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December 9, 1999

Sandra Thurman
Director
White House
Office of National AIDS Policy
736 Jackson Place, N.W.
Washington, D.C. 20503

Dear Ms. Thurman:

It was a pleasure meeting you at the Magic Johnson Foundation reception. As a person who created the only AIDS Law Center to provide direct legal services to the HIV + community in Michigan, I applaud your commitment and personal efforts on behalf of this population. Please know if there is anything that I can do to assist you in Michigan, I'll be delighted to do so.

As I indicated when we met, I prepared a white paper on legal issues regarding children orphaned by AIDS. I'm enclosing a copy of that paper, together with a brochure on our law center for your perusal. The issues presented during the symposium were painted in terms of health (medical) and social services issues, but ultimately, in many countries, as well as in the United States, the ultimate decision regarding children (and youth under 18), is determined by courts and the various laws which govern them. The legal system, in many instances, can be equally traumatizing for young people as well as adults who've had no previous exposure to it, particularly in the United States and I'm sure in other countries which may not have as much bureaucracy, but which have various levels of corruption. I'd be delighted to work on these issues with you and your office if you deem it appropriate.

CLIENT INTAKE AND REPRESENTATION CENTERS (CADILLAC TOWER)

Child and Family Law Center
Downtown Law Center
Bankruptcy Law Center
AIDS Law Center

3500 Cadillac Tower
Detroit, MI 48226
(313) 962-0466
(313) 962-0229 Fax

CLIENT INTAKE AND REPRESENTATION CENTERS

Highland Park Law Center
14528 Second Avenue
Highland Park, MI 48203
(313) 868-7677
(313) 868-8453 Fax

LASED Intake Center
4138 West Vernor
Detroit, MI 48209
(313) 962-0466
(313) 554-2242 Fax

ACCESS Intake Center
12740 W. Warren
Dearborn, MI 48126
(313) 945-8380
(313) 624-9418 Fax

Butzel Intake Center
7737 Kercheval
Detroit, MI 48214
(313) 925-0357

SUBURBAN LAW CENTER

Suburban Law Center-Ecorse
3715 W. Jefferson
Ecorse, MI 48229
(313) 843-3869
(313) 841-7540 Fax

Suburban Law Center-Redford
12121 Hemingway
Redford, MI 48239
(313) 937-8291
(313) 937-8893 Fax

LAW RELATED EDUCATION CENTER

Children's Center for Justice and Peace
14528 Second Avenue
Highland Park, MI 48203
(313) 868-7677
(313) 868-8453 Fax

Senior Outreach Enrollment Project
12121 Hemingway
Redford, MI 48239
(313) 937-8291
(313) 937-8893 Fax

MEDIATION AND SPECIAL PROGRAMS

WCNLS Mediation Center
3400 Cadillac Tower
Detroit, MI 48226
(313) 962-0466
(313) 962-6374 Fax

Housing Placement Center
455 Fort Street
Detroit, MI 48226
(313) 964-1975
(313) 964-4354 Fax

ADMINISTRATIVE OFFICE

34th FLOOR CADILLAC TOWER BUILDING
DETROIT, MI 48226
(313) 962-0466
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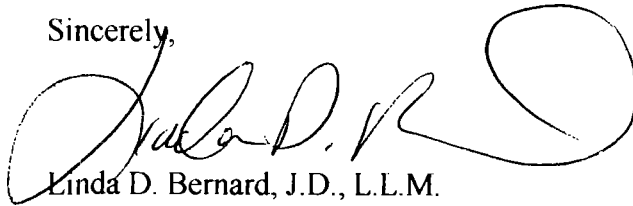
Letter to Sandra Thurman
December 9, 1999
Page Two

I'd also appreciate being put on your bidders list and receive copies of all solicitations in order to possibly supplement funding for our office. We have only two lawyers in the unit. They are extremely dedicated and hardworking, but their caseloads are in the hundreds. For that reason, any assistance that you could provide would be greatly appreciated. In addition, I have one paralegal and one outreach education person in the unit, both of whom have AIDS and have limited schedules.

Once again, I enjoyed meeting you and look forward to continued dialogue.

At WCNLS **"We Better Our Best"**TM

Sincerely,

A handwritten signature in black ink, appearing to read "Linda D. Bernard". The signature is fluid and cursive, with a large loop at the end.

Linda D. Bernard, J.D., L.L.M.
President & CEO

LDB/zmk

Enclosure

What is Wayne County Neighborhood Legal Services?

Wayne County Neighborhood Legal Services (WCNLS) is a Michigan non-profit corporation providing legal representation, law-related education/outreach, mediation services and special programs designed to take "Total Action Against Poverty."

AIDS Law Center

Until recently society identified AIDS care only in terms of medical treatment and prevention. However, AIDS has also created a "legal care" crisis of universal proportions. Powers of attorney and a will are needed. The AIDS Law Center (ALC) addresses these needs.

Discrimination against persons with HIV is widespread. HIV positive persons frequently face job loss, loss of medical insurance coverage and other important benefits thus causing an escalating cycle of financial crisis often resulting in poverty.

Who is eligible?

The ALC provides compassionate legal services to AIDS/HIV positive residents of Southeastern Michigan, their families, and/or significant other. So that no one is excluded from the project's services, the ALC does not charge clients legal fees.

What types of legal services are provided?

AIDS law: includes specific laws which are applicable to HIV positive individuals regarding:

- confidentiality
- a minor's care & treatment
- medical care
- custody & guardianship
- employment
- criminal sexual conduct
- HIV transmission
- partner notification
- anti-discrimination

The ALC addresses the needs of AIDS/HIV positive persons through direct, on site client representation, public education and client counseling in a **confidential** environment.

Consumer law: includes bankruptcy, collection actions with threat of foreclosure or garnishment, debtor-creditor actions, and utility law matters.

Family law: includes divorce, visitation, adult abuse, child abuse and support & property issues.

Housing law: includes housing discrimination, homelessness, federally subsidized housing, landlord/tenant matters, public housing, lockouts, evictions, repairs and foreclosures.

Income maintenance law: includes disability, social security, supplemental security income, unemployment compensation and Aid to Families with Dependent Children (AFDC).

Individual rights law: includes health status disclosure, discrimination due to health status in regards to employment, housing, insurance or health care.

Probate law: includes wills and estates, living wills, guardianships of minors and powers of attorney, patient advocate forms.

What types of education programs are provided?

- ALC client education project — legal rights seminars for HIV positive persons.
- AIDS community education project — includes a broad range of seminars, legal forums, and "Ask the Lawyer" presentations.
- AIDS youth education project — geared toward furthering youths' (ages 9 - 21) understanding of the law and preventing further transmission of the virus.

Why an AIDS Law Center?

ALC seeks to enforce the laws guaranteeing that persons with HIV have the right to fully participate in our society. The ALC helps individuals take control over basic decisions they face in confronting HIV in their own lives.

Overview of WCNLS Services

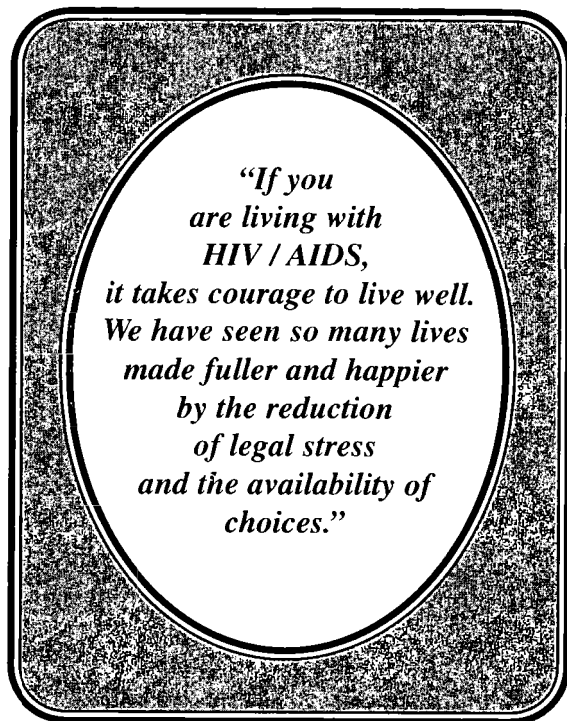
Wayne County Neighborhood Legal Services provides high quality **legal, mediation** (alternative dispute resolution), **law-related education**, and **community outreach services**, as well as **special proactive programs designed to uplift persons from poverty**.

Specialized educational services target the needs of youth and the elderly. Additionally, **housing placement services** assist those who are at risk of homelessness.

Clients are potentially eligible for free legal services in the following areas:

- abuse and neglect cases
- AIDS law
- bankruptcy
- child welfare
- education
- employment
- family (domestic violence, divorce, custody, support, visitation, adoption)
- foster / nursing home care
- guardianships
- health
- housing
- immigration
- individual rights
- juvenile justice
- mental health
- public benefits (Family Independence Agency, unemployment compensation, SSI)
- social security
- utilities
- wills

The AIDS Law Center is principally funded by the Detroit Health Department, Ryan White Title I, and a grant from the State Bar of Michigan's Interest on Lawyers' Trust Account (IOLTA). Services are free. Tax deductible contributions are welcomed.



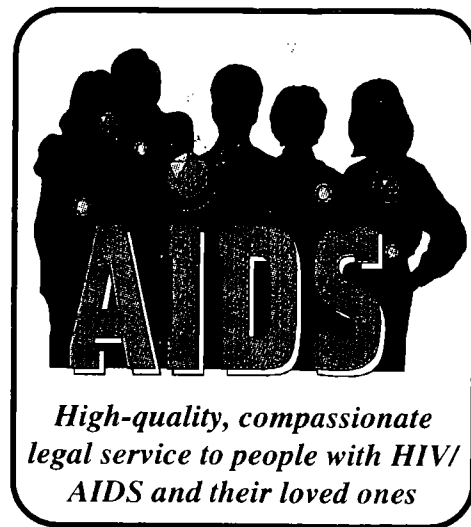
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AIDS Law Center



Wayne County Neighborhood Legal Services



CHILDREN ORPHANED

BY

PARENTS WITH AIDS:

A PRIMER ON THEIR LEGAL SERVICE NEEDS



A PERSPECTIVE FROM THE UNITED STATES

COMPILED BY

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**CHILDREN ORPHANED
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PARENTS WITH AIDS:
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A PERSPECTIVE FROM THE UNITED STATES

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**Linda D. Bernard, Esq.
President & CEO
Wayne County Neighborhood Legal Services
Detroit, MI USA**

INTRODUCTION

The U.N. Convention On The Rights Of The Child defines children as persons under 18 years of age.

According to Dr. David Michaels (an epidemiologist at City University of New York Medical School):

- ◆ By the year 2000 between 72,000 and 125,000 children and teenagers in the United States will have lost their parents to HIV/AIDS. An additional 60,000 young adults (18 and older) also will have lost their mothers.
- ◆ 93,000 to 112,000 healthy children will be born to HIV-infected mothers between 1992 and 2000.
- ◆ AIDS-affected families are a heterogenous population and should not be stereotyped ... AIDS should be reconceptualized as a disease that not only affects individuals, but destroys families and communities.

In Orphans Of The HIV Epidemic: Unmet Needs In Six U.S. Cities (c 1994), Carol Levine and Gary L. Stein indicated that:

- ◆ Most orphaned youngsters are not HIV-infected but are at high risk for a range of behavioral and developmental problems, as well as for engaging in high-risk behaviors associated with HIV transmission.
- ◆ Although a broad range of services is required, including health care, the most urgent needs are for mental health services, including bereavement counseling; transitional services for the

reorganized family to help overcome the loss of AIDS-related benefits following the parent's death; housing supports; appropriate evaluations and referrals by juvenile justice and school staff to community-based services; and, **legal services**.

Children orphaned by AIDS (or those who soon will be) have legal representation needs attendant to other urgent needs described above. These needs become even more acute when the orphaned child is HIV+.

Children orphaned by AIDS have the following legal representational needs:

- ◆ Permanency Planning (Guardianships, Powers of Attorney, Adoption, Foster Care);
- ◆ Education (Discipline, Special Education, Truancy);
- ◆ Income Maintenance
- ◆ Delinquency
- ◆ Health Care
- ◆ Confidentiality (if the orphan is HIV+)
- ◆ Discrimination (if the orphan is HIV+)

Since most children orphaned as a result of AIDS are from poor families, they would be entitled to free legal services from legal aid attorneys funded through governmental and private funding (e.g. the Legal Services Corporation, IOLTA [Interest On Lawyer Trust Account] state funding, United Way). However, because resources are limited, the vast majority of financially eligible persons are not served. If these orphaned children do not receive the legal assistance (together with other social services) they require, their life may spiral into homelessness, addiction, incarceration, unemployment, and even premature death.

PERMANENCY PLANNING

I. Traditional Guardianship

A parent or someone else can petition the court to appoint a guardian for the child. In some states a child who is 14 years or older may file a petition on their own behalf. If the judge approves the proposed guardian and signs an order appointing the guardian, the guardian has the authority to act for the child as soon as the order is signed. The court usually gives custody of the child to the guardian. In general, any person who is interested in the welfare of a child can go to court to petition for guardianship. The court will have to decide if the petitioner's age, health, employment status, child raising experience, etc., qualifies the

petitioner as a guardian. Depending upon the guardianship order, a person may be either a general or a special (limited) guardian on a temporary or permanent basis.

A. Full Guardianships

A court will generally grant you full guardianship if:

- 1) The parents of the child have let the child live with the petitioner, but have not given the petitioner legal authority (such as a power of attorney) to care for the child.
- 2) Both parents' rights have been suspended or terminated by:
 - (a) a prior court order,
 - (b) a judgment of divorce or separate maintenance,
 - (c) death,
 - (d) court order of mental incompetency,
 - (e) disappearance, or,
 - (f) jail, prison or other similar confinement.

B. Special (Limited) Guardianship

A court will grant a special (limited) guardianship when the parent(s) voluntarily grants guardianship to the petitioner. This petition must be filed during the life of the parent(s). The proposed limited guardian and the parent(s) must agree to comply with a court approved placement plan which outlines the following information:

- 1) the reasons for the placement
- 2) visitation and contact plans between the parent(s) and child
- 3) the proposed duration of the guardianship
- 4) who will support the child and how
- 5) any other agreements regarding the child and the plan

Once the plan is established, it cannot be changed unless by court order.

II. Testamentary Guardianship

The parent expresses in their will whom they would nominate to take care of their child(ren) as guardian upon the parent's death. The court is not bound to approve the nomination. Generally, meaningful review of a testamentary guardianship appointment only occurs if a relative of the child contests the parent's choice of guardian. Unfortunately, the parent's wishes may be ignored by the court due to the presumption that HIV+ parents have acted irresponsibly, are incapable of parenting, or suffering from dementia.

III. Standby Guardianship

Only a few states have developed this kind of guardianship. Only the parent can petition the court to appoint a standby guardian without relinquishing control or custody of her children. The court still has to approve the standby guardian using the same criteria as if the person were appointed as a guardian. The parent decides when the guardianship goes into effect. A standby guardianship proceeding can only be brought by a parent suffering from a progressive, chronic condition or an irreversible, fatal illness. The standby guardian has concurrent authority with the parent. Thus, parents do not relinquish any of their authority, but instead share it with the guardian. Standby guardianship statutes give extended family members or friends authority to make decisions affecting the welfare of the children, including such things as enrolling children in school or making decisions about medical treatment. Thus, parents do not relinquish any of their authority, but instead share it with the guardian. Furthermore, if the parents choose to end the standby's authority, they may do so.

IV. Parental Powers Of Attorney

A Parental Power of Attorney is a form that gives the holder the legal right to do things that a parent could do. This can be important in certain situations. For example, if the child needs medical treatment, the doctor or hospital may want to deal only with someone who has the legal power to make decisions. The parental power of attorney is a piece of paper that is signed by the parent giving the named party the power to do certain things on behalf of the child. The power of attorney can list specific types of decisions that the named party has the power to make, such as medical decisions (a special power of attorney). Or, it can give the named party almost the same power to make decisions that a parent can make (a general power of attorney).

A Parental Power of Attorney is good to use if:

- ◆ The child's parent is willing and available to sign the forms
- ◆ The named party needs to make decisions for the child
- ◆ The named party needs this power for more than a very short time

- ◆ The named party and the child's parent want the parent to be able to take back their power quickly at a later time by simply signing another document stating that the power of attorney is revoked
- ◆ Court involvement is not wanted

V. Adoption

The heart of the adoption procedure is the approval by a judge of the transfer of rights with due regard for the welfare of the child and the parental qualifications of the adopters. The adopting parents may be HIV+, may be gay, may be a single individual, may be elderly, may be of a different race, etc. The child may be HIV+ which would include issues of mandatory testing of the child for HIV/AIDS, disclosure issues of the child's health status to the prospective parents, etc. Disclosure of the health status of the proposed adoptive parents is required by law.

VI. Foster Care

When a child is placed in foster care, regardless of whether the placement results from a charge of abuse or neglect or abandonment against a parent or from a parent's illness and inability to care for the child, the parent loses much control over subsequent events. For example, the parent relinquishes the ability to determine when the child will be returned and is not consulted about decisions affecting the child's welfare. Communication between parent and foster parent are typically discouraged. Agencies rarely attempt to facilitate meaningful visits between parent and child. The foster care system usually presumes it is dealing with a bad, or at best, an inadequate parent, and accords that parent or other relatives little authority. The foster care system is not known for promoting a smooth transition for the child to become accustomed to the new parents intended to be permanent custodians of the child, exacerbating the child's already developing emotional problems. Finally, if the child is HIV+, the child is entitled to special accommodating services from the foster care organization to meet their needs.

EDUCATION

The child may require legal representation in the following areas:

- ◆ Due process hearings and appeals in special education and educational delinquency cases,
- ◆ "Manifestation hearings" and appeals under the Individuals With Disabilities In Education Act, where a conduct problem may be a manifestation of a disability,

- ◆ Section 504 hearings and school protection plan proceedings where a student is the victim of physical or sexual assault at school.

Usually the orphaned child will have special education needs which their school has not provided them. If the orphaned child is HIV+ symptomatic, that child may qualify for special physical services relating to their illness.

If the orphaned child has emotional problems stemming from their parent's death, the child may qualify for special education if one or more of the following exists:

- ◆ Inability to build or maintain satisfactory interpersonal relationships within the school environment;
- ◆ Inappropriate types of behavior or feelings under normal circumstances;
- ◆ General pervasive mood of unhappiness or depression;
- ◆ Tendency to develop physical symptoms of fear associated with personal or school problems;
- ◆ The term "emotionally impaired" also includes persons who, in addition to the above characteristics, exhibits maladaptive behaviors related to schizophrenia or similar disorders. The term emotionally impaired does not include persons whose behaviors are primarily the result of intellectual, sensory, or health factors.

Children orphaned by AIDS also may need legal assistance in obtaining the following:

- ◆ Seeking school enrollment
- ◆ Obtaining school records
- ◆ Qualifying for school nutrition programs

INCOME MAINTENANCE

Children orphaned by AIDS require legal representation on behalf of themselves and their care giver to become eligible for financial assistance from the government:

- ◆ Temporary Assistance for Needy Families
- ◆ Food Stamps
- ◆ Head Start
- ◆ Social Security

For children who are themselves infected with HIV, one of the critical issues in assuring both financial support and access to health care is eligibility for SSI benefits which, in most states, also qualifies the recipient for Medicaid. SSA has promulgated regulations for determining SSI eligibility for people disabled by HIV/AIDS. For children and adolescents with HIV infection, the regulations include an expanded number of listed impairments.

Orphaned children are also entitled to Social Security Survivorship Benefits until they become an adult.

◆ Foster Care Subsidy

An inequality exists between federal and state benefits available to guardians and foster parents. Guardians (no matter what type), commonly grandparents and maternal aunts, cannot become eligible for the enhanced subsidies available to foster parents and some adoptive parents. Therefore, the person asked to become a guardian may want to become a foster parent. Federal law says that if a child is in foster care, the government must provide financial help and services, including cash assistance, to foster families. The government is also supposed to provide special programs and services to the parents, including counseling.

DELINQUENCY

Orphaned children may involve themselves in activities which would be criminal if not for their age. These children are entitled to due process hearings similar to adult criminal justice proceedings.

Some delinquent orphaned children of parents with HIV/AIDS can trace their delinquency to the psychiatric trauma resultant from their experiences in dealing with their parents dying and the bereavement process, mitigating factors for the child's defense.

John Bowlby, in his book *Loss: Sadness and Depression* (c 1980), explains why some orphaned children from HIV/AIDS homes develop delinquent behaviors after their parent's death. He attributes their delinquency to the following causes:

- ◆ Breakup of the home and frequent changes in the child's care giver have a severe impact on those children;
- ◆ Discontinuities of care, temporary foster homes, and other factors have proved to be very detrimental to the child;
- ◆ Often children of HIV+ parents are not informed about the cause of their parent's

illness; in other cases, the children know about the illness, but it is kept a family secret. They cannot discuss the illness with others for fear of an adverse reaction due to the stigma attached to HIV. This complicates the grieving process immeasurably.

- ◆ Most of these children come from families that have already had serious problems prior to the onset of the HIV, for example, drug use.

HEALTH CARE

The orphaned child will require medical care and the ability to pay for the medical services. The orphaned child and their care giver may need legal representation to assist the care giver in qualifying the orphaned child for private or governmental health care insurance. The orphaned child may have difficulty in qualifying for the care giver's health insurance through their care giver's employer. The orphaned child may have difficulty in qualifying for Medicaid, state sponsored health insurance (e.g. Michigan's MI-CHILD program), or Hill Burton Uncompensated Care (i.e. federal funds available to some hospitals to treat low-income patients despite unpaid hospital bills).

CONFIDENTIALITY

The orphaned child who is also HIV+, in some states, has rights and duties under various confidentiality statutes. In Michigan, the following rights and duties would apply for the orphaned child:

I. No One Has A Right To Know That The Child Is Infected With HIV/AIDS

A person that knows that the child is infected with HIV/AIDS cannot tell third parties without the child's (i.e. the care giver's) permission. This means that employers, co-workers, doctors, insurance companies, service providers of any type -- perhaps even family and friends -- have no right to know about the child's illness unless the care giver approves.

II. The Child (I.E. The Care Giver) Must Give Other People Permission To Reveal That The Child Is Infected

If the child is infected, no one that the child/care giver tells can give this information to anyone else unless the child/care giver gives them specific permission to disclose the information. Unauthorized disclosure is a misdemeanor and a fine up to \$5000, or both. The care giver could also sue on the child's behalf for \$1000 or actual damages, whichever is greater.

III. There Are Some Exceptions For Health Care Workers And Doctors

- A. Test Results To The Health Department
- B. Reporting To Protect Sexual Partners And Needle Sharing Contacts
- C. Reporting To Prevent Transmission Of The Disease, To Diagnose Or Care For A Patient, Or To Protect The Health Of An Individual

DISCRIMINATION AND CIVIL RIGHTS VIOLATIONS

I. Employment Discrimination

The orphaned child, upon reaching the age of 15 (usually), may want to enter the workforce to earn money. However, if the child is HIV+, or falsely perceived to be HIV+, employers have a myriad of ways of discriminating against the child. Wrongful discharge from employment is not the only form of employment discrimination facing persons with HIV. Employees who are infected with HIV and persons who are perceived as possibly being infected may be isolated from co-workers, transferred against their will, denied certain work assignments, and have their hours of work reduced. In fact, some employers will utilize such a strategy in the hopes that the employee will "voluntarily" quit or resign. In this way, employers attempt to deprive their employees of insurance, pension, and medical benefits, gambling that the employee with HIV disease will be too weak or demoralized to fight to defend his or her legal rights. The orphaned child's attorney can utilize antidiscrimination laws (e.g. the Americans With Disabilities Act, the Rehabilitation Act of 1973, the Federal Employee Retirement Income Security Act, Title VII of the Civil Rights Act, and state law) to redress the illegality.

II. Public Accommodation Discrimination

Denial of access to public accommodations (e.g. schools, stores, retail and wholesale establishments, public facilities, hospitals, clinics, nursing homes, rehabilitation programs, funeral homes, public transportation, medical offices, and anywhere else that provides goods or services to consumers) based on the child's HIV infection or AIDS diagnosis is most often illegal under federal and state disability statutes, and may violate local and county antidiscrimination ordinances. As in employment discrimination law, the applicant to the program or the person seeking admission to the public accommodation must be "otherwise qualified" for the program or activity and therefore must meet the reasonable requirements for admission to or participation in the public accommodation. The orphaned child's attorney can utilize antidiscrimination laws (e.g. the Americans With Disabilities Act, the Rehabilitation Act of 1973, the Civil Rights Act, state law and administrative regulations) to redress the illegality.

III. Housing Discrimination

The child orphaned due to AIDS may encounter housing discrimination when their care giver tries to either maintain their current housing or seeks new housing. Landlords turn off utility service or refuse to make repairs in apartments or houses, persons harass neighbors suspected of having AIDS, property owners attempt to evict HIV+ persons, and real estate agents steer prospective home buyers away from homes in which persons with HIV disease have lived. The orphaned child's attorney can utilize antidiscrimination laws (e.g. Federal Fair Housing Act, the Americans With Disabilities Act, the Rehabilitation Act of 1973, state law and administrative regulations) to redress the illegality.

IV. Civil Rights Violations

The child who is HIV+ is also granted general civil legal protections that protect victims of domestic violence, stalking and harassing communications. These victims (or their care givers) have the right to file criminal complaints and civil actions for court ordered protection. Perpetrators may be ordered to stay away from these victims and to cease and desist from any further threats or contacts. Violators of the personal protection order may be held in contempt of court and jailed.

CONCLUSION

This brief survey of the legal service needs of children orphaned by parents with AIDS is not exhaustive. However, a strong argument can be made that without access to legal services (especially free legal services for the majority of these clients who are poor), the child has a substantial risk of not enjoying a stable and nurturing care giving environment (which may result in deviant behavior) and lose access and enjoyment of education, health care, housing, employment, and entitlements. Each government should adopt the UN Convention On The Rights Of The Child, aspire to ensure that no child is mistreated or ignored, and to all examine each nation's laws to develop a workable legal framework to let no child go without the basic necessities of life, and no parent to die with worries about their child(ren)'s future.