



## **“Life Doesn’t Wait”**

### **Romania’s Failure to Protect and Support Children and Youth Living with HIV**

Glossary .....	1
I. Summary .....	4
Methods.....	8
II. Key Recommendations.....	10
To the Government of Romania.....	10
To the European Union.....	10
To Other International Donors.....	11
III. Background .....	12
IV. Findings.....	15
Discrimination in and Barriers to Access to Education.....	15
Vocational Education.....	21
Violations of the Right to Health.....	23
Access to Medical Services.....	23
Access to Mental Health Care .....	27
Access to Medications.....	31
Access to Medications for Opportunistic Infections.....	32
Access to Antiretroviral Therapy.....	35
Violations of the Right to Privacy and to Information.....	37
Violations of the Right to Privacy.....	37
Criminalization of Transmission of HIV.....	40
Disclosure of HIV Status, Sex Education, and the Right to Information .....	44
Sex Education .....	47
Discrimination and Barriers to Employment .....	50
V. Government Response and Failures to Protect Children.....	54
Inadequate Complaint Mechanisms.....	54
County Directorates of Child Protection.....	54
The National Council for Combating Discrimination.....	58
Inadequate Monitoring and Investigations of Abuse and Neglect.....	60
Inadequate Support for Caregivers of Children Living with HIV .....	64
De-institutionalization on the Cheap: The Case of Vidra Orphanage .....	66

Aging Out of the Child Protection System.....	70
Arbitrary Procedures for Receiving State Subsidies .....	75
Adult Complex Assessment Committees .....	78
VI. Human Rights Standards in International and Romanian Law.....	82
Children’s Right to Protection and Care .....	82
The Right to Protection from Discrimination .....	85
The Right to the Highest Attainable Standard of Health .....	86
The Right to Education .....	90
The Right to Information.....	92
The Right to Privacy .....	94
VII. Detailed Recommendations .....	98
To the Government of Romania.....	98
General Recommendations.....	98
Protection and Care for Children and Youth Living with HIV .....	99
Combating Discrimination against People Living with HIV .....	99
The Right to Health .....	100
The Right to Education .....	101
The Right to Information.....	101
The Right to Privacy .....	101
To the European Union.....	102
To Other International Donors.....	102
VIII. Conclusion .....	103
Acknowledgements.....	104

## Glossary<sup>1</sup>

***AIDS:*** The acquired immunodeficiency syndrome is a fatal disease caused by HIV, human immunodeficiency virus. Currently, antiretroviral drugs slow down replication of the virus and can greatly enhance quality of life, but they do not eliminate HIV infection.

***Antiretrovirals (ARVs):*** Drugs that inhibit the ability of retroviruses (such as HIV) to multiply in the body. The antiretroviral therapy recommended for HIV infection is referred to as highly active antiretroviral therapy (HAART), which uses a combination of medications to attack HIV at different points in its life cycle.

***Directorate for Child Protection (Direcția pentru Protecția Copilului, DPC):*** Child protection bodies under the supervision of county (or in the case of Bucharest, sector) councils. DPCs have primary responsibility for intervention in cases of child abuse and neglect, including investigating cases of suspected abuse or neglect, and providing services to the child and his or her family.

***Global Fund to Fight AIDS, Tuberculosis, and Malaria:*** An independent public-private partnership established in 2001, and the largest global fund in the health domain. It works to attract, manage and disburse additional resources to make a sustainable and significant contribution to mitigate the impact caused by HIV, tuberculosis, and malaria in countries in need, while contributing to poverty reduction as part of the Millennium Development Goals.

***HIV:*** The human immunodeficiency virus. HIV destroys the body's ability to fight off infection and disease, ultimately leading to AIDS.

***HIV-negative:*** Showing no evidence of infection with HIV (e.g. absence of antibodies against HIV) in a blood or tissue test. An HIV-negative person can be infected if he or she is in the window period between HIV exposure and detection of antibodies.

***HIV-positive:*** Showing indications of infection with HIV (e.g. presence of antibodies against HIV) on a test of blood or tissue. Synonymous with seropositive. Test may occasionally show false positive results.

---

<sup>1</sup> This glossary draws on a number of sources, including the May 2006 UNAIDS Editors' Notes for authors, [online] [http://data.unaids.org/pub/InformationNote/2006/EditorsNotes\\_en.pdf?preview=true](http://data.unaids.org/pub/InformationNote/2006/EditorsNotes_en.pdf?preview=true).

***National Authority for Persons with Handicap (Autoritatea Națională pentru Persoanele cu Handicap, ANPH):*** The highest administrative body charged with addressing disability issues, including diagnosis, drafting budgets, developing and coordinating policy, and collecting statistics. In July 2003 it became part of the Ministry of Labor, Social Solidarity and Family.

***National Authority for the Protection of the Rights of the Child (Autoritatea Națională pentru Protecția Drepturilor Copilului, ANPDC):*** An agency under the Ministry of Labor, Social Solidarity and Family that is mandated to coordinate and control Romania's child rights protection and promotion activities, including monitoring implementation of the UN Convention on the Rights of the Child, and Romania's Law 272/2004 on the Protection and Promotion of the Rights of the Child.

***National Committee on Fighting against AIDS (Comisia Națională de Luptă Anti-Sida, CNLAS):*** An expert committee of the Ministry of Health charged with overseeing medical trends of the HIV pandemic in Romania, maintaining the national database and making medical decisions on the treatment provided nationally. The Ministry of Health dissolved the committee in mid-2006, merging its mandate with that of the broader Ministry of Health Commission on Infectious Diseases.

***National Committee for HIV/AIDS Surveillance, Control and Prevention (Comisia Națională pentru Supravegherea, Controlul și Prevenirea Cazurilor de Infecție HIV/SIDA, multi-sectoral committee):*** An inter-ministerial, multi-sectoral body established by Law 584/2002 to monitor and coordinate HIV/AIDS policy and implementation. The commission is under the authority of the prime minister, and in addition to government agencies includes representatives from nongovernmental organizations, people living with HIV, and has as observers UN agencies, the private sector, and donors.

***National Council for Combating Discrimination, (Consiliul Național pentru Combaterea Discriminării, CNCD):*** Created by government order in 2001, the National Council is responsible for implementing government anti-discrimination policies. Its powers include investigating individual cases of discrimination, issuing sanctions in cases of discrimination, and proposing affirmative actions and special measures for the protection of persons confronted with rejection and marginalization.

**National Health Insurance House, (Casa Națională de Asigurări de Sănătate, CNAS):** An independent government agency charged with administering the social health insurance system, including the social health insurance fund.

**Opportunistic Infections:** Illnesses caused by various organisms, some of which usually do not cause disease in persons with healthy immune systems. Persons living with advanced HIV infection may suffer opportunistic infections of the lungs, brain, eyes and other organs. Opportunistic illnesses common in persons diagnosed with AIDS include *Pneumocystis carinii* pneumonia; cryptosporidiosis; histoplasmosis; other parasitic, viral and fungal infections; and some types of cancers.

**Phare:** One of the three pre-accession instruments financed by the European Union to assist the applicant countries of Central and Eastern Europe in their preparations for joining the European Union. Phare programs aim to strengthen public administration and institutions, promote convergence with the European Union's extensive legislation, and promote economic and social cohesion.

**UNAIDS:** The Joint United Nations Programme on HIV/AIDS coordinates the UN's global response to HIV/AIDS. UNAIDS is sponsored by ten UN agencies: the UN High Commissioner for Refugees (UNHCR), the UN Children's Fund (UNICEF), the World Food Programme (WFP), the UN Development Programme (UNDP), the UN Population Fund (UNFPA), the UN Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), the UN Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

**Universal Precautions:** Standard infection control practices to be used universally in healthcare settings to minimize the risk of exposure to pathogens, e.g. the use of gloves, barrier clothing, masks and goggles (when anticipating splatter) to prevent exposure to tissue, blood and body fluids.

## I. Summary

*Life doesn't wait for these children.... We understand that this country has problems but we are one of the problems and we need a share of the attention. We need them to listen to us.*

—Ioana A. (not her real name), foster mother of a youth living with HIV

More than 7,200 Romanian children and youth between age fifteen and nineteen are living with HIV—the largest such group in any European country. They are Romania's miracle children, the survivors among the more than 10,000 children infected with HIV between 1986 and 1991 in hospitals and orphanages as a direct result of government policies that resulted in large numbers of children being exposed to contaminated needles and “microtransfusions” of unscreened blood. A key aspect in this medical miracle has been the early provision and progressive expansion of access to antiretroviral drugs. Romania has been rightfully praised for being the first country in Eastern Europe to provide universal access to antiretroviral therapy. But the commitment to universal access to antiretroviral therapy has not been matched by an equal commitment to combat the pervasive stigma and discrimination against people living with HIV that frequently impede their access to education, medical care, government services, and employment. Even more troubling, there is no government plan in place to ensure that the thousands of children living with HIV who are aging out of existing social protection programs have the skills and support necessary to become productive, integrated adult members of Romanian society.

Fewer than 60 percent of Romanian children living with HIV attend any form of schooling, despite legislation providing for free and compulsory education through tenth grade or until age eighteen. Romanian law bars children who are more than two years older than their grade level from attending mainstream classes, making many children living with HIV “too old” because they have fallen behind due to long periods of hospitalization or substandard educational programs in government institutions. While these children should be eligible for tutoring, distance education, or special classes to help them catch up, few such programs exist, and those that do may be inappropriate or inaccessible to children living with HIV. Those who do attend school risk ostracism, abuse, and even expulsion if their HIV status becomes known. Other children living with HIV are inappropriately relegated to special schools with inferior resources. Nongovernmental organizations (NGOs) and children we spoke with described incidents where children living with HIV were taunted by classmates, threatened by other students' parents, and abused by teachers. In some cases the harassment put

children's health at risk, as when a teacher punished a child by forcing him to stand outside for hours in freezing weather, or when students and teachers left a child who had collapsed at school unattended. Children who manage to complete the eighth grade face a new set of hurdles if they wish to attend vocational programs in the cosmetology, child care, food service, and hospitality fields, where Romanian law requires mandatory HIV testing.

Children and youth living with HIV also face discrimination in access to necessary medical services including dental care, dermatological care, ear, nose and throat specialists, gynecological care, mental health care, routine and emergency surgery, and emergency transport for patients who are bleeding. Doctors often refuse treatment to children and youth living with HIV, or try to discourage them from coming by repeatedly rescheduling appointments, asking them to come back after all other patients have left, or referring to them as "AIDS people" in front of other patients. And while children and youth living with HIV are more susceptible than their disease-free peers to depression, anxiety, and psychiatric disorders, few outpatient mental health care programs exist to treat them. Psychiatric hospitals sometimes refuse to treat HIV-positive children and youth even when they are suffering from serious psychiatric disorders, and nutrition and living conditions in many psychiatric facilities are so substandard that in-patient care in those facilities poses a risk to their health.

Discrimination also impedes children and youth's access to medications for HIV and for opportunistic infections. By law, medications for common opportunistic infections should be paid for by the state and available through private or hospital pharmacies. However, frequently these drugs are not available at hospital pharmacies because the state has not provided funding for them, and private pharmacies may refuse to fill these prescriptions for fear that they will not be reimbursed. In addition, some families of HIV-positive children refuse to take prescriptions with "AIDS" written as a diagnosis to private pharmacies because they fear the consequences of breaches of confidentiality. Despite Romania's stated commitment to providing antiretroviral treatment to everyone who meets the relevant medical criteria, access to antiretroviral treatment varies from county to county, and hospitals that dispense antiretrovirals are prevented from budgeting for anticipated delivery delays or shortages.

The prevalence of stigma and discrimination against people living with HIV in Romania places particular importance on children's right to privacy. However, breaches of confidentiality about individuals' HIV status are common and rarely punished. Medical personnel, school officials, social workers, municipal staff, and postal workers are all common sources of leaked information, as are court documents, certificates of disability,

and required or ad hoc medical testing for employment. In addition, provisions in the Criminal Code set harsh penalties for the knowing transmission of HIV and encourage government officials, police, doctors, and even private individuals to engage in ad hoc “monitoring” of children and youth living with HIV who are suspected of engaging in unprotected sex. This risk of prosecution or monitoring appears to fall disproportionately on girls and women living with HIV, and may make HIV-positive youth less likely to seek assistance and support in a whole range of areas—from police protection to health services—for fear of disclosing their HIV status and exposing themselves to prosecution or monitoring.

Romanian law and practice also discriminates against children in their exercise of the right to information. Children have no automatic right to know of their HIV status without parental consent. Where that consent is absent, children and youth are unable to exercise their right to make informed decisions on medical treatments, educational and employment plans, and their sexual lives. Doctors and social workers cannot counsel children on their disease and on the reason they must adhere to complicated therapies that often have serious side effects, or fully explain the dangers of unprotected sexual intercourse. And while access to information on HIV and reproductive health is a crucial part of the right to health, children and youth living with HIV frequently have limited access to this: information on reproductive health and HIV transmission is currently provided primarily in an optional class offered once during the seventh grade, making it inaccessible to the more than 40 percent of children living with HIV who do not attend school, and to those children and youth who are sexually active but who have not yet reached the seventh grade.

Romanian law provides for mandatory medical testing for a wide variety of jobs where the risk of HIV transmission is minimal, including hair dressers, beauticians, manicurists, child care staff, medical personnel, food services, and cleaning staff in the tourist industry. Employers and doctors also order ad hoc HIV testing for jobs where testing is not mandatory. HIV-positive youth have little recourse when denied jobs based on their HIV status, because employment discrimination cases are difficult to litigate and may draw further attention to their HIV status because court documents are not private.

The Romanian authorities rarely enforce laws prohibiting discrimination against people living with HIV, and the law provides few real sanctions for those who discriminate. The National Council for Combating Discrimination, the body charged with implementing Romania’s primary anti-discrimination legislation, is not well known, works primarily on complaints received from individuals and NGOs, and has no offices outside of Bucharest, the capital, to facilitate filing complaints or conducting investigations. In the few instances where it has intervened in cases involving people living with HIV, its interventions have

been largely limited to mediation in cases of children expelled from schools (where it is nevertheless difficult to reverse the damage done by breaches of confidentiality), or the imposition of fines that are too small to serve as a meaningful deterrent, and which are paid to the government and not to the victim.

According to the United Nations Children's Fund (UNICEF), the majority of children and youth living with HIV have spent some portion of their lives in state institutions, with "disastrous effects" on their development. While most HIV-positive children no longer live in institutions, their deinstitutionalization was and is often a haphazard process with little attention to the children's best interests. In many cases child protection authorities returned children to families without counseling them on their children's history and special needs, and without support for families that still face the same problems that contributed to their original decision to abandon the child. NGOs we spoke with told us that in at least some cases children were returned without prior warning to families who did not even know the child was still alive. Children deinstitutionalized in these circumstances are at an increased risk of abuse and neglect.

While children living with HIV in theory have recourse to police, municipal staff, and county-level Directorates of Child Protection in cases of abuse or neglect, these agencies lack the skilled staff to monitor, investigate, and intervene to protect them. Children and youth living with HIV who reported to these bodies instances of serious abuse rarely received meaningful assistance. In one extreme case, Laura K. (not her real name) told us that when she ran away from home to escape domestic violence, police told her "that I couldn't leave home because I was sick. They said I couldn't have a boyfriend or get married, I had to stay inside."

However problematic the benefits and protections of the child protection system are for children living with HIV, the situation for many young adults is likely to be worse. The government has no real plan for what will happen to HIV-positive children living in institutions, group homes, foster care, or extended family placements after they turn eighteen, and many children fear that they will find themselves on the streets if and when they are forced to leave institutions or payments to their caregivers end. While the law allows for the extension of some child protection measures after eighteen, many children will not qualify for these extensions, and no procedures exist to help children apply for the relevant programs. Children who receive disability subsidies are also likely to see the amount of these subsidies drop as they are reevaluated under the stricter criteria for adults with disabilities. While adults living with HIV often can and should be encouraged to work, our investigation suggests that decisions on the disability benefits they receive are often highly arbitrary, and in some instances appear to reflect committee members' ignorance and bias against people living with HIV. Even if this process were

not arbitrary, high levels of societal discrimination and the low levels of life skills of many children and youth living with HIV raise serious questions about their ability to become self-supporting at eighteen without assistance.

## **Methods**

This report is based on field research conducted in Bacău, Bucharest, Constanța, Giurgiu, and Ilfov counties in February 2006, and follow-up telephone and email contacts through June 2006. Two Human Rights Watch researchers conducted individual interviews with thirty-five children and youth age sixteen to twenty living with HIV, as well as a group interview with nineteen children and youth living with HIV (representing nineteen of the twenty-four affiliates of the National Union of Organizations of Persons affected by HIV/AIDS (UNOPA), a Romanian nongovernmental organization). The children and youth we interviewed represent a broad cross-section of Romania's rural and urban children and youth living with HIV, and included those living with birth families, in extended family placements, foster care placements, NGO-run group homes, hospitals, and in the Vidra placement center, one of the few remaining orphanages for children living with HIV.

We also conducted more than sixty-five interviews with birth and foster parents of children and youth living with HIV; medical staff and care-givers at infectious disease hospitals, regional HIV monitoring centers, an orphanage, and the Ministry of Health's expert body, the National Committee on Fighting against AIDS; staff of NGOs working with children and youth living with HIV; state counselors to the president and to the prime minister; the under-secretary of state and staff of the National Authority for Protection of the Rights of the Child; the president and staff of the National Council for Combating Discrimination; the advisor on HIV/AIDS to the National Authority for Persons with Handicap; the executive director and deputy director of the Constanța county General Directorate for Social Assistance and Child Protection and the deputy director of Ilfov county General Directorate for Social Assistance and Child Protection; and UNICEF and UNAIDS representatives in Romania. Valentina Coțescu, president of the National Committee for HIV/AIDS Surveillance, Control and Prevention, declined to meet with us.

Interviews were conducted in almost all cases in the Romanian language, in a private setting. All participants consented to the interviews and those who requested it were given assurances of confidentiality. No incentives were provided in exchange for the information given. All individuals were told that they could end the interview at any time or could decline to speak on specific issues. The names of children and youth living with HIV and their parents or guardians have been changed to preserve their privacy.

We assess the treatment of children and youth living with HIV according to international standards, as set forth in the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social, and Cultural Rights, the Convention on the Rights of the Child, the European Convention for the Protection of Fundamental Human Rights and Freedoms, the International Guidelines on HIV/AIDS and Human Rights, and other international human rights instruments. These instruments establish that children have the right to health, education, information, and privacy, among other rights.

In this report, in accordance with the Convention on the Rights of the Child, “child” refers to anyone under the age of eighteen.<sup>2</sup> The term “youth” refers to anyone under the age of twenty-six, the maximum age for a young person to continue to receive a child protection measure under Romania’s Law on the Protection and Promotion of the Rights of the Child law (see below).<sup>3</sup>

---

<sup>2</sup> The Convention on the Rights of the Child defines a child as “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.” Convention on the Rights of the Child, November 20, 1989, G.A. Res. 44/25, U.N. Doc. A/RES/44/25 (entered into force September 2, 1990), art. 1.

<sup>3</sup> Law No. 272/2004 on the protection and promotion of the rights of the child, from June 21, 2004, Official Gazette 557 from June 23, 2004, art. 51(2).

## **II. Key Recommendations**

### ***To the Government of Romania***

- Provide effective and appropriate sanctions for discrimination against people living with HIV in relation to access to and enjoyment of services or goods. Sanctions should be enforceable against all civil servants and medical, social, and educational personnel who breach confidentiality.
- End mandatory HIV testing as a condition of employment and ensure that persons living with HIV are not unnecessarily prevented from working or attending vocational school.
- Ensure that people living with HIV have adequate access to necessary routine and emergency medical care, including mental health care and palliative or hospice care for persons with terminal stage AIDS, and to medications needed to treat HIV and common opportunistic infections.
- Protect children and youth living with HIV from abuse and neglect, and ensure that HIV-positive children and youth with mental and physical disabilities enjoy the right to special care suitable to their condition.
- Ensure that children and youth living with HIV are fully informed on how their rights and benefits will change after turning eighteen, and that children and youth in foster, extended family, and residential care are adequately prepared for independent living. Provide appropriate continuing services to young adults who many require them.
- Ensure that children and youth living with HIV have access to education that is appropriate to their needs, including access to accurate information on reproductive health and HIV and AIDS.
- Repeal article 384 of the Criminal Code, which criminalizes the knowing transmission of HIV.
- Reform the working methods and membership of the National Committee for HIV/AIDS Surveillance, Control and Prevention to ensure that it is able to fulfill its mandate, as provided under Law 584/2002.

### ***To the European Union***

- Insist that the Romanian government take steps to enforce the prohibition on discrimination on the basis of HIV status and to provide an appropriate remedy to victims of such discrimination.

- Ensure that adequate implementation of anti-discrimination legislation with regard to HIV status forms an integral part of broader EU efforts to promote equality and non-discrimination in Romania.
- Encourage the Romanian government to adopt all necessary legal and policy measures set out in the recommendations above as soon as possible, making clear that accession to the EU will not mean an end to active EU pressure in this regard. In cooperation with the Romanian government, formulate concrete benchmarks for the reform steps that are required to meet the recommendations above, with specific timelines for their fulfillment.

### ***To Other International Donors***

- Prioritize funding for the labor and social integration of adolescents aging out of Romania's child protection system, with an emphasis on the needs of adolescents living with HIV. Such funding should be conditioned on a clear set of benchmarks and on legal and policy change.
- Urge the government of Romania to act quickly to fulfill its commitment to take over Phare and Global Fund to Fight AIDS, Tuberculosis, and Malaria projects on HIV currently being implemented by NGOs. Consider giving bridge funding to NGOs providing crucial services to persons living with HIV, to ensure that their beneficiaries are not left without these services during the transition.
- International financial institutions such as the World Bank and the European Bank for Reconstruction and Development should incorporate language reflecting the concerns expressed in this report in their next country strategies for Romania, and encourage the Romanian authorities to pursue reforms to address them.

### III. Background

Between 1986 and 1991, at least 10,000 children contracted HIV in Romania.<sup>4</sup> The rapid spread of HIV among Romania's children can be directly traced to the policies of Nicolae Ceaușescu, the country's then dictator.<sup>5</sup> Under Ceaușescu's leadership Romania saw a steep rise in child malnutrition and abandonment as pronatalist policies were promoted including a virtual ban on contraception, abortion, and divorce, alongside disastrous economic policies that made Romania one of the poorest countries in Europe. As hospital and orphanage staff struggled to keep these children alive, they relied heavily on antibiotic injections and "microtransfusions," under the mistaken belief that small transfusions of blood from an apparently healthy person would boost infants' nutritional and immunological status.<sup>6</sup> But Romania did not begin screening blood and blood products for HIV until 1990, and hospital and orphanage staff often failed to properly sterilize needles to prevent transmission of HIV and other blood-borne diseases. According to records from this period, it was not unusual for children in some hospitals and orphanages to receive 120 injections during a four-week period.<sup>7</sup>

---

<sup>4</sup> Romania's National Committee for HIV/AIDS Surveillance, Control and Prevention, in its 2006 progress report to UNAIDS states that "Over 7,000 of the children infected in the late 80s are living now and most of them are in the age group 16 – 18." According to the Ministry of Health's expert committee on HIV/AIDS, as of December 31, 2006 3,622 children had died of AIDS in Romania. The expert committee defines children as persons under 14 at the time of the diagnosis. See National Committee for HIV/AIDS Surveillance, Control and Prevention, Country Indicators, January 2003 –December 2005 Reporting Period, [online] [http://data.unaids.org/pub/Report/2006/2006\\_country\\_progress\\_report\\_romania\\_en.pdf](http://data.unaids.org/pub/Report/2006/2006_country_progress_report_romania_en.pdf) (retrieved May 31, 2006) p. 4; and Ministry of Health, National Commission for Combating AIDS, Prof. Dr. Matei Balș Institute for Infectious Diseases, Date Statistice HIV/SIDA in Romania la 31 Decembrie 2005 ("Statistics on HIV/SIDA in Romania on December 31, 2005,") [online] <http://www.cnlas.ro/hiv/statistica.htm> (retrieved March 9, 2006) . Even today new cases of children infected during this period are still being discovered, and it is impossible to estimate how many children may have succumbed to malnutrition, common childhood illnesses, tuberculosis, and other conditions without having being diagnosed as HIV-positive.

<sup>5</sup> For a more detailed discussion of these policies and their implication for the spread of HIV/AIDS in Romania, see Human Rights Watch, "Romania's Orphans: A Legacy of Repression," *A Human Rights Watch Report*, vol. 2, no. 15, December 1990.

<sup>6</sup> Dr. Rodica Mătușa coordinated care for over 1,700 children living with HIV as director for pediatric AIDS at Constanța's Municipal Hospital from 1989 until 2003. She told Human Rights Watch that 50 percent of these children were infected by transfusions, "especially children in orphanages," 30 percent by contaminated needles, and 20 percent by vertical transmission from infected mothers. "Sailors spread the disease to prostitutes who spread it through blood donation—one vial [of blood] was given to several children because they were just babies so they only needed 50 or 60 ml [of blood]. I can prove that if the child didn't get HIV through vertical transmission all the cases were children who were hospitalized at one hospital." Human Rights Watch interview with Dr. Rodica Mătușa, president, Asociația Speranța, Constanța, February 13, 2006.

<sup>7</sup> Human Rights Watch, "Romania's Orphans: A Legacy of Repression," p. 9.

Today, more than 7,200 of the roughly 11,200 people living with HIV in Romania are children and youth age fifteen to nineteen.<sup>8</sup> While the numbers of children living with HIV appear small in comparison to those in the countries of sub-Saharan Africa, they are shockingly high for a European country, especially given that Romania's total population is only 22 million.<sup>9</sup>

There is little government data on basic social protection indicators for many of these children, and what exists is of questionable reliability. The National Authority for the Protection of the Rights of the Child, the government body responsible for monitoring implementation of child protection standards, only collects data on the approximately 3,400 children living with HIV registered with General Directorates for Social Assistance and Child Protection. The National Authority for Persons with Handicap only collects data on an even smaller number of children who have applied for and received certificates of disability, a process that some families forego out of fear of breaches of confidentiality, as we will discuss later.<sup>10</sup>

Of particular concern is the lack of adequate monitoring of abuse and neglect of children living with HIV who remain in institutions, or who have been de-institutionalized to birth family, extended family, or foster care placements. According to UNICEF, in 1992 67 percent of all children living with HIV lived in institutions, with disastrous effects on the development of these children as they became deprived of other social services and of education.<sup>11</sup> Since then the numbers of children placed outside of their birth families has fallen considerably, but according to data from the National Authority for the Protection of the Rights of the Child more than 700 children living with HIV remain in

---

<sup>8</sup> Ministry of Health, National Commission for Combating AIDS, Prof. Dr. Matei Balș Institute for Infectious Diseases, "Statistics on HIV/SIDA in Romania on December 31, 2005.

<sup>9</sup> The latest EUROHIV surveillance report lists the total number of pediatric AIDS cases for the entire WHO European region to be 10,949 at the end of 2004—see European Centre for Epidemiological Monitoring of AIDS (EUROHIV), *HIV/AIDS Surveillance in Europe End of the Year Report* (Saint-Maurice: Institut de veille sanitaire, October 2005), No. 71, Table 18, p. 34. Romania's statistical data on children living with HIV/AIDS have several significant shortcomings: Romanian HIV/AIDS databases follow the practice of the United States Centers for Disease Control (CDC) of categorizing children over fourteen as adults for statistical purposes, and thus combine data on persons fifteen through nineteen in a single category; new cases of children infected in the 1987-1991 period still are being diagnosed; and little is known about the prevalence of HIV/AIDS among commercial sex workers (a group known to include large numbers of children) and among street-living youth and children, because there has been little testing of these groups, although both groups are known to have high rates of other sexually transmitted infections.

<sup>10</sup> As of September 30, 2005, the National Authority for Persons with Handicap had in its records 3,108 children living with HIV/AIDS, including seven children in institutions. Statistics of the National Authority for Persons with Handicap, on file with Human Rights Watch.

<sup>11</sup> See National Agency for the Protection of the Rights of the Child, Consolidated Analytical Country Report – Romania – 2003, (Draft), 2, 13, 18-19 and UNICEF, et al., *The Situation of Child and Family in Romania*, (May 1998), p. 88.

extended family placements, foster care placements, NGO-run group homes, and state-run group homes and orphanages.<sup>12</sup> Eduard Petrescu, the national officer for UNAIDS' Romania office, told Human Rights Watch,

The process of de-institutionalization of HIV children was not well thought through: children were sent to places without services, sometimes to remote villages, to families that had had no contact with them for years and didn't know anything about AIDS. ...It was done in a hurry to report that it was solved. From a medical point of view it was probably not a very good idea, and it was probably not even good for family reasons—most children didn't go to their families.

Petrescu said he was unaware of what had happened to these children because “[t]here was no strong group to argue for their rights like there was for children with families,” adding, “It is hard to raise the case of a few children with HIV in the broader deinstitutionalization context—we don't have major signals that these children don't have access to services”<sup>13</sup>

---

<sup>12</sup> Of the 3,390 children living with HIV registered with the Directorates of Child Protection, 2,680 are living in biological families, 121 in extended family placements, 290 in private placement centers, 244 in public placement centers, and 55 in foster care. Statistical Data on Children with HIV/AIDS registered with the General Directorates for Social Assistance and Child Protection on March 31, 2005, on file with Human Rights Watch.

<sup>13</sup> Human Rights Watch interview with Eduard Petrescu, national officer, UNAIDS, Bucharest, February 6, 2006.

## IV. Findings

### ***Discrimination in and Barriers to Access to Education***

*We tried and failed to integrate the first child in the public school [in 1997]. Then last September [2005] we tried again.... The school's management rejected the child. The school management blames the other parents but it is the management and the mayor's office too. We wanted to enroll the boy in the first grade and the reaction was very violent—a group of parents in the headmaster's office, all men, pointing fingers at the boy and threatening with fists and saying, "This child should not be here!" We made a complaint to the National Council for Combating Discrimination and the school inspectorate fined the school, but the child doesn't want to go back.*

—Maria Alexe, Fondazione Bambini in Emergenza, Singureni,  
February 10, 2006

UNICEF estimates that fewer than 60 percent of children living with HIV in Romania attend any form of school.<sup>14</sup> Paula Bulancea, UNICEF's consultant on AIDS in Romania, told Human Rights Watch, "Here in Bucharest everything looks OK but there are still many problems with implementation outside of Bucharest.... We met two weeks ago with school inspectorates and teachers in Constanța and even now teachers are saying, 'why do we have these children in our classes and why can't we know their status?'"<sup>15</sup> Staff at Romanian Angel Appeal, an NGO providing services to people living with HIV in sixteen counties, told us, "Of the children we see, 23.3 percent have dropped out of school, and 11.7 percent have never attended school. We have organized ten camps each with twenty to thirty children, and in many cases we have sixteen-year-olds who are functionally illiterate and can barely write their names. This is a major concern. We are thinking about vocational training or protected workshops for these children because it is clear that they are not going to be hired."<sup>16</sup>

Discrimination is a major factor in children living with HIV dropping out of school, or deciding to attend distance education or special classes that may not meet their educational needs but reduce their exposure to harassment. At its most blatant, school

---

<sup>14</sup> The UNICEF estimate is based on National Authority for Protection of the Rights of the Child data on school enrollment for the roughly 3,400 children registered in its database. Human Rights Watch interview with Paula Bulancea, consultant on HIV, UNICEF, Bucharest, February 8, 2006.

<sup>15</sup> Ibid.

<sup>16</sup> Human Rights Watch interview with Silvia Asandi, general manager, and Adela Bohiltea, program director, Romanian Angel Appeal, Bucharest, February 6, 2006.

administrators who learn that a child is HIV-positive may tell the child's parents or guardians that that the child can no longer attend that school. Members of the Lizuca Association in Bacău told us, "A boy was deaf and he was sent by the parents to the deaf and mute school in Onești. There he was tested without the approval of his parents and the social worker in Onești sent a note to the parents: 'Your son has AIDS, come and take him.'"<sup>17</sup> Monica E. (not her real name), a parent in Constanța, told us,

An institutionalized child faced very difficult problems. The child was thrown out of school. [We] gathered fifteen or twenty people in that area—priests, people from the municipality, etc.—but we still had problems from the teaching staff who insisted on knowing exactly who the children with HIV in the school were. They said, "I'm twenty-two, I came to teach at a normal school and I don't want to get sick." This was [this school year].<sup>18</sup>

A psychologist at Romanian Angel Appeal summarized a pattern of breaches of confidentiality that we heard from many NGOs and children: "Status disclosure is usually from a school nurse or doctor, or the parent tells the class master who tells other staff. There is no required disclosure but often parents may inform officials [in order] to protect other children [in the class] because they know that schools don't have first aid kits with needed gloves and other materials. Also, children are often exempted from sports and that takes the school doctor's permission and the doctor breaks confidentiality."<sup>19</sup>

Eighteen-year-old Natalia L. (not her real name), a student in a vocational school, told us, "The class master, the teachers and the school master know [I am HIV-positive]. They figured it out from the certificate used to get an exemption from the sports' class. I took it to the class master and she asked; 'What do you have?' I just could not say that word so I told her 'Take a look at the paper.'"<sup>20</sup> Ramona Ferent, director of the Bacău office of ARAS, told us of one case where

the mother informed the class master who manipulated the [other students'] parents and the teachers so that the child was rejected and

---

<sup>17</sup> Human Rights Watch interview with Ana Vătavu, executive director, Mihaela Ondu, member, and Eugenia O. (not her real name), member of the Lizuca Association, a member organization of UNOPA, February 13, 2006.

<sup>18</sup> Human Rights Watch interview with Monica E. (not her real name), Constanța, February 14, 2006.

<sup>19</sup> Human Rights Watch interview with Gabi Mareș, psychologist, and Anca Grigoraș and Flavia Olaru, social workers, Romanian Angel Appeal, Bacău, February 13, 2006.

<sup>20</sup> Human Rights interview with Natalia L. (not her real name), Bacău, February 14, 2006.

kicked out and even after an intervention the child did not want to go back. We arranged for her to go to a different school where the teachers were welcoming her and she refused because the friends of the mother worked in that school and [she feared they would discover her HIV status because] they know that she should be in a different grade.<sup>21</sup>

Even when school administrators do not directly deny children living with HIV the right to attend school, their failure to prevent harassment by teachers, classmates, and/or classmates' parents can have devastating impact. Many of the children we spoke to were terrified that someone at school would learn of their HIV status, and sometimes created elaborate stories to explain their frequent absences for medical and administrative reasons. Anemona D. (not her real name), seventeen, told Human Rights Watch that she had not told her teachers or her classmates her diagnosis. "I did not tell them because I saw my classmates, they are mean, very mean, they look at you and despise you." She told us that she had managed to keep her HIV status a secret by arranging to have hepatitis B listed as the reason for her exemption from sports classes. "I don't want them to know. There is a girl in the school who is positive as well, after she opens a door I saw people taking a tissue and wiping the knob."<sup>22</sup>

Some children whose status was known described instances of abuse and neglect by school staff and classmates that put their health at risk. Nicu T. (not his real name), seventeen, dropped out of school after completing eighth grade. He told us,

All the children made fun of me at my school. They said things like "Don't touch him, you'll get it." The adults saw it but didn't do anything. One time I fell under a tree and I couldn't get up and I asked my classmates to help me but no one would and I was there for half an hour before I could get up. I was in seventh grade then... My mother told the teacher everything and they told the children not to call me names but it didn't help. In fourth grade a teacher hit me in the head with a shoe heel and my mother saw her do it. [That teacher] was fined but now she is back teaching again.<sup>23</sup>

The foster mother of a youth living with HIV in Constanța told us,

---

<sup>21</sup> Human Rights Watch interview with Ramona Ferent, executive director, ARAS, Bacău, February 13, 2006.

<sup>22</sup> Human Rights Watch interview with Anemona D. (not her real name), Bucharest, February 18, 2006.

<sup>23</sup> Human Rights Watch interview with Nicu T. (not his real name), Constanța, February 14, 2006.

The law forces the school to accept the child but the child is placed in the last desk. I know a case this year where the teacher punished a child by putting the child outside for four hours when it was five or ten degrees below zero and she knew the child had HIV.... Nothing happened to the teacher. There were no written complaints because we thought it would hurt the child more because he had to live there.<sup>24</sup>

To overcome such discrimination, children whose HIV status is known sometimes re-enroll in other schools without disclosing their status to the new school, but this usually is not an option for children living in small rural communities where other schools may be far away, or for children who live in group homes or orphanages known to the community to be homes for children with HIV. Delia Goia, a social worker for the Foundation for the Development of People, described the incredible efforts it took that NGO to keep two of their clients in school “after everyone in the community found out from the municipality, and the parents in the community pressured the school to expel them.” She said,

After they were expelled from regular classes they went to school after hours with boys who were also too old for their classes because they were dropouts. They went to classes for one or two hours per day.... The afternoon class didn't work out because the older girl graduated from fourth grade and was told special classes were only for younger students. So finally we found another solution. We pay 4 million lei [ROL][U.S.\$145] per month for transport for the two girls who are now almost eighteen and nineteen and in the fourth and fifth grade, [but because] this year they are in a special school they should graduate from eighth grade.<sup>25</sup>

The limited number of accessible and appropriate educational programs for children and youth living with HIV is a particular problem for the many children who have serious educational deficits. These deficits can be the result of having missed years of schooling because of illness or rejection by schools, because of developmental delays stemming from grossly inadequate care in state institutions, or because those educational programs provided to children in state institutions were and often continue to be substandard.

---

<sup>24</sup> Human Rights Watch interview with Ioana A. (not her real name), the foster mother of an HIV-positive youth, Constanța, February 15, 2006.

<sup>25</sup> Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People (*Fundația pentru Dezvoltarea Popoarelor*, FDP), Bucharest, February 7, 2006.

Although legal provisions for special education exist that could help these children realize their educational potential, implementation of these provisions has been left to local schools and school inspectorates, which often cite inadequate resources as a barrier to providing these services.<sup>26</sup>

Children living with HIV who are offered special classes may find themselves dumped in classes that do not meet their educational needs, including programs for children with behavioral problems, classes that mix widely disparate education levels, and classes that do not offer a full range of subjects needed to qualify for entrance to vocational or high schools. A 2005 study by the Open Society Institute and the Romanian NGO Pentru Voi found that “Special schools in Romania offer substandard education in the form of basic reading and counting skills, and thus fail to equip their students with genuine, marketable skills that would allow them to access employment after graduation.”<sup>27</sup>

Paula Bulancea of UNICEF told Human Rights Watch,

Of the 60 percent of children with HIV/AIDS who are in school, 20 percent are in special schools but not all of them need to be there. The special schools are for children with disabilities and have a curriculum that may be different from the regular curriculum. Most special schools are for children with mental disabilities. There are also many children in distance learning programs. The children in those programs go to visit school once or twice a semester.<sup>28</sup>

Social worker Delia Goia told us,

---

<sup>26</sup> For example, article 15(10) of the Education Law provides for in-home tutoring for children with special educational needs who are unable to move for as long as education is mandatory, and article 15(11) provides for special classes for children who are two years older than the average age of the class they want to attend. Law No. 268/2003 from June 13 2003, on amending and completing Education Law No. 84/1995, arts. 15(10) and 15(11). See also Law No. 519/2002 of July 12, 2002, on approving the Emergency Ordinance 102/1999 on special protection and the employment of persons with handicap, Official Bulletin No.555 from July 29, 2002, art. 17.

<sup>27</sup> Open Society Institute and Pentru Voi, “The Rights of People with Intellectual Disabilities: Access to Education and Employment, Romania,” August 31, 2005, [online] [http://www.eumap.org/topics/inteldis/reports/national/romania/id\\_rom.pdf](http://www.eumap.org/topics/inteldis/reports/national/romania/id_rom.pdf), (retrieved May 23, 2006), pp. 15, 45-50.

<sup>28</sup> Human Rights Watch interview with Paula Bulancea, consultant on HIV, UNICEF, Bucharest, February 8, 2006.

We had one girl who dropped out of school because she had missed so many years. She hasn't gone to school for two years. There are very few special schools, and if you don't live in a city you have to commute or live in a boarding school to attend one. That family didn't try to get home schooling. But home schooling is more theoretical than available in practice. We have tried to do home schooling without much success.<sup>29</sup>

A member of the Lizuca Association, an NGO for people living with HIV in Bacău, told us that outright rejection of students by school authorities there had decreased after the school inspectorate fired a school master, but that access to special classes remained a problem.

There are special classes to rehabilitate [those children with special needs] but they are in Bacău [city] and the big majority live in the countryside, so it is hard for them to come to those classes, particularly when it is cold. In some places there are no schools for fifth through eighth grades, so they have to walk a lot to go to the nearest neighboring school. The children are sensitive and fragile and it is hard for them and sometimes they are just encouraged by the families to drop out. We have parents who say "why push the child to go to school, when the child is going to die anyway?" There are children who are extremely isolated and who spend most of the time with their parents. They do not go anywhere.<sup>30</sup>

Nicu T., the seventeen-year-old from Constanța quoted earlier, told us, "I wanted to go to high school but it is too far away to go to in winter. It is eight kilometers from my home to the high school."<sup>31</sup>

Călin S. (not his real name), a bright, well-spoken eighteen-year-old, told Human Rights Watch that he left school in the fifth grade because

---

<sup>29</sup> Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

<sup>30</sup> Human Rights Watch interview with Ana Vătavu, executive director, Mihaela Ondu, member, and Eugenia O. (not her real name), member of the Lizuca Association, a member organization of UNOPA, Bacău February 13, 2006.

<sup>31</sup> Human Rights Watch interview with Nicu T. (not his real name), Constanța, February 14, 2006.

the doctor said I should not go to school because I should not overstress my liver. I never went back to school and it is my greatest disappointment. I tried to go back to school here at the hospital in the special school but it is boring to me. I need more. I go to classes only when I am in hospital but I need more advanced teaching. I would like grammar and history and Romanian, but it isn't enough. I want to learn something that will captivate me.<sup>32</sup>

### ***Vocational Education***

Children and youth who do manage to make it through the eighth grade capacity examination face a new set of hurdles if they attempt to apply for certain types of vocational education. Without any objective, reasonable justification, and inconsistent with Romanian anti-discrimination legislation, Romanian law requires mandatory HIV-testing for a large number of jobs, including hairdressers, beauticians, manicurists, medical nurses and child care staff in nurseries and kindergartens, food preparers and servers, and cleaning staff in the tourist industry.<sup>33</sup> As a result, vocational schools sometimes also ask their students to be tested for HIV as a condition of enrollment, and in some cases youth known to be HIV-positive have been pressured to leave or to transfer to another program, or prevented from participating in the required practical portions of the curricula.

Luiza T. (not her real name) told Human Rights Watch,

When I graduated from eighth grade I failed math the first time but passed the second time. But there were no places at the high school so I went to vocational school in food preparation. We are not allowed to do the practical classes. There is another HIV-positive classmate as well so we told the class master and the director that we are HIV-positive and the first year everyone else had practical classes in restaurants on Wednesday but not us. First we worked on invoices and receipts in the school but after that we would stay home because the headmaster said he would not force teachers to come in to teach us on that day. In the tenth grade on September 15 [the first day of classes] the class master

---

<sup>32</sup> Human Rights Watch interview with Călin S. (not his real name), Bucharest, February 18, 2006.

<sup>33</sup> See *Barriers to Employment*, below. UNAIDS does not support mandatory testing of individuals on public health grounds, and takes the position that all HIV testing of individuals must be confidential, accompanied by counseling, and only be conducted with informed consent, meaning that it is both informed and voluntary. UNAIDS/WHO Policy Statement on HIV Testing, June 2004, [online] [http://data.unaids.org/una-docs/hivtestingpolicy\\_en.pdf](http://data.unaids.org/una-docs/hivtestingpolicy_en.pdf) (retrieved May 28, 2006).

called us at the end of the classes and said that the director said that we had to go to another school because this is not the right vocation for us and that we have to find a different school. But it was too late in the year to find places in high school.<sup>34</sup>

Luiza T. said that after interventions by the National Union of Organizations of Persons Affected by AIDS (UNOPA) and the media she was eventually allowed to enroll in a different vocational program in a field that did not require HIV testing.

Octavian N. (not his real name) told us that when he studied food and business in vocational school,

we were supposed to do three weeks of practical courses and for that we needed medical tests first. The school nurse who knew me for a long time and knew my problems wouldn't give me my chart ... so eventually we went to the deputy headmaster and told him everything.... Fortunately I have good grades and my class master and teachers supported me and said that there is no reason to ask me to leave so I was not kicked out.<sup>35</sup>

Madelina D. (not her real name) told Human Rights Watch that she was able to enroll in a vocational school for manicure without being tested for HIV, but left after only a short while out of fear that she would be expelled once other students began to ask if she had AIDS. She described an incident when she was supposed to do the manicure of a fellow student at school, and there was an issue of whose manicure kit to use.

I was scared and she said, "What's wrong with you, AIDS?" And I said "What if I were, you should protect yourself." And anyway they were always looking at me and when they taught us about HIV during a manicure or haircut and I said "A person doesn't necessarily have pustules." They had suspicions and when I saw that they were looking at me funny I just left.<sup>36</sup>

---

<sup>34</sup> Human Rights Watch group interview with nineteen teenagers representing UNOPA affiliates in seven counties, Bucharest, February 9, 2006.

<sup>35</sup> Ibid.

<sup>36</sup> Human Rights Watch interview with Madelina D. (not her real name), Bucharest, February 18, 2006.

Mandatory HIV testing as a prerequisite to enrollment in vocational educational programs is an unjustifiable interference in a potential student's right to privacy. The unfounded use of HIV status to deny children full participation in vocational education programs is discriminatory and a violation of the right to education.

### ***Violations of the Right to Health***

To date Romania has been largely successful in providing children living with HIV with universal access to antiretroviral (ARV) therapy, but this success is fragile, and short-term shortages still occur. The government has given far less attention to combating the widespread stigma and discrimination against people living with HIV that limits broader access to medical services, including access to other medications and to HIV- and non-HIV-related health care, or to ensuring that children and their families receive the counseling and support needed to help them understand their condition and comply with the often complicated medical treatments children need to maintain their health. What services do exist are often ad hoc solutions arranged by NGOs and individual doctors, do not reach all children living with HIV, vary widely in their quality, and in many cases are dependant on foreign funding. Two major sources of foreign funding for HIV treatment and prevention, the European Union's Phare and the Global Fund to Fight AIDS, Tuberculosis, and Malaria, will end in 2008, and according to NGOs, other funding for HIV prevention and treatment programs is shrinking.<sup>37</sup>

### ***Access to Medical Services***

*You have to have good contacts if an HIV-positive child needs surgery, and if a child has appendicitis—whoo! What a problem.*

—Ernestina Rotariu, executive director, Health Aid Romania

*The Ministry of Health order says that an HIV-positive person has to disclose his status to receive medical care, but most people don't disclose after the first time they are denied treatment because of status. Denial of services happens all the time all over*

---

<sup>37</sup> Upon accession to the European Union Romania would have the opportunity to replace Phare monies with other EU funding, but those funds would not be targeted to HIV prevention and treatment and could not be used to provide services. They would also be administered directly by the Romanian government, raising concerns over the government's ability to supervise these funds, the sustainability of existing programs once they are turned over to local authorities, and the degree of NGO access to funding. Human Rights Watch interview with Bogdan Chirițoiu, state counselor to the president of Romania, Bucharest, February 16, 2006. For more information on Romania's Phare and Global Fund grants, see the portfolio of Romania's Global Fund grants at <http://www.theglobalfund.org/Programs/Portfolio.aspx?countryID=ROM&lang=>, and the portfolio of Romania's Phare grants at [http://ec.europa.eu/comm/enlargement/fiche\\_projet/index.cfm?page=415460&c=ROMANIA](http://ec.europa.eu/comm/enlargement/fiche_projet/index.cfm?page=415460&c=ROMANIA).

*the country, not just in small towns. Why? The Ministry of Health has issued an order on universal precautions but no clear standards or accreditation exist so they are not implemented. And for some people it is a money issue—they fear loss of other patients. And then there is just fear. When you aren't prepared as a doctor to understand HIV and how it is transmitted, and you know your hospital doesn't use universal precautions, your instinct is to look out for yourself—although it doesn't work the same way for hepatitis B and hepatitis C.*

—Eduard Petrescu, national officer, UNAIDS, Bucharest

Discrimination against people living with HIV, often fueled by ignorance and fear, is an ongoing barrier to their access to dental care, dermatological care, ear, nose and throat specialists, gynecological care, mental health care, routine and emergency surgery, and to emergency transport for patients who are bleeding. Existing mechanisms to address discrimination are not well known and have been ineffective in combating discrimination against persons living with HIV.

Children and youth Human Rights Watch interviewed described doctors continually rescheduling appointments, physically segregating HIV-positive patients, or telling them to come back after all other patients had left. In some instances there were breaches of confidentiality that amounted to harassment: people who persevered in seeking treatment from a family or specialist doctor reported that it was not unusual for medical staff to label patient files with “AIDS” or call out the turn of “the AIDS person” in crowded waiting rooms. Nineteen-year-old Anica M. (not her real name) described what happened when she revealed her HIV status to a dentist. “The first time I went there it was OK. Then I told her that she has to put on gloves because I am positive and she said that she has to protect herself and refused to see me.”<sup>38</sup> Members of the Lizuca Association in Bacău told Human Rights Watch,

If you go to a family doctor and tell him your status he is going to delay and postpone so it is easier for you to go and get treated when the [Romanian Angel Appeal] mobile unit comes here. In the winter of 2005 in Buhuși a girl was brought to the emergency room with appendicitis. They said that they don't have “sterile equipment” and they sent her to Bacău. From Bacău she was sent back to Buhuși, and at that point her parents called the infectious diseases unit and they made the phone calls,

---

<sup>38</sup> Human Rights Watch interview with Anica M. (not her real name), Bucharest, February 16, 2006.

and she was under surgery a day later. Her parents did not want to file a complaint against the doctors.<sup>39</sup>

While care was reportedly good in children's wings of infectious disease hospitals, some youth and NGO staff described instances of orderlies refusing to provide care to children and youth living with HIV. Eighteen-year-old Ivan N. (not his real name) told us, "The medical staff at Colentina [the commonly used term for the Balș Infectious Diseases Hospital] treat us well except for some orderlies (*infirmiera*). The head of nurses is good and tells them not to yell at us. They shout at us when we can't go to the bathroom by ourselves or if we don't want to eat or can't eat."<sup>40</sup> Nineteen-year-old Ioana P. (not her real name) described one example of pernicious harassment when at eighteen she was transferred from the children's wing to the adult wing of the Balș Infectious Diseases Hospital.

They look at you as if you are a piece of dirt in their office. The [woman] doctor told me "What did you do, honey? You went on the streets and slept around and now you come to me for treatment?" It was like a thunderbolt, as if the sky collapsed on my shoulders. I went to have a virginity test and I showed her the results after that. She didn't say anything.<sup>41</sup>

Romanian law prohibits direct discrimination based on HIV status, but in practice these provisions are not enforced and specialist doctors frequently use indirect means to avoid treating HIV-positive patients.<sup>42</sup> Romania's College of Physicians, responsible for interpreting and implementing the Code of Medical Ethics and supervising, investigating and ruling on the professional behavior of physicians, has not actively pursued disciplinary measures against doctors who discriminate based on HIV status or breach confidentiality.<sup>43</sup> When asked why there had been so few efforts to sanction doctors, the chairperson of the Ministry of Health's expert committee on HIV/AIDS, Dr. Adrian Streinu-Cercel, argued that it would be a mistake to sanction doctors who discriminate against persons living with HIV: "Rejection is human. There is training for medical staff

---

<sup>39</sup> Human Rights Watch interview with Ana Vătavu, executive director, Mihaela Ondu, member, and Eugenia O. (not her real name), member of the Lizuca Association, a member organization of UNOPA, Bacău, February 13, 2006.

<sup>40</sup> Human Rights Watch interview with Ivan N. (not his real name), Bucharest, February 8, 2006.

<sup>41</sup> Human Rights Watch interview with Ioana P. (not her real name), Bucharest, February 18, 2006.

<sup>42</sup> See Law No. 27/2004 on approving the governmental ordinance 77/2003 on modifying Ordinance 137/2000, art. 2.

<sup>43</sup> See Law Concerning the Exercise of the Profession of Physician, the Creation, Organization and Functioning of the Romanian College of Physicians, No. 74/1995.

but no plan for sanctions. The physician has the choice on whether to treat an HIV-positive patient. If a doctor is forced to treat a patient there may be malpractice.”<sup>44</sup>

Some NGOs and infectious disease doctors have attempted to overcome discrimination in access to medical treatment by expanding their own services to include other medical specialties, and by building local networks of specialist doctors whom they convince to accept referrals of HIV-positive patients and train in universal precautions. While an improvement, these efforts have important limitations: they typically cover only a few specialties, rarely include surgical and emergency procedures, and are not easily accessible to people living at a distance from the hospital or clinic providing the services. The mother of an HIV-positive child in Constanța told us,

A major problem is children with dental problems. There is a dental practice at the Romanian-American Children’s Center but it is only for treatment of cavities and things like that. My boy is missing teeth but the clinic doesn’t do that kind of work. Many families are in this situation—it is a problem of money and of finding a dentist who will do this work. I had to save for a month [to pay for my son’s treatment]. These dental problems also cause nutritional problems and image problems.<sup>45</sup>

Lina A. (not her real name), an HIV-positive mother of a teenage child who has AIDS, told us,

We have had problems with the ear, nose, and throat doctor. He yelled at us when we were in the waiting room and told all the other patients to leave because we have HIV. That was last year. I avoid going to other doctors. I’ve had many experiences like that. The ear, nose and throat doctor was a referral from the clinic. Either the clinic or we have to bring the universal precautions supplies and we have to go only at the end of working hours. I doesn’t matter if it is an emergency, we have to wait.<sup>46</sup>

---

<sup>44</sup> Human Rights interview with Dr. Adrian Streinu-Cercel, general director, and Dr. Mariana Mărdărescu, coordinator, Balș Institute of Infectious Diseases, Bucharest, February 20, 2006.

<sup>45</sup> Human Rights Watch interview with Regina M. (not her real name), mother of an HIV-positive child, Constanța, February 15, 2006.

<sup>46</sup> Human Rights Watch interview with Lina A. (not her real name), Constanța, February 14, 2006.

Equally important, efforts to expand specialist medical services attached to facilities providing care for people living with HIV (as opposed to ensuring that medical personnel do not discriminate and consistently apply universal precautions, both of which would improve health care for all Romanians) risk reinforcing existing perceptions of the dangers of contact with persons living with HIV. In the words of one specialist treating children living with HIV, “We solve the problem in an abnormal way: special schools, special doctors, special dentists. It solves the problem but it isn’t a solution.”<sup>47</sup>

## Access to Mental Health Care

International studies suggest that Romanian children living with HIV are likely to have a greater need for mental health care than their disease-free peers.<sup>48</sup> Yet Romania provides almost no mental health services tailored towards HIV-positive children and youth who may require therapy, psycho-social support and behavior modification programs, or appropriate psychiatric care, and the situation is expected to worsen as the number of children and youth in need of palliative care grows. Romania’s troubled mental health system<sup>49</sup> lacks staff and facilities to provide these services, and the few NGOs and infectious disease hospitals that do provide some mental health services are unable to treat serious mental illnesses and are not accessible to all children living with HIV.<sup>50</sup> During interviews with us, doctors, children, and NGO staff described cases of disturbed children and youth who were unable to obtain appropriate mental health care even when their behavior made them a danger to themselves and to others.

---

<sup>47</sup> Human Rights Watch interview with Dr. Dan Duiculescu, director of the pediatric AIDS, Victor Babeş Infectious Diseases Institute, Bucharest, February 10, 2006.

<sup>48</sup> Studies have consistently demonstrated that children living with HIV display higher levels of subjective distress than their disease-free peers, and that this distress is associated with developmental deficits and disability. This distress may be aggravated by the many stressors associated with HIV infection, including disclosure of HIV status, stigma, fear of death, and family conflict. Children and adolescents living with HIV also have a significantly higher risk of developing diagnosable psychiatric disorders. Brown LK, Lourie KJ, Pao M. “Children and Adolescents Living with HIV and AIDS: A Review.” *Journal of Child Psychology and Psychiatry*, Vol. 41, No. 1, 2000, pp. 81-96.

<sup>49</sup> In September 2005, the European Committee of Social Rights, the body tasked with reviewing Romania’s compliance with the European Social Charter, concluded that Romania was not complying with the right to health guaranteed in that Charter. Referring to visits by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, the Social Committee noted “various reports concerning the alarming situation in certain psychiatric hospitals,” and concluded that “the living conditions in certain psychiatric hospitals are manifestly inadequate.” Conclusions of the European Committee on Social Rights, Romania, September 2005, [online] [http://www.coe.int/t/e/human\\_rights/esc/3\\_reporting\\_procedure/2\\_recent\\_conclusions/1\\_by\\_state/Romania\\_2005.pdf](http://www.coe.int/t/e/human_rights/esc/3_reporting_procedure/2_recent_conclusions/1_by_state/Romania_2005.pdf)

<sup>50</sup> For a general overview of the problems in mental health care in Romania, see UN Economic and Social Council, Commission on Human Rights, Sixty-first session, Report submitted by the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health, Mission to Romania, E/CN.4/2005/51/Add.4, February 21, 2005, [online] <http://daccessdds.un.org/doc/UNDOC/GEN/G05/11/56/PDF/G0511156.pdf?OpenElement>, paras. 59-68.

Ernestina Rotariu, the executive director for Health Aid Romania, an NGO providing housing and services for children and young adults living with HIV, described her most recent effort to get mental health services for a child in her care:

A month ago we had to write a letter to the National Council for Combating Discrimination because we were refused treatment for children in a psychiatric hospital in Bucharest. We had the child in the car and took her to hospital and I hear that the doctor who admitted her was punished for doing so. They kept the child for a few days and then they told us “You have to continue the treatment yourselves.” But we had already tried that so I said, “Make sure that the treatment will work first.” They said, “It is safer to keep her in your house where all the children have HIV than it is in our hospital where the children don’t have HIV.”

At the time of our interview the National Council for Combating Discrimination had not yet taken action on the case, and the Directorate of Child Protection was reportedly planning to send the girl back to her home county, where her access to mental health care was likely to be even more limited than in Bucharest.<sup>51</sup>

Ghita S. (not his real name), a member of an UNOPA affiliate in Galați, told Human Rights Watch,

In Galați there was a case a few days ago where a mental diseases hospital refused to hospitalize and treat an HIV-positive patient who was very self-destructive. He would cut himself on the stomach and threaten the medical staff with a knife so the medical staff sent the patient to the infectious disease hospital.<sup>52</sup>

Zaharia B. (not his real name) told us, “In Suceava a person was denied mental health hospitalization and now we are trying to support him.... It is serious enough to have mental disabilities but if you also have AIDS, you are half in the grave already.”<sup>53</sup>

---

<sup>51</sup> Human Rights Watch interview with Ernestina Rotariu, executive director, Health Aid Romania, Bucharest, February 9, 2006.

<sup>52</sup> Human Rights Watch group interview with nineteen teenagers representing UNOPA affiliates in seven counties, Bucharest, February 9, 2006.

<sup>53</sup> Ibid.

Staff at the National Authority for the Protection of the Rights of the Child told Human Rights Watch that “children who switch from HIV to AIDS and develop dementia and should be hospitalized in a mental facility face problems when the staff finds out their status and try to release the person before his condition is stable. But they can’t be hospitalized in an infectious disease hospital because of their mental condition—there is no psychiatric staff. We can’t do a lot in this situation. We can request talks or submit a complaint to the Ministry of Health, or the Directorate of Child Protection can develop services for children who are in the terminal stage, but they are very expensive and require a neuro-psychiatrist.”<sup>54</sup>

Without specifically tailored facilities, even if admission to regular in-patient psychiatric facilities is not obstructed, treating HIV-positive children and youth with mental illnesses there can in and of itself pose a risk to their health. In his February 2005 report on his visit to Romania, the U.N. Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health, Paul Hunt, expressed concern over Romania’s “continuing widespread provision of mental health care in large psychiatric institutions, with inadequate rehabilitation services, and the insufficient number of community-based mental health-care and support services,” saying that “[t]he centralized and institutionalized model of care denies those with mental disabilities the rights to be, as far as possible, treated and cared for in the community in which they live, and to live and work in the community.”<sup>55</sup>

The European Committee of Social Rights reached a similar conclusion on the “manifestly inadequate” living conditions and “alarming situation” in certain psychiatric hospitals, which it found to violate Romania’s obligations under the right to health guaranteed under the European Social Charter.<sup>56</sup>

A 2004 report by Amnesty International on conditions in six Romanian mental health facilities found that “the reported living conditions in many of the psychiatric wards and hospitals, the ill-treatment of patients, methods of restraint and enforcement of seclusion, the lack of adequate habilitation and rehabilitation or adequate medical care as well as the failure to investigate impartially and independently reports of ill-treatment” rose in many instances to the level of torture or cruel or degrading treatment or

---

<sup>54</sup> Human Rights Watch interview with Ioana Nedelcu, under-secretary of state, Ali Cranta, expert on the National HIV/AIDS Commission, and Violeta Cleferie, member of the control unit, National Authority for the Protection of the Rights of the Child, Bucharest, February 17, 2006.

<sup>55</sup> Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health, Mission to Romania, para. 65.

<sup>56</sup> Conclusions of the European Committee of Social Rights, Romania, September 2005, pp. 10-11.

punishment.<sup>57</sup> A May 2006 report by Mental Disability Rights International on conditions for children housed in adult psychiatric facilities found that “[t]he abusive conditions and lack of care constitute ‘inhuman and degrading treatment’ under article 3 of the ECHR [European Convention for the Protection of Fundamental Human Rights and Freedoms]. The absence of adequate nutrition, the dangerous use of physical restraints, the lack of hygiene and the exposure to communicable diseases threaten the right to life under article 2 of the ECHR.”<sup>58</sup>

In a few instances, children and NGO staff also described past use of what appear to have been strong sedatives to control children at Vidra Placement Center No. 7, a government institution created in the late 1980s to house children living with HIV. Gogu P. (not his real name), a seventeen-year-old former resident of the Vidra Placement Center, told us, “They made fake files claiming that we had mental problems. They were destroying a child’s life in that environment. They sent a child to [psychiatric] Hospital No. 9 because we were calling names and fighting against each other. Just to make sure that their lives were easy, they took us to Hospital 9 and required medication to calm us down. When I am eighteen I will go and ask to see the medical exams and my medical file to see what they gave me. They wanted to see this bad side of us. In Vidra we didn’t take our medication because we wanted to die; we took nails in order to die.”<sup>59</sup>

Claudia Terragni is program coordinator for the Foundation for the Development of People, an NGO that helped de-institutionalize some thirty children from Vidra and continues to provide services to children still living at the facility. She told us, “We saw in Vidra that some children were given psychotropic drugs—very strong drugs not for children were given when visitors were coming, and this was even when the children were calm. Then we made a complaint but the inspection was done by a local official and he said there was no problem, and the staff didn’t want to work with us after that.”<sup>60</sup>

---

<sup>57</sup> Amnesty International, “Romania: Memorandum to the government concerning inpatient psychiatric treatment,” AI Index: EUR 39/003/2004, p. 2. Among the abuses that pose a special risk to people living with HIV/AIDS were instances of unheated wards in mid-winter that in several cases resulted in deaths from hypothermia, lack of adequate medical care for psychiatric and somatic illnesses, inadequate hygiene, and nutrition so inadequate that “long-term patients in many wards and hospitals appeared to be malnourished.” *Ibid.*, pp. 6-11.

<sup>58</sup> Mental Disability Rights International, “Hidden Suffering: Romania’s Segregation and Abuse of Infants and Children with Disabilities,” May 10, 2006, [online] <http://www.mdri.org/projects/romania/romania-May%209%20final.pdf>, p. iv.

<sup>59</sup> Human Rights Watch interview with Gogu P. (not his real name), Bucharest, February 8, 2006.

<sup>60</sup> Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

Another issue that complicates treatment of mental health problems is a lack of consensus in Romania over what services are necessary and how they should be provided, with some doctors adopting an extremely narrow vision of what conditions require treatment. When Human Rights Watch asked the co-chairperson of the Ministry of Health's expert committee on HIV/AIDS about reports of denial of access to mental health services, Dr. Streinu-Cercel told us, "It isn't a big deal. Psychiatric problems—dementia and encephalopathy—only affect 1 percent of this population."<sup>61</sup> This focus on central nervous system disease ignores other more common conditions that may require mental health care, including depression and anxiety, and underestimates the likelihood that the prevalence of these problems is increasing. At the same meeting another member of the expert committee on HIV/AIDS, pediatrician Dr. Mariana Mărdărescu, told Human Rights Watch that in her view "[p]rograms for psycho-social-emotional issues are more important than medical issues now because we already won the medical battle [with antiretroviral treatment]." Dr. Mărdărescu added,

We don't have these diagnoses [of dementia and encephalopathy] in our population yet, and I underline "yet," with the one exception of Vidra [placement center for children living with HIV]. ... The longer they survive the more they will have these problems. In Bucharest we always have contacts with Obregia [psychiatric] hospital or Staționarul Titan psychiatric facility whenever there are problems and I ask for hospitalization if necessary. But in my opinion 90 percent of the cases are psycho-emotional because they are mad at the parents and about the disease.<sup>62</sup>

### ***Access to Medications***

The right to the highest attainable standard of health is a right of progressive realization, meaning that governments are required "to move as expeditiously and effectively as possible toward [its] full realization," while guaranteeing certain core obligations.<sup>63</sup> Among these obligations are ensuring nondiscriminatory access to health facilities, especially for vulnerable or marginalized groups; providing essential drugs; and ensuring equitable distribution of all health facilities, goods and services.<sup>64</sup> Romania's stated commitment to providing universal access to antiretroviral therapy for all people living

---

<sup>61</sup> Human Rights interview with Dr. Adrian Streinu-Cercel, general director, and Dr. Mariana Mărdărescu, coordinator, Balș Institute of Infectious Diseases, Bucharest, February 20, 2006.

<sup>62</sup> Ibid.

<sup>63</sup> Committee on Economic, Social and Cultural Rights. General Comment no. 14. The Right to the Highest Attainable Standard of Health, paras. 30, 31.

<sup>64</sup> Ibid., paras. 12, 43, 44.

with HIV who meet the relevant medical criteria, and to subsidizing medications for HIV-related opportunistic infections, is an important step toward fulfillment of the right to health for people living with HIV. However, implementation of this commitment remains uneven, especially outside of major cities, and arbitrary decisions on what medications are covered and discrimination and stigma against people living with HIV prevent some individuals from benefiting from subsidized medications for opportunistic infections.

## Access to Medications for Opportunistic Infections

Children and youth living with HIV are vulnerable to a range of opportunistic infections and to central nervous system and other disorders, including some that can be fatal if left untreated. Romania's National Health Insurance House is supposed to cover the cost of medications for common opportunistic infections, and patients can have their prescriptions for opportunistic infections filled free of charge at either hospital pharmacies or private pharmacies. However, supplies of drugs commonly used to treat HIV-related medical conditions are often unavailable in hospital pharmacies, and are unavailable at some private pharmacies or only available at full price.

Dr. Sorin Rugină, the general manager of Constanța's Clinical Infectious Diseases Hospital, told Human Rights Watch that "there have been periods of time when... the National Health Insurance House would not release prescriptions if patients went to fill them [at the hospital pharmacy] so we ordered from the general fund of the hospital. But this is a limited solution. We cannot interrupt ARV therapy to pay for other medications. The National Health Insurance House should select the drugs covered based on our requests. The HIV budget should include a specific budget for opportunistic diseases." He added that his hospital relied on "other sources" for frequently used medications, like Daraprim, used to treat toxoplasmosis but not covered by the National Health Insurance House, and for covered medications for cerebral infections, diarrhea, and other conditions because "generally the drugs for opportunistic diseases are not constant."<sup>65</sup> Dr. Dan Duiculescu of the Victor Babeș Infectious Diseases Institute in Bucharest told Human Rights Watch that demand for drugs for opportunistic infections outstripped supplies provided by the National Health Insurance House, so "the hospital must provide them and we don't have money for it so we can only provide ARVs....[T]he problem is that some drugs are very expensive. Seventy percent of the total drug costs in this hospital are for the HIV pavilion."<sup>66</sup>

---

<sup>65</sup> Human Rights Watch interview with Dr. Sorin Rugină, hospital director and head of the regional monitoring center, Constanța, February 14, 2006.

<sup>66</sup> Human Rights Watch interview with Dr. Dan Duiculescu, director of pediatric AIDS, Victor Babeș Infectious Diseases Institute, Bucharest, February 10, 2006.

The infectious diseases hospitals that appear to be among the most successful in coping with these shortages are those that work closely with NGOs which often help cover the costs of needed medications. Staff at one such NGO showed Human Rights Watch a five-inch high pile of recent prescriptions for medications for HIV-related conditions that their NGO had paid for, and told us, “We spend about \$700 per month for drugs. That doesn’t count donations of drugs we get from other sources.”<sup>67</sup> But even NGOs receiving large donations from pharmaceutical companies are not able to make up all the shortfalls. A staff member at the Romanian-American Children’s Center in Constanța told us, “Drugs for opportunistic diseases are not available at all times, and it depends on what donors provide. When there are small amounts the beneficiaries come here with their prescriptions, but we haven’t had anything in stock since the beginning of the year.”<sup>68</sup>

Other hospitals appear to make decisions on which prescriptions to fill depending on the price of the medication, or pass responsibility to a different hospital if the child is from another county. Teo M. (not his real name) told us, “In my hospital they give us free prescriptions but they say that they don’t have expensive drugs. If the drugs cost more than ROL100,000 [U.S.\$3.60] they say that they don’t have it or that they reached the limit and will only give drugs up to that monthly amount.”<sup>69</sup> Eighteen-year-old Laura K. (not her real name) told us,

Every month I have pustules all over my body but when I went to the pharmacy they said they didn’t have the medicine for it. Three or four months ago I was hospitalized and I had pustules and the doctor said it wasn’t a problem and didn’t give me medication for it. That doctor sent me here because I don’t want to be on [a particular antiretroviral medication] anymore and she didn’t know what to do. The doctors here gave me a prescription for the pustules and told me to take it to [my home county] hospital. If the pharmacy there has it they should give it to me but our pharmacy is not so good at making medications and this drug is made in the pharmacy.<sup>70</sup>

Drugs for opportunistic infections that are unavailable at hospital pharmacies should be available without charge at private pharmacies, but NGOs and families of HIV-positive

---

<sup>67</sup> Human Rights Watch interview, (name withheld by request), February 7, 2006.

<sup>68</sup> Human Rights Watch interview with a staff member of the Romanian-American Children’s Center, (name withheld by request), Constanța, February 15, 2006.

<sup>69</sup> <sup>69</sup> Human Rights Watch group interview with nineteen teenagers representing UNOPA affiliates in seven counties, Bucharest, February 9, 2006.

<sup>70</sup> Human Rights Watch interview with Laura K. (not her real name), Constanța, February 15, 2006.

children told us that some people living with HIV feel unable to use private pharmacies because their prescription lists “AIDS” in the diagnosis and they fear that the pharmacy will breach confidentiality or otherwise treat them badly. Olga E. (not her real name) told us, “I went to get drugs from a pharmacy and when the pharmacist saw the diagnosis she asked me for my ID and stared at me and kept on asking ‘Is that you?’ and then looked at the computer and told me that the drugs were not in stock. I don’t know if it was true or not. She asked me three times, ‘Is this you?’”<sup>71</sup>

In other cases pharmacies reportedly refuse to fill prescriptions for covered medications on the grounds that the National Health Insurance House does not actually reimburse them for these medications.<sup>72</sup> Simona Zamfir of Save the Children Romania told us, “They say that the prescriptions are free but this is false. You go with a prescription and the pharmacist says he will not fill it because the National Health Insurance House won’t pay for it—drugs for associated diseases like pneumonia. If we can afford it we pay for it.”<sup>73</sup> A member of the Lizuca Association in Bacău told us, “We receive free prescriptions for generics from the doctors but in the pharmacies they do not take them. We have to go to the National Health Insurance House and they call the pharmacies and suddenly the drugs are available for free. I myself have gone to the pharmacy and the pharmacist shouted to the room ‘I don’t have anything for AIDS.’”<sup>74</sup> Regina M. (not her real name), the mother of an HIV-positive child in Constanța, said,

I don’t know who is responsible for it but many times you have to buy the drug for opportunistic infections, even if you are hospitalized. My child had conjunctivitis and the hospital gave me the prescription and I had to pay ROL900,000 [U.S.\$33]. . . . If we go to an outside pharmacy we [also] pay and we don’t get reimbursed. There is limited stock and we don’t get priority and there are issues of confidentiality. I would rather

---

<sup>71</sup> Human Rights Watch group interview with nineteen teenagers representing UNOPA affiliates in seven counties, Bucharest, February 9, 2006.

<sup>72</sup> While Human Rights Watch did not interview anyone at the National Health Insurance House who could confirm this allegation, based on public reports it appears that non-payment or delayed payment for covered medication is a problem that is not limited to drugs for HIV/AIDS-related conditions, but also extends to other drugs covered by the National Health Insurance House, and affects pharmacies’ willingness to fill prescriptions for covered medications.

<sup>73</sup> Human Rights Watch interview with Simona Zamfir, program coordinator, Save the Children Romania, Bucharest, February 9, 2006.

<sup>74</sup> Human Rights Watch interview with Ana Vătavu, executive director, Mihaela Ondu, member, and Eugenia O. (not her real name), member of the Lizuca Association, a member organization of UNOPA, February 13, 2006.

pay than [try to use a subsidized prescription and] have half the neighborhood know.<sup>75</sup>

Paying the full price for expensive medications is not an option for many children living with HIV. Octavian L. (not his real name) told us, “The drugs for meningitis and streptococcus are expensive—Difulcan [Fluconazole] is ROL400,000 [U.S.\$14.50] per day, and you have to take it for life and it is very hard to get. My friend has been in hospital since September because her mother cannot buy her the drugs.”<sup>76</sup>

### Access to Antiretroviral Therapy

Romania began providing children access to antiretroviral therapy in 1995, but access to treatment did not become widespread until after the government announced a National Plan of Action for Universal HIV/AIDS Care and Treatment in 2001.<sup>77</sup> While there is no cure for HIV, ongoing access to antiretroviral therapy reduces the virus’s ability to replicate and thus can significantly improve children’s health, development, and lifespan by improving immune system function and decreasing their susceptibility to associated infections, malignancies, and complications. Interruptions in therapy allow the virus to multiply, adding to the cumulative damage to the child’s immune system and vital organs. Interruptions also can increase the likelihood of developing drug resistant strains of HIV, and the chances of passing the infection to others if there is unprotected sexual contact or contact with open wounds.

Doctors, AIDS experts, and people living with HIV told Human Rights Watch that interruptions in antiretroviral medications had decreased in 2005 but that the system itself remained flawed. Under the current system doctors at nine regional HIV monitoring hospitals are supposed to provide monthly estimates of antiretroviral needs to the National Health Insurance House, which then approves antiretroviral delivery via a system of distributors contracted through a national tender.<sup>78</sup> Doctors responsible for

---

<sup>75</sup> Human Rights Watch interview with Regina M. (not her real name), mother of an HIV-positive child, Constanța, February 15, 2006.

<sup>76</sup> Human Rights Watch group interview with nineteen teenagers representing UNOPA affiliates in seven counties, Bucharest, February 9, 2006.

<sup>77</sup> The government introduced antiretroviral therapy in 1995 (ZDF), double therapy in 1996 (ZDF+ddC, and ZDF+3TC in 1997), triple therapy in late 1997 (2NRTI+1IP and HAART operational), and quadruple therapy in 1999. For information on the national plan of action, see National Action Plan for Universal Access to HIV/AIDS Treatment and Care, [online] <http://www.un.ro/unaid/National Action Plan for Universal Access to HIV.doc> (retrieved May 31, 2006).

<sup>78</sup> The last national tender was in 2003, and a new tender is expected to take place sometime in 2006 or 2007. Human Rights Watch interview with Dr. Mariana Mărdărescu, coordinator, and head nurse Popovici, Matei Balș Institute for Infectious Diseases, Bucharest, February 8, 2006..

ordering antiretrovirals in Bucharest said that their estimates of the amounts and kinds of antiretrovirals needed in a given month were generally accurate but that problems occurred because the health system did not allow them to plan for shortages caused by bureaucratic delays by government agencies or contracting distributors, customs delays, or unexpected changes in the quantity or kinds of antiretrovirals required. Dr. Adrian Streinu-Cercel, general director of the Prof. Dr. Matei Balș Institute of Infectious Diseases, told us, “The problem is when we increase the amount [of antiretrovirals requested] and the National Health Insurance House does not review the request on time.”<sup>79</sup> Dr. Dan Duiculescu, director of pediatric AIDS at the Victor Babeș Infectious Diseases Institute, told us that “In general the supplies come on time but there may be a delivery system problem—something with the distribution network. [The patients] may have to come in more than once to get their drugs, maybe two times instead of once to get them. Sometimes we can deliver them by post.”<sup>80</sup> Those doctors and patients who described good access to antiretrovirals often also described careful juggling by individual doctors who made up for periodic interruptions in supplies of specific drugs by lobbying pharmaceutical companies and NGOs for donations, collecting and redistributing medications from patients who had died, and doling out supplies for a few days at a time instead of a month at a time.

According to Save the Children Romania, an NGO working with children living with HIV in seven counties, the situation is considerably worse in some areas outside of Bucharest. Program Coordinator Simona Zamfir said, “There are problems with continuity of access to specific medications. The interruptions are different for each region. At least once a year the [antiretroviral] treatment is interrupted and can be for up to a month. It depends on the bid and then the bid date is postponed and there are no reserve supplies. I think the last time was at the end of the first half of last year—May/June 2005—and the gap lasted for about four months.”<sup>81</sup>

Experts we spoke with attributed current antiretroviral supply interruptions to poor capacity for planning, implementation, and monitoring of the supply process by the Ministry of Health, the National Health Insurance House, and local governments. Eduard Petrescu, the national officer for UNAIDS in Romania, told Human Rights Watch, “The health sector is underfinanced, and there was a crisis in 2005 when the government decided to pay off historical debts in November and didn’t have enough

---

<sup>79</sup> Human Rights interview with Dr. Adrian Streinu-Cercel, general director, and Dr. Mariana Mărdărescu, coordinator, Matei Balș Institute for Infectious Diseases, Bucharest, February 20, 2006.

<sup>80</sup> Human Rights Watch interview with Dr. Dan Duiculescu, director of pediatric AIDS, Victor Babeș Infectious Diseases Institute, Bucharest, February 10, 2006.

<sup>81</sup> Human Rights Watch interview with Simona Zamfir, program coordinator, Save the Children Romania, Bucharest, February 9, 2006.

money to cover other costs.... The people are poorly paid, working in a system that doesn't have a clear mandate and responsibilities—how can that work? As long as the government is poorly run this sector will not work well.”<sup>82</sup> Paula Bulancea, an expert on HIV for UNICEF, told us that interruptions in antiretrovirals were “a matter of budgets and of the government’s ability to pay. Sometimes there are interruptions of one or two months. A few years ago the interruptions were countrywide but last year it was only in certain counties like Vaslui that are very poor.... Other counties manage their budgets well, perhaps because they have collaborations with outside groups that can give supplementary supplies of ARVs. Also, some ARVs are more expensive than others and that can effect costs.”<sup>83</sup>

Ongoing access to life-prolonging antiretroviral therapy should not rest on whether a child is lucky enough to live in a city that is relatively well administered and well served by doctors and NGOs able to make up for government shortfalls. Romania must do more to address longstanding barriers to the timely distribution of antiretroviral therapy throughout the country, including addressing deficiencies in the planning, implementation, and monitoring of the supply process that have a discriminatory impact on some groups of children and youth living with HIV.

## ***Violations of the Right to Privacy and to Information***

### ***Violations of the Right to Privacy***

Breaches of confidentiality of medical information on HIV status and related information are commonplace in Romania and rarely punished. In addition to the various types of confidentiality breaches noted above, Human Rights Watch found instances of information on individuals’ HIV status included in easily accessible hospital databases and medical charts, on public documents and widely circulated documents required for receiving government services, and on court documents.

Staff at Romanian Angel Appeal’s Bacău office told us, “We are concerned about the circuit of information in the [Bacău county] hospital. This is a common database and any nurse can access the internal network. The staff in other units of the hospital can check the status of the patients here.”<sup>84</sup> Staff at the Romanian Association Against AIDS (ARAS)’s Bucharest office told us, “We have a section on legislation in our workshops for professionals in social work, educators, etc., and [even after the workshops] they still

---

<sup>82</sup> Human Rights Watch interview with Eduard Petrescu, national officer, UNAIDS, Bucharest, February 6, 2006.

<sup>83</sup> Human Rights Watch interview with Paula Bulancea, consultant on HIV, UNICEF, Bucharest, February 8, 2006.

<sup>84</sup> *Ibid.*

keep asking us, ‘Don’t I have to tell someone?’ about a client’s HIV status. People think the community has rights and not the individual.”<sup>85</sup> Corina Macoveanu of the National Council for Combating Discrimination told Human Rights Watch that breaches of confidentiality were “a real problem in hospitals. In Arad [county] there was a case of a girl who didn’t know her diagnosis who found out when she saw ‘HIV’ written on the door of her room. She wanted to commit suicide as a result of that. When we went there two or three months later we still saw ‘HIV’ written on doors.”<sup>86</sup>

According to Paulian Sima of the National Authority for Persons with Handicap, “All references to the [kind of] disability have been removed from the certificates of disability and in this way somebody who is not a professional cannot find out the medical condition of the owner—it is a code so it is difficult for a person from outside to know the diagnosis. We had problems in the past with breaches of confidentiality. We are trying to comply with the law on protection of private data, and we are trying to comply with it by establishing codes for the diseases.”<sup>87</sup> However, NGO staff and children we spoke with told us that the key to the coded conditions still appears in footnotes on disability certificates, making it easy for anyone who takes the time to read the fine print to learn a person’s HIV-positive status, and that doctors and officials sometimes still spell out HIV status on other documents.

Information on HIV status can appear on a wide range of other documents as well. Human Rights Watch has in its possession court documents and subpoenas sent to a person living with HIV who sued the government; his HIV status was clearly printed in these public documents and correspondence, making it possible for neighbors and postal service workers to learn his status. In Singureni, the testing commission included “HIV” next to the names of children living with HIV on the public list of results of the 2005 eighth grade school exam results.<sup>88</sup> In some other counties postal workers received lists of names of people living with HIV eligible to receive nutrition subsidies.<sup>89</sup>

---

<sup>85</sup> Human Rights Watch interview with Monica Dan and Liana Velica, project coordinators, Romanian Association Against AIDS (*Asociația Română Anti Sida*, ARAS), Bucharest, February 17, 2006.

<sup>86</sup> Human Rights Watch interview with Csaba Ferenc Asztalos, president, and Corina Macoveanu, steering committee member, National Council for Combating Discrimination, Bucharest, February 21, 2006.

<sup>87</sup> Human Rights Watch interview with Paulian Sima, expert, National Authority for Persons with Handicap, Bucharest, February 20, 2006.

<sup>88</sup> Human Rights Watch interview with Maria Alexe, *Foundation Bambini in Emergenza*, Sigureni, February 10, 2006.

<sup>89</sup> Human Rights Watch interview with Monica Dan and Liana Valica, project coordinators, Romanian Association Against AIDS, Bucharest, February 17, 2006.

Fear of breaches of confidentiality by municipality staff cause some families of children living with HIV to forego subsidies administered by municipalities. Social workers at the Foundation for the Development of People, an NGO providing services to children living with HIV, told Human Rights Watch,

Social workers at some village and city halls are sometimes cashiers or other employees. When people come to get their subsidies they stand in the hallway and call out, “Let the AIDS patients come in.”... Out of the fifty-five birth families that we work with there are over twenty who refuse to take subsidies for fear of breaches of confidentiality.<sup>90</sup>

Ștefania Mihale, social worker at the Romanian-American Children’s Center in Constanța, told us she knew of at least ten children who did not claim their subsidies because of fear of disclosure, adding “A lot of parents in rural areas are still afraid to go to family doctors or to the municipality for services because they feel that the law doesn’t protect them.”<sup>91</sup> Victoria A., an HIV-positive mother of a young child who is also HIV-positive, told us, “I get a social aid allowance for my baby, but not for the disease. I’ve heard that there is money for AIDS but we don’t want people in the village to know so we don’t apply.”<sup>92</sup>

Even when the immediate damage caused by a breach of confidentiality fades, the carryover effects of forced disclosure of HIV status can last for years. Eighteen-year-old Laura K. (not her real name), told Human Rights Watch that she endured months of taunting by schoolmates and then by other villagers after her seventh grade school master disclosed her HIV status to a teacher who then told the other students. The taunting eventually died down she said, but “now the entire village knows I am sick.” As a result of this knowledge, when she fled domestic violence police ordered Laura K. to return home: “I spent two weeks living with a neighbor and then my mother went to the police to tell them I ran away to hang out with boys and the police told me that I couldn’t leave home because I was sick. They said I couldn’t have a boyfriend or get married, I had to stay inside.”<sup>93</sup>

---

<sup>90</sup> Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

<sup>91</sup> Human Rights Watch interview with Ana Maria Schweitzer, director, and Ștefania Mihale, social worker at the Romanian-American Children’s Center, and Dr. Cambria, an infectious disease specialist at the Constanta Municipal Hospital who also sees patients at the Romanian-American Children’s Center, Constanța, February 14, 2006.

<sup>92</sup> Human Rights Watch interview with Victoria A. (not her real name), Bucharest, February 16, 2006.

<sup>93</sup> Human Rights Watch interview with Laura K. (not her real name), Constanța, February 15, 2006.

## Criminalization of Transmission of HIV

Romania's Criminal Code punishes the knowing transmission of AIDS with imprisonment for five to fifteen years. Not only is this criminalization in itself problematic, but the penalty is significantly harsher than for transmission of other sexually transmitted diseases.<sup>94</sup> Infectious disease doctors in Bucharest and Constanța told Human Rights Watch that they were aware of this legislation and complied with requests by police and prosecutors to provide information about patients living with HIV, although their accounts of what information they were obligated to provide and what acts were criminalized varied.

Dr. Sorin Rugină, general manager of the Constanța Clinical Infectious Diseases Hospital told Human Rights Watch that police and prosecutors had contacted his hospital for information on patients living with HIV, although there had not been any proven cases of sexual transmission among teenagers in Constanța. In one case, he said, “[t]he authorities asked for information on one girl suspected of commercial sex work.... [She is a] girl who is seventeen who left here, had a baby, and came back here. This was a girl who was living with a family and left home because of problems there. The police and the prosecutor were the ones who contacted us in the case of this girl.” Dr. Rugină declined to answer our questions on the kinds of information requested and supplied, and quickly moved to another case involving an adult, saying

In another case it was a pedophile who was our patient and we had to keep him in hospital. The prosecutor wanted us to keep him hospitalized until he was cured! We said, “We can't, there is no cure.” But we kept him until he died six months later. But it started a debate on what information to disclose. They can ask if a patient is in our care and we say yes or no. In such cases we ask the patient to sign papers saying they know the legal implications. These are a few cases. An HIV patient can only be accused of willingly spreading HIV if practicing prostitution.<sup>95</sup>

---

<sup>94</sup> The Criminal Code also criminalizes knowing transmission of a venereal disease by imprisonment for one to five years. Romanian Criminal Code, arts. 384(1), 384(2). In addition to the Criminal Code, Law No. 584/2002 states that “HIV/AIDS persons who know their status are legally responsible for voluntary transmission of the infection if this happened in circumstances that they are responsible for,” and “HIV infected persons which do not know their status are not legally responsible if they transmit HIV infection.” Law No. 584/2002, arts. 8(4), 8(5).

<sup>95</sup> Human Rights Watch interview with Dr. Sorin Rugină, hospital director and head of the regional monitoring center, Constanța, February 14, 2006.

Dr. Rugină told Human Rights Watch that in other cases where he suspected that a teenager was engaging in unprotected sex,

we go to the NGOs to try to get the NGOs to monitor them. We tell [the teenagers] about the criminal code, and they have to sign an affidavit that they know the consequences of knowingly infecting someone. We ask everyone who is not living with families who is suspected of commercial sex work to sign an affidavit. There are one or two cases of teenagers who are sixteen, seventeen, and don't have a stable residence so we are trying to refer them to NGOs or hospitalize them in the chronic ward, but we can't hospitalize everyone. We don't have the resources, but for the time being we cope.<sup>96</sup>

Dr. Dan Duiculescu, the head of pediatric AIDS at the Victor Babeș Institute for Infectious Diseases, told Human Rights Watch there had been some situations where he believed that a patient was having unprotected sex, saying “usually we try to solve such situations through counseling, and through the notification of partners.”<sup>97</sup> Later he said, “We are contacted sometimes by the authorities about children’s age and HIV status,” but that this information was “not in connection with commercial sex work.”<sup>98</sup>

The risk of potential criminal prosecution may make HIV-positive youth less likely to seek assistance and support in a whole range of areas—from police protection to health services—for fear of disclosing their HIV status and exposing themselves to prosecution or monitoring. Legislation such as is on the books in Romania acts as a barrier to young persons seeking health care where they know that the police may be informed of their status or the fact that they are receiving medication.

Staff at Romanian Angel Appeal told Human Rights Watch of one case of extortion of a child living with HIV, where the family had come to them rather than to the police. “This came to us this week. The girl is seventeen, and she had sex with a guy who knew she had HIV, but when his parents also found out it was a huge scandal and they all came here. He was tested and he is HIV-negative, but now he is blackmailing the girl—

---

<sup>96</sup> Ibid.

<sup>97</sup> Human Rights Watch interview with Dr. Dan Duiculescu, head of pediatric AIDS, Victor Babeș Infectious Diseases Institute, February 10, 2006.

<sup>98</sup> Ibid.

he asked her to give him RO500,000 [U.S.\$18] or he will go and tell in school that she is HIV-positive.”<sup>99</sup>

In a conservative society like Romania, assumptions of proper behavior for girls and biases against members of minority groups can also place girls at additional risk for police harassment if their HIV status is known to the community. A member of an UNOPA affiliate told Human Rights Watch that his group had followed several HIV-positive Roma girls and had even sought assistance from the police and the mayor’s office in “monitoring” the girls, based on his group’s assumption that because the girls were seen “with a different group of boys every weekend” they must have been engaging in unprotected sex.<sup>100</sup> Another UNOPA member recounted a police investigation in Constanța of “a girl who was HIV-positive, after a boy approached her and she told him she had HIV and he insisted on sleeping with her anyway and he became infected.”<sup>101</sup>

Demands that some children and youth sign affidavits that could be used to prosecute them if an alleged partner is later found to be HIV-positive, and ad hoc “monitoring” of certain children and youth suspected of being sexually active, are practices that can lead to serious violations of the right to privacy, including forced disclosure of an individual’s HIV status to potential partners and the community. These practices also appear to be used in a discriminatory manner against girls and young women seen as not conforming to social norms. Furthermore, while Human Rights Watch has no evidence of retaliation against children and youth who refuse to sign affidavits, the very fact that the request for the affidavit comes from a doctor who controls access to life-prolonging medication and who may have been the child’s primary physician for a decade or more raises serious questions about how voluntary and informed their decisions are.

The creation of a specific criminal offence applicable only to persons with HIV serves only to exacerbate the discrimination, prejudice and stigmatization experienced by youth with HIV. It is also contrary to international norms on public health policy and HIV. The International Guidelines on HIV/AIDS and Human Rights state:

Criminal and/or public health legislation should not include specific offenses against the deliberate and intentional transmission of HIV but rather should apply general criminal offenses to these exceptional cases.

---

<sup>99</sup> Human Rights Watch interview with Gabi Mareș, psychologist, and Anca Grigoraș and Flavia Olaru, social workers, Romanian Angel Appeal, Bacău, February 13, 2006.

<sup>100</sup> Human Rights Watch group interview with nineteen teenagers representing UNOPA affiliates in seven counties, Bucharest, February 9, 2006.

<sup>101</sup> Ibid.

Such application should ensure that the elements of foreseeability, intent, causality and consent are clearly and legally established to support a guilty verdict and/or harsher penalties.<sup>102</sup>

A Council of Europe Committee of Ministers Recommendation states that in relation to penal laws and transmission of HIV:

The priority in controlling transmissible diseases, including HIV/Aids, is the introduction of preventive measures and information designed to develop awareness and a sense of responsibility among the public.

Sanctions relating to the transmission of transmissible diseases and HIV/Aids should be envisaged within the context of existing offences, and the institution of criminal proceedings should be considered as a last resort.

Such criminal proceedings should be aimed at sanctioning those who, in spite of information and awareness building campaigns to prevent the spread of HIV/Aids, have nevertheless endangered the lives, physical integrity or health of others.<sup>103</sup>

The criminalization of transmission of HIV as a discrete criminal offence creates both practical barriers to combating the transmission of HIV and obstacles for those living with HIV in accessing and enjoying basic rights such as health services.

First, there are practical limitations to the application of the law, because a significant percentage of those living with HIV are unaware of their HIV status. There is also the difficulty—if not impossibility—of proving HIV transmission due to a specific, or series, of potential exposures. Furthermore, the existence of HIV transmission criminalization laws may impede efforts to promote disclosure to children and youth of their HIV-

---

<sup>102</sup> Office of the United Nations High Commissioner for Human Rights (OHCHR) and UNAIDS, "HIV/AIDS and Human Rights: International Guidelines," U.N. Doc. HR/PUB/9, para. 29(a). For a fuller discussion of the position of UNAIDS on criminalization, including recommendations for legislation and practice, see UNAIDS, "Criminal Law, Public Health and HIV Transmission: A Policy Options Paper," UNAIDS/02.12E, June 2002.

<sup>103</sup> Council of Europe Committee of Ministers Rec(93)6E / October 18, 1993, concerning prison and criminological aspects of the control of transmissible diseases including AIDS and related health problems in prison, [online] <https://wcd.coe.int/ViewDoc.jsp?id=622079&BackColorInternet=9999CC&BackColorIntranet=FFBB55&BackColorLogged=FFAC75> (retrieved June 20, 2006).

positive status or voluntary HIV testing, to reduce stigma and prevent discrimination, and to provide broader legal protection for individuals living with HIV.

Finally, the law is likely to have a greater impact on girls and female youth than on boys and males. As indicated above, the law may be used against women if they are deemed not to conform with appropriate sexual behavior for women, and women—even if they are aware of their HIV serostatus—are often unable to negotiate the use of HIV prevention methods and are vulnerable to being forced into unprotected sex as a result of violence, or threats of violence.

While disclosure of HIV status to sexual partners is the ideal, laws that criminalize HIV transmission discount the real obstacles, and threats of violence, which can result if partner disclosure is mandated.

If there are particular circumstances in which criminal sanctions may be warranted for egregious, harmful HIV-related behavior (such as the intentional, deliberate or reckless infection of someone with HIV), existing criminal offences such as assault or battery could be used.

### ***Disclosure of HIV Status, Sex Education, and the Right to Information***

*The child has the right to know what happens with his body and as a doctor it is hard for me to pray to God for the child not to ask me about his disease. If they are aware, they develop differently, they are able to make different life plans and also make decisions about their sexual life. One out of two is sexually active.*

—Dr. Mariana Mărdărescu, coordinator, Matei Balș Institute for Infectious Diseases

Providing patients with information on their HIV status is a key part of HIV counseling, yet a 1990 Ministry of Health regulation prohibits medical personnel from informing children of their HIV status without consent from a parent or guardian, and parents and guardians are not required to inform children of their HIV status.<sup>104</sup> While subsequent legislation appears to supersede this ban on disclosure, infectious disease doctors

---

<sup>104</sup> Ministry of Health Order No. 1201 on the epidemiologic surveillance and medical assistance of persons infected with HIV (October 16, 1990) states that "the diagnosis will be communicated only to the patient and in the case of sick children, only to their parents and guardians."

consistently told Human Rights Watch that they were barred by law from disclosing HIV status to children without the parents' consent, and that this limitation on diagnostic disclosure to children made it difficult for them to convince children who did not know their diagnosis to comply with often unpleasant life-prolonging therapies.<sup>105</sup> High levels of stigma and discrimination against people living with HIV further encourage parents to avoid disclosure to their children, or to lie outright to them.

Pediatrician Dr. Mariana Mărdărescu's description of the challenges of working with children who did not know their diagnosis was typical of the experiences of doctors we spoke with. She told us,

The lack of disclosure has a disastrous impact. Children have suspicions about this or they hide their doubts. As they do not understand what their disease is you cannot have a proper discussion with them. It is hard to convince them, you can't talk to them because there is a wall raised by the parents. It is hard to build anything with them, hard to explain the illness and the treatment. . . . When they know each other, they open up and the solidarity is amazing but the parents are still asking to be hospitalized with the children to prevent this type of interactions [so the children won't discover their disease]. We have children who are now eighteen or nineteen years old and now their parents want to disclose their status but it is very hard. How can you tell him that you lied to him? They are afraid of the reaction of the children but they also have to justify the lie. Some children refused to meet with the rest of the family or they say, "If I find out that I am positive, I will kill myself." They say it only waiting for a confirmation. It is a vicious circle that precludes effective treatment: they refuse the medication with justification because they don't know.<sup>106</sup>

Over the last several years NGOs have worked to convince parents to inform children and youth of their HIV status, but the success of these programs varies. Staff at Romanian Angel Appeal's Bacău office told Human Rights Watch that only about 65 percent of the children in that county had been informed of their diagnosis, although

---

<sup>105</sup> The Law on the Rights of the Patient obligates doctors to inform their patients of the diagnosis, the general health, the evolution of the disease, the treatment recommended as well as the alternatives. It does not distinguish between adults and children in this regard, and under Romanian legal practice should supersede Ministry of Health Order 1201 because it is a law rather than a ministerial order and is more recent. Law No. 46/2003 on the rights of the patient, arts. 4, 6.

<sup>106</sup> Human Rights Watch interview with Dr. Mariana Mărdărescu and head nurse Popovici, Matei Balș Institute, February 8, 2006

“the rest know but there is no confirmation for them or the parent does not want the disclosure and we cannot override their decision.”<sup>107</sup> In some cases these late disclosures can be very traumatic. Mary Veal of Hope for Health told Human Rights Watch, “We had one child threaten to kill himself when he found out that the parents had lied about the diagnosis. He didn’t speak with his parents for a month.”<sup>108</sup>

Some doctors were reluctant to disclose a child’s HIV status to him or her without parental consent even after the child turns eighteen. Dr. Mărdărescu told Human Rights Watch, “I received a call from a parent of a patient who is twenty-one who has not disclosed the diagnosis and called today to say, ‘My son is coming today, you tell him.’”<sup>109</sup>

Counseling teenagers who do not know they are HIV-positive to postpone sexual activity or to use condoms if sexually active is particularly challenging because doctors cannot fully explain to them the risk unprotected sex poses to their own health and the health of others. Mary Veal at Hope for Health told us, “We had a boy who came here from Giurgiu who died a couple of weeks ago from measles. We found out that he had slept with a girl from his village. He leaves quite a legacy behind. He didn’t know he was HIV-positive because his parents didn’t tell him.”<sup>110</sup>

Because many older children and youth nevertheless suspect that they have HIV, not having the right to know about their HIV status and also exposes them to potential criminal prosecution for the knowing transmission of HIV, given that a defense of not having known their HIV status may be difficult to prove.<sup>111</sup> Dr. Paul Marinescu, the director of the Singureni Infectious Diseases Hospital, told Human Rights Watch,

In two families who don’t want to disclose the child’s diagnosis the children are now older and will be a source of infection. I hope the parents will eventually disclose—they agree in principle and promise to tell the children but so far they have not done so. I think the children already know. It is impossible to go for six years to a day clinic only for

---

<sup>107</sup> Human Rights Watch interview with Gabi Mareş, psychologist, and Anca Grigoraş and Flavia Olaru, social workers, Romanian Angel Appeal, Bacău, February 13, 2006.

<sup>108</sup> Human Rights Watch interview with Mary Veal and Ana Filip, Hope for Health, Bucharest, February 7, 2006.

<sup>109</sup> Human Rights interview with Dr. Adrian Streinu-Cercel, general director, and Dr. Mariana Mărdărescu, coordinator, Balş Institute of Infectious Diseases, Bucharest, February 20, 2006.

<sup>110</sup> Human Rights Watch interview with Mary Veal and Ana Filip, Hope for Health, Bucharest, February 7, 2006.

<sup>111</sup> The Criminal Code sets the age of criminal liability at sixteen, and children between the ages of fourteen and sixteen can be held criminally liable if they showed discernment at the time of the crime. Romanian Criminal Code, Official Gazette, No. 303 from April 12, 2005, arts. 113.

HIV and not know what they have.... We use social workers and a psychiatrist to explain protection measures and the dangers of casual sex but we haven't told them "you are sick and you can make your girlfriend sick."<sup>112</sup>

Dr. Mariana Mărdărescu of the Matei Balș Institute for Infectious Diseases told us, "In the day care clinic we have a form with the provisions from the Criminal Code for the parents who refuse to disclose. But parents can say: 'I made him, I will kill him.'"<sup>113</sup>

### ***Sex Education***

Access to accurate information on reproductive health, including information on how to prevent the sexual transmission of HIV and other diseases, is crucial to children's ability to protect themselves and others as they begin to express their sexuality.<sup>114</sup> Romania's National Strategy on HIV/AIDS calls for "universal access of young people attending any school level to the necessary knowledge about HIV/AIDS prevention methods and associated risks," and Romania has recently begun to implement some programs on sex education, including some programs on HIV education.<sup>115</sup> However these programs generally consist of one optional class during the seventh grade, and are not monitored for consistency and accuracy of information.<sup>116</sup> They are also by their nature unlikely to reach the large numbers of children living with HIV who do not attend school or, because of their educational delays, may become sexually active before they reach seventh grade.<sup>117</sup> Pediatric AIDS specialist Dr. Dan Duiculescu questioned the adequacy of the government's approach, saying,

---

<sup>112</sup> Human Rights Watch interview with Dr. Paul Marinescu, director, Singureni Infectious Diseases Hospital, Giurgiu, February 10, 2006.

<sup>113</sup> Human Rights Watch interview with Dr. Mariana Mărdărescu and head nurse Popovici, Matei Balș Institute for Infectious Diseases, Bucharest, February 8, 2006.

<sup>114</sup> Romania has a specific obligation to provide such sex education as one of its commitments under the European Social Charter, Article 11: With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in co-operation with public or private organizations, to take appropriate measures designed inter alia:

- 1 to remove as far as possible the causes of ill-health;
- 2 to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
- 3 to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.

<sup>115</sup> Government of Romania, *National Strategy for surveillance, control and prevention of HIV/AIDS cases, 2004-2007* (Bucharest: UNICEF, 2004), p. 12.

<sup>116</sup> Human Rights Watch interview with Adena Manea, project coordinator, Youth for Youth, Bucharest, February 9, 2006.

<sup>117</sup> For example, Youth for Youth, an NGO program that does extensive outreach to children and youth outside of school grounds, does not target children living with HIV/AIDS for services. *Ibid.*

We need to start talking about sex much earlier. It isn't easy in countries like Romania to talk about sex, especially in the family and in school. I talk to the children I see but it needs to be done more, and to be tailored specifically to each child.<sup>118</sup>

Human Rights Watch's interviews with children and youth living with HIV revealed a wide variation in their knowledge of how to prevent sexual transmission of disease. The most knowledgeable children and youth generally had benefited from sex education programs provided by NGOs and could explain how HIV is transmitted and how sexual transmission and mother-to-child transmission could be prevented. In some cases these children even acted as peer educators, traveling to other schools to present on HIV or bringing information from home to distribute to their classmates. The least knowledgeable—often children and youth from rural areas or those who had lived in state institutions—lacked even rudimentary knowledge about condom use, and in some cases displayed dangerous misunderstandings about how to prevent sexual transmission.

Ivan N. (not his real name), an HIV-positive youth living at Vidra Placement Center No. 7, told Human Rights Watch, “No one has given me information on HIV. I’ve heard about transmission—if you cut yourself and touch another wound or if you make love. I’ve heard some people talk about it. There is no sex education in our school but [Vidra director] Dr. Monica [Bîrlodeanu] said they would bring someone to talk to us about it.... None of the children at Vidra are having sex now [so] I don’t know if it would be useful to have sex education but it would be good to have more information on transmission—some know about it and some don’t”<sup>119</sup> Stephan P. (not his real name), also living at the Vidra Placement Center, was unable to name any ways to prevent transmission of HIV, and told us, “I don’t know how much about HIV or how it is spread. No one has given me this information.” Stephan P. said what he did know he had “figured out from other children,” and when asked what he knew about condoms, he said, “I’ve heard about condoms but we don’t use them. I’ve heard that men and boys can use them but they are not for us. No one at Vidra is having sex.”<sup>120</sup>

---

<sup>118</sup> Human Rights Watch interview with Dr. Dan Duiculescu, director of pediatric AIDS, Victor Babeş Infectious Diseases Institute, Bucharest, February 10, 2006.

<sup>119</sup> Human Rights Watch interview with Ivan N. (not his real name), Bucharest, February 8, 2006. None of the children living at Vidra whom Human Rights Watch interviewed described receiving education on HIV/AIDS from school or orphanage staff, but a social worker for an NGO that provides services to some of these children told Human Rights Watch that she believed that there was a new sex education class at Vidra but that she had not seen the curriculum. Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

<sup>120</sup> Human Rights Watch interview with Stephan P. (not his real name), Bucharest, February 8, 2006. NGO staff and others familiar with the facility told Human Rights Watch that when there had been more children at the

Seventeen-year-old Anton R. (not his real name), an HIV-positive student in a public school, told us, “There is no sex education at our school. It is an issue that is off limits in our school. A student asked the class [teacher] why, and she said that high school is not for teaching this subject. It is a [confessional] school and so they think it is not appropriate.”<sup>121</sup> Asked about sexual transmission of HIV, Natalia L. (not her real name), eighteen, told us she had not used a condom when she had had sex for the first time the previous summer because “I don’t think it is transferred this way, not if you do it only once even if unprotected.”<sup>122</sup>

Romania’s failure to ensure that children living with HIV have adequate access to information on reproductive health and sexual transmission of disease is all the more disturbing when one considers that many children and youth have begun or will soon begin their sexual lives. Estimates by doctors at the monitoring hospitals in Bucharest of the percentage of children living with HIV who were sexually active ranged from 15 to 50 percent.<sup>123</sup> Staff at Romanian Angel Appeal’s Bacău office estimated that at least 25 percent of the children living with HIV they serve have had at least one sexual contact, adding:

We push for sex education but it is also a matter of distance and time. Most of those involved in the groups where we speak about sexually transmitted diseases and reproductive health are from the city. But 50 percent of the population in Bacău county is rural, and access to services for those who live outside Bacău is a serious problem. [Only] 20 percent of the cases of children living with HIV are in Bacău city and the rest cannot commute for fifty or eighty kilometers, for two hours, for these services. There is nothing you can find in the countryside and the assumption is that they are not sexually active.<sup>124</sup>

---

facility there had been several couples who appeared to be sexually active, and that there may have been some instances of sexual abuse of younger or smaller children by older or larger children. Human Rights Watch telephone interview with an individual familiar with the situation of children at Vidra over a number of years (name withheld by request), February 7, 2006; and Human Rights Watch interview with Delia Goia, social worker, Foundation for the Development of People, Bucharest, February 8, 2006.

<sup>121</sup> Human Rights Watch interview with Anton R. (not his real name), Bucharest, February 8, 2006.

<sup>122</sup> Human Rights interview with Natalia L. (not her real name), Bacău, February 14, 2006.

<sup>123</sup> Human Rights Watch interview with Dr. Mariana Mărdărescu and, head nurse Popovici, Matei Balș Institute, February 8, 2006; Human Rights Watch interview with Dr. Dan Duiculescu, director of pediatric AIDS, Victor Babeș Infectious Diseases Institute, Bucharest, February 10, 2006.

<sup>124</sup> Human Rights Watch interview with Gabi Mareș, psychologist, and Anca Grigoraș and Flavia Olaru, social workers, Romanian Angel Appeal, Bacău, February 13, 2006.

The provision of health-related information, including sexual education and information, is an important part of the rights to health and to private life,<sup>125</sup> and often the right to life, survival, and development of the child. Under the European Social Charter, Romania is obliged to provide children and young persons with health education, including information on the prevention of sexually transmitted diseases including HIV.<sup>126</sup>

Romania must do more to ensure that children and youth living with HIV have adequate access to the knowledge and skills they will need to protect themselves and others as they begin to express their sexuality. Sexual education and HIV awareness programs should reach children both in and out of formal education, and include clear messages on the correct use of condoms to prevent transmission of HIV and other sexually transmitted diseases.

### ***Discrimination and Barriers to Employment***

*I worked in Europa [flea market], in the fruit markets, usually I did black [market] labor. This is the only place where they don't ask for medical exams, so I looked for work on the black market even if that means working in the cold.*

—Andreea L. (not her real name), twenty-five, Bucharest

*It is too much to wish to work in a shop because everywhere I would go they would ask me to show them my medical exams. That is hitting below the belt. Why would I need medical exams to sell shoes?*

—Anemona D. (not her real name), seventeen, Bucharest

As already noted above in the discussion of vocational education, Romania discriminates in law and practice against people living with HIV by arbitrarily prohibiting persons known to be HIV-positive from working in certain fields. Romanian law also promotes

---

<sup>125</sup> Article 8 of the European Convention for the Protection Human Rights and Fundamental Freedoms (ECHR) requires that people are entitled to important information that has an impact on their health or quality of life and will allow them to make decisions about their personal life, see *Mikulić v. Croatia*, judgment of February 2, 2002, ECHR 2002-I; *Guerra and others v. Italy*, judgment of February 19, 1998, Reports 1998-I; *Lopez Ostra v. Spain*, judgment of December 9, 1994, Series A 303-C; and *Gaskin v. the United Kingdom*, judgment of July 7, 1989, Series A no. 160.

<sup>126</sup> See Conclusions of the European Committee on Social Rights, Romania, September 2005, p. 12. The Romanian government has failed to provide the European Committee of Social Rights with relevant information on its provision of sex education and prevention of transmission of HIV despite requests since 2003.

discrimination by failing to protect individuals from HIV tests performed without informed consent by public and private employers.

Romanian law on medical testing of employees is complicated, contradictory, and poorly understood by those who implement it. Romania's Labor Code requires prospective employees, apprentices, and students taking practical courses during their vocational or professional education to obtain a medical certificate attesting to their suitability for that specific type of work, despite legal provisions prohibiting employment discrimination based on disability, and guaranteeing people living with HIV the "unbounded and unlimited right to work."<sup>127</sup> Other provisions in the Labor Code set forth specific medical exams as a prerequisite to employment in the fields of health, catering and food sales, and education.<sup>128</sup> In addition, all types of employees, private contractors, freelancers, students in training programs, and apprentices fulfilling professional training are required to meet labor safety norms that include mandatory medical exams at the date of appointment and periodically thereafter.<sup>129</sup> Based on the results of the medical exam a labor doctor can suggest that a potential employee seek employment in a different field or can refer the potential employee to specialized medical services. The labor safety norms over and above the general mandatory medical exams specify mandatory HIV testing at the time of employment and periodically thereafter for those seeking jobs as hairdressers, beauticians, manicurists, medical nurses and child care staff in nurseries and kindergartens, and medical personnel and auxiliary staff in the medical services.<sup>130</sup> Employees in the food industry (both in preparing and serving or selling the food) and cleaning staff in the tourism industry must also be tested for infectious diseases and cannot work until cured.<sup>131</sup>

---

<sup>127</sup> For example, Law No. 584/2002 requires the state "to promote non-discriminatory professional development" of persons living with HIV and to ensure their "unbounded and unlimited right to work," and the Labor Code prohibits "any direct or indirect discrimination in relation with an employee, on grounds of gender, sexual orientation, genetic characteristics, age, nationality, race, skin color, ethnicity, religion, political options, social origin, disability, family situation or family responsibility, belonging to a trade union." Law No. 584/2002, arts 7(1)(a), 7(1)(b); and Labor Code, Law No. 53/2003, Official Bulletin No. 72 from February 5, 2003, arts. 5, 27, 28(d).

<sup>128</sup> Labor Code, art. 27(6).

<sup>129</sup> See Law on Labor Protection, No. 90/1996 from July 12, 1996, Official Bulletin No. 157 from July 23, 1996, art. 3, and Joint Order 508/2002 of the Ministry of Health and the Ministry of Labor and Social Solidarity on the approval of the General Norms for Labor Protection, Official Bulletin 880 from December 6, 2002, arts. 48, 56, 57. The medical exam in view of employment establishes: a) ability, b) compatibility, c) that the potential employee has no illnesses that would endanger the health and the security of other employees, d) that the potential employee has no illnesses that could jeopardize the security of the unit and/or the quality of the goods produced or services provided, and e) that the person to be employed is not a risk for the health of the population served.

<sup>130</sup> *Ibid.*, fiche 132, 136, 137.

<sup>131</sup> *Ibid.*, fiche 128, 133.

As a result of this legal emphasis on medical testing, private and public employers regularly require job applicants to undergo medical examinations that may include HIV testing even when not required by law, either because the employer requests it or because the doctor doing the examination orders the test without informed consent. NGOs with which Human Rights Watch spoke believe that persons known or discovered to be HIV-positive frequently are denied employment or, if already employed, encouraged to resign, but say that these cases are difficult to document and litigate because victims fear publicity and because HIV status is rarely stated as the reason for rejection.<sup>132</sup> Officials at the National Council for Combating Discrimination told Human Rights Watch, “People with HIV try not to mention their illness, and try to solve their problems without publicity. In most cases where there is publicity they accept it and try to move on with their lives. They lack the courage to address public institutions about abuses. Citizens aren’t informed about the anti-discrimination law and their legal options. We have only a few labor complaints but I can’t say that we don’t have discrimination. Labor inspectors know about gender issues but not HIV. We need to provide assistance to victims to document these cases, and we need to try to introduce principles [of anti-discrimination against people living with HIV] in employment.”<sup>133</sup>

Dr. Dan Duiculescu of the Victor Babeş Institute for Infectious Diseases told Human Rights Watch that the restrictions on employment of people living with HIV were far broader than medical concerns warranted. Speaking of employment opportunities for HIV-positive children and youth, he commented, “[From a medical perspective] the majority can have a normal job. There will need to be individual clinical and lab evaluations to know what work the children can do. The important thing is for them to start work. There are some with neurological problems and they will need something different but that is a separate issue. I would involve my patients in providing home care, and they can also do this as a job. I would put [a young woman who left a vocational program in cosmetology after students and administrators began to ask questions about her HIV status] to work as a home care worker for people with HIV—I saw it work in Miami.”<sup>134</sup>

---

<sup>132</sup> Human Rights Watch interview with Mirela Petreanu, president, *Pro Sanatatea 2000*, an UNOPA affiliate, February 14, 2006; Human Rights Watch interview with Silvia Asandi, general manager, and Adela Bohiltea, program director, Romanian Angel Appeal, Bucharest, February 6, 2006.

<sup>133</sup> Human Rights Watch interview with Csaba Ferenc Asztalos, president, and Corina Macoveanu, member of the steering committee, National Council for Combating Discrimination, Bucharest, February 21, 2006.

<sup>134</sup> Human Rights Watch interview with Dr. Dan Duiculescu, director of pediatric AIDS, Victor Babeş Infectious Diseases Institute, Bucharest, February 16, 2006.

To date few children and youth living with HIV have sought formal employment that would subject them to HIV testing, in part because of their young age and in part because of fear that doing so would place them at risk of their HIV status becoming known in the wider community. Staff at Romanian Angel Appeal told Human Rights Watch, “Employment is also a sensitive issue. Some of them due to their medical diagnosis have certificates for the first degree of disability with a personal assistant and they cannot work—they would have to choose between work and state assistance.”<sup>226</sup> This dilemma is exemplified by nineteen-year-old Anica M. (not her real name) who told Human Rights Watch, “I tried to get a job in a coffee shop. I pretended that I had no idea what is going on, and I applied together with five other people. They asked us to take the medical exams. They rejected me and two others. Probably it was because of the medical exams but how can I say? We are young adults now and we need to work. We are bored at home. You get the money from the state and you have nothing to do.”<sup>226</sup>

Staff at Romanian Angel Appeal also remarked that “Some of those who chose to work had problems with their health and their condition deteriorated.”<sup>227</sup>

---

<sup>226</sup> Human Rights Watch interview with Gabi Mareș, psychologist, and Anca Grigoraș and Flavia Olaru, social workers, Romanian Angel Appeal, Bacău, February 13, 2006.

<sup>136</sup> Human Rights Watch interview with Anica M. (not her real name), Bucharest, February 16, 2006.

<sup>226</sup> Human Rights Watch interview with Gabi Mareș, psychologist, and Anca Grigoraș and Flavia Olaru, social workers, Romanian Angel Appeal, Bacău, February 13, 2006.

## V. Government Response and Failures to Protect Children

In the more than a decade and a half since the fall of the Ceaușescu government, Romania has made surprisingly few advances in creating effective responses to the stigma and discrimination faced by people living with HIV. Children and youth living with HIV face an additional disadvantage, because those charged with their care and protection—educators, medical personnel, agencies administering subsidies, caregivers in and out of institutions, and even child protection staff—too often share the biases and ignorance about HIV of the broader society, while too many children and youth living with HIV lack the skills, information, and resources to demand their rights without assistance. Even more puzzling is the government’s failure to plan for the coming of age of a population in which it has invested so many resources: after years of committing government and foreign funding to keeping these children alive, the government now seems unwilling to provide the last bit of assistance that some will need to help them become and remain integrated, productive adult members of society.

### ***Inadequate Complaint Mechanisms***

#### ***County Directorates of Child Protection***

*The last complaint we made [to the Directorate of Child Protection] was in January 2006. It was a case of two girls in an extended family who said they were medically neglected. The family didn’t want them to go to the hospital and didn’t believe them when they said they were sick. I made a complaint to the DPC and was told that “Your NGO doesn’t monitor that case so we will have to do the follow up with the NGO that does.” But then they never did make a home visit.*

—Ștefania Mihale, social worker, Romanian-American  
Children’s Center, Constanța, February 14, 2006

Under Romanian law standards for child protection are set at the national level by the National Authority for the Protection of the Rights of the Child, and implementation of these standards is the responsibility of county (or in the case of Bucharest, sector) Child Protection Commissions, primarily through their Directorates of Child Protection (DPCs).<sup>138</sup> County Directorates of Child Protection have the primary responsibility for

---

<sup>138</sup> Law No. 272/2004 on the protection and promotion of the rights of the child, art. 100. The system has been criticized for, among other things, an incoherent plan for funding, poorly defined and conflicting roles and responsibilities, shortfalls in the numbers and professionalism of child protection staff, haphazard implementation of deinstitutionalization policies and continuing high rates of institutionalization of children with special needs, and a failure to prepare institutionalized children for independent living. For a detailed discussion

intervention in cases of child abuse and neglect, and are required by law to start an inquiry whenever learning of suspected abuse or neglect, to provide the child with appropriate services, and to take the child into temporary placement in cases of confirmed abuse or neglect.<sup>139</sup> However, these directorates frequently lack the staffing, vehicles, and other resources necessary to adequately monitor children at risk of abuse or neglect, and to investigate allegations of abuse and neglect. Employees of public and private institutions working with children are required by law to immediately notify child protection directorates of suspected abuse, neglect, or ill-treatment, but the law does not sanction failures to report.<sup>140</sup> Children can also make complaints of abuse to police, but police lack training in the needs of children living with HIV and do not appear to provide effective recourse in cases of child abuse and neglect.

Ciprian M. (not his real name) told Human Rights Watch that no one had investigated his allegations of beatings and neglect by family members, even though he had made complaints to an NGO social worker and the Constanța Directorate of Child Protection. The soft-spoken sixteen-year-old said the abuse began a year earlier, when after years in a state institution government officials found and returned him to his birth family. “Honestly they only took me because of the money.... I had the choice to go back [to my birth family] and ever since I went back they were pleased to see me because they get my allowance, but I don’t get any of it. If I ask my mother for 10 RON (U.S.\$3.60) she pretends not to hear me. I asked her to buy me socks but she pretends not to hear... I should get at least something sometimes.” Ciprian said that as a result of his mother’s refusal to provide him with spending money and basic necessities he had begun working in construction, although the work was ad hoc and provided little income. “I work like an adult but I am not paid like an adult. I go wherever I see a construction site and ask for work.” In addition to this neglect, Ciprian told us that his older brother began beating him when he questioned the brother’s treatment of their mother. “My older brother beats me up since last year. Sometimes I saw my mother crying and I asked her why and I found out it was because my [older] brother was preventing her from doing things. [He] fights with me with fists.” Ciprian said an NGO social worker helped him make a written complaint about the abuse to the Constanța DPC but “no one has come to ask about it.... I want the DPC to come and investigate when I am there because I don’t want to be left alone with them afterwards, because they will beat me. I don’t want

---

of the government bodies responsible for child protection and their shortcomings, see Institute for Marketing and Polls (IMAS), *Child Care System Reforms in Romania* (Bucharest: National Authority for Child Protection and Adoption, and UNICEF, 2004).

<sup>139</sup> Law No. 272/2004 on the protection and promotion of the rights of the child, arts. 91, 92, 94.2.

<sup>140</sup> *Ibid.*, arts. 85(3) and 91.

to stay there anymore. I want to live in a center again. I don't want to think about my family again.<sup>141</sup>

Laura K. (not her real name) an eighteen-year-old from a southeastern county, told Human Rights Watch that she had put up with violent beatings by her alcoholic mother for more than a year:

My mother doesn't treat me right. She beats me with a poker, and she hit my head against a stove. I didn't complain until recently because I thought, "She is my mother." Then I told [a doctor at a regional monitoring hospital] but she said that she couldn't help me because I was over eighteen and she could have helped if I were younger. My mother has a drinking problem. My mother doesn't want to give me my papers for my subsidies. As far as I know I should be able to sign for myself because I am eighteen. I spoke to a social worker at [an NGO], and she said she would help, and both my sisters say they will help me if I leave. I have run away many times.... There are people who would help me but my mother won't give me the papers so I can't leave. I need the disability certificate, the birth certificate, papers for subsidies, she even had my ID but I found it. It has been going on for a year.<sup>142</sup>

No national database of complaints of child abuse and neglect exists, making it difficult to identify patterns of abuses and responses to reported incidents. However, based on our interviews, it appears that failures to investigate and intervene in cases like the ones cited above are common. The lack of effective and accessible complaint mechanisms is aggravated by a lack of clearly understood and enforced roles and responsibilities among the various bodies that could take complaints from children. For example, many directorates of child protection rely heavily on NGOs working with children living with HIV to monitor conditions for these children and investigate instances of suspected abuse, although in many instances these NGOs are limited in their ability to reach all children in the areas they work, or to follow up with children who move outside their geographical area. The reliance on NGOs also creates the possibility of a conflict of interest should the alleged abuse or neglect implicate the NGO, as it could in the case of children living in NGO-run group homes. Children living with HIV could conceivably access directorate of child protection general telephone hotlines, or take their complaints to police, or to municipal social workers or school psychologists. But telephone hotlines

---

<sup>141</sup> Human Rights Watch interview with Ciprian M. (not his real name), Constanța, February 14, 2006.

<sup>142</sup> Human Rights Watch interview with Laura K. (not her real name), Constanța, February 15, 2006.

do not exist in all counties and are not well publicized, police, social workers, and psychologists are rarely trained to recognize and intervene in cases of abuse and neglect of children with HIV, and social workers and psychiatrists are in short supply.<sup>143</sup>

This mishmash of inadequate complaint mechanisms particularly disadvantages children with educational and cognitive deficits, and children isolated in rural and other underserved areas. Save the Children Romania program coordinator Simona Zamfir told Human Rights Watch, “Some children returned to birth families complain that they are abused, sent to beg, but I don’t know where children would go with such a complaint. We thought about handling complaints for them but we realized that we lacked the financial and human resources. There has to be someone whose voice is heard—a complaint from an NGO doesn’t have impact. There are many cases and one NGO cannot do this work alone.”<sup>144</sup> Violeta Clefterie of the National Authority for the Protection of the Rights of the Child told Human Rights Watch that “there are possibilities for interventions but the children don’t know about them and people around the children do not intervene [to stop abuse and neglect].” Clefterie, a member of the National Authority’s control unit, described the complaint mechanisms available to children as telephone hotlines, written complaints to the directorate of child protection, or written complaints to the National Authority for the Protection of the Rights of the Child, although according to her the National Authority had not received any complaints from children. Acknowledging that not all areas have hotlines and that “it is very difficult for a child in rural areas to contact the directorates of child protection directly,” Clefterie suggested that children “could also go to the municipality social worker or to the police” although it was unlikely that rural children would have this option because “there are only social workers and psychiatrists in large schools in large cities,” and “it also depends on the child’s age and what the child knows. The child may be afraid to go to the police because they will be returned to the same environment.” Clefterie added that in cases where the police do learn of child abuse they generally only “write a form and parents pay a fine. The police may or may not notify a social worker. In rural areas the police try to counsel families and only notify the Directorate of Child

---

<sup>143</sup> According to National Authority for the Protection of the Rights of the Child staff, only thirty-nine of the forty-two directorates of child protection have telephone hotlines, and social workers are in short supply because Romania had no schools of social work between 1969 and 1993, and even now graduates only a few social workers per year. Human Rights Watch interview with Ioana Nedelcu, under-secretary of state, Ali Cranta, ANPDC expert on the National HIV/AIDS Commission, and Violeta Clefterie, member of the control unit, National Authority for the Protection of the Rights of the Child, Bucharest, February 17, 2006

<sup>144</sup> Human Rights Watch interview with Simona Zamfir, program coordinator, Save the Children Romania, Bucharest, February 9, 2006.

Protection if there is severe abuse. There is no provision in the law that says, for example, if a parent slaps a child every day there has to be an intervention.”<sup>145</sup>

The absence of effective measures to protect children from abuse raises real questions about Romania’s compliance with its obligations under the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) to protect children from abuse and to provide an effective remedy for children who are at risk of abuse.<sup>146</sup>

### ***The National Council for Combating Discrimination***

As part of its efforts to bring its laws into compliance with European Union standards, Romania was the first country in Central and Eastern Europe to adopt specific anti-discrimination legislation and to create a body charged with combating and preventing discrimination—the National Council for Combating Discrimination. The Council’s mandate allows it to investigate individual cases of discrimination and to propose “affirmative actions and special measures for the protection of persons... confronted with rejection and marginalization,” but thus far it has limited its actions to individual cases.<sup>147</sup> Council staff complained to Human Rights Watch that its budget of “about 700,000 Euro per year” was insufficient to allow it to have “a proper staff” and to be able to open local bureaus so that it would be accessible to people living outside of Bucharest.

Individual victims or an NGO working in the field can file a complaint with the Council in cases of discrimination in a wide variety of fields, including the right to work, the right

---

<sup>145</sup> Human Rights Watch interview with Ioana Nedelcu, under-secretary of state, Ali Cranta, ANPDC expert on the National HIV/AIDS Commission, and Violeta Cleferie, member of the control unit, National Authority for the Protection of the Rights of the Child, Bucharest, February 17, 2006.

<sup>146</sup> Article 3 of the ECHR prohibits torture and inhuman and degrading treatment or punishment, and article 13 requires that there is an effective remedy for anyone who may be a victim of a violation. The European Court of Human Rights has consistently held that States are required to take measures designed to ensure that individuals within their jurisdiction are not subjected to torture or inhuman or degrading treatment or punishment, including such ill-treatment administered by private individuals and that children and other vulnerable individuals, in particular, are entitled to State protection, in the form of effective deterrence, against such serious breaches of personal integrity. The Court has found violations of article 3 in the form of state failure in laws and practice to protect children from abuse by adults and in state care in *A v. United Kingdom*, judgment of September 23, 1998, Reports of Judgments and Decisions 1998-VI; *Z. and Others v. United Kingdom*, judgment of May 10, ECHR 2001-V; and *E. and Others v. United Kingdom*, judgment of November 26, 2002.

<sup>147</sup> Governmental Decision 1279 /2003 on modifying and completing the Governmental Decision 1194/2001 on the organizing and functioning of the National Council for Combating Discrimination, Official Gazette No. 805/2003.

to health, and the right to education.<sup>148</sup> If in such individual cases the Council finds that the discriminatory act amounts to an administrative contravention (misdemeanor) it can levy a fine or issue a warning.<sup>149</sup> However, a review of Council annual reports reveals a failure to address systematic discrimination against people living with HIV and to provide adequate redress to individual victims. For example, in 2004 the Council intervened in only one case of discrimination based on HIV status and did not resolve it.<sup>150</sup> In 2005, the Council received ten petitions claiming discrimination on grounds of HIV status and resolved four of them, and started the investigation ex officio in four other cases and resolved two of them.<sup>151</sup> In most of these cases the Council's intervention consisted of mediation efforts resulting in solutions arrived at at the local level without decisions and fines being issued.<sup>152</sup> What fines the Council did issue typically were small and, by law, go to the state budget and not to the victim of discrimination.

The remedies provided in a 2005 case mentioned earlier in this report bear witness to the inadequacies of this approach. Following a petition filed by an NGO, the Council started its own investigation and confirmed that the headmaster of a school in Singureni, Giurgiu county, had written the HIV status of HIV-positive children graduating from his school on their school files, and that during the final exams, "HIV" was listed next to the names of these children on the public lists of exam results. The Council also found that the headmaster had threatened that if fined he would retaliate against the NGO providing care to these children by requiring it to provide at the beginning of the school year documents showing parental consent to school registration, thus making impossible the registration of abandoned children whose parents could not be found or who refused to complete the paperwork to formally sever their parental rights. In its decision, the Council found the inclusion of the children's HIV status on the public lists

---

<sup>148</sup> Article 22 states "(1) Human rights nongovernmental organizations can appear in court as parties in cases involving discriminations pertaining to their field of activity and that prejudice a community or a group of persons. (2) The organizations provided in the above paragraph can also appear in court as parties in cases involving discrimination that prejudice a natural entity, if the latter delegates the organization to that effect." Law No. 48/2002 on approving the Ordinance 137/2000 on preventing and sanctioning all forms of discrimination, Official Gazette 69 from January 31, 2002, arts. 1(2)(e)(i), 6(7), 1(2)(e)(iv), 11, 1(2)(3)(v), 15, 22(1).

<sup>149</sup> *Ibid.*, art. 20.

<sup>150</sup> National Council for Combating Discrimination, Report January-June 2004, available at <http://www.cncd.org.ro/images/rapoarte/raport%20ian-iun%202004.pdf>.

<sup>151</sup> National Council for Combating Discrimination, Annual Report 2005, available at <http://www.cncd.org.ro>. In 2005 the Council received 382 petitions and started investigations ex officio in seventy-four cases.

<sup>152</sup> National Council for Combating Discrimination interventions in cases involving HIV appear to have been more effective in cases of discrimination in schools in Bucharest, when the registration of pupils living with HIV was refused or when the teachers, school authorities, or other parents harassed children living with HIV with the intent of forcing them to drop out. Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

for the graduation exams to be discriminatory but limited its response to fining the school inspectorate ROL4 million (U.S.\$145) and issuing warnings to the headmaster and to the president of the testing commission who had published the lists with the names.<sup>153</sup>

In another case also from 2005 the Council found that statements to the media by the director of the Vrancea county general directorate for social assistance and child protection, that the solution for sexual activity in the case of children living with HIV is sterilization, were discriminatory but issued only an administrative fine of ROL5 million (U.S.\$181).<sup>154</sup> Council president Csaba Ferenc Asztalos told Human Rights Watch, “The sanctions we have are not sufficient. In most cases they are symbolic. Our sanctions are appealed and we usually win. The fact that we establish proof of discrimination is the main sanction.”<sup>155</sup>

A January 2006 National Council for Combating Discrimination decision issued following a complaint filed by ARAS, the Romanian Anti-AIDS Association, found that there was no discrimination in the case of a woman whose HIV status became known to her entire community after a maternity hospital in Vaslui was put under quarantine because the woman, who had just given birth there, was HIV-positive.<sup>156</sup> When Human Rights Watch asked why there was no finding of discrimination in this case, Council president Asztalos told us, “we don’t have the medical expertise to know if this kind of quarantine is necessary, or routine, or not.” Asztalos added, “Sometimes we ask for help from expert doctors at the Ministry of Health [expert commission on HIV] but they don’t help us much because some of the cases we receive are complaints against them—complaints against doctors on the commission.”<sup>157</sup>

### ***Inadequate Monitoring and Investigations of Abuse and Neglect***

One of the biggest barriers to the adequate functioning of the child protection system is lack of sufficient numbers of skilled social workers at the directorates of child protection and municipalities. This shortage reflects in part a nationwide shortage of trained social

---

<sup>154</sup> National Council for Combating Discrimination, Decision 289 from August 8, 2005.

<sup>154</sup> National Council for Combating Discrimination, Decision 66 from April 1, 2005.

<sup>155</sup> Human Rights Watch interview with Csaba Ferenc Asztalos, president, and Corina Macoveanu, steering committee member, National Council for Combating Discrimination, Bucharest, February 21, 2006. According to Asztalos, the senate was considering draft legislation “to increase the sanctions and reverse the burden of proof.”

<sup>156</sup> National Council for Combating Discrimination, Decision 37 from January 19, 2006.

<sup>157</sup> Human Rights Watch interview with Csaba Ferenc Asztalos, president, and Corina Macoveanu, steering committee member, National Council for Combating Discrimination, Bucharest, February 21, 2006.

workers and psychologists, and low salaries and heavy workloads at directorates of child protection. A 2004 study of the Romanian child protection system found that protection services were “concentrated in large urban areas, while small localities throughout the county are still uncovered,” and that staff at directorates of child protection were “totally out of their league” in providing required services. As a result,

[c]ase monitoring, assistance and closing procedures are poor and often conducted by people with too little training. Moreover, protection measures may sometimes be applied following a single visit by a social worker, concluded with the 7-minute presentation of a summary report before a Commission that has listened to some 100 or more cases that same day. Furthermore, there is no continuity in the monitoring of cases, but rather by type of institution. A case is not monitored by a single case manager or institution, but by a string of social workers from different institutions, according to whose competence the case moves at different stages. Data gathering and reporting are not accurate enough. No viable indicators are developed and used in monitoring the system and the quality of services.<sup>158</sup>

Delia Goia, a social worker for an NGO working with children living with HIV, told Human Rights Watch,

The Directorates of Child Protection need more staff. A single social worker could be responsible for one hundred children, some institutions, and three group homes, for example. Social workers’ work is superficial because their case load is high and there is a lot of staff turnover so they don’t get to know the children in their case loads. A foster family in the third district [of Bucharest] has had their social worker change every two months! The social workers get low pay and work in a rigid environment so they either quit or get promoted, and the promotions are not necessarily based on competence. The children at the Vidra orphanage were never actually visited by the DPC—we NGOs are the only ones who visit them.<sup>159</sup>

---

<sup>158</sup> IMAS, *Child Care System Reforms in Romania*, p. 30.

<sup>159</sup> Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

Staff at the National Authority for the Protection of the Rights of the Child agreed with this assessment, but blamed county council resource allocation decisions for exacerbating the situation in some counties. Violeta Clefterie told us that existing legislation did not clearly specify the types and numbers of specialist staff for all types of services, and even where staffing was specified, it was not implemented. For example, according to Clefterie, social work standards for foster care set a maximum case load of twenty-five foster parents and thirty foster children per social worker, “but not all the counties can comply with this standard.” She added that the National Authority had met with directors of local councils to try to explain the law, and had met with directors of the two schools of social work “to recommend that social work graduates can be informed about Directorate of Child Protection vacancies and sign agreements for training and internships,” but that low salaries and other disincentives remained a serious problem in attracting and keeping skilled social workers.<sup>160</sup>

Several NGOs and parents Human Rights Watch spoke with described social workers and directors at the Constanța directorate of child protection as well-intentioned and helpful, but limited by resources in what they could do. Ștefania Mihale, a social worker at the Romanian-American Children’s Center, told us, “The Directorate of Child Protection here has a lot of problems with money so they aren’t able to help a lot of our children. We help them with social inquiries because they don’t have money for gas so they can’t do family visits. Sometimes we help them assessing the situation of children in extended families too.”<sup>161</sup> Constanța directorate deputy director Mirela Cornelia Gene described an extremely limited role for her agency, saying,

We don’t have the staff to find out directly about abuses against children.... We don’t have the means to evaluate what is going on for children in biological families and we have no legal obligation to monitor children in families and NGO centers. We would need a well defined system to assess it very accurately.... We have one social worker on residential care and five social workers for extended family placement. We would need to have a separate unit to do monitoring and

---

<sup>160</sup> Human Rights Watch interview with Ioana Nedelcu, under-secretary of state, Ali Cranta, ANPDC expert on the National HIV/AIDS Commission, and Violeta Clefterie, member of the control unit, National Authority for the Protection of the Rights of the Child, Bucharest, February 17, 2006.

<sup>161</sup> Human Rights Watch interview with Ana Maria Schweitzer, director, and Ștefania Mihale, social worker at the Romanian-American Children’s Center, and Dr. Cambria, an infectious diseases specialist at the Constanta Municipal Hospital who also sees patients at the Romanian-American Children’s Center, Constanța, February 14, 2006.

evaluation but the legislation in force does not give me the authority to hire the necessary staff.<sup>162</sup>

Gene blamed the shortfalls in staff and funding on the law's failure to set clear guidelines on minimum staffing and funding for child protection activities, saying,

We have a list of standards to protect children's rights but we don't have the staff to implement it. Our funding comes from the National Agency for Child Protection and the National Authority for Persons with Handicap. The local county council also pays but not all that it should and the money from the national government is also less than we need. Every year we propose a budget that would cover all foreseen expenses but what we get is far less.... Last year we had collective dismissals at the level of the entire directorate. More than 300 people lost jobs, and for three months salaries were not paid.<sup>163</sup>

Staff at the National Authority for Protection of the Rights of the Child and the National Authority for Persons with Handicap questioned aspects of this account, and Human Rights Watch is not in a position to assign responsibility for the funding crisis.<sup>164</sup> Regardless of funding, what is clear is that the Constanța Directorate of Child Protection has an extremely limited view of its role, and this limited vision contributes to its failure to adequately protect children living with HIV. One particular weakness is the Directorate's relationship with NGOs providing services to children living with HIV. The Constanța DPC, like many others, relies heavily on NGOs to provide social work services, but this relationship is not well defined. NGO social workers in Constanța and

---

<sup>162</sup> Human Rights Watch interview with Mirela Cornelia Gene, deputy director, Directorate for Child Protection, General Directorate for Social Assistance and Child Protection, February 13, 2006. In a subsequent telephone interview Gene corrected herself, saying that DPC staff also included "three social workers who do files for disability determinations." Human Rights Watch telephone interview with Mirela Cornelia Gene, February 15, 2006.

<sup>163</sup> Human Rights Watch interview with Mirela Cornelia Gene, deputy director, Directorate for Child Protection, General Directorate for Social Assistance and Child Protection, February 13, 2006.

<sup>164</sup> Violeta Clefterie told Human Rights Watch that the Constanța DPC "got money from the national government but there were problems with money from the county council and how they spent it. Money for the entire year was spent in four months and from our point of view the money was spent on programs that were not a high priority." Human Rights Watch interview with Ioana Nedelcu, under-secretary of state, Ali Cranta, ANPDC expert on the National HIV/AIDS Commission, and Violeta Clefterie, member of the control unit, National Authority for the Protection of the Rights of the Child, Bucharest, February 17, 2006. Paulian Sima told us, "Many municipalities decide that money from the central government can be spent on anything they want so they go and build a bridge or repair a road. That is what happened in Constanța. The authorities used the funding from the state budget for other purposes." Human Rights Watch interview with Paulian Sima, expert, National Authority for Persons with Handicap, Bucharest, February 20, 2006.

other counties told us they sometimes made ad hoc interventions in cases of abuse and neglect, but that no standards existed to define the role and responsibilities of non-Directorate social workers. As the director of the Romanian-American Children's Center in Constanța put it, "They need to standardize the social work by the DPC and NGOs to make sure they are doing the same thing. One of the pitfalls is that different NGOs work differently."<sup>165</sup> Romanian-American Children's Center social worker Ștefania Mihale added, "The law allows for the DPC to make an NGO a case manager. We talked to NGOs in Bucharest where this works. Our DPC lacks personnel but so far does not let us be case managers even though we do a lot of the case manager work. This is the case for the Flower House [group home] children—we do the work and the DPC case manager only signs the documents."<sup>166</sup>

### *Inadequate Support for Caregivers of Children Living with HIV*

*There are many families who took children with HIV and they were not trained about HIV so when there were many problems their first impulse is to return the child. It is one thing to go through this knowing what you are expected to do and another for it to be a surprise.*

—Regina M. (not her real name), mother of an HIV-positive child, Constanța, February 15, 2006

Romania's child protection system offers few services to help the caregivers of children living with HIV understand their children's disease and cope with the problems caused by discrimination. The problem is especially acute for children reintegrated in birth and extended families after periods in state institutions, as many of these families are still struggling with the issues that led them to abandon their children in the first place.<sup>167</sup> As in the cases of Ciprian M. and Laura K., mentioned above, children and NGO social workers described instances of children suffering physical abuse or educational and

---

<sup>165</sup> Human Rights Watch interview with Ana Maria Schweitzer, director, and Ștefania Mihale, social worker at the Romanian-American Children's Center, and Dr. Cambria, an infectious diseases specialist at the Constanta Municipal Hospital who also sees patients at the Romanian-American Children's Center, Constanța, February 14, 2006.

<sup>166</sup> Ibid.

<sup>167</sup> Reintegration of institutionalized children into families still facing difficulties, and inadequate support for these families, is a broader problem in Romania. A 2004 study of 141 families who had taken children back found that only 25 percent reported receiving any counseling, and 50 percent reported receiving no assistance at all. Most of the families were very poor, were headed by persons with below average education, and had three or more children under eighteen. In many cases the family's school age children were not attending school, and 60 percent said they had difficulties raising the reintegrated child. IMAS, *Child Care System Reforms in Romania*, pp. 54-56.

medical neglect after being “reintegrated” into birth or extended families without adequate monitoring and support.

Natalia L. (not her real name), recently turned eighteen, was returned to her mother in Bacău a few years ago after years in orphanages. She told us,

[My mother] beats me, every time she feels like it she starts hitting me. In the summertime I run away from home. She uses a belt or a rubber strap to beat me... She told me that when I am an adult I'll have to pay rent if I stay with her... I'll find a different place. But she receives the subsidy now, ROL2,020,000 [U.S.\$73]. She says, “This is my money because I take care of you.” I've never touched that money, I have only the school subsidy which is ROL1,800,000 [U.S.\$65].

Natalia L. told Human Rights Watch that she had complained to the municipality and to the police about the beatings, but the situation had not improved and she didn't know what to do.

How long should I allow her to beat me?... I told the woman [social worker] at the municipality and she said that I did something to deserve it. In the summer I was outside with my friends and [my mother] called me inside for dinner. We started fighting and she threw a marble plate at me. I left. The mayor's office was closed and I had to go to stay with my father and with my grandparents for a week. After a week she was the one coming to grab me. When it happened again I called the police and the policeman said that I should wait on the street. We met and we went together but she did not want to open the door. The policeman spoke with her and eventually she opened the door and she was fined with ROL2 million [U.S.\$72.50]. She paid the fine with my [subsidy] money. After that she threatened that she will take me back to the orphanage. I don't want to go back there.... It is like a prison there.<sup>168</sup>

Ramona Ferent, executive director of ARAS's Bacău office, told Human Rights Watch,

Many of the de-institutionalized children had been taken back due to financial reasons in the original families. They went to ask to get the

---

<sup>168</sup> Human Rights interview with Natalia L. (not her real name), Bacău, February 14, 2006.

children when they found out about the benefits they could receive. One of the boys taken for money by the mother is abandoned months at a time in the hospital. We cannot really do anything, we keep on threatening the parents and sometimes it works. I don't know if the social workers from the municipality fail to monitor these cases because they don't want to or because they can't. There is a lack of motivation for sure.<sup>169</sup>

### ***De-institutionalization on the Cheap: The Case of Vidra Orphanage***

Vidra Placement Center 7 is one of three large residential placement centers created in the late 1980s and early 1990s to care for children living with HIV.<sup>170</sup> Human Rights Watch toured the facility on February 15, 2006, and also interviewed former and current residents, center staff, and staff of NGOs with regular and ongoing contact with current and former residents. The center housed about one hundred children until a formal push for de-institutionalization began in 2001. At the time of our visit there were twenty-two children and youth ages eleven through nineteen living at the facility, including eight living in a separate building for children with severe disabilities or behavior problems. The placement center is scheduled for conversion to a hospital for the elderly, and efforts have been underway for over a year to move the remaining children and youth to other facilities. According to Vasile Marin, deputy director of the Ilfov county General Directorate for Social Assistance and Child Protection,

It was a process of taking them from these institutions and sending them to the original families or to the counties of origin. We have here now only the children from Ilfov [the county where Vidra is located] and from other counties for whom we could not find the parents. None of them had been visited by the parents, or they come from disorganized families. Most came from poor families and had been abandoned in the hospitals.<sup>171</sup>

---

<sup>169</sup> Human Rights Watch interview with Ramona Ferent, executive director, Romanian Association Against AIDS, Bacău, February 13, 2006.

<sup>170</sup> The other two were in Constanța and Bucharest. Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006; Human Rights Watch interview with Dr. Monica Bîrlodeanu, director, and D.I. Medeleanu, administrator, Vidra Placement Center No. 7, Vidra, February 15, 2006.

<sup>171</sup> Human Rights Watch interview with Stephan P. (not his real name), Bucharest, February 8, 2006.

NGOs familiar with the de-institutionalization described a much more haphazard process, with placement center staff actively attempting to sabotage the transfer of children (allegedly to save their own jobs), and children sent with little or no warning to birth or extended families unprepared to accept them.

Health Aid Romania told Human Rights Watch that it had placed three children from Vidra in its group homes, and is under pressure from the Directorate for Child Protection to accept the remaining children. Executive Director Ernestina Rotariu described the de-institutionalization process this way:

First the Ilfov Directorate of Child Protection looked to see where the children were born—the government never adjusted their status to register them in Ilfov county—so they passed the responsibility to the county of birth. Some children were told, “you, you, you, pack because tomorrow you will go.” Some parents got letters while they were not home or had messages left with neighbors saying, “You have to come to Bucharest because you have a child in Vidra who has HIV.”<sup>172</sup>

The Foundation for the Development of People has worked with children from Vidra since 1998, providing services to children still living at the facility and to more than thirty children and youth whom the NGO has helped de-institutionalize. Program coordinator Claudia Terragni told Human Rights Watch,

It is hard to say this but there was an entire organization living from these children. They kept telling us everything was fine and that the families visited these children but when we spoke with them the children said no, it wasn't true. There was only a kindergarten there even though some of the children were ten or twelve years old. We could only find two or three [birth] families and none of them wanted the children back.... This was when the authority passed from the Ministry of Health to the Directorate of Child Protection so it was a difficult time. Social services wanted the children out of the institution but the local staff at the Ministry of Health wanted them to stay and kept saying that the children were terminal stage to prevent them from leaving—saying that we were not organized to care for them properly. In some cases children were threatened to keep them from coming with us. People at Vidra told

---

<sup>172</sup> Human Rights Watch interview with Ernestina Rotariu, executive director, Health Aid Romania, Bucharest, February 9, 2006.

some children not to come with us because we would not treat them well, we would leave them to die, etc, so some children who had agreed to come to our group home changed their minds.... We were supposed to work inside Vidra with the children to decide which children to move out but we were not given enough time so we used criteria like friendships [amongst the children] and psychological strength to decide which children to move. We took thirty children, two went to Health Aid, and four went to another NGO. The rest were sent home or to other smaller institutions. Those who remain have a serious handicap. Some were sent to a DPC house. UNICEF commissioned us to look into what happened to the children at Vidra but the report is not finalized yet. One big problem [we uncovered] is that local authorities worry about a child if the child is in their territory, but don't follow what happens if the child leaves their area. I am sure that any place a child goes is better than Vidra because Vidra was very, very, very bad. We try to follow up but it is very, very hard. In the last few years we saw that local social services are trying to do their best but many times they didn't have a strategy and didn't understand what the government wanted from them, even though Vidra was at the center of attention. I never saw a clear strategy. For us it was good, because they left us alone. The government asked for the UNICEF study on Vidra but now the government says that "we don't have the money to implement the findings so stop the research," and now our group is the one pushing for the study."<sup>173</sup>

Delia Goia, a Foundation for the Development of People social worker who is also a researcher on the UNICEF study told Human Rights Watch,

Only a few children were reintegrated in birth families by the public authorities. Some went to other institutions and some went to NGOs. Some we monitored but we are not aware of state authorities following up on the children who were de-institutionalized from Vidra. Many times birth families came to us to find information on what to do to get benefits. If we knew the family beforehand the situation was better but in many cases the child was sent in a bus to families who were not prepared for them. We had two such cases with serious reintegration

---

<sup>173</sup> Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

problems: the families were not informed about treatment or how HIV is transmitted, and the kids did not feel well but the families did not know what to do. The state did not provide any help to the families who had their children returned. These are poor families who are not well treated by the state. They don't know what questions to ask when dealing with officials, and they get sent from office to office.<sup>174</sup>

Most of the NGOs and children we spoke with told us that conditions had improved at Vidra over the last two to three years under the direction of Dr. Monica Bîrlodeanu, but that serious problems still existed, particularly with violence among children. Delia Goia told us, "Violence in Vidra is now a huge problem because the children are bigger, and they are panicked because they don't know where they are going to go. There used to be a problem of staff being violent but now the problem is that the children are violent among themselves or to staff." Goia said that under Bîrlodeanu staff had begun to intervene to prevent violence among children but with limited effect, adding,

I don't think that this center can be fixed—life has always been like this in this center. It is a fight for survival and the most violent of all got the treats and all the trips. That is life in large institutions and the staff has gotten used to it. The children must be separated into smaller facilities—group homes, foster families.<sup>175</sup>

Of special concern is the building for children with severe disabilities and behavioral problems, officially called Casa Noastra (Our House) but known among children and staff as "Quarantine." At the time of our visit it had more staff present than the main building, and Vidra staff described the children living in Quarantine as "those who cannot take care of themselves or are too violent and put other children in danger."<sup>176</sup> One individual to whom Human Rights Watch spoke who had regular access to Vidra told us that the only clear feature distinguishing all of these children from those in the main building was that "none of them were verbal, although some can communicate in other ways."<sup>177</sup> Children living in the main building described the children in Quarantine as violent, and said that sometimes other children were sent to Quarantine as a form of discipline. Stephan P. (not his real name) has lived at Vidra "for a long time, for as long

---

<sup>174</sup> Ibid.

<sup>175</sup> Ibid.

<sup>176</sup> Human Rights Watch interview with Dr. Monica Bîrlodeanu, director, and D.I. Medeleanu, administrator, Vidra Placement Center No. 7, Vidra, February 15, 2006.

<sup>177</sup> Human Rights Watch telephone interview with an individual familiar with the situation of children at Vidra over a number of years (name withheld by request), February 7, 2006.

as children have been there.” He told us, “There are problems in the Quarantine. The children there have problems or defects. They beat each other and cause trouble. The staff separates them and gives them something to calm them down—pills. Sometimes children get hurt, on their heads, faces, everywhere. It is mostly bruises.” Asked what would make Vidra better, he added, “Bigger children should not beat smaller ones. It happens a lot. The staff splits them up and tells them not to break things.”<sup>178</sup> Ivan N. (not his real name) has also lived in Vidra most of his life. He told us, “The younger children have a separate building. They beat each other and can’t eat by themselves.” Delia Goia told us that Quarantine was also used to punish children “for stealing from the staff,” or, in one case, “for throwing stones at the car of a neighbor who had taunted them. That was two or three years ago and all the children who had thrown stones had their heads shaved and some were sent to Quarantine.”<sup>179</sup>

While staff at Vidra told Human Rights Watch, “We take [the children in Casa Noastra] for medical assessment every three or six months and every time it is required,” accounts by others familiar with the children suggest that this is not the case.<sup>180</sup> A social worker at the Foundation for the Development of People told Human Rights Watch, “Some children have been moved out of Quarantine and have done better intellectually after the move. I don’t visit Quarantine often but when I do the staff there seem more caring than the rest of the staff. The children in Quarantine have the worst CD4 counts [a measure of the health of the immune system], but therapy isn’t working for them. Also, the children in Quarantine don’t go for monitoring every six months because Colentina [the colloquial term for Balș Hospital] doesn’t have capacity to have a nurse assigned to them twenty-four hours a day so they prefer that the children not come. Some children have not gone for treatment for two or more years.”<sup>181</sup>

## ***Aging Out of the Child Protection System***

*Tell the president to not let kids live in the street. It is true that if you are eighteen you have to fly away but you need some kind of support. Help us get a flat. It isn't just me it is all the abandoned kids. We are all asking, where will I go when I won't*

---

<sup>178</sup> Human Rights Watch interview with Stephan P. (not his real name), Bucharest, February 8, 2006.

<sup>179</sup> Goia told Human Rights Watch that she was not aware of head shaving as punishment taking place since Dr. Bîrlodeanu became director. Human Rights Watch interview with Delia Goia, social worker, Foundation for the Development of People, Bucharest, February 8, 2006

<sup>180</sup> Human Rights Watch interview with Dr. Monica Bîrlodeanu, director, and D.I. Medeleanu, administrator, Vidra Placement Center No. 7, Vidra, February 15, 2006.

<sup>181</sup> Human Rights Watch interview with Claudia Terragni, program coordinator, and Delia Goia, Gabriela Georgescu, Justina Haralambescu, and Marius Pawradu, social workers, Foundation for the Development of People, Bucharest, February 7, 2006.

*be able to live here anymore? I don't need anything else. I just need the roots and I can handle the branches.*

—Mădălina D. (not her real name), age twenty, Bucharest

*The government is not planning for the future. They just want to wash their hands when the child turns eighteen. Some children don't want to go to school. It is important that they should have a job, and not just stay as a patient.*

—Dr. Dan Duiculescu, head of pediatric AIDS, Victor Babeş Infectious Diseases Institute

The bulk of the 1987-1991 cohort of children living with HIV is now between sixteen and nineteen years old and quickly aging out of social protection services for children. Yet no coordinated plan exists for their transition to the more limited services available to HIV-positive adults, or for the transition to appropriate assisted-living arrangements for those who may need them. The problem is especially acute for children living in foster, group home, orphanage, or extended family placements, and for formerly institutionalized children who were returned to impoverished and often dysfunctional birth families without adequate monitoring and support for those families. In such cases there is a significant risk that children may be rejected by their caregivers once monetary incentives are reduced or eliminated, or in the case of NGO-run group homes, that diminished foreign funding may make it impossible for some NGOs to provide long-term support to young adults who cannot support themselves because of ill-health, educational or developmental deficits, or employment discrimination.

Generally speaking, Romania's child protection services end at eighteen, although some measures of special protection may continue until age twenty-six if the young person remains in enrolled formal education.<sup>182</sup> In addition, the Law on Protection of the Rights of the Child provides up to two years of social protection to a young person who was the beneficiary of a measure of special protection and who is not enrolled in formal education but who on turning eighteen finds him or herself at risk of social exclusion and does not have the possibility to return to his or her own family. However, this social protection net has many holes that vulnerable young people can fall through: the two-year extension is not automatic, is not widely known, and no procedures exist to help the young person in making the application. The extended protection measures also end if the young person rejects offered employment or housing, even if the offered housing or employment are not suitable to the individual's needs.

---

<sup>182</sup> Law No. 272/2004 on the protection and promotion of the rights of the child, art. 51(3).

Considerable confusion exists over what will happen as children living with HIV age out of the child protection system. Several NGOs working with children living with HIV told us that neither they nor the children they served knew of any government plan for children who turned eighteen. Staff at the Romanian Angel Appeal office in Bacău told us, “Turning eighteen? We don’t know what will happen with them and nobody talks about it. We don’t know if they are going to be protected by the same legislation or if they will benefit from preferential treatment. We have a huge wave [turning eighteen] this year and there will be another one next year.”<sup>183</sup> The deputy director of the Constanța Directorate for Child Protection told Human Rights Watch, “At age eighteen the protection measures end if the child is no longer in school. Normally they should be taken over by the adult protection directorate but we haven’t developed that here. We don’t have specialized services for adults and NGOs have to do that... Not everyone can acquire the skills for independent life. That is the problem we are facing. We are going to have a reform and hope to set up centers to provide real protection for adults. Otherwise they will be in a risky situation.”<sup>184</sup>

Under law, young adults living with HIV who do not qualify for extended child protection measures are nevertheless eligible for some state subsidies. However, these subsidies will in many cases be much less than those they received as children and insufficient to cover housing costs. Program coordinators at ARAS in Bucharest told Human Rights Watch, “We work with a lot of adults with HIV in Bucharest and they have very serious problems because there are almost no placements for adults... The housing market is very bad—in Bucharest it is impossible to pay rent out of the state subsidies if you don’t also work, even though a person living with HIV gets more than twice [as much as] those with other disabilities.”<sup>185</sup> Ștefania Mihale, an NGO social worker in Constanța, told us that finding housing for young adults who had been living in NGO group homes was a challenge. “Some NGOs have moved children to extended families after they turn eighteen. [As adults they] get about ROL4 million [US\$ 145] per month so it is very hard to pay rent. In some smaller towns there may be support from the municipality. In Constanța the situation is very bad because some families had been in state-owned houses that the state is now returning to the rightful owners and they are

---

<sup>160</sup> Human Rights Watch interview with Gabi Mareș, psychologist, and Anca Grigoraș and Flavia Olaru, social workers, Romanian Angel Appeal, Bacău, February 13, 2006.

<sup>184</sup> Human Rights Watch interview with Mirela Cornelia Gene, deputy director, Directorate for Child Protection, General Directorate for Social Assistance and Child Protection, February 13, 2006.

<sup>185</sup> Human Rights Watch interview with Monica Dan and Liana Velica, project coordinators, Romanian Association Against AIDS, Bucharest, February 17, 2006.

having a hard time finding new housing. Some young adults are in hostels but there are really no spaces now so it isn't an option."<sup>186</sup>

An expert at the National Authority for Persons with Handicap told Human Rights Watch that by law young adults living with HIV who had received certificates of disability would be eligible for subsidized housing provided by local councils "but we cannot push the local authorities to provide housing for this category over other [eligible] categories." He added,

The problem is with those leaving the child protection centers. The legislation is not clear [about what happens to them]—they can only be in the center for two years after turning eighteen. We financed NGOs to set up houses for them but the money is never enough. We have a new approach now. We proposed a law to increase subsidies if the person does not have other income, and also to quantify the monetary value of the benefit—assume that the person doesn't want the radio and television subscription but would like to have cable instead, or wants to go by bus and not by train. We proposed an additional 80 RON (US\$ 28.99) for the person to manage. If it is approved it won't go into force before January 1, 2007.<sup>187</sup>

While many youth living with HIV would welcome an increase in cash payments, the subsidies are not designed to meet the needs of those young adults who have led highly sheltered lives, may have significant educational and developmental deficits, and are not now and may not ever be able to live independently. For example, one person familiar with the children still living at the Vidra placement center described them as "very ill-prepared for life—they don't read and write well, and they aren't consulted so they don't have good decision-making skills."<sup>188</sup>

---

<sup>186</sup> Human Rights Watch interview with Ana Maria Schweitzer, director, and Ștefania Mihale, social worker at the Romanian-American Children's Center, and Dr. Cambria, an infectious diseases specialist at the Constanta Municipal Hospital who also sees patients at the Romanian-American Children's Center, Constanța, February 14, 2006.

<sup>187</sup> Human Rights Watch interview with Paulian Sima, expert, National Authority for Persons with Handicap, Bucharest, February 20, 2006.

<sup>188</sup> Human Rights Watch telephone interview with an individual familiar with the situation of children at Vidra over a number of years (name withheld by request), February 7, 2006. This problem is not unique to children living with HIV: A 2004 evaluation of the child protection system found that child protection institutions did not adequately prepare young people for independent living, saying residents of these institutions "lack self-confidence and have little confidence in others. They have not completed their education, have poor career orientation, are incapable of planning their future in a practical manner, and are sometimes emotionally unstable." IMAS, *Child Care System Reforms in Romania*, p. 57.

The need for support in transitioning to independent living is not limited to institutionalized children and youth. Dr. Lumina Enz, a pediatrician at Babeş Institute for Infectious Disease told us, “Some children are not ready. They don’t want to move to a job even if clinically they could because they are afraid. Sometimes they try to do things and come back saying they can’t when I think it is that they are afraid to do it.”<sup>189</sup> A few NGOs have developed small assisted living and sheltered workshop programs for youth in their own group homes, but no government plan exists to provide these services more broadly, or even to provide children and youth living with HIV with information on and assistance in applying for adult subsidies.

Ioana A. (not her real name), the foster mother of a youth living with HIV in Constanța, described her frustration at being unable to secure assistance for her foster son, or even clarify his status after turning eighteen:

The NGO my foster child had been in used to come to make visits to see the child but now that he is eighteen no one comes to visit. I would have wanted help to make long-term solutions. The NGO had a support group for foster mothers but the psychologist and social worker just listened and didn’t provide solutions so some families just took the children back to the foundation when things got difficult. When I went to the DPC they said the child will end up on the street if I don’t keep him.<sup>190</sup>

Some infectious disease doctors told us that they sometimes hospitalized children and young adults living with HIV when they become homeless after being rejected by their families or caregivers and have no other place to go. Dr. Dan Duiculescu told us, “I had an eighteen-year-old who was crazy, he was making problems with the staff and beating smaller children and I had to keep him here because he didn’t want to go home and I preferred to keep him than to have him on the street. I finally found an NGO to take him. The hospital is not the solution. There should be group homes to give them somewhere to stay. The second step should be to put them to work or send them to school.”<sup>191</sup> Dr. Duiculescu later returned to this theme, saying, “You need to stress that we only have a short time—one or two years. I am not afraid of sexual transmission. I

---

<sup>189</sup> Human Rights Watch interview with Dr. Luminita Enz, Victor Babeş Infectious Diseases Institute, Bucharest, February 18, 2006.

<sup>190</sup> Human Rights Watch interview with Ioana A. (not her real name), foster mother of an HIV-positive youth, Constanța, February 15, 2006.

<sup>191</sup> Human Rights Watch interview with Dr. Dan Duiculescu, director of pediatric AIDS, Victor Babeş Infectious Diseases Institute, Bucharest, February 16, 2006.

am afraid of intravenous drug use because that will be on the street and it will explode. The reason we have not so many HIV-positive people among intravenous drug users is because drugs are expensive and the users are so far fairly well-off and educated. But prices will come down.”<sup>192</sup>

While Ioana A., the foster mother quoted above, had thus far managed to continue to support her foster son, she told us that other children’s situations were precarious:

The children turn eighteen but they don’t know the value of money or how to take care of themselves, and the state no longer provides the salary for a personal assistant, and now the family has another child of their own and doesn’t know what to do so what does the foster family do? Leave the child in the street? The authorities just shrug their shoulders and the child becomes like luggage left at the door of the NGO [who had previously cared for the child]. What is the child to feel in this situation?...

The local council and the DPC need to do more. The people at the upper level don’t know what is happening at the lower level. The placement department could do more—so many things move so slowly, you feel that they don’t care. Life doesn’t wait for these children. The Department of Child Protection should have thought things through from the beginning. Even if they didn’t, let’s make a plan now. What happens next? We understand that this country has problems but we are one of the problems and we need a share of the attention. We need them to listen to us.<sup>193</sup>

### ***Arbitrary Procedures for Receiving State Subsidies***

Romania provides a variety of subsidies and other benefits for children living with HIV, but arbitrary and inefficient implementation of these benefits, breaches of confidentiality, and burdensome bureaucratic requirements prevent some children and families who need these benefits from receiving them, and may cause situations that place children’s health at risk. The procedures for accessing disability benefits for adults are even more complex and arbitrary than those for children.

---

<sup>192</sup> Ibid.

<sup>193</sup> Human Rights Watch interview with Ioana A. (not her real name), foster mother of an HIV-positive youth, Constanța, February 15, 2006.

The majority of Romanians living with HIV are poor, and may require assistance to meet the increased nutritional needs associated with HIV.<sup>194</sup> In recognition of these needs, Romanians living with HIV are eligible for a nutrition subsidy of ROL67,000 (U.S.\$ 2.40) per day for children and ROL90,000 (U.S.\$ 3.30) per day for adults.<sup>195</sup> In addition to the nutrition subsidy, people living with HIV are also eligible to apply for benefits for persons with disabilities. The criteria for the disability benefits for children with HIV are broad and the benefits include the salary of a personal assistant even if the child's medical condition does not require one.<sup>196</sup> In most cases the child's personal assistant is a mother or other family member, and many families have come to rely on these combined subsidies, which may constitute a significant portion of the family's income.

Both nutrition and disability subsidies are administered by local municipalities, which has led to wide variations in implementation, and in some cases to significant delays in payments. Paulian Sima, the AIDS expert at the National Authority for Persons with Handicap, told Human Rights Watch that a child's benefits are based on an assessment ("social inquiry") by a social worker for the local authority but "[t]he problem is that it depends on how well informed the person who does the social inquiry is."<sup>197</sup> Project coordinators at ARAS told Human Rights Watch, "The nutrition subsidy is not provided in all municipalities and in some municipalities is provided twice because of a variation in

---

<sup>194</sup> According to the 2004-2007 National Strategy for HIV/AIDS, "a great part of the families having children living with HIV and a large part of the adults live at the poverty line (about 83% of them according to some studies." Government of Romania, *National Strategy for surveillance, control and prevention of HIV/AIDS cases, 2004-2007*, p. 33. A 2003 World Health Organization study estimated that energy requirements were likely to increase by 10 percent in asymptomatic individuals living with HIV, and 20 to 30 percent in symptomatic individuals. In cases of children experiencing weight loss, energy requirements could increase by 50 to 100 percent. The study also noted that "HIV-related infections, such as tuberculosis and diarrhoea, not only have nutritional status as a significant determinant of their incidence and severity, but they also have severe nutritional consequences that commonly precipitate appetite loss, weight loss and wasting." WHO, *Technical Consultation on Nutrient Requirements for People Living with HIV/AIDS* (Geneva, 2003), pp. 4-5.

<sup>195</sup> Article 7 of Law No. 584/2002 provides for a nutrition subsidy, with the amount and agency responsible for distribution specified in Governmental Decision No. 839/2004. Governmental Decision 839/2004 for modifying the Governmental Decision 1177/2003 on the approval of the amount for the monthly nutritional allocation for the persons infected with HIV or suffering of AIDS, Official Bulletin No. 732 from October 20, 2003, arts. 1, 2; Law No. 584/2002 on measures to prevent the spread of AIDS in Romania and to protect persons infected with HIV or suffering from AIDS.

<sup>196</sup> Article 2 of Law No. 519/2002 provides for a first degree disability pension for all children and some adults living with HIV/AIDS. In addition to these benefits, under article 17 of Law No. 519/2002 children living with HIV/AIDS are also eligible to receive double the child allocation, a 50 percent increase of the allocation for children with disabilities, free summer camps once a year, free urban transportation, and twelve free tickets for trains and buses per year. Law No. 519/2002 of July 12, 2002, on approving the Emergency Ordinance 102/1999 on special protection and the employment of persons with handicap, Official Bulletin No.555 from July 29, 2002. Children and youth who are enrolled in school are also eligible for an education subsidy until age twenty-six. Law No. 272/2004, art. 51.

<sup>197</sup> Human Rights Watch interview with Paulian Sima, expert, National Authority for Persons with Handicap, Bucharest, February 20, 2006.

the name of the subsidy in two laws.”<sup>198</sup> The foster mother of an HIV-positive child in Constanța told us,

It has taken the county council half a year to understand the law on the nutrition subsidy. We heard about the law on the Internet and in other places it was enforced immediately but it took six months to be enforced here. So there was an interruption in payments. Mothers took a petition to city hall and no one at the upper level knew about the law and the social workers were stalling and saying they didn’t know. We pressured the vice prefect to call Bucharest and then he filed an order for money to be given to all the HIV-positive persons.<sup>199</sup>

A parent of a child living with HIV in Bacău told us, “The funding for the subsidies came late last year because the person in charge was transferred and there was a new civil servant in charge.”<sup>200</sup>

Burdensome administrative requirements for the nutrition subsidy can create negative incentives that put children’s health at risk. Members of the Lizuca Association in Bacău, told Human Rights Watch,

In order to get the food subsidy from the municipality you have to bring a certificate from the hospital stating that the child was not hospitalized or if hospitalized, that number of days is deducted from the final amount. Such a certificate should be issued every single month together with a statement of the parent that the child was not hospitalized. [It takes] one day to get the certificate from the hospital, one day in the municipality, one day at the General Directorate for Social Assistance and Child Protection. It takes less time if you are from the city but even so, it takes about ROL300,000 [US\$ 11] to go from one place to the other. We had a case of a boy who was brought to the hospital in a very bad condition, when we asked the mother why was he brought so late

---

<sup>198</sup> Human Rights Watch interview with Monica Dan and Liana Velica, project coordinators, Romanian Association Against AIDS, Bucharest, February 17, 2006.

<sup>199</sup> Human Rights Watch interview with Ioana A. (not her real name), foster mother of an HIV-positive youth, Constanța, February 15, 2006.

<sup>200</sup> Human Rights Watch interview with Ana Vătavu, executive director, Mihaela Ondu, member, and Eugenia O. (not her real name), member of the Lizuca Association, a member organization of UNOPA, February 13, 2006.

she said “if I brought him to the hospital earlier I would not have received the food subsidy.”<sup>201</sup>

Doctors we spoke with in Bacău concurred, saying,

The fact that every month there is a list in the municipality with the names [of children with HIV] and specifying if they had been hospitalized or not creates problems. We have had parents who call us only in an emergency and even then they do not bring the child in because they did not want to lose the [nutrition subsidy] money. The [municipality’s] justification is that the families do not need the money for the nutritional supplement because the child is in the hospital. It is a saving for the state because the money for the children who are hospitalized does not come to the hospital to supplement their food here. This is not reasonable because even when the child is hospitalized the parent still has to bring food and supplement the alimentation of the child.<sup>202</sup>

### **Adult Complex Assessment Committees**

In order to continue to qualify for subsidies for persons with disabilities, a young person living with HIV must be reassessed by an adult complex assessment committee. Like the children’s committees, there are forty-seven adult complex assessment committees, one in each administrative district (county or Bucharest city sector), and the committees assign a degree of disability between one and three, with a first degree disability (*gradul de handicap grav*) carrying the greatest benefits. While all children living with HIV automatically qualify for a first degree disability, adults must meet a stricter criterion that should also take into account any opportunistic diseases.<sup>203</sup> Those who no longer qualify for a first degree disability after turning eighteen lose the right to have a personal assistant.<sup>204</sup>

According to Paulian Sima, the HIV expert at the National Authority for Persons with Handicap, children living with HIV who need continuing support should apply for an

---

<sup>201</sup> Ibid.

<sup>202</sup> Human Rights Watch interview with Dr. Liviu Prisăcariu (from Iași) and Dr. Delia Grigoraș, head of the Bacău Hospital Infectious Diseases Unit, Bacău, February 14, 2006.

<sup>203</sup> See Ministry of Health Order 726/ 2002 of 01/10/2002, Official Bulletin 775 from October 24, 2002.

<sup>204</sup> Law No. 519/2002 of July 12, 2002, on approving the Emergency Ordinance 102/1999 on special protection and the employment of persons with handicap, Official Bulletin No.555 from July 29, 2002, art. 17(h).

adult certificate of disability twenty to thirty days before turning eighteen, a process that begins with the individual going to a medical center for a referral to the complex assessment committee, which then orders a “social inquiry,” and finally an in-person review.<sup>205</sup> Sima told Human Rights Watch that the adult process is shorter than that for children because the adult committee meets “three to four times a week,” and “an average period is ten days at a minimum, and thirty days at the maximum if the person understands what documents are required and if they come when they have an appointment—some don’t and they disappear.” He added, “If they have mental problems it takes longer.”<sup>206</sup>

In two cases that Human Rights Watch investigated the process did indeed appear to follow these general outlines. In both instances the young adults lived with educated, involved parents who knew how to navigate the bureaucracy. Eighteen-year-old Călin S. (not his real name) told us, “The process for the complex assessment committee took about two weeks. It is faster if you bribe the doctor. Not all doctors require bribes. The medical records for my mother to be a personal assistant need different tests and stamps from specialist doctors and if you don’t bribe them they just send you back and forth.”<sup>207</sup> In the second case the mother of an eighteen-year-old told us, “I went to the Sixth District DPC. There was an extraordinary woman there who has promised to help. So there is understanding. I will wait to get it this month. I will have a first degree disability certificate for my daughter for an unlimited period of time and they told me that my daughter will receive a pension and nutrition allowance and I can be her personal assistant.”<sup>208</sup>

A more typical experience is for the Adult Complex Assessment Committee to issue a lesser degree certificate of disability, with fewer associated benefits. In some cases such decisions may be appropriate; many people taking antiretroviral therapy can and should be encouraged to work or attend school. The problem is that these decisions often appear to be based on mistaken assumptions of what a person living with HIV should look like and be able to do, tainted by moral judgments about people living with HIV, or the decisions arbitrarily reject the assessments of degree of medical disability provided by infectious disease doctors.

---

<sup>205</sup> Human Rights Watch interview with Paulian Sima, expert, National Authority for Persons with Handicap, Bucharest, February 20, 2006.

<sup>206</sup> Ibid.

<sup>207</sup> Human Rights Watch interview with Călin S. (not his real name), Bucharest, February 18, 2006.

<sup>208</sup> Human Rights Watch interview with Silvia B. (not her real name), Bucharest, February 16, 2006.

Psychological support staff at the Balș Institute for Infectious Diseases told Human Rights Watch that they often helped young adults who were given lesser degrees of disability by the Adult Complex Assessment Committee, saying “we advise them to challenge the decisions and after a while the degree of disability is changed.”<sup>209</sup> Staff at ARAS in Bucharest told Human Rights Watch that their clients regularly faced problems with Adult Complex Assessment Committees that appeared to know little about HIV:

One girl who was switched to the Adult Complex Assessment Committee was asked how many people she slept with because they associate HIV with sex. The committee should not be asking these questions. The law says there should be a president, two specialist doctors from an appropriate medical specialty, a psychiatrist, and an NGO representative on the committee to assess the person’s work capacity, but so far none of our cases have had an infectious disease specialist and the NGO representative is the same in all cases, and not from an HIV NGO. Sometimes the Committee’s doctor’s decision goes against the diagnosis of the infectious disease doctor.<sup>210</sup>

Anica M. (not her real name), nineteen, told Human Rights Watch, “The children’s commission was good. Now in the adults’ commission the doctors ask you “How do you feel?” Of course I said that I am fine, I am under treatment and I am not dying! They concluded that I have degree two. I’ve appealed the decision. I have been taking pills for ten years—of course I look good.”<sup>211</sup>

While decisions to grant a lesser degree of disability can be challenged, the process is time consuming and would be nearly impossible for someone with limited education and life skills to navigate without assistance. More importantly, this arbitrary and lengthy system creates a perverse incentive for people living with HIV to attempt to obtain the highest degree of disability even if their health would permit them to work, because the potential repercussions of not being able to obtain that certification quickly should their health deteriorate are so severe. Staff at ARAS told us,

In Romania the most severe degree of handicap should go to those who cannot move, feed themselves, etc. With HIV the person may not have

---

<sup>209</sup> Human Rights Watch interview with Odette Chirilă and Carina Jalbă, members of the team providing psychological support to patients with HIV/AIDS at Matei Balș Institute, February 8, 2006.

<sup>210</sup> Human Rights Watch interview with Monica Dan and Liana Velica, project coordinators, Romanian Association Against AIDS, Bucharest, February 17, 2006.

<sup>211</sup> Human Rights Watch interview with Anica M. (not her real name), Bucharest, February 16, 2006.

that level of disability at the moment but it takes three to six months to get a determination of disability and in the meantime emergency social services are not developed.<sup>212</sup>

---

<sup>212</sup>Human Rights Watch interview with Monica Dan and Liana Velica, project coordinators, Romanian Association Against AIDS, Bucharest, February 17, 2006.

## VI. Human Rights Standards in International and Romanian Law

The Romanian Constitution provides that international treaties in force are part of domestic legislation, and in cases of conflict, international law applies unless domestic law grants greater protections.<sup>213</sup> Romania is party to international and regional treaties requiring it to ensure children's right to protection and care without discrimination, including their rights to health, education, information, and privacy. These treaties include the International Covenant on Civil and Political Rights; the International Covenant on Economic, Social, and Cultural Rights; the Convention on the Elimination of all forms of Discrimination against Women; and the Convention on the Rights of the Child.<sup>214</sup> Romania is also a party to the regional European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), and the European Social Charter.<sup>215</sup> Both treaties are instruments of the Council of Europe. The Committee of Ministers of the Council of Europe, one of the central institutions of the Council, has also adopted a recommendation on "The ethical issues of HIV infection in the health care and social settings"<sup>216</sup> setting out guidelines on how the rights of persons living with HIV should be respected in line with Council of Europe member states' public health policy.

### ***Children's Right to Protection and Care***

The Convention on the Rights of the Child in article 19 requires states parties to take all appropriate measures to protect children from "all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardians(s) or any other person who

---

<sup>213</sup> Constituția României modificată și completată prin Legea de revizuire a Constituției României nr. 429/2003, republicată de Consiliul Legislativ, București, 23 octombrie 2003. Romanian 1991 (Constitution as revised in October 2003), arts. 11, 20.

<sup>214</sup> See Convention on the Rights of the Child, ratified by Romania on September 28, 1990; International Covenant on Civil and Political Rights, adopted December 16, 1966, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (entered into force March 23, 1976, ratified by Romania on June 27, 1968); International Covenant on Economic, Social and Cultural Rights, adopted December 16, 1966, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, at 49, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3 (entered into force January 3, 1976, ratified by Romania on June 27, 1968); Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), December 18, 1979, G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, at 193, U.N. Doc. A/34/46, 1249 U.N.T.S. 13 (entered into force September 3, 1981, ratified by Romania on September 4, 1980).

<sup>215</sup> European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), European Treaty System No. 005, Rome, November 4, 1950, ratified by Romania on October 20, 1993. The Revised European Social Charter, 1996, European Treaty Series No. 163. The European Social Charter guarantees social and economic human rights and establishes a supervisory mechanism guaranteeing their respect by the States Parties. It was adopted in 1961 and revised in 1996. The 1996 revised European Social Charter, which came into force in 1999, is gradually replacing the initial 1961 treaty. Romania ratified the initial Treaty on October 4, 1994, and the revised Treaty on May 7, 1999.

<sup>216</sup> Recommendation No. R(89)14, adopted by the Committee of Ministers of the Council of Europe, October 24, 1989.

has the care of the child.” Article 20(1) provides that “a child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.” This provision reinforces article 24(1) of the International Covenant on Civil and Political Rights, which guarantees every child “the right to such measures of protection as are required by his status as a minor.”

Romania’s regional human rights commitments impose similar obligations to ensure that “children and young persons have the right to appropriate social, legal and economic protection”<sup>217</sup> and that they are protected from ill-treatment or abuse. Article 3 of the ECHR requires States to take measures designed to ensure that individuals are not subjected to torture or inhuman or degrading treatment, including such ill-treatment administered by private individuals. These measures should provide effective protection, in particular, of children and other vulnerable persons, and include reasonable steps to prevent ill-treatment of which the authorities had or ought to have had knowledge.<sup>218</sup> Individuals must have an effective remedy for preventing such abuses and a mechanism for establishing any liability of State officials or bodies for acts or omissions involving the breach of their rights. Compensation for the non-pecuniary damage flowing from the breach should in principle be available as part of the range of redress.<sup>219</sup>

Regarding children affected and orphaned by HIV, the Committee on the Rights of the Child (the body that interprets the Convention on the Rights of the Child) has interpreted articles 3 (best interests of the child), 20 (children deprived of their family environment), and 25 (review of treatment) of the Convention to include the requirement that states provide assistance “so that, to the maximum extent possible, children can remain within existing family structures.” Where this is not possible, the

---

<sup>217</sup> “Children’s rights under the European Social Charter,” Information Document, November 18, 2005, [online] [http://www.coe.int/T/E/Human\\_Rights/Esc/7\\_Resources/](http://www.coe.int/T/E/Human_Rights/Esc/7_Resources/). Article 17 of the European Social Charter states: “With a view to ensuring the effective exercise of the right of children and young persons to grow up in an environment which encourages the full development of their personality and of their physical and mental capacities, the Parties undertake, either directly or in co-operation with public and private organisations, to take all appropriate and necessary measures designed:

1: (a) to ensure that children and young persons, taking account of the rights and duties of their parents, have the care, the assistance, the education and the training they need, in particular by providing for the establishment or maintenance of institutions and services sufficient and adequate for this purpose;(b) to protect children and young persons against negligence, violence or exploitation; (c) to provide protection and special aid from the state for children and young persons temporarily or definitively deprived of their family’s support; 2: to provide to children and young persons a free primary and secondary education as well as to encourage regular attendance at schools.”

<sup>218</sup> See for example the European Court in *E and others v. United Kingdom*, judgment of November 26, 2002, para. 88.

<sup>219</sup> *Ibid.*, paras 109-110.

committee calls on states to provide, “as far as possible, for family-type alternative care (e.g. foster care)” and notes that “any form of institutionalized care for children should only serve as a measure of last resort.”<sup>220</sup>

Article 23 of the Convention recognizes the additional right of the mentally or physically disabled child to special care and, subject to available resources, to appropriate assistance “designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.”

Article 107 of Romania’s Law 272/2004 on the Protection and Promotion of the Rights of the Child provides for day care, family-type, and residential services for children at risk of or suffering from abuse and neglect.<sup>221</sup> The law defines abuse as “any voluntary action of a person who has a relation of responsibility, trust or authority toward the child, through which the life, the normal physical, mental, spiritual, moral and social development, the bodily integrity, and the physical and mental health of the child are endangered.”<sup>222</sup> Neglect is “the omission, either voluntarily or involuntarily,” of any responsibility “which results in endangerment of the physical, mental, spiritual, moral and social development, the bodily integrity, and the physical and mental health of the child.”<sup>223</sup> The law also prohibits “physical punishments of any kind” and deprivation of rights which may have the same result as neglect, and applies to children in the family and in “any institution that ensures the protection, care and education of children.”<sup>224</sup>

Upon notification of abuse or neglect, the local General Directorate for Social Assistance and Child Protection must investigate and provide any needed day care, family, or residential services.<sup>225</sup> The law grants representatives of the General Directorate for Social Assistance and Child Protection the right to enter institutions and

---

<sup>220</sup> Committee on the Rights of the Child, General Comment 3: HIV/AIDS and the Rights of the Child (2003), CRC/GC/2003/3, paras. 34-35.

<sup>221</sup> Day care services are those designed to support a child and family while the child is still living with the family. Family-type and residential services are provided to children permanently or temporarily removed from their family, and include foster care, extended family placements, and public and private residential placements. Law No. 272/2004 on the protection and promotion of the rights of the child, from June 21, 2004, Official Gazette 557 from June 23, 2004, arts. 107-110.

<sup>222</sup> *Ibid.*, art 89(1)

<sup>223</sup> *Ibid.*, art 89(2).

<sup>224</sup> *Ibid.*, art. 90.

<sup>225</sup> *Ibid.*, art. 92.

private homes to investigate allegations of abuse and neglect, and requires police to provide support in these investigations.<sup>226</sup> In cases of serious ill-treatment, the Criminal Code also provides for criminal punishments.<sup>227</sup>

### ***The Right to Protection from Discrimination***

The Convention on the Rights of the Child in article 2 requires states to take all appropriate measures to ensure that children are protected from discrimination “irrespective of the child’s or his or her parent’s or legal guardian’s race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.” The Committee on the Rights of the Child has interpreted “‘other status’ . . . to include HIV/AIDS status of the child or his/her parents(s).”<sup>228</sup> The International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of Discrimination Against Women, and the European Convention for the Protection of Human Rights and Fundamental Freedoms contain similar protections and are applicable to children and adults.<sup>229</sup>

In addition to prohibiting discrimination, international law also requires states to take affirmative steps to address it. The Committee on the Rights of the Child has underlined “the necessity of providing legal, economic and social protection to affected children to ensure their access to education, inheritance, shelter and health and social services, as well as to make them feel secure in disclosing their HIV status and that of their family members when the children deem it appropriate.”<sup>230</sup> The UN HIV/AIDS and Human Rights International Guidelines recommend that states “enact or strengthen antidiscrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors... and provide for speedy and effective administrative and civil remedies.”<sup>231</sup>

---

<sup>226</sup> *Ibid.*, art. 93.

<sup>227</sup> See Romanian Criminal Code, Law No. 301/2004 Official Gazette, No. 303 from April, 12 2005, art. 229.

<sup>228</sup> Committee on the Rights of the Child, General Comment 3: HIV/AIDS and the Rights of the Child, para. 9.

<sup>229</sup> See International Covenant on Civil and Political Rights, art. 26; International Covenant on Economic, Social and Cultural Rights, art. 2; Convention on the Elimination of All Forms of Discrimination against Women, art. 2; and Convention on the Protection of Fundamental Human Rights and Freedoms, art. 14. The U.N. Commission on Human Rights in 1995 concluded that discrimination on the basis of AIDS or HIV status is prohibited in that it is covered by the term “or other status” in the International Covenant on Civil and Political Rights and other U.N. human rights instruments. Commission on Human Rights, The Protection of Human Rights in the Context of Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS), Resolution 1995/44, adopted without a vote, March 3, 1995.

<sup>230</sup> Committee on the Rights of the Child, General Comment 3: HIV/AIDS and the Rights of the Child, para. 31.

<sup>231</sup> Office of the United Nations High Commissioner for Human Rights (OHCHR) and UNAIDS, “HIV/AIDS and

Romania's Law 48/2002 on Preventing and Sanctioning all Forms of Discrimination defines discrimination as: "any difference, exclusion, restriction or preference... aiming to or resulting in a restriction or prevention of the equal recognition, use or exercise of human rights and fundamental freedoms in the political, economic, social and cultural field or in any other fields of public life."<sup>232</sup> In 2004 the law was amended to explicitly include HIV among protected categories.<sup>233</sup> The law provides for a National Council for Combating Discrimination, with powers to investigate complaints, issue small fines, and propose affirmative actions, but thus far use of this mechanism has been limited (see Section V, above).

Law 48/2002 also permits victims of discrimination to bring a case before the civil courts and ask for damages and for re-establishing the situation before the discrimination occurred.<sup>234</sup> However, such actions require more time, resources and knowledge than is available to many people living with HIV or to the NGOs working in this field.<sup>235</sup>

### ***The Right to the Highest Attainable Standard of Health***

All individuals have the right to enjoy the highest attainable standard of mental and physical health, a right guaranteed by the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, and the Convention on

---

Human Rights: International Guidelines," para. 5.

<sup>232</sup> Law No. 48/2002 on approving the Ordinance 137/2000 on preventing and sanctioning all forms of discrimination, Official Gazette 69 from January 31, 2002, art. 2(1).

<sup>233</sup> Law No. 27/2004 of March 5, 2004, on approving the governmental ordinance 77/2003 on modifying Ordinance 137/2000, Official Bulletin No. 216 from 2004, art. 2. Prior to 2004 persons living with HIV/AIDS were covered as members of a "disfavored category," defined as "the category of persons that is either placed in a position of inequality as opposed to the majority of citizens due to their social origin or to a handicap or is faced with rejection and marginalization due to specific circumstances, such as a chronic non-infectious disease, HIV infection or the status of refugee or asylum-seeker." Law No. 48/2002, on approving the Ordinance 137/2000 on preventing and sanctioning all forms of discrimination, art. 4.

<sup>234</sup> Article 21 states "(1) In all cases of discrimination provided by the ordinance herein, the persons discriminated against shall be entitled to claim damages, proportionally with the prejudice, as well as to claim the re-establishment of the situation prior to the discrimination or the annulment of the situation created by discrimination, in accordance with common law. (2) The claim for damages shall be exempted from judicial taxes. (3) Upon request, the court can order that the competent authorities withdraw the license of legal entities that significantly prejudice the society by means of a discriminatory action or, although have caused a minor prejudice, repeatedly violate the provisions of the law herein." Law No. 48/2002, on approving the Ordinance 137/2000 on preventing and sanctioning all forms of discrimination, art. 21.

<sup>235</sup> The president of the National Council for Combating Discrimination told Human Rights Watch he was unaware of any instance when a person living with HIV had used this provision. Human Rights Watch interview with Csaba Ferenc Asztalos, president, and Corina Macoveanu, steering committee member, National Council for Combating Discrimination, Bucharest, February 21, 2006.

the Elimination of All Forms of Discrimination against Women.<sup>236</sup> This right imposes an obligation on states to take steps necessary for the prevention, treatment and control of epidemic and other diseases.<sup>237</sup> The committee charged with interpreting the covenant has stated that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds,” which include “health status (including HIV/AIDS).”<sup>238</sup>

The right to the highest attainable standard of health is subject to “progressive realization,” under which states parties have a “specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization of [the right].”<sup>239</sup> States must guarantee certain core obligations as part of the right to health. These include ensuring nondiscriminatory access to health facilities, especially for vulnerable or marginalized groups; providing essential drugs; ensuring equitable distribution of all health facilities, goods and services; adopting and implementing a national public health strategy and plan of action with clear benchmarks and deadlines; ensuring reproductive, maternal and child care; taking measures to prevent, treat and control epidemic and endemic diseases; and providing education and access to information for important health problems.<sup>240</sup> According to the committee charged with interpreting the convention, to justify the failure to meet at least these minimum core obligations as based on a lack of available resources, a state party “must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations.”<sup>241</sup>

According to the Committee on the Rights of the Child, states parties’ obligations “extend to ensuring that children have sustained and equal access to comprehensive treatment and care, including necessary HIV-related drugs, goods and services on a basis of non-discrimination.”<sup>242</sup> Expressing concern that “children with disabilities, indigenous

---

<sup>236</sup> International Covenant on Economic, Social and Cultural Rights, art. 12; Convention on the Rights of the Child, art. 24; and Convention on the Elimination of All Forms of Discrimination against Women, art. 12.

<sup>237</sup> International Covenant on Economic, Social and Cultural Rights, art. 12(c).

<sup>238</sup> Committee on Economic, Social and Cultural Rights, General Comment 14: The Right to the Highest Attainable Standard of Health, August 11, 2000, paras. 12(b), 18.

<sup>239</sup> *Ibid.*, paras. 30, 31.

<sup>240</sup> *Ibid.*, paras 12, 43, 44.

<sup>241</sup> Committee on Economic, Social and Cultural Rights, General Comment no. 3. The Nature of States Parties Obligations (Art. 2)(1), UN Doc. E/1991/23., para. 10.

<sup>242</sup> Committee on the Rights of the Child, General Comment 3: HIV/AIDS and the Rights of the Child, para. 28. The committee notes that, “It is now widely recognized that comprehensive treatment and care includes antiretroviral and other drugs, diagnostics and related technologies for the care of HIV/AIDS, related

children, children belonging to minorities, children living in rural areas, children living in extreme poverty or children who are otherwise marginalized in society” may not be able to access the HIV-related health services that are available, the Committee has noted that states parties “must ensure that services are provided to the maximum extent possible to all children living within their borders.”<sup>243</sup>

Recognizing that adolescents have special health and development needs, the Committee on the Rights of the Child has further emphasized that the right to health obligates states “To ensure that adolescents have access to the information that is essential for their health and development and that they have opportunities to participate in decisions affecting their health (notably through informed consent and the right of confidentiality), to acquire life skills, to obtain adequate and age-appropriate information, and to make appropriate health behaviour choices”; to “ensure that health facilities, goods and services, including counselling and health services for mental and sexual and reproductive health, of appropriate quality and sensitive to adolescents’ concerns are available to all adolescents”; and to “implement measures for the prevention of mental disorders and the promotion of mental health of adolescents.”<sup>244</sup> The Committee specifies that:

Before parents give their consent, adolescents need to have a chance to express their views freely and their views should be given due weight, in accordance with article 12 of the Convention. However, if the adolescent is of sufficient maturity, informed consent shall be obtained from the adolescent her/himself, while informing the parents if that is in the “best interest of the child” (art. 3).

---

opportunistic infections and other conditions, good nutrition, and social, spiritual and psychological support, as well as family, community and home-based care.”

<sup>243</sup> Ibid., paras. 20-21.

<sup>244</sup> Convention on the Rights of the Child, General Comment 4: Adolescent health in the context of the Convention on the Rights of the Child, July 1, 2003, paras. 39(b), 39(c), 39(i). The Committee further states that, “Every adolescent with a mental disorder has the right to be treated and cared for, as far as possible, in the community in which he or she lives. Where hospitalization or placement in a psychiatric institution is necessary, this decision should be made in accordance with the principle of the best interests of the child. In the event of hospitalization or institutionalization, the patient should be given the maximum possible opportunity to enjoy all his or her rights as recognized under the Convention, including the rights to education and to have access to recreational activities. Where appropriate, adolescents should be separated from adults. States parties must ensure that adolescents have access to a personal representative other than a family member to represent their interests, when necessary and appropriate. In accordance with article 25 of the Convention, States parties should undertake periodic review of the placement of adolescents in hospitals or psychiatric institutions.” Ibid., para.29.

With regard to privacy and confidentiality, and the related issue of informed consent to treatment, States parties should (a) enact laws or regulations to ensure that confidential advice concerning treatment is provided to adolescents so that they can give their informed consent. Such laws or regulations should stipulate an age for this process, or refer to the evolving capacity of the child; and (b) provide training for health personnel on the rights of adolescents to privacy and confidentiality, to be informed about planned treatment and to give their informed consent to treatment.<sup>245</sup>

Romania's Law on the Protection of the Rights of the Child guarantees children the right to access to medical services and to medication adequate to their condition and paid for by the state.<sup>246</sup> Law 584/2002 on Measures to Prevent the Spread of AIDS in Romania and to Protect Persons Infected with HIV or Suffering from AIDS further guarantees people living with HIV free specialized medical care and free antiretroviral treatment as well as free treatment for diseases associated with HIV.<sup>247</sup> Medical facilities and doctors are obligated to provide care in accordance with their training and the patient's symptoms.<sup>248</sup> However, the government has yet to issue well developed implementing norms for Law 584/2002, despite the requirement in article 20 that "in 30 days from the date when the law comes into force, a normative order with the provisions for the enforcement of the law will be drafted and adopted as Governmental Decision."<sup>249</sup> The norms issued in November 2004 merely reinforce the obligation of governmental authorities to adopt norms, take prevention measures and measures for social protection, and regulate on the confidentiality of data, the treatment, the professional training and the funding of HIV-related activities, without establishing clear deadlines, sanctions and responsibilities.<sup>250</sup>

---

<sup>245</sup> *Ibid.*, paras. 32, 33.

<sup>246</sup> Law No. 272/2004 on the protection and promotion of the rights of the child, art. 43(2).

<sup>247</sup> Law No. 584/2002 of October 29, 2002, on measures to prevent the spread of AIDS in Romania and to protect persons infected with HIV or suffering from AIDS, Official Bulletin No. 814 from November 8, 2002, arts. 10, 11, 16. See also, Order No. 665 of the Ministry of Health on providing antiretroviral medication to HIV/AIDS patients of October 4, 1999.

<sup>248</sup> Law No. 584/2002 of October 29, 2002, on measures to prevent the spread of AIDS in Romania and to protect persons infected with HIV or suffering from AIDS, art. 9.

<sup>249</sup> *Ibid.*, art. 20.

<sup>250</sup> Governmental Decision 2108 of November 24, 2004, on approving the norms for implementing Law No. 584/2002 of October 29, 2002, on measures to prevent the spread of AIDS in Romania and to protect persons infected with HIV or suffering from AIDS, published in the Official Gazette No.1171 from December 10, 2004.

## ***The Right to Education***

Under international law, the right to education is set forth in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, and the Convention on the Elimination of All Forms of Discrimination against Women.<sup>251</sup> These instruments specify that primary education must be “compulsory and available free to all.”<sup>252</sup> Secondary education, including vocational education, must be “available and accessible to every child,” and states parties must “take appropriate measures, such as the introduction of free education and offering financial assistance in case of need.”<sup>253</sup> In addition, the Convention on the Rights of the Child obligates states parties “to take measures to encourage regular attendance at school and the reduction of drop-out rates.”<sup>254</sup> Both primary and secondary education must include elements of “availability, accessibility, acceptability and adaptability.”<sup>255</sup> The Committee on Economic, Social and Cultural Rights defines availability to mean “functioning educational institutions and programmes... to be available in sufficient quantity within the jurisdiction.”<sup>256</sup> Educational institutions must be accessible to all without discrimination, be “within safe physical reach,” and be “affordable to all.”<sup>257</sup> The Committee elaborated that primary education should be “free to all,” and that states parties are “required to progressively introduce free secondary and higher education”<sup>258</sup> (see below).

Under the European Social Charter, Romania has undertaken to “provide children and young persons a free primary and secondary education as well as to encourage regular attendance at schools.”

Like the right to health, the right to education is considered a “progressive right”: by becoming party to the international instruments, a state agrees “to take steps . . . to the

---

<sup>251</sup> Universal Declaration of Human Rights, art. 26; International Covenant on Economic, Social and Cultural Rights, art. 13; Convention on the Rights of the Child, art. 28; Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), art. 10.

<sup>252</sup> Convention on the Rights of the Child, art. 28(1)(a); Universal Declaration of Human Rights, art. 26(1); International Covenant on Economic, Social and Cultural Rights, art. 13(2)(a).

<sup>253</sup> Convention on the Rights of the Child, art. 28(1)(b). Article 13 of the International Covenant on Economic, Social and Cultural Rights provides that secondary education, including vocational education, “shall be generally available and accessible to all by every appropriate means, and in particular by the progressive introduction of free education.”

<sup>254</sup> Convention on the Rights of the Child, art. 28(1)(e).

<sup>255</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 13: The Right to Education, U.N. Doc. E/C.12/1999/10, December 8, 1999, para. 6.

<sup>256</sup> *Ibid.*, para. 6(a).

<sup>257</sup> *Ibid.*, para. 6(b).

<sup>258</sup> *Ibid.*

maximum of its available resources” to the full realization of the right to education.<sup>259</sup> However, while the right to education is a right of progressive implementation, the prohibition on discrimination is not. The Committee on Economic, Social and Cultural Rights has stated: “The prohibition against discrimination enshrined in article 2(2) of the [International Covenant on Economic, Social and Cultural Rights] is subject to neither progressive realization nor the availability of resources; it applies fully and immediately to all aspects of education and encompasses all internationally prohibited grounds of discrimination.”<sup>260</sup> Thus, regardless of its resources, the state must provide education “on the basis of equal opportunity,” “without discrimination of any kind irrespective of the child’s race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.”<sup>261</sup> “Other status,” as explained earlier, includes children’s or their parents’ HIV status.

The Committee on the Rights of the Child has emphasized that children affected by HIV must have equal access to education, stating that states parties are obligated “to ensure that primary education is available to all children, whether infected, orphaned or otherwise affected by HIV/AIDS” and that “States parties must make adequate provision to ensure that children affected by HIV/AIDS can stay in school.”<sup>262</sup>

Romanian law provides for free primary and secondary schooling, and education is compulsory through tenth grade or until age eighteen.<sup>263</sup> The right to education of

---

<sup>259</sup> International Covenant on Economic, Social and Cultural Rights, art. 2(1), and. Convention on the Rights of the Child, art. 28. But see also Committee on Economic, Social and Cultural Rights, General Comment 13, The Right to Education, para. 44 (“Progressive realization means that States parties have a specific and continuing obligation ‘to move as expeditiously and effectively as possible’ towards the full realization of article 13”); and Committee on Economic, Social and Cultural Rights, General Comment 3, The Nature of States Parties Obligations, 5th sess., December 14, 1990, para. 2 (“Such steps should be deliberate, concrete and targeted as clearly as possible”).

<sup>260</sup> Committee on Economic, Social and Cultural Rights, General Comment 13, The Right to Education, para. 31. See also Committee on Economic, Social and Cultural Rights, General Comment 11, Plans of Action for Primary Education, 20th sess., May 10, 1999, para. 10; Committee on Economic, Social and Cultural Rights, General Comment 3, The Nature of States Parties Obligations, para. 2

<sup>261</sup> Convention on the Rights of the Child, arts. 28(1), 2(1); International Covenant on Economic, Social and Cultural Rights, arts. 2, 13. See also Convention on the Elimination of All Forms of Discrimination against Women, art. 10. The Committee on Economic, Social and Cultural Rights has interpreted the prohibition on discrimination and the right to education in article 2(2) and 13 of the ICESCR in accord with the 1960 Convention against Discrimination in Education. Committee on Economic, Social and Cultural Rights, General Comment 13, The Right to Education, paras. 31, 33, 34.

<sup>262</sup> Committee on the Rights of the Child, General Comment 3: HIV/AIDS and the Rights of the Child, para. 18.

<sup>263</sup> See articles 32. 1 and 32. 4 of the Romanian Constitution, and article 6 of Education Law No. 84/1995 of July 24, 1995, Official Bulletin No. 370 from August 3, 1999, as amended by Law No. 268/2003 from June 13, 2003, on amending and completing Education Law No. 84/1995. The European Committee on Social Rights has found that Romania did not conform with its obligations under the European Social Charter because the level of non-attendance in compulsory schooling is manifestly too high. Conclusions of the European Committee on Social Rights, Romania, September 2005, p. 23.

children living with HIV is further specified in Law 584/2002, which states in part that “persons infected with HIV or suffering of AIDS are entitled to social protection and nondiscriminatory treatment in regard of their right to education,” including their integration in the formal education system.<sup>264</sup>

### ***The Right to Information***

International human rights law provides for the right to “seek, receive and impart information of all kinds,” which includes information about an individual’s own health.<sup>265</sup> The Convention on the Rights of the Child further requires states to “ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health.”<sup>266</sup> The Committee on the Rights of the Child, has stated in its general comment on HIV/AIDS that children have the right to access adequate information related to HIV prevention, emphasizing that

Effective HIV/AIDS prevention requires States to refrain from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information, and that, consistent with their obligations to ensure the right to life, survival and development of the child (art. 6) States parties must ensure that children have the ability to acquire the knowledge and skills to protect themselves and others as they begin to express their sexuality.<sup>267</sup>

One aspect of the right to adequate information is the right of a child to information on his or her own HIV-status:

The accessibility of voluntary, confidential HIV counselling and testing services, with due attention to the evolving capacities of the child, is fundamental to the rights and health of children. Such services are critical to children’s ability to reduce the risk of contracting or transmitting HIV, to access HIV-specific care, treatment and support,

---

<sup>264</sup> Law No. 584/2002 on measures to prevent the spread of AIDS in Romania and to protect persons infected with HIV or suffering from AIDS, arts. 3, 7(c).

<sup>265</sup> International Covenant on Civil and Political Rights, art. 19; Convention on the Rights of the Child, art. 13. The European Convention for the Protection of Human Rights and Fundamental Freedoms recognizes a similar right to receive and impart information. ECHR art. 10.

<sup>266</sup> Convention on the Rights of the Child, article 24(2)(e).

<sup>267</sup> Committee on the Rights of the Child, General Comment No. 3 (2003): HIV/AIDS and the rights of the child, para. 16.

and to better plan for their futures. Consistent with their obligation under article 24 of the Convention to ensure that no child is deprived of his or her right of access to necessary health services, States parties should ensure access to voluntary, confidential HIV counselling and testing for all children.<sup>268</sup>

Access to health information is also essential to realizing the human right to the highest attainable standard of health and, ultimately, the right to life.<sup>269</sup> Article 12 of the International Covenant on Economic, Social and Cultural Rights specifically obliges governments to take all necessary steps for the “prevention, treatment and control of epidemic . . . diseases,” such as HIV.<sup>270</sup> The UN body responsible for monitoring the implementation of the International Covenant on Economic, Social and Cultural Rights has interpreted article 12 as requiring “the establishment of prevention and education programmes for behaviour-related health concerns such as sexually transmitted diseases, in particular HIV/AIDS.”<sup>271</sup> In language similar to that of the Committee on the Rights of the Child, the Committee on Economic, Social and Cultural Rights further notes:

States should refrain from limiting access to contraceptives and other means of maintaining sexual and reproductive health, from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information, as well as from preventing people’s participation in health-related matters. . . . States should also ensure that third parties do not limit people’s access to health-related information and services.<sup>272</sup>

The Committee on the Rights of the Child has stated that “accessibility of voluntary, confidential HIV counselling and testing services, with due attention to the evolving capacities of the child, is fundamental to the rights and health of children.”<sup>273</sup>

---

<sup>268</sup> *Ibid.*, para. 22.

<sup>269</sup> Committee on Economic and Social Rights, General Comment 14: The Right to the Highest Attainable Standard of Health, 22nd Sess. (2000), para. 12(b), note 8.

<sup>270</sup> International Covenant on Economic, Social and Cultural Rights, art. 12.

<sup>271</sup> Committee on Economic and Social Rights, General Comment 14: The Right to the Highest Attainable Standard of Health, para. 16.

<sup>272</sup> *Ibid.*, paras. 34-35.

<sup>273</sup> UN Committee on the Rights of the Child, General Comment No. 3 (2003): HIV/AIDS and the rights of the child, para. 22.

The European Social Charter requires that in order to exercise the right to protection of health, states undertake “to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health.”<sup>274</sup>

Romania’s Law 46/2003 on the Rights of the Patient obligates doctors to inform their patients of the diagnosis, the general health, the evolution of the disease, and the treatment recommended as well as the alternatives, but this provision is not enforced in the case of children and young adults living with HIV if parents or guardians object to disclosure (see Section IV, above).<sup>275</sup> Law 584/2002 creates an obligation for dissemination of information about HIV transmission and about appropriate behavior toward persons living with AIDS in all educational institutions, as well as the dissemination of information to the general public about HIV and transmission.<sup>276</sup>

### *The Right to Privacy*

International law requires states to protect individuals against “arbitrary or unlawful interference” with “privacy, family, home or correspondence” and against “unlawful attacks on honour and reputation.”<sup>277</sup> In interpreting this right, the Committee on the Rights of the Child has stated that states “must protect the confidentiality of HIV test results... including within health and social welfare settings, and information on the HIV status of children may not be disclosed to third parties, including parents, without the child’s consent.”<sup>278</sup> Interpreting the parallel provision of the International Covenant on Civil and Political Rights, the Human Rights Committee further specifies that states must take effective measures “to ensure that information concerning a person’s private life does not reach the hands of persons who are not authorized by law to receive, process and use it, and is never used for purposes incompatible with the Covenant,” and

---

<sup>274</sup> European Social Charter, art. 11.

<sup>275</sup> Law No. 46/2003 of January 21, 2003 on the rights of the patient, Official Bulletin No. 51 from January 29, 2003, arts. 4, 6.

<sup>276</sup> Law No. 584/2002, arts. 1(4), 6(a), 6(c), 6(g).

<sup>277</sup> Convention on the Rights of the Child, art. 15; International Covenant on Civil and Political Rights, art. 17. The European Convention for the Protection of Human Rights and Fundamental Freedoms also states that “Everyone has the right to respect for his private and family life, his home and his correspondence”. ECHR, art. 8.

<sup>278</sup> Committee on the Rights of the Child, General Comment 3: HIV/AIDS and the Rights of the Child, para. 24. As noted earlier, informed consent in cases involving children should take into account the evolving capacities of the child, as provided in article 5 of the convention, which acknowledges “the responsibilities, rights and duties” of persons legally responsible for the child to provide appropriate direction and guidance in the exercise of rights contained in the convention. Convention on the Rights of the Child, art. 5.

that individuals have the right to request rectification or elimination of files containing incorrect personal data or data collected or processed contrary to the law.<sup>279</sup>

At a regional level, the European Court of Human Rights, the European Committee of Social Rights and the Committee of Ministers of the Council of Europe have all addressed the crucial issue of privacy and confidentiality concerning a person's health and HIV status. In the case of *Z v. Finland*, the European Court of Human Rights considered that:

.... the protection of personal data, not least medical data, is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention.... Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general.

Without such protection, those in need of medical assistance may be deterred from revealing such information of a personal and intimate nature as may be necessary in order to receive appropriate treatment and, even, from seeking such assistance, thereby endangering their own health and, in the case of transmissible diseases, that of the community....

The domestic law must therefore afford appropriate safeguards to prevent any such communication or disclosure of personal health data as may be inconsistent with the guarantees in Article 8 of the Convention....

... The above considerations *are especially valid as regards protection of the confidentiality of information about a person's HIV infection*. The disclosure of such data may dramatically affect his or her private and family life, as well as social and employment situation, by exposing him or her to opprobrium and the risk of ostracism. For this reason it may also discourage persons from seeking diagnosis or treatment and thus

---

<sup>279</sup> CCPR General Comment No. 16: The right to respect of privacy, family, home and correspondence, and protection of honour and reputation (Art. 17), 08/04/88, para. 10.

undermine any preventive efforts by the community to contain the pandemic ...<sup>280</sup>

The Committee of Ministers of the Council of Europe also set out guidelines on how confidentiality is to be implemented in public health policy in its recommendation on “The ethical issues of HIV infection in the health care and social settings.”<sup>281</sup>

Romanian law contains some provisions that could be used to protect the rights of persons living with HIV, but these provisions lack effective enforcement mechanisms and do not cover all breaches of confidentiality. Law 584/2002 requires employers, civil servants who have access to data, and health system employees to maintain confidentiality of data regarding persons living with HIV, but the law does not provide sanctions for those who breach confidentiality.<sup>282</sup> In addition, these categories do not include many of the positions known to be common sources of breaches of confidentiality, including teachers, mayors, social workers, postal workers, and staff of the local general directorates for social assistance and protection of the child.

A subsequent law addresses confidentiality of medical information in greater detail, but only applies to medical personnel and also lacks clear and effective sanctions. Law 46/2003 on the Rights of the Patient states that “all the information regarding the situation of the patient, the results of the medical investigations, the diagnosis and prognosis, the treatment, the personal data are confidential even after the death of the patient” and “confidential information can be provided only when the patient agrees explicitly or when the law creates a clear obligation.”<sup>283</sup> The law states that “if the medical personnel fails to observe the confidentiality of the patient’s data and the confidentiality of the medical act, as well as other rights of the patient, disciplinary, administrative or criminal liability are triggered in conformity with the law,” but it does not provide a mechanism for reporting, investigating, or enforcing sanctions in cases of breaches of confidentiality.<sup>284</sup>

The Romanian Criminal Code punishes the illegal disclosure of professional secrets with a criminal fine or a prison term of between three and twelve months if the disclosure causes damage to a person.<sup>285</sup> However, criminal investigations can only be initiated based on a complaint by the victim, who must show that the disclosed information is a

---

<sup>280</sup> *Z v. Finland*, Judgment of February 25, 1997 Reports 1997-I, paras 95-96 (emphasis added)

<sup>281</sup> Recommendation No. R(89)14 adopted by the Committee of Ministers of the Council of Europe, October 24, 1989.

<sup>282</sup> Law No. 584/2002, art. 8. The term civil servant (*funcționar public*) used in the law refers to a narrow category of public employees, and not to all persons employed by the state and providing public services.

<sup>283</sup> Law No. 46/2003 of January 21, 2003 on the rights of the patient, arts 21-22.

<sup>284</sup> *Ibid.*, art. 37.

<sup>285</sup> Romanian Criminal Code, Official Gazette, No. 303 from April 12, 2005, art. 214.

professional secret, defined as information received or conveyed in the course of the individual's professional activity, and must prove that damage occurred. As we discussed above, many individuals living with HIV are reluctant to pursue legal complaints about breaches of confidentiality or discrimination for fear of drawing greater attention to themselves, particularly as court proceedings and court documents may themselves be sources of breaches of confidentiality.

Law 584/2002 creates an obligation for the patient to inform the doctor about the seropositive status but does not sanction those who do not.<sup>286</sup>

---

<sup>286</sup> Article 8.3 states: "the patient has the obligation to inform his doctor, including his dentist, about his HIV status, when he is aware of it." Law No. 584/2002 on measures to prevent the spread of AIDS in Romania and to protect persons infected with HIV or suffering from AIDS, art. 8.3.

## VII. Detailed Recommendations

### ***To the Government of Romania***

#### ***General Recommendations***

- Immediately amend the implementing norms for Law 584/2002 on Measures to Prevent the Spread of AIDS in Romania and to Protect Persons Infected with HIV or Suffering from AIDS to include effective and appropriate sanctions for discrimination against people living with HIV in relation to access to and enjoyment of services or goods. Sanctions should be enforceable against all civil servants and medical, social, and educational personnel who breach confidentiality.
- Amend the Labor Code and Ministry of Health and Ministry of Labor and Social Solidarity Joint Order 508/2002 to prevent mandatory HIV testing as a condition of employment, and ensure that persons living with HIV are not unnecessarily prevented from working or attending vocational school.
- Ensure that children and young adults living with HIV are fully informed about how their rights and benefits will change after turning eighteen and that those who need it receive assistance in transitioning to adult services. In particular, the National Authority for the Protection of the Rights of the Child, Directorates of Child Protection and the National Authority for Persons with Handicap should ensure that HIV-positive children and youth are prepared for independent living, and provide appropriate continuing services to young adults who may need them. Special attention should be given to the needs of children and youth at risk of becoming homeless, including those in institutions, foster care, and extended family placement.
- Repeal article 384 of the Criminal Code, which criminalizes the knowing transmission of HIV. In those exceptional cases involving deliberate and intentional transmission of HIV where general criminal provisions apply, ensure that the elements of foreseeability, intent, causality and consent are clearly and legally established to support a guilty verdict and/or harsher penalties under the Criminal Code.
- Reform the working methods and membership of the National Committee for HIV/AIDS Surveillance, Control and Prevention to ensure that it is able to fulfill its mandate, as provided under Law 584/2002. In particular, establish a clear timetable for meetings for the Committee, and expand membership to include all relevant actors, including representatives of the National Committee on the Fight against AIDS and the National Council for Combating Discrimination.

- Preserve the status of the National Committee on the Fight against AIDS as a distinct medical committee within the Ministry of Health mandated to oversee the national HIV/AIDS database, analyze developments and needs for the treatment of HIV in Romania, and propose national policies.

### ***Protection and Care for Children and Youth Living with HIV***

- Create and publicize effective, child-friendly mechanisms to investigate and intervene in cases of abuse and neglect. Such mechanisms should be easily accessible to children and youth living in all parts of Romania, to young children, and to children and youth with educational deficits or physical or mental disabilities. Data on the kinds of complaints and the outcome of investigations, including any protection measures issued and any disciplinary actions or criminal proceedings, disaggregated by district, should be made public on an annual basis.
- Ensure that General Directorates for Social Assistance and Child Protection have sufficient trained staff and resources to monitor children and youth at risk of abuse or neglect, including conducting regular visits to children and youth living with HIV in birth families, extended family placement, foster care, public and private group homes, and placement institutions. The National Authority for the Protection of the Rights of the Child should set standards for DPC and municipal social worker caseloads and should clarify minimum standards and methods for NGO and municipal social worker to facilitate the sharing of information on children at risk of abuse and neglect.
- Ensure that HIV-positive children and youth with mental and physical disabilities enjoy the right to special care suitable to their condition, including adequate access to outpatient mental health care. Wherever possible, children and youth with mental and physical disabilities should be cared for in existing family structures or family-type care, and institutionalization should only be a measure of last resort.

### ***Combating Discrimination against People Living with HIV***

- Ensure that Romanian anti-discrimination legislation provides effective and accessible protection to victims of discrimination based on HIV status, including adequate sanctions and remedies.
- Ensure that the National Council for Combating Discrimination has adequate staffing and resources to fulfill both its mandate to investigate individual complaints and to develop policies and programs to address widespread patterns of discrimination against persons living with HIV. To that end, the Council should expand its in-house expertise on HIV, and open branch offices and other

mechanisms to receive complaints and conduct investigations. It should also develop and publicize written standards and procedures for its work, as well as guidelines for NGOs and individuals on how to document cases of discrimination, with priority given to developing guidelines on documenting health, employment, and educational discrimination against persons living with HIV.

### *The Right to Health*

- Ensure that individuals' ongoing access to antiretroviral medications (ARVs) is not compromised by bureaucratic delays or distance from dispensing centers. To this end, the National Health Insurance House should review its contracting procedures and consider allowing infectious disease hospitals to maintain a buffer supply of ARVs to ensure that therapy is not interrupted by short-term shortages.
- Ensure that persons living with HIV have adequate access to medications needed to treat common opportunistic infections and related conditions. To this end, the National Health Insurance House should ensure that hospitals and private pharmacies receive timely reimbursement for providing covered medications.
- Ensure that children and youth living with HIV have adequate access to necessary routine and emergency medical care, including mental health care and palliative or hospice care for persons with terminal-stage AIDS. Investigate and sanction medical personnel who discriminate against persons living with HIV or breach confidentiality.
- Ensure that all children and youth living with HIV have access to information on their diagnosis and confidential counseling on HIV prevention and treatment, including information on sexual health, consistent with their evolving capacities. In particular, ensure that children's right to informed consent and their right to information on their diagnosis are effected even in the absence of parental consent to inform them of their HIV status.
- Ensure that local authorities properly implement legislation providing subsidies to persons living with HIV, and that bureaucratic delays, burdensome reporting requirements, and breaches of confidentiality do not act as barriers to children and youth receiving the nutritional and financial support they are entitled to by law.

### *The Right to Education*

- Ensure that children and youth living with HIV have access to education that is appropriate to their needs, including by adopting measures to combat drop-out of children living with HIV and to promote their integration into the formal education system. Special attention should be given to the needs of children who may require additional assistance to overcome deficits caused by having dropped out of school or attended substandard educational programs in state institutions, or who have developmental or mental disabilities.
- Train teachers and headmasters on HIV, including information on the special needs of children living with HIV, how to prevent transmission of the disease, and how to intervene effectively to stop bullying.
- Amend Law 584/2002 to include educational staff among those required to keep confidentiality, and to provide effective sanctions against those who breach confidentiality, discriminate against children and youth living with HIV, or fail to protect them from harassment by others.

### *The Right to Information*

- Ensure that children and youth living with HIV have access to accurate information on reproductive health and HIV, including information on how to prevent the transmission of HIV and other sexually transmitted diseases. This information should be compulsory in all schools and also be available to children and youth living with HIV who are not attending formal education programs, should begin at an early age, and should be monitored to ensure that the content is accurate and complete.

### *The Right to Privacy*

- End the practice of including HIV diagnoses on medical prescriptions, and ensure the confidentiality of information about HIV status on disability certificates, medical certificates, court records, and other documents. To this end, the National Authority for Persons with Handicap should ensure that the key for its disability codes is separate from its certificates of disability.
- Amend Law 584/2002 to provide clear and adequate sanctions for breaches of confidentiality of information on HIV status and treatment, with particular attention to breaches of confidentiality in schools, hospitals and clinics, the postal service, national and local government offices, and official documents. The law should include accessible mechanisms for reporting, investigating, and enforcing these sanctions.

- Conduct an information campaign among all relevant professional groups to clarify their obligation to maintain privacy unless instructed by a judge to provide information for the prosecution of a crime.

### ***To the European Union***

- Insist that the Romanian government take steps to enforce the protections against discrimination on the basis of HIV status and provide an appropriate remedy to victims of such discrimination.
- Ensure that adequate implementation of anti-discrimination legislation with regard to HIV status forms an integral part of broader EU efforts to promote equality and non-discrimination in Romania.
- Encourage the Romanian government to adopt all necessary legal and policy measures set out in the recommendations above as soon as possible, making clear that accession to the EU will not mean an end to active EU pressure in this regard. In cooperation with the Romanian government, formulate concrete benchmarks for the reform steps that are required to meet the recommendations above, with specific timelines for their fulfillment.
- Prioritize health sector reforms in future funding to Romania, including funding for nongovernmental organizations providing services for persons living with or affected by HIV.

### ***To Other International Donors***

- Prioritize funding for the labor and social integration of adolescents aging out of Romania's child protection system, with an emphasis on the needs of adolescents living with HIV. Such funding should be conditioned on a clear set of benchmarks and on legal and policy change.
- Urge the government of Romania to act quickly to fulfill its commitment to take over Phare and Global Fund to Fight AIDS, Tuberculosis, and Malaria projects on HIV currently being implemented by NGOs. Consider giving bridge funding to NGOs providing crucial services to persons living with HIV to ensure that their beneficiaries are not left without these services during the transition.
- International financial institutions such as the World Bank and the European Bank for Reconstruction and Development should incorporate language reflecting the concerns expressed in this report in their next country strategies for Romania, and encourage the Romanian authorities to pursue reforms to address them.

## **VIII. Conclusion**

Romania's advances in providing universal access to antiretroviral treatment to people living with HIV are being undermined by its failure to ensure the human rights of children and youth living with HIV. The government should take urgent action to combat discrimination against people living with HIV, particularly in the fields of access to education, medical care, social protection, and employment; ensure confidentiality of HIV-related information on individuals; and put in place legislation, programs, and policies to ensure that the rights of youth living with HIV are protected as they transition to adulthood.

## Acknowledgements

This report was written by Clarisa Bencomo, researcher with the Children's Rights Division, based on research conducted by Clarisa Bencomo and Romanița Iordache, consultant in the Europe and Central Asia Division of Human Rights Watch. It was reviewed by Michael Bochenek, deputy director of the Children's Rights Division; Joseph Amon, director of the HIV/AIDS Program; Holly Cartner, director of the Europe and Central Asia Division; Aisling Reidy, senior legal advisor; and Ian Gorvin, consultant to the Program Office of Human Rights Watch. Tanya Cox, EU advocacy coordinator, Veronika Szente-Goldston, advocacy director in the Europe and Central Asia Division, and Rebecca Schleifer, researcher in the HIV/AIDS Program provided valuable advice during the writing of the report. Production assistance was provided by Raneë Adipat, Fitzroy Hepkins, Andrea Holley, and Elizabeth Siegel. This report was translated into Romanian by Romanița Iordache.

A number of experts and nongovernmental organizations in Romania assisted with this research. Human Rights Watch gratefully acknowledges staff members of the Asociația Speranța pentru Ocrotirea Bolnavilor cu SIDA, Foundation for the Development of People, Fondazione Bambini in Emergenza, Health Aid Romania, Hope for Health, the Lizuca Association, Pro Sanatatea 2000, the Romanian-American Children's Center, Romanian Angel Appeal, the Romanian Association against AIDS (ARAS), Save the Children Romania, the National Union of Organizations of Persons Affected by AIDS (UNOPA), World Vision, and Youth for Youth.

We also thank medical staff of the Victor Babeș Institute for Infectious Diseases, the Bacău Hospital Infectious Diseases Unit, the Matei Balș Institute of Infectious Diseases, the Constanța Municipal Hospital, the Singureni Hospital of Infectious Diseases, and the Giurgiu day clinic of the Hospital of Infectious Diseases.

State Counselor to the President Bogdan Chirițoiu, State Counselor to the Prime Minister Ioan Roman, the president and staff of the National Council for Combating Discrimination, and staff of the National Authority for Persons with Handicap, the under-secretary of state and staff of the National Authority for the Protection of the Rights of the Child, and the staff of the Constanța and Ilfov General Directorates for Child Protection were generous with their time in responding to our questions about government policies and practices.

We also thank Eduard Petrescu of UNAIDS and Paula Bulancea and Tania Goldner of UNICEF.

This report would not have been possible without the assistance of the many Romanian children and youth living with HIV who, along with their parents and foster parents, shared their experiences and dreams with us.

Human Rights Watch thanks the following donors for their generous support to the work of the Children's Rights Division: the Susan A. and Donald P. Babson Charitable Foundation; the Bloomberg Foundation; the Connemara Fund; the Countess Moira Charitable Foundation; the Independence Foundation; the Link Foundation; and the Oak Foundation.