

## 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>

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<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.