## Nova Law Review

Volume 12, Issue 3

1988

Article 14

# Children with AIDS: A Need for a Clear Policy and Procedure for Public Education

Laura F. Rothstein\*

\*

Copyright ©1988 by the authors. *Nova Law Review* is produced by The Berkeley Electronic Press (bepress). https://nsuworks.nova.edu/nlr

# Children with AIDS: A Need for a Clear Policy and Procedure for Public Education

Laura F. Rothstein

#### Abstract

One cannot open a newspaper, watch the television news, or even watch a favorite sitcom without being aware of the degree to which Acquired Immune Deficiency Syndrome (AIDS) has permeated our society.

KEYWORDS: AIDS, policy, children

## Children with AIDS: A Need for a Clear Policy and Procedure for Public Education\*

Laura F. Rothstein\*\*

#### I. Introduction

#### A. Overview

One cannot open a newspaper, watch the television news, or even watch a favorite sitcom without being aware of the degree to which Acquired Immune Deficiency Syndrome (AIDS) has permeated our society. The issue is having a profound impact on the workplace, on health care and on insurance. Children with AIDS are uniquely affected by a disease they cannot understand, which results in death within two or three years. The public fear of AIDS, while based on unfounded beliefs about its transmissibility, is understandable — AIDS kills people. However, the manifestation of that fear in the form of ostracism is an unacceptable response — particularly where children are concerned. The number of children with AIDS is growing and the increasing presence of children with AIDS in public schools makes it important to develop a clear cut and consistent policy relating to these children.

Much already has been written about whether AIDS is a handicap under section 504 of the Rehabilitation Act and/or the Education for All Handicapped Children Act of 1975. The constitutional implications of privacy issues and decisionmaking about the participation or nonparticipation of children with AIDS in public education have also been

<sup>\* © 1987</sup> 

<sup>\*\*</sup> Professor of Law, University of Houston; B.A., 1971, University of Kansas; J.D., 1974, Georgetown University; author of RIGHTS OF PHYSICALLY HANDICAPPED PERSONS (1984). This article is adapted from a book by Professor Rothstein entitled Special Education Law, published by Longman, Inc., 1989. Nova Law Review expresses its appreciation to Longman for allowing its adaptation.

The medical evidence is quite clear that AIDS is spread by exchange of bodily fluids, and is not spread by casual contact. In spite of that strong evidence, the fear of AIDS is very high, because current evidence also indicates that AIDS is probably inevitably fatal.

explored.2

This article will generally review the issues raised in those scholarly analyses and the presumption will be that the Rehabilitation Act, the EAHCA, the Constitution and most state and local policies do not adequately provide a rational decisionmaking process about the participation of children with AIDS in public schools. The focus of the article will be a proposal regarding what specifically is needed for rational decisionmaking. While this article will provide concrete proposals to amend and adapt existing law to respond to the decisions about participation, it will not propose a response to the issues of confidentiality. Instead, it will raise issues that are in need of assessment in that area.

#### B. Children with AIDS

AIDS is a disease syndrome that is usually divided into three levels. The initial level is the presence of the AIDS virus, while the second level is the presence of less severe symptoms of infection referred to as AIDS Related-Complex (ARC). The third level is full-blown or clinical AIDS, where the virus has destroyed the disease fighting cells in the body to such a degree that rare malignancies or serious opportunistic infections take hold. Persons with AIDS (PWA) who have clinical AIDS almost always die within two years of diagnosis.

In May, 1986, it was projected that as of May 1987, there would be more than 40,000 people with clinical AIDS and of this number

<sup>2.</sup> See generally Jones, The Education for All Handicapped Children Act Coverage of Children with Acquired Immune Deficiency Syndrome (AIDS), 15 J.L. & EDUC. 195 (1986); Mandell, The Exclusion of Children with AIDS from School: An Analysis of the Law, 10 MD. L. F. 31 (1987); Schwarz & Schaffer, AIDS in the Classroom, 14 HOFSTRA L. REV. 163 (1985); Comment, Protecting Children with AIDS Against Arbitrary Exclusion from School, 74 CALIF. L. REV. 1373 (1986); Comment, AIDS in the Classroom: Room for Reason Amidst Paranoia, 91 DICK. L. REV. 1057 (1987); Comment, Enforcing the Right to a Public Education for Children Afflicted with AIDS, 36 EMORY L.J. 603 (1987); Comment, Opening the Schoolhouse Door for Children with AIDS: The Education for All Handicapped Children Act, 13 B.C. ENVIL. AFF. L. REV. 583 (1986); Comment, The Constitutional Right of Informational Privacy: Does It Protect Children Suffering from AIDS, 14 FORDHAM URB. L. REV. 927 (1986); Comment, Undoing a Lesson of Fear in the Classroom: The Legal Recourse of AIDS-linked Children, 135 U. PA. L. REV. 1986. See also R. WEINER, AIDS: IMPACT ON THE SCHOOLS (1986); AIDS AND THE LAW, ch 5 (1987) and Veilleux, AIDS Infection as Affecting Right to Attend Public School, 60 A.L.R. 4th 15 (1988).

<sup>3.</sup> R. WEINER, supra note 2 at ch. 2.

In sum, the number of children with AIDS will certainly increase and these children will not necessarily be found in large cities. It is therefore essential that all school systems incorporate a policy relating to children with AIDS in their schools. Furthermore, it is more constructive to establish a policy before a crisis occurs. As the following discussion illustrates, while several school systems have done an admirable job of implementing a policy, there is a crucial need to have a more consistent policy on at least a state-wide basis, if not on a national basis. Section IV of this article clarifies the reasons for this and Section V provides recommendations for specific state and federal policies which warrant revision. Before examining these issues however, it is necessary to first understand how current law addresses children with AIDS in public school settings.

#### II. AIDS as a Handicap

## A. The Education for All Handicapped Children Act of 1975

### 1) The definition of handicapped

The Education for All Handicapped Children Act of 1975<sup>11</sup> (hereinafter EAHCA) was passed in response to judicial decisions in 1971 and 1972<sup>12</sup> which held that the denial of education to handicapped children is a violation of the equal protection and due process clauses of the fourteenth amendment to the U.S. Constitution. The legislative history indicates that almost four million children were being denied equal educational rights. To encourage states to provide appropriate programming for handicapped children, Congress passed what is basically a grant statute. The EAHCA provides federal funding to support special education.<sup>13</sup> A condition of the funding however, is that states es-

<sup>10.</sup> Id. at 50.

<sup>11. 20</sup> U.S.C. § 1400 (1976). The regulations are found at 34 C.F.R. §§ 300.121-174 (1987). For an in-depth review of the EAHCA requirements, see L. ROTHSTEIN, RIGHTS OF PHYSICALLY HANDICAPPED PERSONS, ch. 2 (1984) and cumulative supplements [hereinafter RPHP].

<sup>12.</sup> Pa. Ass'n for Retarded Children v. Pa., 334 F. Supp. 1257 (E.D. Pa. 1971) [hereinafter PARC]; 343 F. Supp. 279 (E.D. Pa. 1972) and Mills v. Bd. of Educ. 348 F. Supp. 866 (D.D.C. 1972). These decisions are judicial approval of settlements.

<sup>13.</sup> It is important to recognize that under the judicial rulings in PARC, 334 F. Supp. at 1257 and Mills, 348 F. Supp. at 866, states are constitutionally required to provide education to handicapped children. The EAHCA therefore, is a subsidization of what states must already do.

tablish a plan with very specific substantive and procedural components. The underlying principles of the EAHCA are that states must provide "a free, appropriate education which emphasizes special education and related services"14 to all handicapped children of specified ages. This education is to be provided to non-handicapped children to the maximum extent appropriate16 - sometimes referred to as the "mainstreaming mandate." On the other hand, the program for a handicapped child is to be individualized to meet the unique needs of the child.16 The procedural rights afforded under the EAHCA include a right to notice and an impartial hearing at any stage when the school and the parents disagree over whether the child should be evaluated, or what the individualized program for the child should be and how it should be implemented.17 A recent amendment to the EAHCA even provides that parents may recover attorneys' fees and costs if they prevail in a dispute about the child's special education.18 Another amendment to the EAHCA provides for additional grants to be available to state educational agencies under two programs: one for handicapped children ages zero through two and an even stronger incentive program for programs serving handicapped children ages three through five.19

The major issue under the EAHCA as it pertains to children with AIDS, is whether they fit the statute's definition of "handicapped". A handicapped child is one who is "mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, or other health impaired. . . or. . . with specific learning disabilities, who by reason thereof require[s] special education and related services."20

Health impairments therefore, are one of the categorical conditions included within the definition. It is not clear however, whether children who test positive for the AIDS virus, but who do not have ARC or clinical AIDS, would be considered to be health impaired. In addition, children with ARC or clinical AIDS may be considered to be

<sup>14. 20</sup> U.S.C. § 1400(c) (1982).

<sup>15.</sup> Id. at § 1412(5)(B). See RPHR, supra note 11, at § 2.15.

<sup>20</sup> U.S.C. § 1414(a)(5). See RPHR, supra note 11, at § 2.16. 17. 20 U.S.C. § 1415(b); 34 C.F.R. §§ 300.503-507. See RPHP, supra note 11, at §§ 2.23-2.26.

<sup>18. 20</sup> U.S.C. § 1415(4)(B) (West Supp. 1987).

<sup>19.</sup> Education of the Handicapped Act Amendments of 1986, Pub. L. No. 99-457, 100 Stat. 1145 (1986).

<sup>20. 20</sup> U.S.C. § 1401(1) (1982) (emphasis added). See RPHP, supra note 11, at § 2.13.

health impaired within the meaning of the definition, but they will not in all cases "require special education and related services" by reason of the health impairment. Unless the symptoms of the disease or the opportunistic infections resulting from the disease become so chronic that the child requires home-bound instruction or some other special education or related service, the child would not seem to meet the definition of a handicapped child under EAHCA.

A recent decision in Illinois adopted precisely this reasoning.<sup>21</sup> A child with one of the other handicapping conditions listed in the statute would be eligible for protection under the EAHCA, and it is quite possible that some children with AIDS have handicapping conditions such as mental retardation, visual impairments, or learning disabilities that require special education and related services, but not all children with AIDS have other handicapping conditions. Ryan White, for example, does not have any handicapping condition.

In sum, while some children with AIDS may find protection under the EAHCA, it is far from clear that all will.

#### 2) Substantive and Procedural Protections

Those children who meet the definition of "handicapped" under the EAHCA are entitled to all of the substantive and procedural protections afforded by the EAHCA. The mainstreaming mandate requires that "to the maximum extent appropriate, handicapped children. .[should be] educated with children who are not handicapped,"<sup>22</sup> and that anything other than regular classroom placement occurs "only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."<sup>23</sup> Those opposed to permitting a child with AIDS in the regular classroom are certain to argue that where a child poses a danger to others or is at risk of exposure to illness by being around other children, mainstreaming is not "appropriate" and that child should be excluded.

Under existing EAHCA procedural protections, a dispute as to whether the regular classroom placement is appropriate could take a substantial amount of time to resolve. Even following EAHCA deadlines, a decision by the hearing officer and a review of the hearing of-

<sup>21.</sup> Doe v. Belleville Pub. School Dist., 672 F. Supp. 342 (S.D. III. 1987).

<sup>22. 20</sup> U.S.C. § 1412(5)(B) (1982).

<sup>23.</sup> Id.

ficer's decision at the state agency level can take as long as seventy-five days.24 Furthermore, if there is an appeal from that decision, a judicial decision could take months or even years. For a child with AIDS. whose average life expectancy is probably only two years, the exclusion for even a few weeks is a substantial hardship. Mark Hoyle, a teenager from Swansea, Massachusetts, with hemophilia, who contracted AIDS from a blood transfusion, was supported in his desire to attend school by school administrators. There were no time consuming litigation or EAHCA procedures to prevent his attendance. Mark died a year after the school administration's decision to allow him to attend school. Avoiding the delays of EAHCA dispute resolution meant that Mark was not denied the one thing he wanted — to be with his friends.25

In addition to the time involved in EAHCA procedures is the issue of who the decisionmaking body should be. The EAHCA requires that if there is a disagreement between the parents and the school, there is a right to an impartial due process hearing.26 However, states vary as to who the hearing officer may be, such as an attorney, educator, layperson, etc. Whether EAHCA hearing officers in each state are appropriate decisionmakers about public school attendance for children with AIDS has not been closely studied. While it may be that the current system is appropriate, it is certainly an issue for further consideration.

In sum, even if all children with AIDS are found to be handicapped within the EAHCA, there remain questions about whether the procedures currently in place and the substantive standards are appropriate for decisions concerning these children.

### B. Section 504 of the Rehabilitation Act

Prior to the passage of the EAHCA, Congress had passed the Rehabilitation Act of 1973,27 which was a comprehensive statute intended to address problems of discrimination on the basis of handicap. Section 504 of the Rehabilitation Act provides that:

No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be

<sup>24.</sup> See 34 C.F.R. § 300.512. See also RPHP, supra note 11, at § 2.28.

<sup>25.</sup> R. WEINER, supra note 4, at 51-56. See also Patinkin, Children with AIDS: Two Towns, Two Very Different Legacies, Houston Chronical, Sept. 7, 1987, § 5, at

<sup>26. 20</sup> U.S.C. § 1415(b) (1982). See also RPHP, supra note 11, at § 2.25.

<sup>27.</sup> Pub. L. No. 93-112, 87 Stat. 355 (1973).

denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.28

Public educational agencies at the state or local level is are recipients of federal financial assistance through a variety of programs, including the Education for All Handicapped Children Act, and, therefore, are subject to the mandate of Section 504.29

#### 1) Definition of handicapped person

Under the Rehabilitation Act, a handicapped person is one who

(i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.30

Although many individuals infected with the AIDS virus are able to carry out major life activities, at least until the point when they have clinical AIDS, it is arguable that these individuals are "regarded as having . . . an impairment." They would, therefore, be covered by the Rehabilitation Act, at least so long as they can carry out the essential functions of the program<sup>31</sup> i.e., attend school.

In School Board v. Arline,32 the Supreme Court addressed the language relating to "regarded as". It held that a school teacher with tuberculosis was handicapped under Section 504. While the Court specifically stated in a footnote that it was not deciding whether someone with AIDS was protected under the Rehabilitation Act, the general consensus since that decision has been that the Arline reasoning would result in a finding that AIDS is a handicap.33

1266

<sup>28.</sup> Id.

Regulations implementing Section 504 for public education are found at 34 C.F.R. § 104.1-61. See also RPHP, supra note 11, at §§ 2.08-2.11.

<sup>29</sup> U.S.C. § 706(7)(B).

Southeastern Community College v. Davis, 442 U.S. 397, 405 (1979). 31.

<sup>32. 107</sup> S. Ct. 1123 (1987).

Chalk v. U.S. District Court, No. 87-6418, slip op. (9th Cir. Nov. 18, 1987) (teacher with AIDS was handicapped and was also otherwise qualified under Section 504 and posed no significant risk to students in the classroom); Thomas v. Atascadero Unified School Dist., 662 F. Supp. 375 (C.D. Cal. 1987) (children with AIDS are handicapped under Section 504); Ray v. School Dist., 666 F. Supp. 1524 (M.D. Fla. 1987). See also Shuttleworth v. Broward County, 639 F. Supp. 654 (S.D. Fla. 1986) (case involving employment under Section 504, employee with AIDS not required to

#### 2) Otherwise qualified

While in all likelihood future judicial decisions will hold that AIDS is a handicap under Section 504, a determination that an individual fits the definition of handicapped is only the first step towards challenging a discriminatory practice. The definition specifies that the individual must be "otherwise qualified." The first U.S. Supreme Court case to address any issue under Section 504 was Southeastern Community College v. Davis.34 There, the Court found that a nursing student with a hearing impairment was not otherwise qualified to participate in the training program because she could not meet the program's requirements in spite of her handicap. 35 Recipients of federal financial assistance are not obligated to make substantial modifications or fundamental alterations36 to the program to accommodate the handicapped. They are, however, required to make reasonable accommodations where these do not pose an undue hardship on the program. 37 It should be noted that the Court in Arline, while finding tuberculosis to be a handicap, remanded the case for a determination as to whether the plaintiff was otherwise qualified.38 The Court indicated that issues such as the duration and severity of the condition and the probability of whether the disease would be transmitted required a factual determination in order to decide whether she was "otherwise qualified." The Court noted that: "[A] person who poses a significant risk of communicating an infectious disease to others in the workplace will not be otherwise qualified. . .if reasonable accommodation will not eliminate that risk."39 The court further stated that a determination of that risk should be based on "reasonable medical judgments given the state of

exhaust administrative remedies did not specifically address whether AIDS is a handicap under Section 504). State courts have also ruled that AIDS is a handicap under state handicap discrimination laws. See Cronan v. New Eng. Tel. Co. 41 Fair Employment Prac. Cases 1273 (D. Mass. 1986); California Fair Employment & Hous. Comm. v. Raytheon C., Cal. Fair Employment & Hous. Commn. NFLSP, 83-84, LI-031p, L-33676, 87-04 (Feb. 5, 1987).

<sup>34. 442</sup> U.S. 397 (1979).

<sup>35.</sup> Id.

<sup>36.</sup> Id. at 413.

<sup>37. 34</sup> C.F.R. § 104.12(a) (1987). This regulation refers to employment practices. The regulations do not specify, but it would seem logical to infer, that the undue hardship defense would be available in contexts other than employment where Section 504 applies.

<sup>38.</sup> Arline, 107 S. Ct. 1123 at 1132.

<sup>39.</sup> Id. at 1131, n.16.

medical knowledge, about. . . the nature. . . duration. . . and severity of the risk. . . and. . . the probabilities the disease will be transmitted and will cause varying degrees of harm."40

Applying this standard, the presumption should be that, as a general rule, a child with AIDS is otherwise qualified because the weight of medical knowledge indicates that AIDS is not casually transmitted. This presumption may be rebutted in specific cases, such as where because of a child's behavior (biting) or manifestation of symptoms (open sores, oozing lesions that cannot be covered, etc.) there is a risk of communicating the disease. Also, if the child with AIDS is at a point where the immune system is so depressed that exposure to ordinary childhood infections, such as colds and chicken pox, would pose a serious danger to that individual child, it may be that that child is not otherwise qualified to attend regular school. In either case, where the child is at risk or poses a risk, generally the child would at least be "otherwise qualified" for homebound instruction, unless the child is simply too ill to do schoolwork. In sum, children with AIDS will probably be entitled to Section 504 protection.

## 3) The interaction of the EAHCA and Section 504

Children with AIDS are covered under Section 504. Because schools receive federal financial assistance, they are subject to the nondiscrimination requirements of Section 504. It would seem, therefore, that it is not essential to find statutory coverage under the EAHCA. It is important however, to recognize several factors that make it relevant whether children with AIDS are covered under the EAHCA. First, Section 504 only refers to nondiscrimination. The EAHCA, however, contemplates subsidization and affirmative efforts to ensure that handicapped children can benefit from education. While Section 504 case law indicates that some reasonable accommodation must be provided to meet the nondiscrimination standard, the level of accommodation required under the EAHCA goes beyond what is required under Section 504. Second, while Section 504 was passed in 1973, before the 1975 EAHCA, the regulations under Section 504 were not finalized until 1978, and there is no detailed framework for schools to follow. 42 Finally, Section 504 has not been the statutory basis for most special

<sup>40.</sup> Id. at 1131 (quoting Brief for Am. Med. Ass'n).

R. Weiner, supra note 2 at ch. 2.
 See C.F.R. § 104.31-.40 (1987).

education judicial decisions.43 In fact, the Supreme Court in 1984 in Smith v. Robinson44 held that where a remedy is available under the EAHCA, Congress intended that Section 504 and Section 1983 of the Civil Rights Act45 not be the basis for seeking relief.46 Because of the lack of clarity as to whether children with AIDS do have a remedy under the EAHCA, it may be problematic for courts to determine whether Section 504 is available as a vehicle for relief when addressing issues of participation in public schools.

#### C Constitutional issues

Because all states provide public education, it is clear that states may not violate the fourteenth amendment by denying equal protection or due process in providing the education. While education has not yet reached the level of a fundamental right, the Supreme Court recognized in Plyler v. Doe47 that education is entitled to a heightened scrutiny test because of its importance in society.

Another means of obtaining a higher degree of scrutiny, other than finding that a fundamental or important right is involved, is to demonstrate that the group being classified, excluded, or discriminated against by the state is a suspect class.48 The Supreme Court has thus far not addressed the issue of whether individuals with AIDS are a suspect class. It has, however, given some discussion to the issue of whether handicapped individuals, specifically mentally retarded persons, are a suspect class. In the case of City of Cleburne v. Cleburne Living Center,49 the Court found that mentally retarded individuals are not a suspect or even a quasi-suspect class. The Court found that although mentally retarded individuals have a reduced ability to function in the world, there is substantial diversity within the group.50 It found that the group was not politically powerless because there is a substantial body of legislation protecting them, and that this legislation is sup-

<sup>43.</sup> See generally RPHP, supra note 11, at ch. 2.

<sup>468</sup> U.S. 992 (1984). 44.

<sup>42</sup> U.S.C. § 1983. 45.

For a discussion of this issue, see RPHP, supra note 11 at §§ 2.35, 2.36, 2.39.

<sup>47. 457</sup> U.S. 202, 216 (1982).

San Antonio Indep. School Dist. v. Rodriquez, 411 U.S. 1, 28 (1973).

<sup>49.</sup> 105 S. Ct. 3249 (1985).

<sup>50.</sup> Id. at 3256.

ported by the public.<sup>51</sup> Finally, and perhaps most pertinent, the Court noted the amorphous nature of the class of mentally retarded persons and suggested that there are problems of distinction within other groups such as "the disabled. . and the infirm." Given this analysis, it seems unlikely that the Supreme Court will find PWA to constitute a suspect or a quasi-suspect class.

There is a positive side to the Cleburne decision, however. While the Court declined to apply a suspect classification to mentally retarded individuals and applied the rational basis test, the Court struck down the challenged state action. The Court held that the denial of a special permit to a group home for mentally retarded individuals was not rationally related to a legitimate state purpose. The Court found that the arguments relating to safety and fear of the elderly neighbors were not only unsubstantiated, but that the denial rested on "irrational prejudice against the mentally retarded."53 The Court also noted that "mere negative attitudes or fear, unsubstantiated by factors which are properly cognizable in zoning proceedings, are not permissible bases for treating a home for the mentally retarded differently from other dwellings."54 Even if the majority were biased against the group, their objections cannot be permitted to violate the equal protection clause. 55 This language should be helpful to PWA who are claiming equal protection violations. While there may in some cases be a majority of residents in a particular school district who do not think that children with AIDS should be permitted to attend school, these prejudices are unsubstantiated by the weight of medical opinion.

Given the above analysis, it seems quite probable that a child with AIDS who is being excluded from school or being denied participation on an equal basis would be successful in a constitutional claim. It should be noted, however, that the holding in Smith v. Robinson<sup>56</sup> is that if the EAHCA provides a remedy, it shall be the exclusive avenue through which the case must proceed. Again, the lack of clarity as to the application of the EAHCA to children with AIDS makes it unclear as to the degree to which a constitutional remedy will be permitted.

<sup>51.</sup> Id. at 3256, 3257.

<sup>52.</sup> Id. at 3256.

<sup>53.</sup> Id. at 3260.

<sup>54.</sup> Id. at 3259.

<sup>55.</sup> Id. at 3260.

<sup>56. 468</sup> U.S. 992 (1984). See supra text accompanying note 48.

### III. Confidentiality in the School Setting

#### A. The Problem of Confidentiality

There is no question that having AIDS is a stigma. In fact, the stigma even attaches when a family member has AIDS or has a high risk lifestyle, <sup>57</sup> or when a roommate is known to have AIDS, or is erroneously regarded as having AIDS. Adverse parental reactions to the fact a child with AIDS might be in the same classroom or even in the same school building as their children have run the gamut from a massive boycott in New York City<sup>58</sup> when it was known that a second grader with AIDS would be attending school somewhere in New York City to burning down the home of the Ray family in Arcadia, Florida, because the three Ray boys had contracted AIDS through blood transfusions. <sup>59</sup> The television image of one of the Ray boys standing alone on the playground, kicking at a lump of dirt, all too clearly highlights how lonely it can be to have AIDS.

It should be noted, however, that there have been more positive situations where it was known that a child with AIDS was attending school. In Swansea, Massachusetts, the community not only did not oppose the attendance of fourteen year-old Mark Hoyle, but they rallied around him—even holding fundraising events to help pay for medical expenses.<sup>60</sup>

The real and legitimate concern with the stigma must be balanced with the concern that there may be school personnel who need to know about the child's condition. First, in order to protect the child with AIDS, it is essential that the child not be exposed to infections from other children, such as an outbreak of chicken pox. Second, in order to protect others from being infected by the AIDS virus, it is essential to follow precautionary measures should the child with AIDS have bleeding, or open sores. The argument could be made that all educational personnel should be given in-service training and told to follow

<sup>57.</sup> See R. WEINER, supra note 4, at 41-50.

<sup>58</sup> Id

<sup>59.</sup> Patinkin, supra note 25, at 2. See also Belsie, How Schools Cope With AIDS, CHRISTIAN SCIENCE MONITOR, Sept. 3, 1987. For a discussion of Chicago area schools' reaction to this issue, see Kirp, The High Road, CHI. TRIBUNE, Dec. 6, 1987 (Magazine) at 12, an excerpt from D. KIRP, SUFFER THE CHILDREN (Publication in fall 1988).

<sup>60.</sup> See R. WEINER, supra note 4, at 51-59.

<sup>61.</sup> See CDC Guidelines, supra note 8 at Appendix A.

precautionary procedures for all children. But these procedures require the use of gloves in some cases and taking certain other precautions that are not currently routine practices by most educators. For example, a child with AIDS who has a bloody nose on the playground should probably not be assisted by someone with chapped hands who does not wear gloves. It may be unrealistic to expect all educators to treat all children as though they have AIDS in all situations where precautions are called for. Where a child is known to have AIDS, the school personnel can take appropriate precautions at all times with respect to that child. An argument is sometimes made with respect to behavior in the community at large that because of the period of time in which the presence of the AIDS antibody may not be detectable, there is no assurance that any child does not have AIDS.62 This argument is made for sexual practices and for health care practice in medical settings.63 Because of the major means by which at least pediatric AIDS is acquired, however, in almost all cases, the child's parents will know that the child has AIDS or is at risk for having AIDS. This may not be so true for teenagers whose drug use and sexual practices may make it less clear to the parents that the child is at risk for having AIDS.

Assuming that it is decided that school personnel who are in contact with the child on a regular basis should be advised that the child has AIDS, there is a very difficult question of who those personnel are. Should only the regular classroom teacher be told? The school nurse? The principal? What about the fact that in a typical school week, the child will have music class, physical education, art and other activities taught by someone other than the regular classroom teachers? A child is as likely to have a bloody nose in art class as in the regular class. Should all these teachers know? The problem is that even if only one teacher knows, and even if that teacher knows the matter is confidential, human nature will take its course, and the fact that the child has AIDS will become known not only to other school personnel who do not need to know but to parents of other children.

The issue of confidentiality is clearly a difficult one, and perhaps one that is in need of constructive discussion before a decision is made about confidentiality in the school setting. There are, however, a num-

<sup>62.</sup> Id. See also Stewart, Port Arthur School Learns Pupil Died of AIDS, HOUSTON CHRONICAL, Sept. 12, 1987, § 1, at 11. The pupil involved was a kindergarten student who had open sores that the teacher bandaged during the school year. The child died in the summer after the kindergarten year.

<sup>63.</sup> R. Weiner, supra note 2, at 129-134.

ber of existing sources of law and policy that already affect this area, and perhaps are in need of reconsideration with respect to children with AIDS.

#### B. Constitutional Issues

The primary constitutional principle at stake with respect to confidentiality is the fourth amendment as it relates to searches and seizures. The concern for people with AIDS is at two levels. First is the collection of the data (if mandatory screening of school children were to be adopted). Second is the dissemination of the information to various individuals and agencies.

There is currently no proposal to screen all school age children for AIDS, 64 but virtually all states have laws relating to disclosure of information about individuals with communicable diseases, and many are beginning to enact new laws specifically dealing with individuals with AIDS. These laws relate to a variety of disclosure issues — when must school and health officials notify state authorities that an individual has AIDS or another communicable disease, which authorities are to be notified, what confidentiality requirements are there relating to disclosure of the information to others, and what are the remedies and penalties for violating confidentiality requirements.

The constitutionality of state and local practices relating to disclosures of this type is not clearly delineated by the Supreme Court<sup>65</sup> and there are conflicts among the circuits regarding whether an individual's privacy is violated when disclosure of personal information is permitted.<sup>66</sup> As a comprehensive study of this topic noted:

Lower courts disagree about (1) whether the Supreme Court has recognized a constitutional right to informational privacy; (2) what test, if any, should be used to weigh the competing interests; and (3) what information should be deemed personal.<sup>67</sup>

<sup>64.</sup> The cost of such a screening program could preclude it, unless the schools required that the screening be done by the child's family physician, just as proof of TB tests, etc. is currently provided by the family physician. However, the National Education Association, the nation's largest teacher's union opposes mandatory involuntary testing of students or employees. R. Weiner, supra note 2, at \_\_\_\_.

<sup>65.</sup> See Note, The Constitutional Right of Informational Privacy: Does It Protect Children Suffering From AIDS, 14 FORDHAM URB. L. REV. 927, 935 (1986).

<sup>66.</sup> Id. at 937.

<sup>67.</sup> Id. at 938.

The conclusions drawn by the author of that study are that disclosure of information that a child has AIDS by government employees to anyone other than school health officials (school administrators and teachers) to facilitate research on the issue is constitutionally impermissible. 69

## C. The Family Educational Rights and Privacy Act

The Family Educational Rights and Privacy Act70 (commonly known as the Buckley Amendment) applies to all public and private educational institutions receiving federal financial assistance. The regulations under the law are complex and not always clear on certain issues, but the law basically prohibits disclosure of personally identifiable medical or educational information to parties outside the institution.71 Even employees of the school must have a legitimate reason for examining the student files.72 This gives rise to questions about which educational personnel would need to know that a student has AIDS. Theoretically, teachers should not be given ready access to student files without a legitimate bona fide reason for seeing a particular file. The school is supposed to have a system of keeping track of who sees files and for what reason. It is quite probable that this requirement is not currently being carefully complied with, but that because of the concern for privacy relating to identifying children with AIDS, new efforts may be needed to ensure that teachers and other educational personnel are not given access casually.

#### D. State Laws

In addition to the federal FERPA relating specifically to access to, and disclosure of, student records, there are a variety of state laws that potentially impact on the issue of confidentiality. State open records laws, medical practice laws, communicable disease laws and employee right to know laws all potentially impact on the disclosure of the identity of a child with AIDS. In addition, there are common law tort ac-

<sup>68.</sup> Id. at 962.

<sup>69.</sup> Id. at 929.

<sup>70. 20</sup> U.S.C. § 1232g.

<sup>71. 20</sup> U.S.C. § 1232g(b)(1) & (2)(A).

<sup>72. 20</sup> U.S.C. § 1232g(b)(4)(A).

<sup>73.</sup> Id. See also W. Valente, Education Law Public and Private § 16.41 (1985).

tions relating to libel, slander, invasion of privacy and negligence that may well impact this issue.

## IV. Problems with Current Policies on Children with AIDS and Public Education

Sections II and III looked at the two primary issues affecting children with AIDS - exclusion and confidentiality. Current federal law leaves several gaps in addressing both of these issues. While some state and local educational agencies have adopted policies that more specifically address these issues, there are a number of problems with those policies in many cases. First, some state and local school boards have policies of exclusion.74 Furthermore, those states that do permit admission on a case by case basis, in some cases place the final decision in the hands of the school board, a group too likely to be affected by politics. Second, while many states have adopted or adapted guidelines provided by the Center for Disease Control (CDC),75 these guidelines do not go far enough in addressing the issues of exclusion and confidentiality. They also do not provide procedures for resolving disputes. They are useful as a starting point, but they do not provide a complete policy on children with AIDS. Before looking at the specific gaps in coverage, it is important to first examine what the CDC Guidelines provide.

#### A. CDC Guidelines

The CDC Guidelines were developed and published in August of 1985. The Guidelines apply to children who are tested positive for the AIDS virus, as well as those with ARC or clinical AIDS.

The Guidelines are premised on the fact that current medical evidence indicates that "casual person-to-person contact as would occur among schoolchildren appears to pose no risk." The lack of information about younger children and neurologically handicapped children lacking control of body secretions is noted as a caveat to this premise. This

<sup>74.</sup> The Board of Education of Carroll County, Georgia has a policy banning children and employees with AIDS. AIDS POLICY AND LAW, at 3 (1986). Billsin, Florida would bar pupils and teachers with AIDS from schools, AIDS POLICY AND LAW, at 7 (1986). New Haven, Connecticut's public school policy is to exclude children with AIDS, although state policy is contrary. N.Y. TIMES, Nov. 8, 1987, at 30, col. 4.

<sup>75.</sup> See CDC Guidelines infra note 61 at Appendix A. Current information on AIDS issues can be obtained from the Center for Disease Control, Atlanta, Georgia.

group is noted as perhaps being worthy of different treatment both in terms of the risk of transmission of AIDS to other children and the risk to the child with AIDS.

The Recommendations, which are included as an Appendix to the article, provide in general the following:76

- 1) case by case decisionmaking regarding participation;
- 2) decisionmaking by a team (including child's physician, public health personnel, child's parent or guardian, and personnel involved in proposed educational program, such as the classroom teacher);
  - 3) presumption of inclusion for MOST children;
- 4) a more restricted environment for preschool and neurologically impaired children until further study of transmission in these settings is done;
  - 5) precautions in handling child's bodily fluids;
  - 6) routine procedures for handling bodily fluids of ALL children;
- 7) continuing monitoring of the child's hygienic practices and appropriate responses to any changes;
- 8) children in risk groups (such as those born to mothers with AIDS) might be considered for being tested for AIDS in order to avoid giving vaccinations that might be dangerous and to monitor behavior and exposure to infections;
  - 9) no mandatory screening as a condition of enrollment;
- 10) educational personnel should respect right to privacy, and maintain confidentiality as much as possible;
- 11) provide education to parents, children and educators about AIDS and how it is transmitted.

A number of state and local school boards have now used these guidelines as the starting point or have adopted similar policies for dealing with children with AIDS.<sup>77</sup> It would be useful, however, if a comprehensive federal policy were developed on this issue to provide a more consistent treatment of this issue.

<sup>76.</sup> Id. at Guideline # 3.

<sup>77.</sup> See R. Weiner, supra note 4, at Appendix F (State of Connecticut Guidelines) and Appendix G (School District of Philadelphia Guidelines).

#### B. EAHCA Procedures

Before turning to specific issues that are problems under current policies, it is useful to review the decisionmaking process under the EAHCA in order to analyze where gaps exist. The EAHCA provides that when a decision is to be made about the appropriate placement of a child, the initial step is to develop an individualized educational program (IEP)78 at a meeting initiated by the school. The parents are given notice of the meeting and have a right to attend. Other participants at the meeting would include a special education supervisor, the teacher, and other appropriate personnel.79 The IEP includes the child's present level of performance, annual goals and short term objectives, the services to be provided and the extent of participation in regular educational programs, the time frame for programming, and the criteria for evaluating the program. 80 The program cannot be initiated without parental consent, unless there is a final resolution through due process procedures. In other words, if the parents refuse to agree to the IEP proposed by the school, the program cannot be implemented unless the school's proposal is upheld through an impartial hearing, along with a right of appeal. Either the school or the parents can request that a hearing be held if there is a disagreement about the program.

If the parents request a hearing, the hearing must be held and a decision rendered within forty-five days of the request.81 They have a right to have a counsel at the hearing, a right to present evidence, and a right to a record of the hearing.82 Two requirements relating to the hearing are relevant to decisions that might be made about children with AIDS. First, the hearing officer must be impartial (although the EAHCA does not specify any particular type of expertise required of the hearing officer).83 The reason this issue is relevant is that a decision about participation in school by a child with AIDS should be made by someone with a particular type of expertise — such as a lawyer or physician. The second due process issue of particular relevance is that the parents have the right to decide whether the hearing shall be open

<sup>78. 20</sup> U.S.C. § 1412(4),(6). See also RPHP, supra note 11, at § 2.16.

<sup>79. 34</sup> C.F.R. § 300.344. The child may also attend if appropriate.

<sup>80.</sup> Id. at § 300.346. For a more complete discussion of due process issues, see RPHP, supra note 11, at § 2.23-2.31.

<sup>81. 34</sup> C.F.R. § 300.512(a).

<sup>82.</sup> Id. at § 300.508(a).

<sup>83.</sup> Id. at § 300.507(b)(2).

or closed.<sup>84</sup> This is important because of the stigma that may attach to a child who is known to have AIDS. Having a closed hearing may facilitate confidentiality.

Once the hearing decision is made, either party may seek review by the state educational agency (which must be completed within thirty days of the request)<sup>85</sup> and seek review of that decision in a state or federal court of competent jurisdiction.<sup>86</sup>

Another EAHCA procedural issue that is particularly relevant to decisions about children with AIDS is the "stay put" mandate. As a general rule, unless the parents and public agency agree otherwise, the child is to remain in the current educational program in which the child is enrolled, until the dispute is resolved.87 If the child is enrolling initially, the child, with parental consent, must be placed in the public school program until the proceedings have been completed.88 The two major exceptions to this rule are where a placement is made by the private placement because they believe the school's placement is not appropriate and they ultimately prevail in that belief89 and where the child presents a serious behavior problem. 90 While there may be some cases in which a child with AIDS manifests biting or other behavior to justify removal under the second exception, there is currently little case law to clarify what would happen if the school wanted to remove the child with AIDS who currently has no behavior problems. Would the "stay out" provision be applicable? If so, it is possible that a removal by the school could be viewed as a bad faith act, which might even justify the award of damages in appropriate circumstances. 91 Also, what if the child with AIDS, although not having a behavior problem, had oozing lesions or other physical manifestations of potential risk? Although it seems probable that removal pending resolution would be permissible under those circumstances, no caselaw under the EAHCA has addressed this question.

<sup>84.</sup> Id. at § 300.508.

<sup>85.</sup> Id. at § 300.510.

<sup>86.</sup> Id. at § 300.511.

<sup>87.</sup> Id. at § 300.513.

<sup>88.</sup> Id.

<sup>89.</sup> Burlington School Committee v. Department of Educ., 471 U.S. 359 (1985).

<sup>90.</sup> RPHP, supra note 11, at § 2.30.

<sup>91.</sup> Id. at § 2.22, 2.39.

#### V. Recommendations

While some states and local educational agencies have already adopted procedures that address some of the problems that exist because of procedural gaps in the CDC Guidelines and the EAHCA procedures, most have not adequately addressed these issues. The following discussion highlights the major specific issues that should be addressed and, in some cases, proposes a specific change. For some issues the precise resolution is not clear, but what is clear is that Congressional attention through hearings with public comment, or possibly Department of Education revised regulations with opportunity for public comment, might resolve those issues.

1) Amend the definition of "handicapped individual" to include children with AIDS under the EAHCA

Because of the confusion over whether children with AIDS are covered under the EAHCA<sup>92</sup> and because the procedures under Section 504 do not adequately respond to decisions about children with AIDS,<sup>93</sup> the EAHCA should be amended to include children with AIDS as handicapped. The definition should incorporate language to ensure protection not only for those children with clinical AIDS, but those who have tested positive for the HIV virus and those with ARC. The definition should also extend to children who may not even have AIDS, but who have family members with AIDS or who are suspected of having AIDS.<sup>94</sup> This will enable the parents of these children to take advantage of the procedural protections of the EAHCA in cases where the school wishes to exclude a child because of unfounded fears about the child's condition.

2) Provide for expedited decisionmaking regarding decisions about children with AIDS

As was previously noted,96 the due process administrative proce-

<sup>92.</sup> See supra text § II(A)(1).

<sup>93.</sup> See supra text § II(A)(3).

94. In Ocilla, Georgia, the school wanted to exclude a child whose sister had died of AIDS and whose mother was an asymptomatic carrier of AIDS. The child, who tested negative for AIDS, was finally admitted when the mother indicated a willingness to have the child live with the grandmother. R. Weiner, supra note 4, at 31-33.

<sup>95.</sup> See supra text § IV(B).

dures, while relatively speedy in responding to many placement decisions, are currently inadequate for decisionmaking about the appropriate placement of children with AIDS. Even with no delays, the process from request of due process hearing through a hearing, a decision, and a review by the state administrative agency, if necessary, can take two and a half months. That may seem inconsequential in some types of placement decisions, but for a child with AIDS, it can be a large portion of his or her remaining lifetime. Mark Hoyle lived only a year after the time he was diagnosed. Had his parents been required to go through the time consuming due process procedures, he would have lost much of the fall semester—half of his remaining life.

A recent case in California demonstrates that decisions about participation of individuals with AIDS can be made quickly. The case of Chalk v. United States District Court, 97 involved a schoolteacher with AIDS who had been removed to a desk job. The district court and the Ninth Circuit were able to render their decisions in a fairly expedited manner. The suit was filed in federal district court on August 6, 1987. The motion for preliminary injunction was denied by the district court. The Ninth Circuit granted an expedited appeal, heard oral argument on December 10th, and rendered its decision eight days later. 98

The issues relating to whether to include a child with AIDS are the child's behavior and condition. It would seem that any dispute about whether the child posed a risk to other children or was at risk himself or herself would be relatively simple to resolve when compared to some of the difficult special education disputes such as residential placement. If agreement about the placement of the child with AIDS cannot be resolved in the IEP meeting, a hearing should be held within five days of the request, and a decision by an impartial hearing officer should be rendered within three days after the hearing. While this might seem to be unusually burdensome, it is unlikely that such hearings would be requested with any frequency, and the consideration for the child's shortened lifespan outweighs the administrative inconvenience. Should either the parents or the school wish to seek state administrative review of the impartial hearing officer's decision, the review and decision should be completed within five days. Again, the interests of the child outweigh the burden to the state agency.

It is possible that a problem with the expedited procedure could

<sup>96.</sup> See supra text accompanying note 28.

<sup>97.</sup> No. 87-6418, slip op. (9th Cir. Nov. 18, 1987).

<sup>98.</sup> See R. WEINER, supra note 2 at 1.

attention to ensuring that the personnel attending and participating in closed hearings are aware of confidentiality requirements under federal and state law and the penalties for violating these requirements are made clear to those attending.

## 5) The presumption should be for inclusion

CDC Guidelines indicate that because AIDS is not spread by casual contact, that most school children in most situations pose no risk to others. While there are some caveats regarding preschool children and children who do not have control of certain of their behaviors, or who have symptoms such as open sores, most children with AIDS should be included in the regular classroom. The burden, therefore, should be on the school to establish why the child should be placed in a setting more restrictive than the regular classroom, such as homebound instruction.

## 6) The IEP should provide for monitoring of changes in the child's condition

In order to avoid the need for frequent IEP meetings, state and local agencies might consider a policy of providing for monitoring and adjusting the placement should certain conditions occur. For example, for a child who currently has no symptoms, the IEP could indicate that if the child develops certain symptoms (such as open sores) or certain behaviors (such as biting), the child would be removed from the classroom so long as those symptoms or behavior exist. The IEP could state that homebound instruction would be provided for those days when the child could not attend school. While not all situations could be anticipated, school policy should be that IEP indicate how to handle changes in condition so far as possible.

## 7) Personnel development

The CDC Guidelines recommend that educational personnel inform educators about AIDS and its transmission. The regulations under the EAHCA require schools to have a comprehensive system of personnel development.<sup>103</sup> The regulations should be revised to incor-

103. 34 C.F.R. § 300.380-.386.

<sup>102.</sup> See CDC Guidelines, supra note 8 at Appendix A.

porate the CDC recommendation, and personnel development for educators should include mandatory training about AIDS and its transmission, as well as about appropriate hygiene practices.

#### Conclusion

The preceding recommendations may not be the best means of responding to decisionmaking about children with AIDS and public education, but they are a starting point for considering an appropriate legislative response to this issue. Section 504 of the Rehabilitation Act is not adequate procedurally to respond to these cases. The CDC Guidelines do not go far enough — they do not specify what happens in cases where there is disagreement among the panel of people discussing the child's placement. The most logical procedure for these decisions is the due process procedures of the EAHCA. On the whole they have proven to be very good procedures for achieving the goals of the EAHCA that of ensuring that ALL handicapped children receive an appropriate education in the least restrictive setting possible. And administrators are familiar with them. They are also protected somewhat from politics. Unfortunately, they are not entirely adequate for the unique issue of whether a child with AIDS should be admitted to the regular classroom setting. The procedures are too slow and may be flawed in other respects. But the major step of ensuring that the definition of a handicapped child entitled to these procedural protections includes a child with AIDS, or even one with the stigma of AIDS, is an essential first step. The adjustment of the timetable for due process decisionmaking is a second essential step. The other issues can be dealt with as deemed appropriate.

The number of children with AIDS is growing. Each of these children deserves the opportunity to participate in the normal life of a child as much as possible. The adoption of EAHCA and state procedures will ensure that decisions affecting these children will have some degree of consistency. It is imperative that Congress act soon before a patchwork of inadequate state policies is developed. Children with AIDS do

not have time to wait.

### Appendix A

Centers For Disease Control Recommendations For The Education And Foster Care of AIDS-Infected Children August 1985

The information and recommendations contained in this document were developed and compiled by the Centers for Disease Control (CDC) in consultation with individuals appointed by their organizations to represent the Conference of State and Territorial Epidemiologists, the Association of State and Territorial Health Officers, the National Association of County Health Officers, the Division of Maternal and Child Health (Health Resources and Services Administration), the National Association for Elementary School Principals, the National Association of State School Nurse Consultants, the National Congress of Parents and Teachers and the Children's Aid Society. The consultants also included the mother of a child with acquired immunodeficiency syndrome (AIDS), a legal advisor to a state education department and several pediatricians who are experts in the field of pediatric AIDS. This document is made available to assist state and local health and education departments in developing guidelines for their particular situations and locations.

These recommendations apply to all children known to be infected with human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV). This includes children with AIDS as defined for reporting purposes (Table 1); children who are diagnosed by their physicians as having an illness due to infection with HTLV-III/LAV but who do not meet the case definition; and children who are asymptomatic but have virologic or serologic evidence of infection with HTLV-III/LAV. These recommendations do not apply to siblings of infected children walks.

infected children unless they are also infected.

#### Background

The Scope of the Problem As of August 20, 1985, 183 of the 12,599 reported cases of AIDS in the United States were among children under 18 years of age. This number is expected to double in the next year. Children with AIDS have been reported from 23 states, the District of Columbia and Puerto Rico, with 75 percent residing in New York, California, Florida and New Jersey.

## Table 1. Provisional Case Definition For Acquired Immunodeficiency Syndrome (AIDS) Surveillance Of Children

For the limited purposes of epidemiologic surveillance, CDC defines a case of pediatric acquired immunodeficiency syndrome (AIDS) as a child who has had:

- 1. A reliably diagnosed disease at least moderately indicative of underlying cellular immunodeficiency, and
- 2. No known cause of underlying cellular immunodeficiency or any other reduced resistance reported to be associated with that disease.

The diseases accepted as sufficiently indicative of underlying cellular immunodeficiency are the same as those used in defining AIDS in adults. In the absence of these opportunistic diseases, a histologically confirmed diagnosis of chronic lymphoid interstitial pneumonitis will be considered indicative of AIDS unless test(s) for HTLV-III/LAV are negative. Congenital infections, e.g., Toxoplasmosis or herpes simplex virus infection in the first month after birth or cytomegalovirus infection in the first 6 months after birth, must be excluded.

Specific conditions that must be excluded in a child are:

- 1. Primary immunodeficiency diseases—severe combined immunodeficiency, DiGeorge syndrome, Wiskott-Aldrich syndrome, ataxiatelangiectasia, graft versus host disease, neutropenia, neutrophil function abnormality, agammaglobulinemia, or hypogammaglobulinemia with raised IgM.
- 2. Secondary immunodeficiency associated with immunosuppressive therapy, lymphoreticular malignancy, or starvation.

The 183 AIDS patients reported to CDC represent only the most severe form of HTLV-III/LAV infection, i.e., those children who develop opportunistic infections or malignancies (Table 1). As in adults with infection, many infected children may have milder illness or may be asymptomatic.

Legal Issues. Among the legal issues to be considered in forming guidelines for the education and foster care of HTLV-III/LAV-infected children are the civil rights aspects of public school attendance, the protections for handicapped children under 20 U.S.C. §§ 1401-1461 and 29 U.S.C. § 794, the confidentiality of a student's school record under state laws and under 20 U.S.C. § 1232(g) and employee right-to-know statutes for public employees in some states.

Confidentiality Issues. The diagnosis of AIDS or associated illnesses evokes much fear from others in contact with the patient and may evoke suspicion of life styles that may not be acceptable to some persons. Parents of a HTLV-III/LAV-infected children should be aware of the potential for social isolation should the child's condition become known to others in the care or educational setting. School, day-care and social service personnel and others involved in educating and caring for these children should be sensitive to the need for confidentiality and the right to privacy in these cases.

#### ASSESSMENT OF RISKS

Risk Factors for Acquiring HTLV-III/LAW Infection and Transmission. In adults and adolescents, HTLV-III/LAV is transmitted primarily through sexual contact (homosexual or heterosexual) and through parenteral exposure to infected blood or blood products. HTLV-III/LAV has been isolated from blood, semen, saliva and tears, but transmission has not been documented from saliva and tears. Adults at increased risk of acquiring HTLV-III/LAV include homosexual/bisexual men, intravenous drug abusers, persons transfused with contaminated blood or blood products and sexual contacts of persons with HTLV-III/LAV infection or in groups at increased risk for infection.

The majority of infected children acquire the virus from their infected mothers in the prenatal period. In utero or intrapartum transmission are likely, and one child reported from Australia apparently acquired the virus postnatally, possibly from ingestion of breast milk. Children may also become infected through transfusion of blood or blood products that contain the virus. Seventy percent of the pediatric cases reported to CDC occurred among children whose parent had AIDS or was a member of a group at increased risk of acquiring HTLV-III/LAV infection; 20 percent of the cases occurred among children who had received blood or blood products, and for 10 percent, investigations are incomplete.

Risk of Transmission in the School, Daycare or Foster-Care Setting. None of the identified cases of HTLV-III/LAV infection in the United States are known to have been transmitted in the school, daycare, or foster-care setting or through other casual person-to-person contact. Other than the sexual partners of HTLV-III/LAV-infected patients and infants born to infected mothers, none of the family members of the over 12,000 AIDS patients reported to CDC have been reported to have AIDS. Six studies of family members of patients with HTLV-III/LAV infection have failed to demonstrate HTLV-III/LAV transmis-

sion to adults who were not sexual contacts of the infected patients or to older children who were not likely at risk from perinatal transmission.

Based on current evidence, casual person-to-person contact as would occur among schoolchildren appears to pose no risk. However, studies of the risk of transmission through contact between younger children and neurologically handicapped children who lack control of their body secretions are very limited. Based on experience with other communicable diseases, a theoretical potential for transmission would be greatest among these children. It should be emphasized that any theoretical transmission would most likely involve exposure of open skin lesions or mucuous membranes to blood and possibly other body fluids of an infected person.

Risks to the Child with HTLV-III/LAV Infection. HTLV-III/LAV infection may result in immunodeficiency. Such children may have a greater risk of encountering infectious agents in a school or daycare setting than a home. Foster homes with multiple children may also increase the risk. In addition, younger children and neurologically handicapped children who may display behaviors such as mouthing of toys would be expected to be at greater risk for acquiring infections. Immunodepressed children are also at greater risk of suffering severe complications from such infections as chickenpox, cytomegalovirus, tuberculosis, herpes simplex and measles. Assessment of the risk of the immunodepressed child is best made by the child's physician, who is aware of the child's immune status. The risk of acquiring some infections, such as chickenpox, may be reduced by prompt use of specific immune globulin following a known exposure.

#### Recommendations

- 1. Decisions regarding the type of educational and care setting for HTLV-III/LAV-infected children should be based on the behavior, neurologic development and physical condition of the child and the expected type of interaction with others in that setting. These decisions are best made using the team approach, including the child's physician, public health personnel, the child's parent or guardian and personnel associated with the proposed care or educational setting. In each case, risks and benefits to both the infected child and to others in the setting should be weighed.
- 2. For most infected school-age children, the benefits of an unrestricted

setting would outweigh the risks of their acquiring potentially harmful infections in the setting and the apparent nonexistent risk of transmission of HTLV-III/LAV. These children should be allowed to attend school and after-school daycare and to be placed in a foster home in an unrestricted setting.

- 3. For the infected preschool-age child and for some neurologically handicapped children who lack control of their body secretions or who display behavior, such as biting, and those children who have uncoverable, oozing lesions, a more restricted environment is advisable until more is known about transmission in these settings. Children infected with HTLV-III/LAV should be cared for and educated in settings that minimize exposure of other children to blood or body fluids.
- 4. Care involving exposure to the infected child's body fluids and excrement, such as feeding and diaper changing, should be performed by persons who are aware of the child's HTLV-III/LAV infection and the modes of possible transmission. In any setting involving an HTLV-III/LAV-infected person, good handwashing after exposure to blood and body fluids and before caring for another child should be observed, and gloves should be worn if open lesions are present on the caretaker's hands. Any open lesions on the infected person should also be covered.
- 5. Because other infections in addition to HTLV-III/LAV can be present in blood or body fluids, all schools and daycare facilities, regardless of whether children with HTLV-III/LAV infection are attending, should adopt routine procedures for handling blood or body fluids. Soiled surfaces should be promptly cleaned with disinfectants, such as household bleach (diluted one part bleach to 10 parts water). Disposable towels or tissues should be used whenever possible, and mops should be rinsed in the disinfectant. Those who are cleaning should avoid exposure of open skin lesions or mucous membranes to the blood or body fluids.
- 6. The hygienic practices of children with HTLV-III/LAV infection may improve as the child matures. Alternatively, the hygienic practices may deteriorate if the child's condition worsens. Evaluation to assess the need for a restricted environment should be performed regularly.
- 7. Physicians caring for children born to mothers with AIDS or at increased risk of acquiring HTLV-III/LAV infection should consider testing the children for evidence of HTLV-III/LAV infection for medical reasons. For example, vaccination of infected children with live virus vaccines, such as the measles-mumps-rubella vaccine (MMR), may

be hazardous. These children also need to be followed closely for problems with growth and development and given prompt and aggressive therapy for infections and exposure to potentially lethal infections, such as varicella. In the event that an antiviral agent or other therapy for HTLV-III/LAV infection becomes available, these children should be considered for such therapy. Knowledge that a child is infected will allow parents and other caretakers to take precautions when exposed to the blood and body fluids of the child.

- 8. Adoption and foster care agencies should consider adding HTLV-III/LAV screening to their routine medical evaluations of children at increased risk of infection before placement in the foster or adoptive home, since these parents must make decisions regarding the medical care of the child and must consider the possible social and psychological effects on their families.
- 9. Mandatory screening as a condition for school entry is not warranted based on available data.
- 10. Persons involved in the care and education of HTLV-III/LAV-infected children should respect the child's right to privacy, including maintaining confidential records. The number of personnel who are aware of the child's condition should be kept at a minimum needed to assure proper care of the child and to detect situations where the potential for transmission may increase (e.g., bleeding injury).
- 11. All educational and public health departments, regardless of whether HTLV-III/LAV-infected children are involved, are strongly encouraged to inform parents, children and educators regarding HTLV-III/LAV and its transmission. Such education would greatly assist efforts to provide the best care and education for infected children while minimizing the risk of transmission to others.

For more information, contact Centers for Disease Control, 1600 Clifton Road, Bldg. 6, Room 277, Atlanta, Ga. 30333.