carney*.<sup>72</sup> Additionally, family law standards should evolve in the context of a changing society.

Convincing Family Court judges in New York City to focus on unconventional legal precedents is made more difficult by the overcrowded and stressful conditions of Family Court.<sup>73</sup> In these circumstances, it is difficult to get judges to consider discrimination law at all. The challenge for advocates of HIV-

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68. The ADA definition of disability encompasses substance users and alcoholics, but the definition of "qualified individuals" excludes employees or applicants who are "engaging in the illegal use of drugs, when the covered entity acts on the basis of such use." 42 U.S.C. § 12114 (1994). The ADA states, however, that this provision is not meant to exclude individuals who have completed or are participating in a supervised rehabilitation program and are no longer engaging in the use of illegal drugs. *See id.*

69. *See supra* note 33.

70. No. 01-A-01-9304-CH00188, 1994 WL 649148 (Tenn. Ct. App. Nov. 18, 1994).

71. *Id.* at \*4.

72. *See Carney*, 598 P.2d at 44.

73. *See Sexton*, *supra* note 31, at A1 ("The players themselves acknowledge that the system often works badly or barely works at all, but they differ on where to place the blame.").

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positive parents is to insist that judges give these cases the time and attention they deserve.

IV. THE LAW: HIV AND OTHER DISABILITIES IN CUSTODY AND VISITATION DETERMINATIONS

A. The Treatment of Disabilities in Custody Cases

[T]he essence of parenting . . . lies in the ethical, emotional, and intellectual guidance the parent gives to the child throughout his formative years . . . a handicapped parent is a whole person to the child who needs his affection, sympathy, and wisdom to deal with the problems of growing up. Indeed, in such matters his handicap may well be an asset: few can pass through the crucible of severe physical disability without learning enduring lessons in patience and tolerance.<sup>74</sup>

This passage represents the underlying philosophy of *Carney*, the seminal California case on evaluating disability in custody determinations. The *Carney* court set aside prejudices about people with disabilities and addressed directly what it meant to be a parent.<sup>75</sup> The decision, cited most often by courts making custody determinations where one of the parties is disabled,<sup>76</sup> appears to be the first case to rely on state disability law in a custody case. The case also is noteworthy because it articulates a standard for determining the effect of a disability on a parent's ability to care for the children. This Part examines the relevance of *Carney* in custody and visitation cases where one of the parties has a disability.

The court in *Carney* examined the effect of a custodial father's paralysis on his ability to care for his children in deciding whether the father's disability was a "changed circumstance" sufficient to warrant an award of custody to the mother after the father had maintained custody for five years.<sup>77</sup> The court held that custody decisions cannot be based on a parent's disability alone.<sup>78</sup> Rather, the court must evaluate carefully all the relevant facts to "determine whether the parent's condition will in fact have a substantial and lasting adverse effect on the best interests of the child."<sup>79</sup> According to the court in *Carney*, the factors that should be considered in determining whether a parent's disability will have a lasting impact on the child include: 1) the parent's actual and potential physical capabilities; 2) how the parent has adapted to the disability; 3) how the child and other members of the household have adapted; and 4) any special contributions the parent makes to the family.<sup>80</sup>

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74. *Carney*, 598 P.2d at 44.

75. *See id.*

76. Many commentators have reviewed the *Carney* decision and the cases that follow it. *See* Barrett & Flint, *supra* note 3, at 176-78; Cooper, *supra* note 30, at 74-75; Mahon, *supra* note 3, at 1125-28; *see also* Kristine Cordier Karnezis, Annotation, *Parent's Physical Disability or Handicap as Factor in Custody Award or Proceedings*, 3 A.L.R.4th 1044 (1981) (analyzing *Carney* and other cases that have held that a parent's physical disability does not render the parent per se unfit to have custody).

77. *See Carney*, 598 P.2d at 39-44.

78. *See id.* at 42.

79. *Id.*

80. *See id.*

The *Carney* court was pioneering in both its understanding of prejudices against people with disabilities and in its treatment of the father's disability and its impact on the children. The father in *Carney* was a quadriplegic who was attempting to overcome his severe physical limitations. The court's finding that the father's disability would not interfere with his parenting abilities was based on the court's vision of what it means to be a parent, as well as its disapproval of the lower court's judgment, which was "affected by serious misconceptions as to the importance of the involvement of parent in the purely physical aspects of their children's lives."<sup>81</sup> The most significant contribution of *Carney* is the articulation of factors that courts should consider, which are designed to eliminate the consideration of prejudicial factors. Advocates for parents with disabilities must ensure that these factors are evaluated on a case-by-case determination.

The *Carney* decision, however, is of limited use to the Family Court practitioner. The factors listed in *Carney*, while focusing on seemingly objective standards, nonetheless leave open a wide margin for covert prejudices to surface.<sup>82</sup> The decision also was based on an enlightened vision of parenting that other courts may not share. In addition, in crowded Family Court, such as in New York City, judges often do not have time to reflect upon their own prejudices.<sup>83</sup> Decisions about how complex cases such as these will proceed generally are made from the bench in minutes.<sup>84</sup> Courts frequently decline to consider factors articulated in precedent because of time pressures. Instead, judges react only to the facts before them.

#### B. The Treatment of HIV in Reported Custody Decisions

After more than fifteen years of the HIV epidemic, there are now many reported cases examining the significance of a parent's HIV status in the context of custody cases. This Part will examine four distinct themes addressed by these cases: 1) HIV transmission and the risk of harm to the child; 2) a parent's physical ability to care for the children; 3) a parent's potentially shortened life span; and 4) a parent's failure to disclose his or her HIV status.

The potential risk of harm to the children is, of course, a relevant inquiry in child custody determinations. In considering the risk of harm to a child from a parent's HIV status, almost all of the HIV-related cases focus on whether the

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81. *Id.* at 41.

82. See discussion *infra* Part VI (examining the pervasiveness of prejudice in a court where most decisions are based on the court's discretion).

83. See Sexton, *supra* note 31, at A1 (quoting a senior city prosecutor in Brooklyn as saying "[t]here are judges with agendas").

84. See THE FUND FOR MODERN COURTS, *supra* note 10, at 9 (stating that "judicial personnel of the Family Court are severely overburdened," and finding that judges spend very little time on each case).

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children are at risk of HIV exposure.<sup>85</sup> These cases uniformly hold that a parent's HIV status poses no threat to the child since HIV cannot be transmitted from a parent to a child through casual contact.<sup>86</sup> The cases rely on testimony presented by medical experts at trial that HIV can only be transmitted perinatally or through blood or blood products, sharing infected needles, or sexual contact involving the exchange of bodily fluids.<sup>87</sup> The cases also refer to other medical studies and literature that establish how difficult it is for a parent to transmit HIV to other household members.<sup>88</sup> Such evidence refutes allegations that a parent's HIV infection places the children at risk of physical harm.

At this point in the HIV epidemic, the fact that HIV cannot be transmitted through casual contact is so well-established that there should never be a need for a hearing on this issue. Even the most enlightened individuals, however, may have hidden, albeit unfounded, fears about transmission. This possibility reflects the importance of raising the transmission issue even where it is not raised by other parties; bringing such fears out in the open where they can be confronted generally is preferable to the consequences of hidden apprehensions.

A more complex and challenging issue raised by some of the reported decisions is whether a parent's health status has an impact on her ability to care for her children. This inquiry requires an evaluation of the parent's specific physical and mental conditions and an examination of how the parent is dealing with these conditions. Curiously, none of the cases that address HIV in custody or visitation determinations look to the standard articulated in *Carney* to determine the parent's ability to care for his or her children.<sup>89</sup> In fact, the HIV-related cases that have examined a parent's physical capacity evaluate the facts without regard to any legal standard.<sup>90</sup>

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85. See, e.g., *Stewart v. Stewart*, 521 N.E.2d 956, 964 (Ind. Ct. App. 1988) (concluding that medical evidence and available studies indicate that AIDS is not transmitted through everyday household contact); *Newton v. Riley*, 899 S.W.2d 509, 511 (Ky. Ct. App. 1995) (concluding that there is no risk of HIV-infection to children living with an HIV-positive step-parent and therefore finding no reason to modify the custody order); *Conkel v. Conkel*, 509 N.E.2d 983, 987 (Ohio Ct. App. 1987) (holding that an order granting a homosexual father increased visitation could not be overturned where no evidence was presented that the father was HIV-positive); *Doe v. Roe*, 526 N.Y.S.2d 718, 725 (N.Y. Sup. Ct. 1988) (stating that a claim that the children would be in danger from living with their father if he was HIV-positive could not stand because of the overwhelming evidence that the HIV virus is not spread casually); *Steven L. v. Dawn J.*, 561 N.Y.S.2d 322, 324-25 (N.Y. Fam. Ct. 1990) (reciting undisputed testimony that the HIV virus has not been contracted through everyday household contact).

86. See *Stewart*, 521 N.E.2d at 964.

87. See, e.g., *Steven L.*, 561 N.Y.S.2d at 324-25; *Jane W. v. John W.*, 519 N.Y.S.2d 603, 604 (N.Y. Sup. Ct. 1987).

88. See, e.g., *Steven L.*, 561 N.Y.S.2d at 325; *Doe*, 526 N.Y.S.2d at 725. For a discussion of this evidence, see Helena Brett-Smith & Gerald H. Friedland, *Transmission and Treatment*, in AIDS LAW TODAY, *supra* note 13, at 18, 23-29.

89. The *Carney* decision articulated four factors for courts to consider in deciding whether a parent's disability will affect the child's best interest: how other members of the household have adjusted to the disability; the special contributions made by the disabled parent in spite of, or because of, the disability; the disabled parent's actual and potential physical abilities; and how the parent had adapted to the disability. See *Carney*, 598 P.2d at 42; see also *supra* notes 77-84 and accompanying text.

90. See, e.g., *John T. v. Carraher*, 538 N.W.2d 761 (Neb. Ct. App. 1995); *Jane W.*, 519 N.Y.S.2d at 604; *Steven L.*, 561 N.Y.S.2d at 324-25.

For example, in *Steven L. v. Dawn J.*,<sup>91</sup> a Family Court judge in Brooklyn found that it would not be in the “child’s best interest to be left in the sole care of a person who was seriously incapacitated because of an illness or disease.”<sup>92</sup> The court continued the award of custody to the mother because “although she has felt weak at times, she has not been incapacitated by her condition and has maintained primary care for her daughter at a high level of performance.”<sup>93</sup> Without explicitly stating so, the court in *Steven L.* evaluated whether the parent was the “sole” caretaker and whether she was “seriously incapacitated.”<sup>94</sup> In this case, the mother’s “high level of performance” was sufficient.<sup>95</sup> The court raises the question of whether a parent’s capacity should be evaluated in terms of whether other caretakers are involved.

In *Jane W. v. John W.*,<sup>96</sup> a mother sought to limit her daughter’s visitation with her HIV-positive father who had developed several HIV-related conditions, including tuberculosis and *pneumostyis carinii pneumonis* (PCP).<sup>97</sup> The court relied on traditional visitation case law that grants parents liberal visitation in the absence of any harm to the child posed by the visits.<sup>98</sup> In considering the father’s rights, the court identified the only relevant issue as whether the father could care for the child during visits.<sup>99</sup> The court granted the father visitation since the father was “entirely capable of caring for the child” and had cared for the child throughout her life.<sup>100</sup> Curiously, the court did not examine the father’s particular physical limitations even though he had serious medical conditions.<sup>101</sup>

Similarly, in *John T. v. Carraher*,<sup>102</sup> the court found that it was in the child’s best interests to remain with his foster mother because her ability to care for him was compromised only by her illness only “at an uncertain point in the future. She is presently fully capable of parenting [the boy] . . . .”<sup>103</sup> In contrast, in *H.J.B. v. P.W.*,<sup>104</sup> the appellate court affirmed the lower court’s finding that a father’s HIV status was a material change in circumstance despite a lack of any specific

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91. 561 N.Y.S.2d 322 (N.Y. Fam. Ct. 1990).

92. *Id.* at 324.

93. *Id.* at 326.

94. *Id.*

95. *Id.*

96. 519 N.Y.S.2d 603, 604 (N.Y. Sup. Ct. 1987).

97. PCP is an HIV-related opportunistic infection caused by a parasite that naturally occurs in almost every person’s lungs, becoming problematic when the immune system is stressed. See JOHN G. BARTLETT & ANN K. FINKBEINER, *THE GUIDE TO LIVING WITH HIV INFECTION* 63, 113 (1991).

98. See *Jane W. v. John W.*, 519 N.Y.S.2d 603, 605 (N.Y. Sup. Ct. 1987).

99. See *id.*

100. See *id.*

101. One explanation for the court’s failure to examine the father’s physical limitations is that the case involved visitation with, not custody of, his child. In visitation cases, the court is supposed to consider whether visitation will cause danger to the child. See *supra* note 37. In custody cases, for the most part, courts determine what is in the child’s best interests. See *supra* note 33. Based on these legal standards, an evaluation of a parent’s physical abilities should be different in a visitation case than a custody case. In reality, courts seem equally concerned about the impact of an HIV-positive parent’s illness in visitation cases as in custody cases, especially where overnight visits are involved.

102. 538 N.W.2d 761 (Neb. Ct. App. 1995).

103. *Id.* at 771.

104. 628 So. 2d 753 (Ala. Civ. App. 1993).



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evidence of the father's physical or emotional condition.<sup>105</sup> The court instead focused on the father's failure to disclose his HIV status to the court.<sup>106</sup>

In considering the physical capabilities of an HIV-positive parent, it is significant that an HIV-positive person's health is unpredictable, but likely will deteriorate over time and may lead to death. The deterioration of a person's health is markedly different than disabilities such as the father's paralysis in *Carney*, which is not likely to lead to increased incapacity or death. Most reported custody cases involving an HIV-infected parent do not address directly the parent's future death and its impact on the children. While HIV-positive people are living longer than in the past, and in fact could live a long time, a medical provider cannot predict how long a particular parent will live. Another characteristic that distinguishes HIV from many disabilities is that an HIV-infected individual's physical condition will improve and deteriorate cyclically.<sup>107</sup>

Courts that have addressed the issue of a parent's shortened life span have held that this possibility should not justify removing children from their custodial parent.<sup>108</sup> The rationale for this policy is described eloquently by the court in *John T.*:

Life is indeed uncertain, and no child is guaranteed that he or she will proceed through childhood or adolescence with his or her parents healthy or even alive. There is no doubt that parental illness and death are very hard on children. It is our task to put aside the fact that the foster mother has AIDS, an illness laden with emotion. Instead, we view the matter as we would a case involving any potentially terminal illness of a parent. . . . [P]arents suffer and die from illness, and their children observe this and suffer with their parents. However, the children hopefully learn that although painful, death is a natural part of the cycle of life.<sup>109</sup>

The critical point raised by the court in *John T.* is that courts cannot always protect children from their pain and suffering. The impulse to shield children from suffering in Family Court is very strong, as the purpose of the court is to protect children from harm.<sup>110</sup> While this impulse is understandable, and the goal of Family Court is laudable, judges often are forced to try to accomplish the

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105. See *id.* at 754-56.

106. See *id.*

107. See Brett-Smith & Friedland, *supra* note 88, at 38; see also BARTLETT & FINKBEINER, *supra* note 97, at 50-51 (describing typical developments of HIV infection).

108. See *John T. v. Carraher*, 538 N.W.2d 701, 772-73 (Neb. Ct. App. 1995) (holding that a foster mother's HIV status did not justify the removal of her foster child from the home); *Doe v. Roe*, 526 N.Y.S.2d 718, 726 (N.Y. Sup. Ct. 1988) (denying maternal grandparents' motion to compel father to submit to an HIV test because even if father had AIDS and a shortened life span, this would not justify removing children from their long-term custodian).

109. *John T.*, 538 N.W.2d at 772-73. Although *John T.* deals with a foster mother, not a biological parent, the language in the case can be applied to biological parents or other caretakers. In fact, the court in *John T.* found that the foster parents were "parents" in the child's eyes. See *id.* at 772.

110. It is generally agreed that courts with jurisdiction over custody disputes serve both a child protective function and a private dispute resolution function. See THE FUND FOR MODERN COURTS, *supra* note 10, at 4; Robert H. Mnookin, *Child-Custody Adjudication: Judicial Functions in the Face of Indeterminacy*, 39 LAW & CONTEMP. PROBS. 226, 291-93 (Summer 1975).

impossible task of safeguarding children from emotionally difficult situations.<sup>111</sup> HIV advocates must challenge courts to resist the impulse to protect children from painful situations without regard for the rights of the parents and the well-being of the family. In the case of a seriously incapacitated parent, courts should look carefully at the facts to determine whether the children's physical and emotional needs are being met. In this way, the court will be assured that there is no "substantial and lasting adverse effect on the best interests of the child."<sup>112</sup>

The articles and commentaries examining the issue of HIV and custody fail to note that the HIV status of many HIV-positive individuals is not known at the outset to the court or to other parties involved in the litigation.<sup>113</sup> In most of these cases, it will be unnecessary to disclose a party's HIV status because it is not relevant to the case.<sup>114</sup> Attorneys should consider, however, that in certain cases, failure to disclose one's status has been noted disapprovingly by the court. In *H.J.B. v. P.W.*,<sup>115</sup> a lower court's finding that the father lacked credibility was upheld where "the father failed to disclose his true medical condition until the day of trial, and that he failed to disclose pertinent evidence as to his personal health . . . ."<sup>116</sup> The court had noted that this failure was

tantamount to an attempt to secrete his true health status from the Court. . . . [This had] the effect of casting suspicion on the credibility of his testimony previously given . . . regarding his views toward promiscuity, the gay lifestyle and his fears of danger attending each. Certainly, this is an issue which could have a

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111. The impulse is, of course, not limited to Family Court judges. Many adults feel that children should not be confronted with, and should be sheltered from, issues surrounding serious illness and death. See Karolynn Siegel et al., *Psychosocial Adjustment of Children with a Terminally Ill Parent*, 31 J. AM. ACAD. CHILD ADOLESCENT PSYCHIATRY 327, 327 (1992).

112. *In re Carney*, 598 P.2d 36, 42 (Cal. 1979).

113. The fact that HIV is not known to others might mean that HIV-related discrimination is not present; it does not negate, however, the importance of the parent's HIV status in a case. Attorneys should talk to their clients about whether the client should disclose their status to their children, relatives, case workers, and the court. Such discussions are necessary to determine whether disclosure will resolve a tension that exists because the party's HIV status is being withheld. Very often disclosure will explain behavior, such as frequent medical appointments or hospitalizations, that otherwise may trouble the court or child welfare workers. Disclosure also may help the client achieve his or her objectives in the litigation. If, for example, a case is being delayed or visitation is limited, disclosure may help advance the case. Ultimately, the parent must balance the benefit of disclosing the information with the potential harm of stigma that such disclosure may cause. Disclosure issues and a parent's confidentiality rights are discussed more fully *infra* Part V.

114. The client is under no obligation to disclose this information, and most clients choose not to disclose their status to the court because of a fear of discrimination. If their medical condition has been put at issue, however, then the client must comply with requests for information about their medical condition. In one case, a judge advised us that if our client refused to provide medical records, then she would make an "adverse inference" against him about his medical condition. Clients should be advised about this possibility up front so that they are prepared to share this information if necessary.

115. 628 So. 2d 753 (Ala. Civ. App. 1993).

116. *Id.* at 754-55.

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significant bearing on the mental, physical, emotional and spiritual well-being of the minor child involved and should be taken into consideration . . . .<sup>117</sup>

The court in *John T.*<sup>118</sup> also examined a foster mother's failure to disclose her HIV status, but treated the case differently. The court held that it was in the child's best interests to remain with the foster mother and her husband.<sup>119</sup> The foster mother had failed to disclose her illness in her initial foster parent application, and the court acknowledged that if she had disclosed her HIV status, her application probably would have been denied.<sup>120</sup> The court noted, however, that the child had been living with the foster mother for years, and had come to recognize her as his parent.<sup>121</sup>

The court in *John T.* found that the foster mother's "deception" should not be used to decide the outcome of the case, which instead should be based on the best interests of the child.<sup>122</sup> The court stated that "[w]e cannot say it is *per se* against the child's best interests that his parents have hidden a health condition which generates from some quarters a degree of discrimination, hysteria and paranoia."<sup>123</sup> This statement reflects an understanding of how difficult it is for many HIV-positive individuals to disclose their HIV status because they fear discrimination and prejudice. This fear is even more pronounced in the context of Family Court and the foster care system, where the individual has much at stake in getting custody of, or visitation with, her children. Parents should be mindful, however, that their failure to disclose their status may be perceived negatively by the court.

## V. BARRIERS HIV-INFECTED PARENTS FACE IN THE COURTROOM

This Part examines how the Family Court process and factors that are endemic to Family Court result in discriminatory and harmful treatment of HIV litigants. The most significant factors to consider in this analysis are the discretion of judges, the extensive time delays and postponements in Family Court, and the disclosure of a parent's HIV status by investigators or other parties. Each of these factors and how they result in the unfair treatment of HIV-positive parties in Family Court will be examined in turn.

Judges have a great deal of discretion both in how cases proceed and in the ultimate outcome of the case. Nowhere is this discretion more pronounced than in Family Court, where the legal standards relied upon inherently are subjec-

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117. *Id.* at 755 (quotations omitted); see also *John T.*, 538 N.W.2d at 770-71 (stating that the court is not unconcerned about deception practiced by foster parents in failing to reveal the foster mother's HIV positive status).

118. 538 N.W.2d 761 (Neb. Ct. App. 1995)

119. See *id.* at 773.

120. See *id.* at 771.

121. See *id.* at 772.

122. See *id.* at 771.

123. See *id.* at 772. The court refers to *Doe v. Borough of Barrington*, 729 F. Supp. 376, 385 (D.N.J. 1990) (finding that a police officer's disclosure of the plaintiff's HIV status violated the Fourteenth Amendment), for examples of such strong reactions.

tive.<sup>124</sup> These standards leave open many opportunities for a judge to inject bias or prejudice against an individual based on race, ethnicity, disability or perceived disability, and whether an individual has a substance use addiction or history of addiction. Prejudice also can be based on the personal characteristics or qualities of a litigant, such as their personality or how they dress.

The impact of prejudice and bias on HIV-positive litigants is not limited to judges. Most cases involving foster care or custody disputes also involve a court-appointed lawyer for the children. In New York, these attorneys are called "law guardians."<sup>125</sup> Law guardians yield vast power in custody and foster care cases. Faced with complicated and emotional cases, and with overcrowded and stressful conditions, judges are inclined to follow the law guardian's recommendation.<sup>126</sup> Without sufficient resources and training on complex issues such as HIV or drug addiction, law guardians often recommend what the child wants, without making a proper determination about whether what the child wants also is in the child's best interests.<sup>127</sup> In cases in which HIV is a relevant issue, the law guardians' lack of HIV-related information and training is troublesome, particularly since they are making recommendations that often are given the most weight in court.

Inherent bias and prejudice invariably have a huge impact on a practice that involves representing poor HIV-positive people, most of whom are African-American and/or Latina. Judges often make presumptions about litigants based on their race and economic status and often are misinformed about the nature of HIV. One of the most difficult aspects of challenging discrimination in court is that it rarely is articulated expressly by the court or by other parties. In many cases, the judge and other parties are not even aware of their own biases. Subtle forms of prejudice are difficult to realize and confront in the course of litigation.

The frequently disparaging attitude of judges, opposing counsel, and law guardians toward an individual with a history of substance use is the most

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124. The role of the judge's discretion in Family Court cases and the highly subjective nature of the decisions have been widely discussed. See, e.g., Mahon, *supra* note 3, at 1096-97, 1108 ("More than any other type of legal dispute, child custody and visitation battles invite judges to use their personal perceptions, ideals, and prejudices to arrive at their determinations."). Nevertheless, judicial decisionmaking in these cases is highly complex. See Mnookin, *supra* note 110, at 255-62 (analyzing the complexity of judicial determinations in terms of limited information available to the judge, the difficulty in predicting outcomes, and the need to assign values in assessing possible outcomes).

125. See N.Y. FAM. CT. ACT §§ 242, 249 (McKinney 1983 & Supp. 1997-1998) (requiring a law guardian to be appointed in all child protective proceedings).

126. See Kim Nauer, *Guilty Until Proven Innocent*, CITY LIMITS, Nov. 1994, at 22 (noting that because "no one—including judges—wants to be blamed for putting a child back into [an unsafe home environment]," the child welfare agency's decision regarding the child is almost always followed by the court). A lawyer's representation of children raises complex issues about the lawyer/client relationship and the role of the lawyer with respect to client decisionmaking. See generally Michael J. Dale, *Practical Considerations in Representing Children*, in REPRESENTING THE CHILD CLIENT ch. 9 (Mark I. Soler et al. eds., 1992).

127. The role of a child's wishes in custody cases is discussed in more detail *infra* notes 165-74 and accompanying text.

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common and difficult bias to address in court.<sup>128</sup> Too often, hysteria and stereotypes about parents with drug use histories dominate the decisionmaking process about whether children are at risk from a parent's drug addiction or history of drug addiction.<sup>129</sup> The improper reliance on stereotypes and prejudice stems from negative attitudes toward drug users,<sup>130</sup> a lack of training on the part of judges and child welfare workers about drug addiction, treatment, and recovery,<sup>131</sup> and a lack of "consistently applicable criteria" for measuring the risk of danger to children.<sup>132</sup> In foster care cases, judges routinely rely on the child protective agency to make a decision about the children and then follow that decision without examining whether the facts of the case support the agency's decision.<sup>133</sup> Yet in cases involving drug addiction, child protective workers and other professionals "often feel angry with women who use drugs heavily," which can interfere with the service providers' ability to help the women and provide them with needed services.<sup>134</sup> As a result, regardless of what they have accomplished in their lives, parents who have histories of drug abuse face an uphill battle in overcoming these histories and in regaining custody of their children.<sup>135</sup> Moreover, attitudes about drug abuse often have racial overtones.<sup>136</sup> Unfortunately, these cases are complicated further by the fact that drug addiction is difficult for individuals to overcome and the process often involves periods of relapse.<sup>137</sup> Furthermore, a parent's drug addiction has a profound impact on her children even where the parent has overcome her addiction.<sup>138</sup>

The sluggish speed of the Family Court, perhaps more than any other factor, has a discriminatory effect on people with HIV. Although people with HIV can live for a long time, especially with the advent of combination therapies,<sup>139</sup>

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128. See generally Mary E. Taylor, Annotation, *Parent's Use of Drugs as Factor in Award of Custody of Children, Visitation Rights, or Termination of Parental Rights*, 20 A.L.R.5th 534 (1995 & Supp. 1997) (describing how common it is for drug abusing parents to lose parental rights or at least the right to custody or visitation).

129. See Azzi-Lessing & Olsen, *supra* note 30, at 17 (discussing the negative impact drug abuse has on the custody claims of parents, particularly mothers).

130. See *id.* at 16-18.

131. See *id.*

132. See Barry Zuckerman, *Effects on Parents and Children*, in *WHEN DRUG ADDICTS HAVE CHILDREN: REORIENTING CHILD WELFARE'S RESPONSE* 49, 56 (Douglas Besharov ed., 1994).

133. See Nauer, *supra* note 126, at 20, 22 (describing how courts generally follow a course that they perceive as legally "safe" in foster care cases).

134. See Zuckerman, *supra* note 132, at 55.

135. See generally RICHARD WEXLER, *WOUNDED INNOCENTS: THE REAL VICTIMS OF THE WAR AGAINST CHILD ABUSE* 212-18, 269-71 (1990) (describing how parents with drug use histories are mistreated by the child welfare system, including the tendency of agencies to demand ideal parenting before children can be returned home).

136. See PHILLIP O. COFFIN, *THE LINDESMITH CTR., COCAINE & PREGNANCY* 2 (1997) ("Regardless of similar or equal levels of illicit drug use during pregnancy, African-American and Latina women constitute 80% of those prosecuted for delivering drug-exposed children and are much more likely than Caucasian women to be reported to child welfare agencies for prenatal drug use." (citations omitted)).

137. See Azzi-Lessing & Olsen, *supra* note 30, at 17.

138. See Zuckerman, *supra* note 132, at 60-61 (observing that substance abuse negatively affects parents and children).

139. See discussion *infra* Part VII.

many litigants in court already are sick and do not know how long they will live. Even those who are well live with the fear that they could become sick at any time. Living with HIV therefore adds a sense of urgency to the process of gaining custody of, or visitation with, their children. The stress of Family Court itself often makes people increasingly ill.

In one typical case, South Brooklyn Legal Services represented a father, Henri, in a custody petition he filed against his sister-in-law. The sister-in-law, a doctor, had moved to New York City from Tennessee to take care of Henri's children after his wife had died.<sup>140</sup> Henri was sick, but still was able to take care of himself and his children with assistance. In opposing Henri's custody petition, his sister-in-law submitted an affidavit from the deceased mother saying that Henri had an alcohol problem.<sup>141</sup> On Henri's behalf, South Brooklyn Legal Services submitted evidence from his social worker and his treating doctor, both of whom had been working with him for years, that these allegations were untrue. Despite the fact that the only evidence of Henri's alcoholism was the deceased mother's affidavit, the court was reluctant to increase visitation until mental health exams were performed. It took nearly a year for these exams to be completed. During this year, South Brooklyn Legal Services repeatedly made motions for increased visits and gradually succeeded in increasing visits from three hours of supervised visits a week to weekend visits. In light of the father's right to custody under the appropriate legal standard of a parent against a non-parent,<sup>142</sup> this was a small victory.

Unfortunately, Henri's case is not unusual. The Family Court process is arduous, and it is hard particularly on parties who do not have custody or visitation with their children. For people with HIV, it potentially has even more dramatic consequences. As the cases of Denise<sup>143</sup> and Henri illustrate, the length and stress of the process may mean that HIV-infected parents become increasingly ill while being unable to spend quality time with their children before their death.

Unwarranted or unfair HIV disclosure by other parties in court is an additional factor that can affect HIV-positive litigants adversely by infringing upon

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140. Henri had been separated from his wife for three years when she died. Six months before her death, he had filed a visitation petition against her because she suddenly had ceased visitation. The petition still was pending when she died, and he still had not obtained visitation privileges with the children. At the time, Henri was living with his fiancée and had a home attendant.

141. The affidavit was written in support of the mother's last will and testament, which appointed her sister as a guardian. Some law offices have their clients sign such affidavits when they are not appointing the other living parent as the guardian.

142. See *supra* note 8.

143. See discussion *supra* Part I.

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their right to the confidentiality of their HIV-related medical information.<sup>144</sup> How an attorney should address disclosure and confidentiality concerns depends on the source and purpose of the disclosure. In Family Court cases, HIV confidentiality issues arise in cases where an individual's status is disclosed by an opposing party in court papers, orally in court by opposing counsel, or by a child welfare worker assigned to or investigating the case for the court, or a mental health expert examining parties in the case.

It is common for a party's HIV status to be disclosed in court papers, including petitions, answers, and reports of court-ordered investigations. In Brooklyn Family Court, clerks draft petitions based on the information provided by the petitioner. The petition then is served on the respondent, sometimes by leaving it at the respondent's house. In these cases, the information often is visible to anyone in the household. Similarly, court-ordered investigations sometimes result in written reports that indicate a party's HIV status. These reports then are provided to the court and the other parties in the case and their attorneys.

In one of the Project's cases, Jackie found a custody petition posted on her door regarding her adult daughters' children who lived with her. The petition alleged that Jackie had HIV and might be hospitalized one day, even though Jackie did not have custody of her grandchildren. I made a successful motion to redact her HIV status from the custody petition based on the potential for harm to her and because the information was irrelevant, as my client was asymptomatic and was not the legal custodian. My client was satisfied with the result because she did not want this information to be included in the court file, where it could be used against her later. She also had been concerned about disclosure to other household members. Making a motion to redact HIV-related information and/or to seal the record is one way to reduce the potential for injury in an individual case. Unfortunately, once the information has been disclosed to household members or to other individuals, some harm may have occurred.

In the case of court-ordered investigations, the attorney has slightly more control over disclosure. Prior to disclosure, the attorney should prepare the client for the fact that the information may be disclosed in a written report. The attorney also can encourage the investigator not to disclose the information. Over the years, investigators have dealt with this problem of confidentiality by indicating that the parent has a "terminal" or "chronic" illness instead of HIV.

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144. Most states have statutes that protect HIV-related information. See, e.g., AIDS Confidentiality Act of Illinois, 410 ILL. COMP. STAT. 305/9 (West 1997); N.Y. PUB. HEALTH LAW § 2782 (McKinney 1996 & Supp. 1997-1998). The right to HIV confidentiality also has been recognized as a constitutional right to privacy. See *Doe v. City of New York*, 15 F.3d 264 (2d Cir. 1994) (holding that the New York City Human Rights Commission violated the plaintiff's right to privacy by issuing a press statement that included sufficient information to identify him and his HIV status); *Doe v. Borough of Barrington*, 729 F. Supp. 376 (D.N.J. 1990) (finding that family members' privacy rights were violated by disclosure of their HIV status); *Woods v. White*, 689 F. Supp. 874 (W.D. Wis. 1988), *aff'd*, 899 F.2d 17 (7th Cir. 1990) (holding that a prisoner's right to privacy was violated by the disclosure of his HIV status by prison medical staff to non-medical personnel and other inmates). A litigant's right to confidentiality in Family Court is circumscribed by the court's need for information to determine what is in the child's best interests. For example, in New York, a parent waives his or her psychologist-client privileges by contesting custody and, thereby, putting her mental and physical well-being at issue. See *Baecher v. Baecher*, 396 N.Y.S.2d 447, 448 (N.Y. App. Div. 1977).

In reality, the court and other parties know that this usually is a disguise for HIV. The best way to address these issues is systemic; HIV advocates and the courts should develop policies and procedures that protect parties from the disclosure of their HIV-related information in petitions and court-ordered investigations.<sup>145</sup>

Disclosure by another party in court raises different issues. These disclosures clearly are legal, as disclosures by private parties do not violate most confidentiality laws or the Constitution.<sup>146</sup> The advocate's role in these cases is to ensure that the HIV-related information is not considered improperly by the court. The attorney must evaluate whether the disclosure is relevant to the proceeding, as it is in many cases. If a party's HIV status is being disclosed by an attorney for no reason other than to prejudice an opposing party, then the HIV advocate should rely on local ethical rules prohibiting such behavior to challenge the disclosure. The advocate then either can ask the judge to admonish the attorney or can make a complaint to the disciplinary committee against the proffering attorney.

The disclosure of a parent's HIV status by child protective agencies to other parties is more actionable than disclosure by private parties or by investigators in a court-ordered investigation. In my own experience and discussions with other HIV advocates, it is common for foster care agencies and child welfare agencies to disclose a parent's HIV status improperly to other family members, neighbors, or friends. Such disclosures have the potential to cause extreme pain to an HIV-positive individual who may not be prepared to disclose this information and probably would not want it disclosed in this manner. In one case, the Legal Action Center filed a law suit on behalf of the parent against what was then known as the Child Welfare Agency ("CWA"), alleging that the CWA improperly disclosed a parent's HIV status to police officers, who then disclosed the information to neighbors and friends of the family.<sup>147</sup> In addition to individual relief, the complaint asked the court to force the CWA to develop written protocols and training procedures to ensure confidentiality.<sup>148</sup> The case was settled by the parties, unfortunately, without the agency agreeing to develop such policies and procedures.<sup>149</sup> HIV advocates should address these confidentiality issues by holding child protective agencies accountable through litigation, as did the Legal Action Center. In addition, advocates should work with child protec-

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145. See *infra* Part VIII.

146. The New York State HIV Confidentiality Law, for example, prohibits disclosure by health and social service providers and state and local government agencies and employees who provide health or social services. See N.Y. PUB. HEALTH LAW § 2782 (McKinney 1993 & Supp. 1997-1998). An individual's right to privacy is grounded in the Due Process Clause of the Constitution, which has been interpreted to prohibit unnecessary *governmental* disclosures of medical information. See *Doe v. Borough of Barrington*, 729 F. Supp. 376, 382 (D.N.J. 1990) (citing *Whalen v. Roe*, 429 U.S. 589, 599-600 (1977) (stating that the Fourteenth Amendment protects an individual's interest in avoiding disclosure of personal matters)).

147. See *Estate of Mary Doe v. New York City Dep't of Soc. Servs.*, No. 93 Civ. 8385(JFK)(MHD), 1995 WL 619864, at \*1 (S.D.N.Y. Oct. 23, 1995).

148. See *id.* at \*2.

149. See Interview with Susan Jacobs, Senior Staff Attorney, Legal Action Center, in New York, N.Y. (Sept. 25, 1997).



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tive agencies to ensure appropriate policies and procedures for protecting confidentiality.

## VI. SEEMINGLY NEUTRAL FACTORS THAT RESULT IN DISCRIMINATORY RULINGS

This Part discusses factual considerations that are raised in court, either by judges or by other parties in cases involving foster care, custody, or visitation, that present unique challenges to HIV-positive parents. The primary considerations are the parent's physical ability to care for the children, the parent's possible death and long-term ability to provide for the children, the emotional harm to the children of being exposed to the parent's illness, and the children's wishes not to visit or live with the parent.<sup>150</sup> Each of these factors appear to be neutral, nondiscriminatory factors. Because these factors are related directly to the parent's HIV status, however, their presence in a case creates a strong likelihood of discrimination, even if such discrimination is unintentional or is hidden behind seemingly benevolent motivations.

As discussed above, none of the HIV-related reported cases follow the standard articulated in *Carney* or offer an alternative standard for evaluating whether an HIV-infected parent physically is able to care for a child.<sup>151</sup> Without an established standard for courts to follow in assessing whether, and how, a parent's physical impairments should affect a custody or visitation determination, there is ample opportunity for courts to deny, inappropriately, custody or visitation to an ill parent. In practice, a parent's physical limitations often have a profound impact on how the court proceeds, and there are many unanswered questions about how these limitations should be assessed.

The evaluation of a parent's illness on a child is slippery in nature. For example, South Brooklyn Legal Services represented a mother, Eleanor, in a custody case filed by the father of her twelve-year-old son Darren.<sup>152</sup> The father's petition sought custody solely on the ground that the mother physically was incapable of caring for her son because she was HIV-positive. Eleanor had cared for Darren for most of his life, and changing custody would separate him from

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150. Another significant factor, which this article will not address in detail, is the child's HIV status. In many cases, the child's HIV status will be raised as a justification for not awarding custody of the child, or returning the child, to the parent. Generally, the rationale provided is that the parent is not prepared to deal with the child's special needs. In reality, a child's HIV status often is raised by parties or the court because they blame the mother for giving her child HIV.

151. See *supra* Part IV.

152. Eleanor and her husband separated when Darren was three, and Eleanor was given custody. She also had a five-year-old daughter who had a different father. Eleanor was very incapacitated; her mother had come up from the South to live with her, and she had a home attendant and a caretaker for the children. Darren, however, was having a very hard time with his mother's illness, and wanted to live with his father so that he did not have to witness his mother's illness.

his sister.<sup>153</sup> The evidence also showed that he was being cared for adequately. Darren was dressed every day, taken to school, and had all his meals prepared for him; his grandmother helped him with his homework. Despite this evidence, however, the judge made it clear from the beginning that she intended to grant custody to the father; she seemed to be influenced strongly by the son's desire to live with his father.<sup>154</sup>

The standard governing this case was whether there was a "material change in circumstances" that affected Darren's best interests warranting a change in custody.<sup>155</sup> While the mother's change in health was indisputably a "material change in circumstance," the more difficult determination was whether removing him from his mother's custody was in Darren's best interests. In this case, Eleanor did everything she could to make sure her child was provided for, and the child was in no physical danger. Nonetheless, the judge assumed that it would be in Darren's best interests to change custody to the father because his mother was terminally ill. The judge did not consider carefully how Darren's exposure to his mother's terminal illness, as compared to his removal from her care, affected his best interests. Rather, the judge assumed, without the benefit of any expert testimony, that it would be in Darren's best interests to be with his healthy father rather than to witness his mother's illness. Without a standard for evaluating how exposure to a parent's illness affects the child's best interests, the illness can be used unfairly against the parent, as it was in this case.

An issue related to the parent's current physical capabilities is the parent's possible future death and inability to provide for the child. The issue of permanency and a parent's future health status often is raised in the context of foster care cases, perhaps because of the requirements of the federal Adoption Assistance and Child Welfare Act of 1980.<sup>156</sup> The concept of "permanency planning"<sup>157</sup> originates in the Act, which was passed in response to a foster care reform movement to reduce the amount of time children spend in foster care and to

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153. In most jurisdictions, keeping siblings together is an important factor to consider in custody cases. See, e.g., *Eschbach v. Eschbach*, 436 N.E.2d 1260 (N.Y. 1982). In *Eshbach*, the New York Court of Appeals noted that "the stability and companionship to be gained from keeping the children together is an important factor for the court to consider [in custody cases]. . . . [Siblings] need each other's strengths and association in their everyday and often common experiences, and to separate them, unnecessarily, is likely to be traumatic and harmful." *Id.* at 1264 (citation omitted). For additional cases discussing why siblings should be kept together, see MCCAHEY ET AL., *supra* note 4, § 12-36, 37.

154. See discussion *infra* notes 170-72 and accompanying text (discussing the role of the child's wishes in these cases).

155. See *supra* note 33 (providing a description of the legal standard in cases involving a change in custody).

156. Pub. L. No. 96-272, 94 Stat. 500 (codified as amended in scattered sections of 42 U.S.C.).

157. "Permanency planning" is a term now used widely in the HIV community to describe an HIV-positive parent's process of planning for what will happen to their children in the event that the parent becomes incapacitated or dies. Many HIV advocates prefer to use an alternative term for this process, "future care and custody planning," so the terms are not confused. Permanency planning is being used here in its original meaning under federal foster care law.

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provide them with permanency.<sup>158</sup> Federal law requires that children in foster care be reunified with their families as soon as possible and be freed for adoption or guardianship when reunification is not possible.<sup>159</sup> The child must have a permanency plan that is reviewed every six months and a hearing on the permanent plan for the child after twelve months.<sup>160</sup>

Parents with children in the foster care system, as compared to those seeking custody, face additional barriers to maintaining their relationships with their children because they are subject to greater scrutiny about their behavior and parenting abilities.<sup>161</sup> For HIV-positive parents in this environment, their HIV status often is used against them,<sup>162</sup> and they may face greater barriers to seeking custody and visitation than do parents in custody cases. The foster care system's emphasis on the child's permanency plan encourages foster care workers to question what will happen to the children in the future if they are returned to their parent. Often, workers question the wisdom of returning the child if the parent is going to become sick and die.<sup>163</sup> Usually, the presumption is unspoken and therefore is difficult to challenge directly.

In the case of Robert, however, this unfair presumption was raised overtly. Robert's case illustrates many of the problems a parent experiences in seeking reunification with a child who has been in foster care. Robert came to the Project seeking the return of his two-year-old daughter from foster care. She had been living with her mother's aunt in kinship foster care since her birth. Although Robert had been visiting with his daughter regularly and had been drug-free for more than two years, the foster care agency had done little to make preparations for Robert to be reunified with his daughter. In addition, both the foster parent and foster care worker had made several comments to Robert indicating that they did not think the child should live with him because he was HIV-positive; they were concerned that he could not care adequately for his daughter.

The Project opposed the agency's petition to extend foster care placement in court, and helped Robert to document his efforts to prepare for his daughter's return, which included counseling and acquiring parenting and homemaking

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158. See generally Mark Hardin, *Legal Placement Options to Achieve Permanence for Children in Foster Care*, in FOSTER CHILDREN IN THE COURTS 128, 128-92 (Mark Hardin ed., 1983) (explaining the movement to enact laws that ensure children stability in permanent settings); John J. Musewicz, *The Failure of Foster Care: Federal Statutory Reform and the Child's Right to Permanence*, 54 S. CAL. L. REV. 633, 633-765 (1981) (discussing federal reforms designed to ensure a child's right to a "healthy and secure" family environment).

159. See 42 U.S.C. § 675 (1994).

160. See 42 U.S.C.A. § 675(5)(B), (C) (West Supp. 1997).

161. This additional scrutiny may seem fair since parents in foster care cases either have placed their children in foster care voluntarily or have been determined to have abused or neglected their children. In fact, the standard in foster care cases is less strict than in custody cases that look at the best interests of the child. The stated standard of review is lower than in a custody battle between two parents, but in practice, there is far greater scrutiny in these types of cases. In New York foster care cases, for example, the state must prove that returning children to their parents would not place them in imminent danger of becoming neglected. See N.Y. FAM. CT. ACT § 1031 (McKinney 1983 & Supp. 1997-1998).

162. See Felicia R. Lee, *Difficult Custody Decisions Being Complicated by AIDS*, N.Y. TIMES, Mar. 4, 1995, at A1 (discussing the foster care system's reluctance to return children to HIV-infected parents).

163. See *id.*

services. In court, the foster care agency did not raise Robert's HIV status as a barrier to returning the child. The judge consequently examined the only relevant issue in the case—Robert's fitness as a parent—and he was able to regain custody of his daughter. Without aggressive advocacy, Robert likely would have been unsuccessful in challenging the foster care agency in court.

While a parent's future health status and possible death may be used inappropriately in a particular case, these issues are relevant in foster care and custody cases.<sup>164</sup> It is important to inquire about the child's long-term stability and to ask whether the parent has an appropriate plan in place for the child's future. Although HIV-positive parents should not be held to a higher standard than other parents whose futures likewise are uncertain, parents faced with a terminal illness nonetheless can benefit from developing such plans. Parents should never be denied custody because their children may be taken care of by someone else in the future. At the same time, parents should be prepared to show that they have a viable plan in place for their children and to demonstrate that custody and visitation arrangements are consistent with that future custody plan. For example, if the plan stipulates that a cousin will have custody of the children, it is helpful to show how the cousin currently is involved in the children's lives. If a parent has a plan in place, the issue of the child's permanency should never be a barrier to obtaining or maintaining custody.

The emotional effect of a child's exposure to her parent's illness is another factor often raised in court to deny or limit custody or visitation.<sup>165</sup> These allegations are very difficult to challenge because emotional harm to a child is undoubtedly a relevant consideration in custody and visitation cases. Yet the fact that the parent's illness causes the children pain should not be the basis of a custody decision.<sup>166</sup> The inquiry into the child's emotional response to illness or death should be even less relevant in cases where the legal standard is the fitness of a parent, rather than the broader standard of "best interests."<sup>167</sup> The parent should be required to show only that they are dealing with the emotional difficulties the children may be experiencing, for example, by facilitating therapy or counseling for the children. The HIV advocate should be prepared to demonstrate through expert psychological testimony that while witnessing the illness of a parent may be difficult emotionally, removing the child from the parent, or hiding the illness, may cause even more harm to the child.<sup>168</sup> Further, the advo-

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164. The possibility or likelihood of a parent's death is a difficult consideration for courts and other parties to raise directly. It is important for HIV advocates to recognize that even if this issue is not raised, it may be relevant and therefore it is important to confront it directly.

165. See Melvin Lewis, *The Special Case of the Uninfected Child in the HIV-Affected Family: Normal Developmental Tasks and the Child's Concerns About Illness and Death*, in FORGOTTEN CHILDREN OF THE AIDS EPIDEMIC 50, 51 (Shelley Geballe et al. eds., 1995) (suggesting that in some circumstances a child of an HIV-positive parent "may only develop an insecure or anxious attachment to the caretakers and a limited sense of self-worth").

166. See *John T. v. Carraher*, 538 N.W.2d 761, 772-73 (Neb. Ct. App. 1995) (holding that the Department of Social Services could not remove a child from his foster home because of his foster mother's HIV-infection).

167. See *supra* note 33 (discussing the differing legal standards for custody).

168. See *Steven L. v. Dawn J.*, 561 N.Y.S.2d 322, 324 (N.Y. Fam. Ct. 1990) (describing a doctor's testimony that when a parent is dying, custodial changes should be minimized to prevent further harm to the child).

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cate should argue that it may be in the child's best interests to remain with the parent so that the child can process her loss with the parent instead of on her own after the parent's death.<sup>169</sup>

The relationship between the parent's illness and the child's reaction to it is more complex when the child expresses that she does not want to live with, or visit, an HIV-positive parent. Although the child's preference is only one factor to be considered in a custody case, that preference could play a deciding role.<sup>170</sup> Courts must consider whether the child is of sufficient age and maturity to make an intelligent choice,<sup>171</sup> must ascertain the child's preference, and must give an appropriate weight to the preference. Naturally, the older a child is, the more likely the judge will consider the child's wishes as a factor.<sup>172</sup>

Although the child's wishes regarding custody is not an issue raised solely in HIV cases, it is brought up frequently in these cases and fosters unique concerns. In HIV-related cases, the child's wishes are influenced, and often confused, by a fear of the parent's illness and possible death, as well as by feelings of anger and guilt about the parent's illness and, in some cases, possible substance use. The feelings of children whose parents have AIDS are complicated by the stigma of AIDS as socially unacceptable. These powerful and confusing feelings warrant the intervention of a professional to help the child sort out these emotions.

The role of the HIV advocate in these cases is to insist that the court and other involved parties look more deeply into what the child is saying to examine other issues that may be present. The best strategy is for the advocate to arrange therapy for the child, or for the parent and child, if possible. Therapy will give children the opportunity to express their feelings of fear and anger to their parents, which they otherwise may not be able to do. In Eleanor's case,<sup>173</sup> her child's wishes could have determined the outcome of the case even though he was only twelve years old and was experiencing great difficulty watching his mother suffer without the benefit of counseling. Whether the child wants to be removed or not, it is not always in a child's best interests to be removed from a dying parent.<sup>174</sup>

## VII. ADVANCES IN HIV TREATMENT: WHERE DO WE GO FROM HERE?

For the first time since the start of the HIV epidemic, there has been a radical change in the information the public is receiving about HIV. In the past year,

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169. See Cooper, *supra* note 30, at 77-78.

170. See MCCAHEY ET AL., *supra* note 4, § 12-5.

171. In the author's experience, judges seriously consider the wishes of children as young as four or five.

172. See MCCAHEY ET AL., *supra* note 4, § 12-5.

173. See *supra* notes 152-55 and accompanying text.

174. See MCCAHEY ET AL., *supra* note 4, §§ 12.5-.9 (discussing the considerations used to evaluate a child's decision about guardianship); see generally CLAUDIA L. JEWETT, HELPING CHILDREN COPE WITH SEPARATION AND LOSS (1982) (providing a guide for parents to help their children through losses such as divorce and death).

publicity about HIV has focused primarily on advances in new HIV treatments<sup>175</sup> and has contributed to a decrease in the death rates among people with AIDS.<sup>176</sup> The evidence clearly shows that people with HIV are living longer and healthier lives as a result of both these new treatments and advances in prophylactic treatment of opportunistic infections.<sup>177</sup> Although many people with HIV/AIDS will not benefit from the new treatments,<sup>178</sup> there is overall agreement that the management of HIV disease is improving for most HIV-positive people in the United States.<sup>179</sup>

In the face of these positive changes, the renewed sense of hope and optimism in the HIV community cannot be overstated. HIV is now considered by many as a "chronic" illness instead of a "terminal" illness.<sup>180</sup> It is clear from the medical progress in treating HIV that the illness is changing; the approaches and strategies of HIV advocates in these cases also must change. The new medical advances potentially will have a positive impact on HIV-related custody, visitation, and foster care cases. Courts and child protective workers may be less likely to presume that a parent will become sick and die, and less likely to deny parents custody on the basis of their HIV status. HIV advocates also can use the new information about HIV, coupled with progress in treatment, to lessen the potential harm of a parent's HIV status on the children.

While these developments are encouraging for the HIV community as a whole, the fact remains that the rate of HIV infections and the need for services continue to increase.<sup>181</sup> The advances also have had less of an impact on poor HIV-positive women, who are most likely to be involved in HIV-related custody, visitation, and foster care cases. In addition, while AIDS-related death rates are

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175. See, e.g., David W. Dunlap, *Hype, Hope and Hurt on the AIDS Front Lines*, N.Y. TIMES, Feb. 2, 1997, § 4, at 3; John Leland, *The End of AIDS? The Plague Continues, Especially for the Uninsured, But New Drugs Offer Hope for Living with HIV*, NEWSWEEK, Dec. 2, 1996, at 64.

176. See Kim Painter, *AIDS Deaths Drop 13% in First Decline*, USA TODAY, Feb. 28, 1997, at 1A; Oscar Suris, *AIDS Deaths Drop Significantly for First Time*, WALL ST. J., Feb. 28, 1997, at B1. Since the first reports of a 13% decrease in the death rate, the CDC has reported that the death rate decreased by 23% from 1995-96. See Centers for Disease Control & Prevention, *supra* note 16, at 863.

177. See Jill A. Cadman, *Some Relief from the Epidemic*, GMHC TREATMENT ISSUES, Mar. 1997, at 1.

178. Some people cannot take the new treatments because of the side effects. See Andrew Jacobs, *The Diagnosis: H.I.V.-Positive*, N.Y. TIMES, Feb. 2, 1997, at B1 (noting that "[b]etween 10 and 30 percent of those who take the grueling course of new AIDS medications fail to respond"); Joe Nicholson & Dave Saltonsall, *For Some, New AIDS Drugs Only a Cure for Hope*, N.Y. DAILY NEWS, Feb. 2, 1997, at News 20. Many cannot afford the new drugs. See Robert Pear, *Expense Means Many Can't Get Drugs for AIDS*, N.Y. TIMES, Feb. 16, 1997, at A1. Others are denied the drugs by doctors who believe their patients cannot comply with the rigorous treatment schedules. See Deborah Sontag & Lynda Richardson, *Doctors Withhold HIV Pill Regimen from Some: Failure to Follow Rigid Schedule Court Hurt Others, They Fear*, N.Y. TIMES, Mar. 2, 1997, at A1. The HIV community also recognizes that the long-term benefits of the new treatments are not known. See Jacobs, *supra*, at B1.

179. See Suris, *supra* note 176, at B1.

180. See Lawrence O. Gostin, *Preface: Hospitals, Health Care Professionals, and Persons with AIDS to AIDS AND THE HEALTH CARE SYSTEM 3, 3-4* (Lawrence O. Gostin ed., 1990); Jacobs, *supra* note 178, at B1.

181. See Julie Makinen Bowles, *Positive Strides, Uphill Climb in AIDS Fight*, WASH. POST, Sept. 22, 1997, at D1 (reporting that AIDS service organizations' caseloads "are growing as HIV-positive people live longer and seek more services"); Liz Willen, *AIDS Overload: City Struggles to Handle Cases*, N.Y. NEWSDAY, Feb. 2, 1997, at A3.

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decreasing, they are doing so at a much slower rate for women.<sup>182</sup> Despite the fact that death rates are decreasing, HIV-positive individuals are still dying prematurely in large numbers,<sup>183</sup> and the rate of new HIV infections continues to rise for women.<sup>184</sup> Moreover, the evidence shows that women are diagnosed with HIV later than men and are less likely to get medical care.<sup>185</sup>

The impact of these advances on the way in which attorneys will represent HIV-positive parents in custody and foster care cases is unclear. In the short term, the effect is likely to be minimal. Thus far, HIV social service providers in high incidence areas have experienced an increase in the number of people seeking assistance.<sup>186</sup> In addition, poor women of color with HIV are less likely to benefit from the advances.<sup>187</sup> Most important, in individual cases where a parent has advanced illness and is suffering from HIV-related symptoms, the many challenging issues that an HIV advocate faces will be unchanged by the advances. For the present, attorneys representing HIV-positive parents in Family Court must continue to find new and effective ways to deal with the difficult issues raised by these cases.

## VIII. CONCLUSION: RECOMMENDATIONS FOR HIV ADVOCATES

One of the first law review articles written on HIV and child custody recommended guidelines for making HIV-related custody decisions that are no less relevant ten years later.<sup>188</sup> In that article, the commentator suggested that courts should not deny custody to HIV-infected parents on the basis of their HIV status alone.<sup>189</sup> In determining the best interests of a child whose parent is HIV-infected, the commentator recommended that

[f]irst, a court should calculate the best interests of the child without reference to the parent's HIV infection; second, it should obtain current information about the diagnosis, transmissibility, and symptoms of HIV infection; third, it should solicit a qualified physician's diagnosis of the parent's present health and probable life expectancy, based on the clinical symptoms of HIV infection; and, fi-

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182. When the CDC initially announced in February 1997 that the death rate for AIDS victims had gone down, the death rate had actually gone *up* by 3% for women. See Cadman, *supra* note 177, at 1. More recently, the CDC announced that while the death rate finally has gone down for women, it has gone down by only 10%, compared to a 25% reduction in the death rate for men. See Centers for Disease Control & Prevention, *supra* note 16, at 863 tbl.1.

183. HIV infection remains a leading cause of death among persons aged 25-44 years. See Centers for Disease Control & Prevention, *supra* note 16, at 866. In New York City alone, of the 15,912 individuals diagnosed with AIDS in 1995 and 1996, 3965 (about 25%) had died by March 1997. See AIDS SURVEILLANCE UPDATE—NEW YORK CITY, *supra* note 19, at 3 tbl.3.

184. See Centers for Disease Control & Prevention, *supra* note 16, at 863 tbl.1 (noting that the AIDS incidence for women increased by two percent in 1995-1996 while it decreased for men by eight percent).

185. See George F. Lemp et al., *Survival for Women and Men with AIDS*, 166 J. INFECTIOUS DISEASES 74, 75-78 (1992) (discussing a study showing a lower survival rate for women than for men with AIDS).

186. See Bowles *supra* note 181, at D1; Willen, *supra* note 181, at A3.

187. See Kathleen A. Ethier et al., *For Whose Benefit? Women and AIDS Public Policy*, in WOMEN AND AIDS: COPING AND CARE 207, 221 (Ann O' Leary & Loretta Sweet Jemmott eds., 1996).

188. See Mahon, *supra* note 3, at 1138-41.

189. See *id.* at 1138.

nally, it should make specific findings as to how the HIV positive parent's health affects the best interests of the child.<sup>190</sup>

While these recommended guidelines remain pertinent, HIV practitioners must move beyond them based on experience with the HIV epidemic in the past decade and with an understanding of how cases in Family Court actually are resolved.

The most significant recommendation in these guidelines encourages judges to conduct individualized assessments about the impact of the parent's HIV status on the children in deciding these cases. For the HIV advocate, the challenge is to convince judges not to make decisions based on their initial judgment about the case, but to make reasoned decisions based on both the facts and the appropriate legal standard. As noted above, this effort particularly is challenging in jurisdictions where judges face overcrowded and stressful courtrooms.<sup>191</sup>

Another significant recommendation is to present judges with information about HIV. Even today, there remains a lack of knowledge and a great deal of misinformation about HIV. The guidelines call upon judges to solicit the opinion of a "qualified physician,"<sup>192</sup> presumably the treating doctor if one exists, regarding the parent's health and life expectancy. Psychological testimony often is much more critical than medical testimony in these cases. Doctors rarely are able to predict a patient's life expectancy with any accuracy, and they have little ability to comment on a parent's physical capacity on a day-to-day basis. While medical testimony may be important evidence that a patient's condition is under control, and that the parent is complying with recommended treatment, psychological testimony, especially if given by a professional working with the family, is more valuable in showing how a parent and children are coping with, and adapting to, the illness.

It is not realistic to expect judges to calculate the best interests of a child "without reference" to the person's HIV status, as the guidelines suggest.<sup>193</sup> While this may be possible when an HIV-positive litigant is asymptomatic, the most difficult cases faced by HIV practitioners are those in which the party is suffering from HIV-related illnesses. In such situations, it is impossible to evaluate the case without reference to the individual's HIV status. Moreover, in most cases, even those in which the party is asymptomatic, the parent's HIV status does have *some* impact on the children.

Finally, the guidelines fail to address the issue of substance abuse, which is a prevalent issue in many of these cases. Practitioners should be diligent in insisting that judges make individualized assessments and do not simply invoke subjective feelings based on a parent's history of substance abuse.

Most important, attorneys must develop systemic strategies to address the problems raised by HIV-related custody cases. Unless attorneys can influence the system as a whole, these cases will continue to be decided based on the sub-

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190. *Id.*

191. See THE FUND FOR MODERN COURTS, *supra* note 10, at 6, 9 (detailing some of the hurdles that advocates must overcome in Family Court in New York City).

192. See Mahon, *supra* note 3, at 1138.

193. *Id.* The guidelines do suggest that HIV infection ought to be considered last to ensure that this factor is not overemphasized. See *id.* at 1139.



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jective decisions of the judge who happens to be hearing the case. First, HIV advocates should address the ways in which the Family Court process generally has a harmful impact on HIV-positive litigants. As discussed above, much of the damage to HIV litigants in Family Court derives from problems within the system as a whole. As with other issues, such as the delivery of health care services, the treatment of HIV-positive individuals in the Family Court system demonstrates how the system does not function properly. In the case of family law, HIV advocates can work with other family law advocates to illustrate the harmful impact of limited resources, overcrowded conditions, time delays, and confidentiality breaches on the low-income poor people whom the court primarily serves.

A second goal for HIV advocates is to ensure that HIV-positive litigants, where possible, have attorneys who are experienced in working with this population. HIV-positive individuals should have access to attorneys who understand HIV-related medical and psychosocial issues, who are comfortable working with HIV-positive individuals, and who have access to, and relationships with, experts in the field. Judges should be encouraged to refer clients to HIV experts, and attorneys should ensure that HIV-positive litigants in Family Court are aware of all potential resources.

A third goal for attorneys who represent HIV-positive individuals is to work with judges, Family Court administrators, law guardians, and court-appointed counsel to address HIV-related issues outside of the individual cases. The potential areas that should be explored include developing policies and procedures that ensure the confidentiality of HIV-related information, instituting the training of judges, lawyers, and law guardians on HIV-related discrimination issues, and establishing guidelines for HIV-related cases that recognize the importance of resolving these cases as quickly as possible. The possible solutions to these issues, of course, will vary by jurisdiction.

Finally, attorneys need to work with other professionals to develop needed research and to secure access to expert medical and psychological testimony to aid judges in deciding HIV-related cases. Although sufficient evidence exists regarding how HIV is transmitted, there has not been enough research, and little documentation is available, on the impact of parents' terminal illness on their children and how such exposure will affect the children in the long term. By working closely with psychological experts, attorneys will be able to help develop the psychosocial expertise that judges need to decide these cases fairly, both for children and their parents.