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"BUT DO YOU HAVE TO TELL MY PARENTS?" THE DILEMMA FOR MINORS SEEKING HIV-TESTING AND TREATMENT

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INTRODUCTION

As the Acquired Immune Deficiency Syndrome (AIDS) epidemic progresses through its second decade in the United States, the virus is spreading more rapidly in new population groups. One of the groups in which the rate of growth is increasing is adolescents. The suggested approach to restraining the spread of the illness is to encourage voluntary, informed testing in order to identify those who are infected so that early medical treatment and social support services can be offered. The legal constraints placed upon minors' ability to consent to medical care[1] facilitates a devastating outbreak of the virus in the teen population. Whereas much of the public debate concerning prevention in the adolescent community has centered on the controversial issues of education and condom distribution, the ability for teen-agers to obtain HIV tests and treatment is also of paramount importance.

This Article discusses how the legal system can assist those battling the spread of HIV-infection among adolescents in the United States. This Article also discusses the evolving legal standards applied to the rights of minors—particularly in the area of health care consent—the research on the cognitive abilities of minors to make medical decisions, and the underlying assumptions embodied in the public policies requiring parental consent to obtain medical treatment. In addition, this Article addresses the role of medical providers and suggests the appropriate level of involvement. Finally, this Article suggests statutes that will encourage minors to seek HIV-testing and treatment.

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1. Medical care includes access to testing and treatment for Human Immunodeficiency Virus (HIV), the virus which the scientific community generally believes is the cause of AIDS.

I. An Outline of the Problem

A. Prevalence of Infection and Risk Behaviors Among Adolescents

A former United States Surgeon General recently expressed concern about the growing problem of AIDS in the adolescent community in our country.[2] She stated that 1,167 adolescents (ages thirteen-nineteen) with AIDS were reported in this country as of March 31, 1993.[3] The number of AIDS cases among persons aged thirteen to nineteen who contracted the virus through heterosexual transmission increased 65% between 1991 and 1992.[4] For adolescent males, 33% became infected by having sex with an infected male, and for adolescent females, 50% became infected through heterosexual contact, and 23% acquired the virus by injecting drugs.[5] These totals do not include the number of teen-agers infected with HIV, but not yet diagnosed with AIDS itself. Because a person can be infected with the virus for ten years or longer before developing full-blown AIDS, it is likely that several of those adults aged twenty to twenty-nine with a diagnosis of AIDS were infected while in their teens.[6] Approximately 20% of AIDS cases occur in this latter age group.[7] As these statistics demonstrate, HIV-infection among this country's youth is a problem of growing significance.

When one looks at the high risk behaviors[8] teen-agers engage in, there is additional cause for alarm. Several studies indicate that high-risk sexual behavior continues in this age group and may even be increasing.[9] A significant number of teen-agers engage in sexual activity: roughly half by the age of nineteen, including 60% of white urban females and 80% of black urban females.[10] 19% of high-schoolers report having had at least four sexual partners dur-

2. Antonia Novello, *Let's Deal With Reality of Teens and AIDS*, Miami Herald, Oct. 31, 1993, at 5M.

3. *Id.*

4. Nat'l Comm'n on AIDS, AIDS: An Expanding Tragedy, The Final Report of the Nat'l Comm'n on AIDS 6 (1993).

5. Novello, *supra* note 2.

6. Lawrence S. Friedman et al., *A Survey of Attitudes, Knowledge, and Behavior Related to HIV Testing of Adolescents and Young Adults Enrolled in Alcohol and Drug Treatment*, 14 J. Adolescent Health 442 (1993).

7. Leo Morris et al., *Measuring Adolescent Sexual Behaviors and Related Health Outcomes*, 108 Pub. Health Rep., Supp. 1, at 31 (1993).

8. Although it is difficult to quantify with exactitude the risk encountered with various behaviors, for the purpose of this essay, high risk behavior refers to unprotected sexual activity with another person and needle sharing by persons injecting drugs.

9. Mary L. Keller, *Why Don't Young Adults Protect Themselves Against Sexual Transmission of HIV? Possible Answers to a Complex Question*, 5 AIDS Educ. & Prevention 220, 221 (1993).

10. Karen Hein, *AIDS in Adolescence: Exploring the Challenge*, 10 J. Adolescent Health 10S, 22S (1989).

ing their lifetime.[11] Even more troubling, one study found that only 29% of sexually active teens consistently use condoms.[12] Not surprisingly, the rate of sexually transmitted diseases (STD) among young persons is also increasing dramatically. The Centers for Disease Control (CDC) reports that major increases in the incidence of gonorrhea among ten to fourteen year-olds (41% among males and 51.2% among females) occurred between 1981 and 1991.[13] The CDC notes that infection with gonorrhea and other STDs may be a co-factor for the heterosexual transmission of HIV and therefore, could result in dramatic increases in HIV acquisition.[14] The CDC also reports that in some regions of the United States, the highest rates of gonorrhea are among fifteen to nineteen year-olds.[15] Overall, between 24% and 30% of reported gonorrhea cases are among adolescents.[16] The transmission of STDs is a clear sign of unprotected sexual activity.

Teen-agers also use mood-altering substances in significant numbers. 90% of high school students have used alcohol, nearly four in ten have tried marijuana, one in ten have tried cocaine, and one in twenty have experimented with crack.[17] Although drugs which are not injected do not directly "cause" HIV-infection, the use of such substances can decrease inhibitions which leads to high-risk behaviors. One study of young college students found that drug or alcohol use was a factor in 25% of the cases when students engaged in sexual intercourse without a condom (a majority of the respondents indicated at least one unsafe episode).[18]

This combination of sobering statistics resulted in the former Surgeon General advocating that all states permit minors to consent for HIV-testing.[19] Public health officials believe that individuals who are unable or unwilling to eliminate high-risk behaviors should have themselves tested for HIV-infection on a regular basis. Currently, eleven states, by statute, permit minors to consent for HIV-testing and ten others authorize minors to consent for diagnosis and treatment.[20] Even among the latter states, however, restrictions sometimes apply. In conjunction with the tests, youngsters need to receive counseling, and for those who are posi-

11. Novello, *supra* note 2.
12. Larry K. Brown et al., *Predictors of Condom Use in Sexually Active Adolescents*, 13 J. ADOLESCENT HEALTH 651 (1992).
13. Centers for Disease Control, *Special Focus: Surveillance for Sexually Transmitted Diseases*, 42 MORBIDITY & MORTALITY WKLY. REP. No. SS-3, at 1, 4 (Aug. 13, 1993) [hereinafter CDC].
14. *Id* at 11.
15. *Id.*
16. *Id.* at 2.
17. Novello, *supra* note 2.
18. Keller, *supra* note 9, at 230.
19. Novello, *supra* note 2.
20. Novello, *supra* note 2.

tive, a treatment regimen that includes appropriate mental health services.

The counseling provided in conjunction with the test should include an explanation of the results, the transmissibility of the virus via sexual and drug use behaviors, and the confidentiality of the information. Shockingly, 47% of adolescents who are tested for HIV do not return for their results.[21] There are many reasons why persons tested for HIV do not return for their results, all of which need to be addressed. This is a problem which warrants study so that the number of teens who seek tests, many of whom presumably engage in behaviors which put them at risk for infection, can be significantly increased. Assurance of confidentiality is one important factor. One study found that 84% of adolescents and young adults in a substance-abuse rehabilitation program would agree to HIV-testing if the test were anonymous and confidential.[22]

An even more significant problem arises for the youth who requires treatment, particularly if the youth's parents are unaware of the diagnosis, because the cost of treatment is prohibitive. Early treatment for HIV-infected individuals is generally recommended by medical practitioners. In addition, the need for counseling may require ongoing mental health services. A method of reimbursement for the necessary medical and counseling services is of critical importance to an adolescent. To effectively assist all adolescents, some need access to care without parental notification.

B. Diversity of the Adolescent Population

One of the problems in offering testing and treatment services to adolescents is the tendency of the legal system to view minors as part of an idealized middle-class model of the nuclear family where parents always act in the best interests of their children. Regardless of the merits of such a family system, the reality of contemporary American society is that many young persons exist in a situation which varies, sometimes to dramatic degrees, from this model. The author of this Article directs a Civil Clinic program which includes a project for severely abused and neglected children. Its clients are children who have had bones broken, been severely burned, or sexually abused by parents and/or their parent's partners. One client was a ten-year old who was impregnated by her mother's lover. Allegedly, this individual also sexually abused her older sister, now a run-away whose whereabouts are unknown. Many of these children not only have low self-esteem, but also, are left in a foster care system with woefully-inadequate resources to

21. *Id.*
22. Friedman et al., *supra* note 6, at 442.

address their psychological trauma. Thus, these children are likely candidates to engage in high-risk behaviors.

It is difficult to estimate the number of abused children, particularly with certain types of abuse. One study of adolescent males noted the broad range of prevalence rates for sexual abuse found in various studies, ranging from 3% to 50%.[23] The variations depend upon where the statistics are gathered and what questions are asked.[24] The consequences of abuse are severe and include depression, self-destructive behavior, inappropriate sexual behaviors, behavioral risk-taking, substance abuse, and suicide attempts.[25] A study which surveyed 84% of Minnesota ninth and twelfth graders found that 4% of white males and 18% of white females and 15% of black males and 29% of black females suffered sexual abuse.[26] In addition, 8% of white males, 15% of white females, 20% of black males and 19% of black females reported being beaten at home.[27] Significantly, the investigators found that abuse was an important moderating factor affecting increased risk-taking behaviors among adolescents, including drinking before having sex.[28] The authors note that their study probably underestimates the problem because it does not include adolescents who dropped out of school.[29] Nor does the study include homeless male youth, who "have disproportionately high rates of multiple abuse histories, including neglect, most of which was never reported to authorities; often, males who run away specifically do so to avoid abuse at home."[30]

In addition to children victimized by their biological families and other adults, there is another large group of adolescents often ignored by society because of moral and religious objections to acknowledging their existence: gay and lesbian youth. Although lesbians constitute one of the lowest HIV-risk groups[31] in American society, young gay males are vulnerable to engaging in behaviors which place them at risk of infection. Researchers found that the

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23. Jeanne T. Hernandez et al., *The Effects of Child Abuse and Race on Risk-Taking in Male Adolescents*, 85 J. NAT'L MED. 593 (1993).
24. *Id.*
25. *Id.* at 594-95.
26. *Id.*
27. *Id.* at 595.
28. Hernandez et al., *supra* note 23, at 595.
29. *Id.*
30. *Id.* at 596 (quoting M. Nasjleti, *Suffering in Silence: The Male Incest Victim*, 59 CHILD WELFARE 269 (1984)).
31. The author mentions risk groups recognizing the dangers of the use of these terms. Individuals are placed at risk for HIV infection by their own behavior, not their association with a group of persons with the same trait or characteristic. Thus, a heterosexual male who engages in intercourse without a condom with multiple partners is at higher risk than a monogamous gay male whose partner is also HIV negative. Nonetheless, in part because of the way that the HIV virus is transmitted, lesbians as a group have a relatively low rate of HIV infection.

age at which most gay men acknowledge their homosexuality is between fourteen and sixteen years of age, and lesbians, between sixteen and nineteen years of age.[32] This acknowledgement often leads to familial strife. One study found that parents of one-half of all lesbian and gay youth rejected the youth due to sexual orientation.[33] Thus, 26% were forced to leave home because of conflicts with family over sexual identity.[34] Such rejection can lead to situations in which high-risk sexual activities or substance abuse is more likely.

II. THE LEGAL RESPONSE TO THE PROBLEM

A. The Issue of Informed, Voluntary Consent

Minors' ability to consent to health care raises issues which legal scholars, policy makers, and social scientists are debating in an attempt to balance the interests of individual freedoms for minors versus family autonomy and integrity. One commentator has argued that American society is evolving to the detriment of children from a "modern" era perception of children as innocent and teenagers as immature, to a "postmodern" era where children are considered competent and teenagers as sophisticated.[35] Using this construct, increasing minors' autonomy to make medical decisions increases the likelihood that they will seek treatment for a disease with the social stigma of AIDS. Studies indicate a number of factors which influence capacity and autonomy in making decisions including cultural contexts, role identities, institutional settings, family context, peer approval, and the nature or gravity of a decision.[36] Thus, it has been found that whereas peer approval may be more important for present-oriented mundane decisions, parental advice is usually sought for future-oriented, life-determining decisions.[37] One study of medical decision-making by children, adolescents, and young adults found that parents continue to influence medical treatment decisions, but the degree of influence may change with the gravity of the medical decision.[38] Some studies indicate that response to adult influence compromises free choice by

32. MARCEL SAGHIR ET AL., MALE AND FEMALE HOMOSEXUALITY (Williams & Wilkins, 1973).

33. Gary Remafedi, *Male Homosexuality: The Adolescent's Perspective*, 79 PEDIATRICS 326 (1987).

34. *Id.*

35. David Elkind, *The Law and Postmodern Perceptions of Children and Youth*, 69 DEN. U. L. REV. 575, 578-79 (1992).

36. David G. Scherer, *The Capacities of Minors to Exercise Voluntariness in Medical Treatment Decisions*, 15 LAW & HUMAN BEHAV. 431 (1991).

37. *Id.* at 434.

38. *Id.* at 442.

minors.[39]

The mental health setting already recognizes that parental consent is often precluded where minors need mental health assistance, especially with at-risk minors.[40] As some social scientists note, the presumption by the legal system that parents will act in the best interests of their children runs counter to the experience of the mental health profession which often sees parents make determinations based upon their own belief systems, preferences, and life-styles.[41] In discussing judicial deference to parental authority and the opinion of Justice Kennedy in *Hodgson v. Minnesota*,[42] two mental health clinicians stated:

> What is most unfortunate is the position that holds the primacy of the family and the presumption that parents will always act in the interest of their children, and consequently sets Supreme Court precedents that can restrict competent, mature adolescents from procuring treatment in their own interest. There may be thousands of adolescents who are victims of both the court system as well as their parents being unable to exercise decisions on their behalf or in their interest. These adolescents are in a sense discriminated against when court rulings consider them the exception.[43]

B. The Evolving Legal Rights of Minors

At common law, minors needed parental consent to obtain medical care.[44] Some state statutes now provide exceptions to that rule.[45] Case law also increasingly recognizes the legal rights of minors.[46] One legal commentator notes the following trends in family law jurisprudence which he finds contradictory to each other: a growing emphasis on privacy and individual rights and a gradually increasing involvement of the legal system into the internal functioning of the family.[47] These trends, however, contribute to the emerging notion that children are entitled to their own legal rights as individuals separate from their status as family members. It is

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39. John M. Shields & Alf Johnson, *Collision Between Law and Ethics: Consent for Treatment with Adolescents*, 20 BULL. AM. ACAD. PSYCHIATRY L. 309, 313 (1992).

40. *Id* at 309.

41. *Id* at 314.

42. 497 U.S. 417 (1990).

43. Shields & Johnson, *supra* note 39, at 318.

44. Zoski v. Gaines, 260 N.W. 99 (Mich. 1935).

45. *E.g.*, ALA. CODE § 22-8-4 (1993) (14 yrs. old); ALA. CODE § 22-11A-19 (1993) (12 yrs. old for treatment of sexually transmitted diseases); CAL. CODE § 34.5 (West 1993) (Deering) (for medical care for pregnancy); N.Y. PUB. HEALTH LAW § 2504 (4) (McKinney) (in emergencies); OR. REV. STAT. § 109.640 (1991) (15 or older); MISS. CODE ANN. § 41-41-3(h) (1992).

46. *E.g.*, Breed v. Jones, 421 U.S. 519 (1975); Goss v. Lopez, 419 U.S. 565 (1975); Tinker v. Des Moines Sch. Dist., 393 U.S. 503 (1969); Planned Parenthood of Cent. Mo. v. Danforth, 428 U.S. 52 (1976).

47. Steven Mintz, *Children, Families and the State: American Family Law in Historical Perspective*, 69 DEN. U. L. REV. 635, 636 (1992).

clear that a minor possesses some constitutional rights in spite of his age.[48] Nonetheless, some restrictions will still be permitted where circumstances warrant. In the medical area, the United States Supreme Court has struggled most with this conflict of competing interests in the area of minors seeking abortions without parental consent.[49] The right of the state to protect the life of the fetus raises an issue which is not present in the HIV-testing and treatment areas, but some of the other issues overlap. In *Bellotti v. Baird*, the Court noted three factors courts consider that traditionally limited the rights of minors: (1) the peculiar vulnerability of children; (2) their inability to make critical decisions in an informed, mature manner; and (3) the importance of the parental role in child rearing.[50] As discussed in section C.1 of this article, the first two assumptions may be unwarranted. However, these cases do make clear that the state may not require parental consent without some type of alternative even for the minor seeking an abortion.

The degree to which family integrity is protected varies depending upon the other interests at stake. At least one legal commentator has opined that the Court's decision in *Ohio v. Akron Center*[51] is inconsistent with its decision in *Cruzan v. Director, Missouri Department of Health*,[52] in which the Court refused deference to the parents of a thirty-two year-old incompetent, comatose patient who sought to terminate artificial feeding.[53] Although various factors distinguish these cases, both address the role of the family in making medical decisions for one of its members. In discussing the amount of trust given to the family members in the two cases, one commentator states:

> Paradoxically, the same intimate association hailed as a source of profound philosophic enlightenment and tolerant respect for life in *Akron Center* was skeptically set aside in *Cruzan* in favor of the authority of anonymous strangers. The court appeared to promote family authority when it upheld a state's entitlement to restrict minors' access to abortion, but restrain family authority when it upheld a state's entitlement to block termination of life-support urged by parents.[54]

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48. *See, e.g., In re* Gault, 387 U.S. 1 (1967); Tinker v. Des Moines Sch. Dist., 393 U.S. 503 (1969).

49. *See* Hodgson v. Minnesota, 497 U.S. 417 (1990) (holding two parent notification requirement constitutional); Ohio v. Akron Ctr. for Reprod. Health, 497 U.S. 502 (1990) (holding parental/judicial consent requirement constitutional); Bellotti v. Baird, 443 U.S. 622 (1979) (holding parental/judicial consent to abortion by minor unconstitutional); Planned Parenthood of Cent. Mo. v. Danforth, 428 U.S. 52 (1976) (holding blanket requirement for parental consent to abortion unconstitutional).

50. *Bellotti*, 443 U.S. at 634.

51. 497 U.S. 502 (1990).

52. 497 U.S. 261 (1990).

53. Martha Minow, *The Role of Families in Medical Decisions*, 1991 UTAH L. REV. 1.

54. *Id.* at 11 (quoting Anita L. Allen, *Court Disables Disputed Legacy of Privacy Right*, NAT'L L.J., Aug. 13, 1990, at S8, S14).

As noted by Professor Minow, this "inconsistency" is a result of the fundamental ambivalence people feel about families. Traditionally, the law not only refused to recognize conflicts within families, it reinforced the authority of the head of household to govern and discipline the other family members.[55] However, this tradition is changing. The Professor noted one study in Massachusetts which found that every pregnant minor who sought an abortion through a court hearing obtained one.[56] In *Hodgson*, Justice Stevens discusses at length the District Court findings about the amount of violence and dysfunction in many American families.[57] He also notes that the judges who adjudicated the parental notification petitions under Minnesota's statute testified that there were no positive effects from the law.[58] Ultimately, Professor Minow argues for allowing the minor to make the decision for an abortion without parental or judicial intervention.[59]

C. Current Statutory Approaches

As noted above, some states have passed statutes which permit minors to be tested for HIV-infection, but most do not have specific provisions. The states which permit testing do so in a variety of statutes. Some statutes permit testing for sexually transmitted disease in general, while others specifically deal with HIV tests.[60] Some set a specific age, while others leave the determination to the discretion of the medical provider.[61] Some states permit minors to consent for medical treatment in general, which presumably includes HIV care.[62]

These statutory approaches must balance the concerns of various actors involved with this process. They include the minor, parents or guardians, the medical provider, and the state. Most still do not deal with all of the practical problems, the most serious of which is reimbursement for treatment expenses. HIV treatments are prohibitively expensive, but should start soon after the person

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55. *Id.* at 8.
56. *Id.* at 10.
57. *Hodgson*, 497 U.S. at 437-41.
58. *Id.* at 441.
59. Minow, *supra* note 53, at 8.
60. *E.g.*, ALA. CODE § 22-11A-19 (1987); ALASKA STAT. § 09.65.100 (4) (1993); ARIZ. REV. STAT. ANN. § 44732.01 (1992); MINN. STAT. ANN. § 144.343 (WEST 1989); NEB. REV. STAT. § 71-504 (1990) (venereal disease); FLA. STAT. ch. 384.30 (1993); N.C. GEN. STAT. § 130A-148 (West 1993); OHIO REV. CODE ANN. § 3701.242(B) (Anderson 1992) (HIV specified statute).
61. *E.g.* COLO. REV. STAT. § 13-22-105 (1989); WASH. REV. CODE ANN. § 70.24.110 (West 1992) (14 or older for STD's); VT. STAT. ANN. tit. 18, § 4226 (1992) (12 or older for venereal disease); FLA. STAT. ANN. § 38430 (West 1993) (discretion of medical provider).
62. *E.g.*, ALA. CODE § 22-11A-19 (1987); MISS. CODE ANN. § 41-41-3 (1992); LA. REV. STAT. ANN. § 40:1095 (West 1992).

discovers the positive test result. Absent the ability to obtain a payment source, the minor is trapped in the unenviable position of foregoing treatment or telling his parents. A delay in making this decision can result in harm to the minor and increase the risk that he will engage in behaviors which will transmit the virus to others. The long asymptomatic stage of HIV permits the minor to avoid taking any action for ten years or longer.

1. Age

Some statutes establish an age at which adolescents can consent.[63] There are a variety of ages at which society allows minors to engage in various activities, such as voting, driving, or drinking alcoholic beverages. Although age is clearly a relevant factor in determining cognitive functional ability and social development, it is questionable whether the designated ages are directly related to the scientific evidence on these matters. As the statistics on venereal disease indicate, children as young as ten engage in unprotected sexual behavior.[64] This is not to imply that engaging in sexual activity indicates the maturity to make decisions concerning the circumstances and consequences surrounding it. The age of consent laws for sexual activity make clear that the issue of maturity is still relevant in consenting to sexual activity. However, the need to protect youngsters from being misled by adults into harmful behavior is different from the need to allow young persons to protect their health by consulting with a medical provider whose purpose is to provide assistance. Therefore, the public health concerns of this epidemic warrant that additional weight be given to options which encourage minors to obtain testing and treatment services.

Although much of the current social science research concerning minors' ability to make health care decisions involves research on the ability to consent to abortion, it is still relevant in other medical contexts. The general consensus among social scientists is that no evidence supports the legal presumption that minors under eighteen are less competent on a cognitive level than adults to consent to abortions.[65] In determining capacity to consent, the following factors are considered: (a) understanding the nature and probable consequences of one's situation; (b) thoroughly considering consequences associated with each alternative, including risks and benefits; (c) comparing alternatives based upon evaluation of conse-

63. *See e.g.*, ALA. CODE § 22-11A-19 (1987); IDAHO CODE § 39-3801 (1971); 410 ILCS 210/4 (1993).

64. See *supra* notes 9-18 and accompanying text for a discussion of adolescent sexually transmitted disease rates.

65. Bruce Ambuel & Julian Rappaport, *Developmental Trends in Adolescents' Psychological and Legal Competence to Consent to Abortion*, 16 L. & HUMAN BEHAV. 129 (1992).

quences; (d) integrating personal values and goals; and (e) making a voluntary, proactive decision that is not overly influenced by others.[66] Naturally, there is considerable individual and ecological variation among minors of the same age. Cognitive and social capacities do not develop uniformly between individuals.[67] In addition, context-specific factors including domain-relevant knowledge and experience, cognitive problem solving skills, affect during decision making, and social support influence the decision-making capacity of any individual.[68] Studies indicate that there is no substantial difference in legal competence between older minors and legal adults.[69] Minors who reach middle adolescence are able to reason abstractly about hypothetical situations, reason about alternatives and consequences, consider multiple variables, and use information systematically to arrive at a decision.[70] One study of pregnant adolescents considering abortion found that minors age fourteen to seventeen are similar to adults in cognitive competence and volition.[71]

In analyzing age restrictions, it is not only useful to consider cognitive development, but also the normal social development of children at various ages. In addition to the abortion studies, there is also research on minors and general medical consent issues. For example, some research indicates that parental preferences heavily influence children making medical decisions at a certain age.[72] The consensus in the social science literature is that adolescents aged thirteen and older are capable of giving informed consent to medical care.[73] However, it is important also to remember that this social development may vary among economic and socio-cultural groups. These variations make flat age restrictions a problem when determining whether an adolescent may make a decision without parental involvement. Nonetheless, given that most adolescents have the cognitive ability to make medical decisions and often consult their parents, the presumption should be that a minor is capable of consenting.[74] This still leaves open the question of who has the power to determine when the presumption can be overcome.

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66. *Id* at 132.
67. *Id* at 133.
68. *Id.*
69. *Id.* at 150.
70. Ambuel & Rappaport, *supra* note 65, at 147-48.
71. *Id* at 148.
72. Scherer, *supra* note 36, at 434.
73. Shields & Johnson, *supra* note 39, at 314. *But see* Scherer, *supra* note 36, at 445.
74. Ambuel & Rappaport, *supra* note 65, at 150.

2. Parents, Guardians, and the State

Another issue concerning consent is the authority of the adult(s) legally responsible for the child. Barring a contrary custody order between parents (e.g., dissolution of marriage, paternity, etc.), most adolescents can obtain medical care with the consent of either parent. In addition, for children with appointed legal guardians, an individual will be designated to make medical decisions. The problems in these settings will vary, depending upon the relationship between the adolescent and the parent or guardian. Further complications arise where the child is caught in an unpleasant custody dispute between the parents. As many family law practitioners can attest, the best interests of the child are often lost in the struggle between parents who see the child as a powerful pawn in the battle to exact emotional revenge. Adolescents at the center of such emotional firestorms are in an emotionally precarious position. It is easy to understand that they would be vulnerable to engaging in high-risk behaviors. Such an adolescent also might feel reluctant to seek permission from a parent for HIV-testing or treatment if he suspects that it might initiate another round of accusations between the parents over proper supervision of the adolescent's sexual conduct.

The issue becomes even more complicated when the state is the legally-designated guardian for the adolescent. For children stuck in the foster care system, the ever-changing array of adults assigned to handle the child's case raises serious issues. Most statutes that address HIV-confidentiality for juveniles have a vague standard allowing for those who "need to know," persons involved in the placement and care of the child, to be informed of the child's HIV status.[75] These statutes provide insufficient limitations upon the discretion of the responsible state agencies. And although meant to protect the minor, these statutes unfortunately fail to recognize the inability of the state to always exercise good judgment in these situations. It is common to have funding for the state agency designated to oversee dependent children[76] be inadequate to guarantee a stable, highly-trained staff which carries appropriate caseloads. As a result, a constantly changing array of caseworkers often handle the case of a child in the foster care system. This turnover makes it difficult for the minor to develop a degree of trust in sharing his concerns with the caseworker. It also increases the number of persons with knowledge about the minor's HIV condition. As any caseworker who works with HIV-positive individuals can attest, the larger the number of persons who have access to a

75. *E.g.*, FLA. STAT. ch. 381.004(f)(11) (1992).

76. Dependency is the term often used to include children within the protective care of the state because of abuse, neglect, or abandonment.

person's HIV status, the more that person's confidentiality is at risk. Unfortunately, the need-to-know standard does not stop with the youth's caseworker. In the experience of the author, whose clinical program assists abused children and persons with AIDS, most caseworkers feel the need to inform the homes or institutions where the child is to be placed about the child's HIV status without respecting the child's confidentiality rights. Therefore, the information is often conveyed not only to the administrator and medical director of a facility, but also to individuals who have only casual contact with the child in the institution and therefore, have no need to be told about the youth's HIV condition. The author is aware of a mentally-handicapped teen for whom the caseworker was unable to obtain placement because he informed potential placements about the child's condition before obtaining a placement within the facility. Although this was illegal behavior by the facilities, the minors involved are unlikely to obtain the legal assistance necessary to enforce their rights. Ironically, the caseworker had not informed the youngster of his condition because he felt that the youth's mental handicap would prevent him from understanding the significance of his condition, a determination which the caseworker was unqualified to make. Thus, persons with no legal right to the information were aware of this young man's condition, but the young man himself was initially kept uninformed.[77]

Consequently, the requirement of parental consent for minors seeking HIV-testing and treatment does not always works in the best interests of minors. Even if it does operate to the best interest of some children, it is dubious to put at risk others harmed by such requirements. In addition, clear standards are needed when the state is the guardian of the child.

3. Health Care Providers

Absent giving the minor complete authority to consent to health care decisions, the legal system has developed alternatives in which other adults may provide consent for minors. In the abortion context, states have developed statutes which provide for judicial proceedings where a minor may seek judicial permission to have an abortion. As discussed above, judicial proceedings which allow the minor to petition the court for permission to avoid parental involvement are problematic.[78] First, there is the serious issue of obtaining legal assistance. Second, legal proceedings are sufficiently intimidating that many young persons would not take ad-

77. The young man was eventually informed of his HIV status after the intervention of an attorney who insisted that he was not only capable of understanding how to protect himself and others, but it was also his right to know.

78. See *supra* notes 49-57 and accompanying text for a discussion of judicial problems in addressing the minor's desire to avoid parental involvement.

vantage of the option even if legal help were available. Third, in the abortion context, the judiciary almost always grants the request, thus raising the concern that this significant barrier provides no benefit except to impede requests.

It would be more problematic to establish a judicial parental by-pass proceeding in the HIV-testing and treatment area. Unlike abortion cases, where the young woman will eventually have a baby if no action is taken, HIV issues can be ignored with no visible consequences for ten years or longer. Teens will more likely fail to seek an HIV test than go through a cumbersome legal proceeding to obtain permission for a test. Similarly, the teen may not seek expensive medical treatment while asymptomatic. Consequently, such teens are unlikely to obtain beneficial care or seek the guidance necessary to change behaviors so as to reduce the risk to others.

As indicated, some researchers believe that minors should be presumed competent unless the health care provider believes otherwise.[79] Some statutes leave the decision whether a parent should be informed to the medical provider.[80] This construct is preferable because it removes the decision from an adversarial legal setting to a health care setting.[81] Nonetheless, the failure to place restrictions upon medical providers in making the decision to test and treat a minor is not necessarily the best alternative. Although better than the situation in which there is no opportunity to circumvent parental consent, this option also presents difficulties. It presumes an objectivity and ability which is not always warranted. It requires the physician to determine the minor's competency to make the determination. Not all physicians are trained to understand the cognitive and social abilities of adolescents. The reliance upon the medical provider also seems to presume that the decision to be tested or treated is only a medical decision. The social and psychological implications of HIV are also significant, however, and it is perilous to ignore these dimensions of the issue. Particularly for testing, the minor may not even come into contact with a physician. Clearly, if the decision is left to the discretion of health care providers, some standards are needed to guarantee some semblance of uniformity of treatment between providers. These standards should outline the factors health care providers should review when determining whether treatment should proceed without parental involvement.

Cumbersome processes which dissuade minors from seeking medical assistance can be dangerous to the efforts to stem the spread of HIV in the adolescent population. The CDC cited the un-

79. Ambuel & Rappaport, *supra* note 65, at 150.
80. *E.g.*, ALA. CODE § 22-11A-19 (1987); 1989 KY. ACTS § 214.185.
81. *Id.* at 150.

availability of clinical services convenient to adolescents as a possible cause of the increase of STDs in the 1980's.[82] In addition, the CDC noted:

> More specifically, care is particularly fragmented for adolescents, and a lack of readily accessible services could have resulted in increases in the amount of time between exposure to an infection, awareness of the symptoms, and diagnosis and treatment. Furthermore, health professionals may not be likely to address issues of sexually transmitted infections or sexuality among adolescents. All these factors could have led to longer periods of untreated infection and consequently to increased transmission of sexually transmitted diseases among adolescents.[83]

For minors to receive treatment without parental consent, legal immunity must be explicit within the relevant statutes. In describing the reluctance of mental health practitioners to treat adolescents without parental consent, it has been noted:

> Despite that fact that review of the legal issues suggests that the mental health practitioner has relatively little to fear from the law in counseling minors without parental consent, most agencies and professional practitioners continue to follow cautious, conservative policies that err on the side of the law and the decision-making power of the parents, and perhaps against the best interest of the adolescent patient.[84]

This concern may be particularly significant in the HIV area where treatment may last several years.

4. Testing v. Treatment

It is arguable that different standards should be utilized in permitting minors to seek testing for HIV as opposed to treatment. While there is no cure for this illness, the need to encourage testing among all individuals exposed to the virus is a paramount goal in fighting the epidemic. Thus, policies which promote testing should emphasize conditions which maximize the willingness of persons to be tested.

A scheme which permits voluntary testing without voluntary treatment is defective. Therefore, a statute such as Louisiana's which permits physicians to treat venereal diseases on the minor's consent, but allows the medical staff to inform the minor's parent of the treatment over his express objection, will serve as a significant barrier to some adolescents.[85] Encouraging a person to seek diagnosis for a terminal illness, but placing barriers to obtaining treatment for that illness is poor policy. It places the juvenile, who is fearful of telling his parents, in a nearly untenable position. A juve-

82. CDC, *supra* note 13, at 10.
83. *Id.*
84. Shields & Johnson, *supra* note 39, at 321.
85. LA. REV. STAT. ANN. § 40:1065.1 (West 1970).

nile who faces abuse or being thrown out of the home for informing his parents of being HIV-positive (or being gay) is unlikely to be tested if he knows that he will be unable to receive treatment without parental involvement. For the state to place a minor in the position of being abused or made homeless in order to seek treatment seems an abrogation of its *parens patriae* powers.[86]

It is also insufficient for a statutory scheme to provide the minor with the legal authority to obtain medical treatment without providing resources for the minor to obtain treatment. In speaking to medical providers, the first question encountered is how the provider will be reimbursed for providing care to the minor if the provider can not tell the parent who pays for the minor's health insurance. Various studies estimate the treatment costs of AIDS to be $50,000 to $150,000 from the time of diagnosis to the time of a patient's death.[87] The theoretical solution to this problem may be politically unattainable in the current climate where there is a limit on government resources available to pay for services. Providing state reimbursement to the physician where private insurance is available is a response whose fiscal impact upon the state is unacceptable to many policy and political analysts. However, the ultimate financial and human cost of not providing medical care to juveniles who are HIV-positive will be even greater. The efforts to reform the health care system need to address this issue and provide a viable option for adolescents who fear that they may be HIV-positive.

It has generally been acknowledged that HIV-testing programs should provide counseling services to persons tested. Counseling should include an explanation of the meaning of test results and advice concerning necessary behavioral changes. In addition, it is critical that individuals who test positive receive information about support groups and psychological counseling due to the significant psychological impact of being diagnosed with a terminal illness. The general need for counseling assistance is even more critical for adolescents. Some researchers indicate that the profound psychological and behavioral impact upon teenagers is so significant that providers should assess the emotional stability and cognitive capabilities of the teenager prior to testing.[88] Those prone to engage in high risk behaviors may increase such behavior upon learning of HIV-positivity. One study of adolescents (thirteen to twenty-three year olds) enrolled in a New England substance abuse program found that 84% would be more likely to leave treatment if they dis-

86. The *parens patriae* power is the state's responsibility for the welfare of its citizens.

87. Hein, *supra* note 10, at 27S.

88. Friedman et al., *supra* note 6, at 444.

covered that they were HIV positive.[89]

5. *Gay and Lesbian Youth*

Gay and lesbian youth face another barrier in seeking permission from their parents in obtaining an HIV test or treatment. As discussed above, most gay and lesbian youth discover their sexual orientation in their teens and a significant percentage experience parental rejection upon acknowledging this fact to their parents.[90] This threat of parental alienation raises an additional barrier to gay and lesbian youth, the importance of which can not be exaggerated. In fact, many gay adult men find themselves revealing their sexual orientation to family members simultaneously with explaining their HIV-positivity. Studies indicate that gay adolescents are generally reluctant to seek medical care.[91] Although some parents may object to the state assisting their children in hiding their sexual orientation, the adolescent should not have his health imperiled because of the parents' inability to accept the sexual orientation of their child.[92]

III. Suggested Solutions

A. *Empowering Minors to Give Informed Consent*

Rather than selecting attributes which attempt to predict competence, but which are of questionable value in doing so, states should attempt to develop procedures which empower minors by providing information and assistance which will maximize their ability to give informed consent. Some social scientists note that there is an evolution from viewing competence as a fixed attribute to one which promotes optimal decision making.[93] This evolving standard places increasing emphasis upon the social process and context of the individual to help the individual make an informed decision, and is suggested for persons with mental disabilities as well as others with questionable capacity to consent.[94] This standard has been characterized as establishing a "participatory," as opposed to "legal-bureaucratic" relationship, between the citizen and

89. *Id.*

90. See *supra* notes 33-34 and accompanying text for a discussion of families' reactions to the revelation of adolescents' sexual orientation.

91. Hein, *supra* note 10, at 23S.

92. It is beyond the scope of this essay to address the arguments that parents have a right to know their children's sexual orientation so they can attempt to change it, except to counter that this desire is dubious because it defies most scientific evidence on the ability to change someone's sexual orientation. The author also suggests that such an attempt impinges upon the child's rights, although the courts have not yet recognized such a right on behalf of children *vis a vis* their parents.

93. Ambuel & Rappaport, *supra* note 65, at 150.

94. *Id.*

the state.[95] This view of a process which values the use of law and procedure to structure, rather than decide, looks at capacity in terms of the decision instead of the status or content of the decision.[96] The social science research thus far supports the assumptions that most adolescent minors are legally competent and that they often consult parents and other adults when making significant personal decisions.[97]

Some will argue that such a system is another intrusion by the legal system that serves to weaken the bonds of the family. However, those minors who have a good relationship with their parents will naturally seek their advice on serious issues. For those who do not, it is unlikely that legal mandates will improve any communication problems. As is evident from the statistics and even recognized in some judicial decisions, the number of youth in the latter type of family setting is significant. They should not be forced to suffer nor should society allow the epidemic to spread more rapidly because of the belief that allowing minors to obtain necessary medical care may weaken the family as an institution.

Where the capacity to consent is a presumption, eventually some adult must determine if the minor may receive treatment without parental involvement. The degree of responsibility to be given to health care providers in determining when parental involvement is necessary needs further exploration. Although allowing health care providers to make the determination of whether a juvenile is competent is not without problems, it is probably preferable to a judicial procedure. Clear standards need to be established, however, regardless of which adult figure determines if the minor is competent. Although age is a factor to consider in determining competency, it should not be determinative. The minor should be presumed competent past a particular age, however, or presumed to have capacity if the minor is referred by some other responsible adult or agency. For example, Colorado permits a physician to furnish birth control procedures, supplies, and information if another physician, clergy, family planning clinic, school, or agency referred the minor.[98] Mental health professionals should be permitted to provide treatment based solely upon their conclusions concerning capacity because they are trained to make such determinations.

95. *Id.* at 151 (quoting JOEL F. HANDLER, LAW AND THE SEARCH FOR COMMUNITY (Univ. of Pa. Press 1990)).

96. *Id.*

97. *Id.*

98. COLO. REV. STAT. § 13-22-105 (1989).

B. Ensuring Utilization of Available Legal Mechanisms

Any statutory scheme devised must address both testing and treatment issues. Both confidential and anonymous[99] testing need to be offered. Treatment must include medical treatment, mental health, and supportive social services. These counseling services are critical in helping the adolescent adjust his behavior so as not to transmit the virus to others. A method of payment needs to be established so that a minor can receive necessary treatment without the fear of reprisal from his parents or guardians. This is an issue which should be addressed in the ongoing debate about health care reform.

None of these services will be useful if adolescents are unaware of how to access them or if they do not know that their confidentiality will be protected. Thus, the availability of the testing and treatment programs must be made known to minors. It must reach those minors who are often difficult to reach, such as those who are homeless or otherwise at-risk. It is precisely these youth who are most vulnerable to contracting the virus. Finally, the program must be able to assure gay and lesbian youth that their right to confidentiality on their sexual orientation will be respected. Whereas parental involvement should be encouraged, it should not be mandated.

IV. Conclusion

It is clear that the United States needs to address the problem of HIV-infection in the adolescent community before it reaches crisis proportions. The number of young persons already infected and the rate of growth in this age group raise ominous concerns. Although the public debate about education and condom distribution is important, it is equally important that minors easily obtain testing and treatment for HIV. It is simplistic and dangerous to assume that mandating parental consent is a viable option for all minors. The reality of the family system in which many minors find themselves prevents them from being able to seek parental consent without placing themselves in peril. This is especially true for gay adolescents whose sexual orientation may increase the danger of physical abuse or exclusion from the home. Although a variety of factors need consideration, the best approach for maximizing testing and treatment is to allow minors to obtain both, without parental consent as a requirement, and to provide standards and guidance to the health care provider or other decisionmaker given discretion to overcome the presumptions of competency. If the

99. At an anonymous testing site, the person being tested never reveals his name.

number of HIV and AIDS cases continue to increase among teens, the importance of these issues will become increasingly clear.