Contribution by Caritas Internationalis to the

OHCHR Study on Children’s Right to Health[[1]](#footnote-1)

Background Information on Caritas Internationalis (International Confederation of Catholic Charities)

Caritas Internationalis is a global Confederation, based in Vatican City State, and comprised of 164 national Catholic Church-related humanitarian assistance, development, and social service organizations working in more than 200 countries and territories in the world. Since 1987, Caritas Internationalis has prioritized, *inter alia*, actions in response to HIV and AIDS and other related illnesses. These initiatives have focused, in particular, on the economic, social, emotional, and Human Rights-related impact of the pandemic, which include a number of core issues related to HIV prevention and treatment for women and children.

In 2009, on the occasion of the 20th anniversary of the United Nations Convention on the Rights of the Child (CRC), Caritas Internationalis launched its “HAART for Children”, an advocacy campaign that urges governments and pharmaceutical firms to take action in order to promote and respect the Right to Health of children living with HIV or HIV/TB co-infection. Through this campaign, Caritas advocates for the elimination of new HIV infections among children, and for early diagnosis and treatment of HIV or HIV/TB co-infection among women and children in all parts of the world. The campaign calls on governments and pharmaceutical companies to: develop and provide child-friendly HIV and TB medicine, especially for infants; further develop low-cost and low-technology testing methods to diagnose such infections among children; and scale up programmes aimed at preventing the transmission of HIV from HIV-positive mothers to their babies, during pregnancy, labour, delivery or breastfeeding. HAART stands for Highly Active Antiretroviral Therapy, the combination of medicines that helps prolong the lives of both children and adults living with HIV. These medicines also help to prevent mother-to-chid transmission of the virus.

Challenges and Barriers to the Full Enjoynment of the Right to Health for Children Living with HIV or HIV/TB co-Infection

Anti-retroviral medications (ARVs) can make the difference between life and death for a significant number of 2,838,000 children under 15 years of age who are living with HIV at the present time[[2]](#footnote-2). If HIV-positive children do not gain access to treatment that is appropriate to their needs, their physical development, and the conditions of the setting in which they live, they may be subjected to unnecessary suffering and die faster than do HIV-positive adults. Regrettably, despite evidence that treatment is very successful in children living with HIV, even in resource-limited settings, there remain significant obstacles to paediatric ARV scale-up. In fact, only 28% percent of children living in low- and middle-income countries and in need of anti-retroviral medications are afforded access to them[[3]](#footnote-3). On an hourly basis, this causes the deaths of 30 children under the age of 15[[4]](#footnote-4). For children living with both HIV and tuberculosis (TB) the situation is even worse: despite the fact that TB remains the main cause of death among children with AIDS, paediatric drug formulations are not available to treat HIV/TB co-infection in children[[5]](#footnote-5).

One major barrier related to paediatric treatment of HIV is the difficulty with detection of HIV in babies younger than 18 months. Several factors may prevent children from being tested: the limited availability of diagnostic tests capable of identifying HIV among infants and adaptable for use in poor settings; the low coverage of prevention of mother-to-child transmission (PMTCT); problems with transportation of specimens and results; the long distances to reach the nearest health centre where a child can be tested; fear of prejudice, stigma and discrimination that a child and their family often face once diagnosed; the lack of knowledge about the importance of testing and treating HIV-infected people and children; weak health and laboratory systems; and lack of capacity in hospitals and clinics to provide follow up with mothers and children after testing. Children infected with the virus before birth, during birth, or through breastfeeding, may not exhibit any symptoms of HIV infection. HIV can be diagnosed in adults by testing blood for antibodies to HIV. In infants under 18 months of age, an antibody test is not effective because the mother’s antibodies are passed to the child as a natural means of protection while the infant develops her/his own immune system. As a result, antibody tests for infants may yield false positive results for up to 18 months. An important method for diagnosis HIV in children is a Polymerase Chain Reaction (PCR) test, which directly identifies the presence of the virus in an infant’s blood cells[[6]](#footnote-6). In high-income countries, children can be tested within 48 hour after birth by using virological tests (PCR tests), and an accurate result can be available within six weeks after birth at the latest. However, PCR tests are not commonly available in poor countries because they require expensive laboratory equipment and trained staff. Moreover, scale-up of testing programmes for children requires investment in training and technical assistance for paediatric health care providers, improvement of laboratory capacity and facilities, and referral networks and community mobilization. In relation to PMTCT, even though treatment is available to prevent the transmission of HIV from mother to child, approximately 330,000 children were newly infected with HIV during 2011[[7]](#footnote-7), mainly through mother-to-child transmission. This was the case, as well, for the 90 percent of the 3.4 million children under 15 years of age who today are living with HIV. If coverage of PMTCT could be increased, not only would there be a great reduction in the number of children newly infected with HIV, but also it would be easier and more effective to start treating the child of an HIV-positive woman immediately after birth, even if diagnostic tools for detecting HIV in children are not available. Indeed, mother‑to‑child transmission of HIV can be reduced to less than 2 percent by increased access to and uptake of effective prevention of mother-to-child transmission programmes.

For children, the course of HIV is particularly aggressive. The virus multiplies rapidly, destroying their defenses against infection and facilitating the development of pneumonia, TB and other opportunistic infections[[8]](#footnote-8). Without adequate care and treatment, as many as one third of children born with HIV will die before their first birthday, and half of them will die before they are two years old. Children being treated with Highly Active Anti-retroviral Therapy (HAART) must take three or more different anti-retroviral drugs several times a day in order to avoid the development of resistance to a single drug and to prevent the virus from progressing into AIDS. These medicines must be formulated differently than those for adults, and in a way that takes into consideration the climactic conditions in the areas in which they will be distributed and used. It also should be noted that, in many low-income settings, clean drinking water, adequate nutrition[[9]](#footnote-9), and supply of electricity are not always available on a continuous basis[[10]](#footnote-10). Until recently, no formulations of antiretroviral medicines were available for specific use among children, “*largely because the HIV medicine market for children was judged too small to warrant investments in such research*”[[11]](#footnote-11). As a consequence, caregivers have to break in half or crush adult tablets, with the risk of under- or over- dosing. The lack of child-friendly fixed dose combinations (FDCs), 3 pills in one, adapted to the climate and conditions of resource-limited settings is major challenge to paediatric AIDS treatment. Paediatricians often have only liquid formulations available[[12]](#footnote-12), and tablet form needs to be taken with food and water, which are difficult to find in remote settings or urban slums. If drugs are not administered in the right dosage, at best they may not yield full benefits and, at worst, they may cause harm.

Also affecting the access of children to ARV treatment is the unacceptable state of health systems in most of the countries hardest hit by the pandemic, and the shortage of skilled healthcare workers, in particular, of paediatricians and nurses familiar with treating children. Unlike adults, children taking ARVs demand constant check-ups and advice from trained personnel in order to receive maximum benefit from and adhere to their respective treatment programs. Moreover, they need to be under treatment protocols that are in conformity with the most updated treatment guidelines issued by the World Health Organization.

These barriers mitigate against the child’s Right to the Highest Attainable Standard of Physical and Mental Health recognized, *inter alia*[[13]](#footnote-13), in the Convention on the Rights of the Child (CRC). In fact, the Convention on the Rights of the Child, to which 193 States have committed themselves to abide, requires States to recognize the right of children to enjoy, without discrimination, the highest attainable standard of health and access to facilities for the treatment of illness and rehabilitation of health. Moreover, States Parties must strive to ensure that no child is deprived of his or her right of access to such health care services. Access to medicines is a fundamental element of the child’s right to health under article 24 of the CRC, as interpreted by the Committee on the Rights of the Child in its General Comment on HIV and AIDS. Indeed, the Committee declared “*States must ensure that children have sustained and non-discriminatory access to comprehensive treatment and care, including necessary HIV-related drugs, goods and services*”. In particular, “*States should negotiate with the pharmaceutical industry to make the necessary medicines locally available at the lowest costs possible*”. Article 24 of the CRC builds on article 6, which recognizes that every child has the inherent Right to Life and that States Parties shall ensure, to the maximum extent possible, the survival and development of the child.

States have the primary responsibility to enhance access to medicines, and “*denying access by children to HIV care and treatment is a blatant demonstration of the failure of the state to deliver its international Human Rights obligations*”[[14]](#footnote-14). Moreover, the Millennium Development Goals (MDGs) recognize that other stakeholders, including pharmaceutical companies, should share this responsibility. The Committee on Economic Social and Cultural Rights also confirmed that the private business sector has responsibilities regarding the realization of the Right to the Highest Attainable Standard of Health. Thus, while governments have the primary responsibility for implementing the Right to Health, pharmaceutical companies can exert a profound impact on the realization of this right. It also must be recognized that pharmaceutical companies set the prices of diagnostic equipment for detecting HIV in children or of paediatric ARVs at an unaffordable level. When they fail to do so, when they do not invest in research and development of much needed medications to treat HIV in children, or when they lobby for legal standards that limit access to medicines for HIV-positive people, these companies obstruct the State’s ability to respect, protect and fulfill the Right to Health, and “*when the child’s Rights to Life and health are being denied, it is not only these rights, but all Human Rights that are in jeopardy*”[[15]](#footnote-15).

Governments and pharmaceutical companies play a major role in access to medicine for children. In order to contribute to the efforts to achieve the full realization of the Right to Health for all, in particular for children living with HIV or HIV/TB co-infection, Caritas Internationalis recommends to the Office of the High Commissioner for Human Rights that the following points be included in its Study and in any recommendations that may issue from this Study:

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| Goal | Target | Actions |
| Access to Paediatric HIV Treatment  | Governments | * Invest in innovative financing mechanisms that aim to promote research and development of paediatric testing and medicines, in particular paediatric triple Fixed Dose Combinations (FDCs) adapted for infants and children living in low- and middle-income settings, 2nd and 3rd line paediatric ARVs and FDCs;
* Improve capacity in laboratories;
* Invest in training and technical assistance for paediatric HIV and HIV/TB health care providers;
* Make every effort to ensure that Trade-Related Intellectual Property Agreements (TRIPs) do not constitute obstacles for access to medicine, most especially among poor and vulnerable populations;
* Develop National Essential Medicines Lists for children which include paediatric FDCs both for HIV and TB;
* Negotiate with the pharmaceutical industry to make necessary paediatric medicines locally available at the lowest cost possible;
* Take measure to increase food security in children as part of a comprehensive response to HIV/AIDS as lack of food is a major barrier to children’s access to medicines;
* Develop national HIV and AIDS strategic plans with a strong focus on PMTCT, diagnosis of HIV and TB in babies and children, and treatment for babies and children living with HIV, HIV/TB co-infection, and other HIV-related opportunistic infections;
* Address children’s access to medicines for children in the broader context of the Social Determinants of Health, bearing in mind that Human Rights are inter-related and mutually reinforcing;
* Fulfill governmental obligations to provide international assistance and cooperation to facilitate access to medicines for children.
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| Access to Paediatric Treatment | Pharmaceutical Companies and Generic Companies | * Develop less expensive Fixed Dose Combinations (FDCs) suitable for babies and children living in poor settings, and 2nd and 3rd line paediatric ARVs and FDCs;
* Address the research and development gaps in medicines for TB/HIV co-infection in infants and children, and in medicines for treating children co-infected with HIV and diseases such as malaria and/or HIV-related opportunistic infections.
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| Access to Paediatric Diagnostic Tools | Governments | * Build national and local laboratory capacity to facilitate HIV and TB diagnosis in infants and children, including skilled staff;
* Develop national policies to make paediatric HIV testing a routine element of care in high burden countries;
* Incorporate paediatric HIV testing into established entry points of care.
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| Scaling-up PMTCT | Governments | * Develop national HIV/AIDS strategic plans which focus on PMTCT;
* Integrate PMTCT programmes into existing public health systems;
* Provide HIV counseling and testing as part of the routine package of screening tests during pregnancy and delivery care;
* Make clinics accessible, for instance, by providing travel services and changing opening hours;
* Increase efforts to reach women who deliver at home;
* Support/develop door-to-door and home-based testing systems always accompanied by counseling;
* Treat babies of HIV-positive women immediately after birth;
* Provide counseling and support on infant feeding options to women living with HIV.
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Examples of Good Practices

**Mai Tam House of Hope – Ho Chi Min City, Viet Nam**

The Mai Tam House of Hope is sponsored and operated by the Roman Catholic Archdiocese of Ho Chi Minh City, and aims at providing shelter, medicines and food within a controlled environment to a targeted group of HIV positive children and mothers. The programme strives to ensure a quality of life consistent with that enjoyed by healthy peers; priority is given to children in need of such services. The objectives of the Centre are to improve the quality of life of orphans and vulnerable children living with HIV and AIDS, and promote independent living and community integration of their families. Children living at the Mai Tam House of Hope are both infected and affected by the HIV pandemic – some are HIV positive or already are displaying symptoms of AIDS-related illnesses, while others, orphans, as a result of the AIDS-related death(s) of one or both parents. When the Mai Tam House of Hope was established in 2005, the founders planned to assist 100 affected women and children, but today Mai Tam – the first and still the only facility of its kind in Ho Chi Minh City – supports more than 500 women and children in need. The number of children treated at the Centre increased from 7 in 2005 to 261 in 2009[[16]](#footnote-16). The Mai Tam House of Hope provides the following services: home-based care; day care centre; complementary nutritional support; tuition fees and educational support; supervision of adherence to ARV treatment; counseling; PMTCT; medical/hospital support; vocational training for mothers; income-generating activities; and shelter. Despite improvements, especially since 2006, Mai Tam House of Hope continues to face several challenges, such as: difficulty with estimating the appropriate dosage for children – lack of ARV child-friendly fixed-dose combinations; problems with assuring a continuous supply of medications; stigma and marginalization faced by the Mai Tam residents, including children, who often are refused entry into school because of the fear expressed by parents of other students attending the school.

**Nyumbani Children’s Home – Nairobi, Kenya**[[17]](#footnote-17)

Founded in 1992, Nyumbani Children's Home is an active response to the rising number of HIV infected children born in Africa every day. Tragically these children are often abandoned anyway, on the mistaken assumption that they are certain to develop and eventually succumb to AIDS. At Nyumbani, “home” in Swahili, children are cared for until a definite assessment of their HIV status can be made: children who are eventually found not to have the virus are adopted or find other homes; children who are found to be HIV-positive are given the best nutritional, medical – in particular anti-retroviral therapy, psychological, academic, and spiritual care. They live at Nyumbani until they become self-reliant. Nyumbani is home to approximately 100 children ranging in age from newborn to twenty-three years old, and coming from all over Kenya despite their tribal or ethnical origin. Children are referred to Nyumbani through national hospitals and through Nyumbani's own community outreach program, Lea Toto. Lea Toto, Swahili for “to raise the child”, is a community-based outreach programme that provids services to HIV-positive children and their families in the Kangemi, Waithaka, Kawangware, Riruta, Mutuini, Ruthimitu, Kibera and Kariobangi communities of Nairobi. Recognizing that orphanages were unable to provide direct support to the growing number of HIV-positive children in the Nairobi area, Nyumbani launched the Lea Toto Program in 1998.  Initially based out of an office at the Children’s Home, Lea Toto workers established a support programme through which HIV-positive children could remain with their caregivers in their communities. In 1999, with funding from USAID, Lea Toto became a full community-based care programme charged to carry out a project targeting HIV-positive children in the Kangemi slums of Nairobi. The Lea Toto project uses the Home Based Care (HBC) model.  All HBC programmes have one goal in common: to improve the quality of life of the affected through a package of comprehensive care for the client and his/her family. This package usually includes: basic medical and nursing care; counseling and psychological support; spiritual guidance; relief for social needs; HIV transmission prevention education; promotion of community empowerment/ownership; and self-help. Experience has shown that Home Based Care and counseling enables clients to live more positively and saves money that would otherwise be spent on hospital care.  In this sense HBC is cost-effective, leading to reduced in-patient hospital stays and a reduced cost per beneficiary. Other programme services provided by Lea Toto are: Voluntary Counseling and Testing (VCT); clinical care for home-bound clients; provision of ARV, since 2005; permanency planning; training of caregivers; nutritional support; business development training/income generation activities; provision of micro-credit services to caregivers. Lea Toto is aimed at providing 3,000 HIV positive children and an estimated 15,000 family members with high quality home based care and counseling services; providing a package of social support services to at least 50% of the 3,000 HIV-positive children and their families; enhancing the ability of targeted local communities to prioritize the needs of HIV-positive children and their families and to carry out activities to meet these needs; and providing the target communities with the skills necessary to negotiate support and maintain safe behavior. Nyumbani Children’s Home and Lea Toto are completed by Nyumbani Village, which provides a family-like setting for orphaned children under the stewardship of elderly adults and seeks to ensure that the children receive love, sustenance, health-care, holistic education and culture transfer, aiming at their physical, psychosocial and spiritual development, and, at the same time, providing holistic care and support for the grandparents in their later years. Through group homes and community services, the Village seeks to harness the energy of youth and the maturity of elders to create new blended families that foster healing, hope and opportunity. The Village also seeks to ensure that the residents in the surrounding communities reach a certain level of self-reliance through the Village sustainability programme.

1. For further information, please do not hesitate to contact Rev. Msgr. Robert J. Vitillo, Head of Caritas Internationalis Delegation to the UN in Geneva (rvitillo@caritas-internationalis.com), and Mr. Stefano Nobile, Caritas Internationalis Advocacy Officer and International Delegate (snobile@caritas-internationalis.com). [↑](#footnote-ref-1)
2. Number of children younger than 15 years living with HIV and not under anti-retroviral treatment. See the UNAIDS Report *Together We Will End AIDS* published in July 2012. [↑](#footnote-ref-2)
3. *Ibid.* The Report points out that “*anti-retroviral coverage is still much lower for children than for adults*”. [↑](#footnote-ref-3)
4. Dr. Karusa Kiragu, *The Global Plan for the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive*, presentation given in conjunction with the Catholic HIV/AIDS Network meeting, 13 October 2011. [↑](#footnote-ref-4)
5. HIV and TB are commonly called the “deadly duo”. TB is the most common opportunistic infection among people living with HIV, and it is the leading cause of death among them. A large number of children infected with TB remain undiagnosed, and worldwide 100,000 children die due to TB every year. Such deaths usually occur among children who are co-infected with TB and HIV. [↑](#footnote-ref-5)
6. See the article *The Challenge of Diagnosis* on www.pepfar.gov. [↑](#footnote-ref-6)
7. UNAIDS, *Together We Will End AIDS*. [↑](#footnote-ref-7)
8. Opportunistic infections are diseases that take advantage of the opportunity offered by a weakened immune system. Such infections might include: tuberculosis, bacterial pneumonia, malaria, herpes simplex and herpes zoster. Anyone can contract these diseases, but people living with HIV contract them at a much higher rate, and it is more complicated to treat them because of drug-interactions. Many of the opportunistic infections that occur when a person has developed AIDS can be fatal. [↑](#footnote-ref-8)
9. See the Joint Written Statement submitted by Caritas Internationalis (International Confederation of Catholic Charities) for the 19th Regular Session of the United Nations Human Rights Council A/HRC/19/NGO/63. [↑](#footnote-ref-9)
10. It has been confirmed that the overall socio-economic situation of people living with HIV is an essential element in determining their effective care and hope for survival. See the Final Report of the Commission on Social Determinants of Health, *Closing the Gap in a Generation – Health Equity through Action on the Social Determinants of Health*, WHO 2008. [↑](#footnote-ref-10)
11. *Paediatric HIV: From a Human Rights Lens*, Caritas Internationalis HAART for Children Newsletter, Issue 2, June 2012, Interview with Prof. Daniel Tarantola, Professor of Health and Human Rights, University of New South Wales, Sydney, Australia. [↑](#footnote-ref-11)
12. Syrups are difficult to dose properly and to administer; they are costly to transport and difficult to store without refrigeration. Since syrups are so difficult to handle, some paediatricians are forced to suspend HIV therapy for some children. Moreover, for grandparents, who are the primary caregivers for orphans due to AIDS, and for older siblings, in child-headed households, it is too complicated to administer the correct dose of ARV using a syringe or a spoon several times per day. [↑](#footnote-ref-12)
13. The Universal Declaration on Human Rights says that “*motherhood and childhood are entitled to special care and assistance*”, which is of particular relevance for the scaling up of programmes to prevent the transmission of HIV from mother-to-child, and for the care of children during and after birth. The Declaration adds in article 25 “*All children* […] *shall enjoy the same social protection*”. The International Covenant on Economic, Social and Cultural Rights, in article 12 paragraph 2, clearly states that access to medicines is an indispensable part of the Right to Health. This means that under International Law, States have a duty to ensure that existing medicines are available within their borders. They also have a responsibility to take measures in order to ensure that much-needed new medicines are developed, become available and are accessible. In the General Comment on HIV and AIDS, the Committee also examined the issue of mother-to-child transmission: “*Infants and young children can be infected with HIV during pregnancy, labor and delivery, and through breastfeeding. States are requested to implement strategies recommended by the United Nations Agencies, including the provisions of essential drugs, e.g. anti-retroviral drugs, appropriate antenatal, delivery and post-partum care, and making voluntary counseling and testing available to pregnant women and their partners. Counseling of HIV-positive mothers should include information about the risks and benefits of different infants feeding options*”. Thus, the measures that should be taken by States to prevent the transmission of HIV from a mother to her children include the following: medical protocols for HIV testing during pregnancy; information campaigns among women concerning mother-to-child transmission; the provision of affordable drugs, and of care and treatment to HIV-positive women, their infants and families, including counseling and infant feeding options. [↑](#footnote-ref-13)
14. Interview with Prof. Tarantola, *op.cit.* [↑](#footnote-ref-14)
15. *Ibid.* [↑](#footnote-ref-15)
16. Presentation of Fr. John Toai, MI, at the Conference *Preventing and Combating Paediatric HIV/AIDS* organized in Rome, Italy, by Caritas Internationalis and the Embassy of the United States of America to the Holy See on October 14-16, 2009, www.caritas.org/includes/pdf/hivaidsreporten.pdf. [↑](#footnote-ref-16)
17. http://www.nyumbyni.org/orphan\_need.htm. [↑](#footnote-ref-17)