

The Full Enjoyment of the Right to Health for Children Living with HIV or HIV/TB co-Infection

Joint Written Statement under Item 2&3 – High Commissioner/Secretary General Thematic Reports (Interactive Dialogue), submitted for the 22th Regular Session of the United Nations Human Rights Council by Caritas Internationalis (International Confederation of Catholic Charities), Associazione Comunità Papa Giovanni XXIII, Company of the Daughters of Charity of Vincent de Paul, **Dominicans for Justice and Peace (Order of Preachers)**, Ecumenical Advocacy Alliance, Edmund Rice International, International Association of Charities, International Volunteerism Organization for Women, Education, Development, Istituto Internazionale Maria Ausiliatrice, New Humanity, and World Vision International.

Anti-retroviral treatment (ART) determines the difference between life and death for a significant number of the 3.3 million children under 15 years of age now living with HIV^[1]. If HIV-positive children do not have access to treatment that is appropriate to their needs, particularly those related to their physical development and the settings in which they live, they may be subjected to unnecessary suffering and die faster than do HIV-positive adults.

Despite evidence that treatment is very successful in children living with HIV, even in resource-limited settings, there remain significant obstacles to expanding access of children living with HIV to ART. In fact, only 28% percent of children living in low- and middle-income countries in need of ART are currently able to access them, compared with 50% of adults^[2]. As a result, 30 children under 15 years of age living with HIV die every hour^[3]. 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.

The Need for More and Better Diagnostics for Children Living with HIV

One major barrier to treating children with HIV is the difficulty of detecting the infection in babies younger than 18 months. Several factors may impede accurate HIV diagnoses among children, including: inaccuracy of standard HIV anti-body testing among babies up to 18 months of age; the limited availability of diagnostic tests capable of accurately identifying HIV among infants that are adaptable for use in low-income settings; low rates of access to prevention of mother-to-child transmission (PMTCT) services; problems with transportation of specimens and results; long distances to health centres where a child can be tested; fear of stigma and discrimination that a child and their family often face once diagnosed; lack of knowledge about the importance of testing and treating HIV-infected adults and children; weak health and laboratory systems; and a lack of capacity in hospitals and clinics to follow-up with mothers and children after testing.

In high-income countries, children can be diagnosed accurately within 48 hours of birth. However, these virological (PCR) tests are not commonly available in low-income 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 health care providers, improvement of laboratory capacity and facilities, and referral networks and community mobilization. In relation to PMTCT, even though interventions are available to prevent the transmission of HIV from mother to child, approximately 330,000 children were newly infected with HIV during 2011^[4], mainly through mother-to-child transmission. This mode of transmission is responsible for 90% of all HIV infections among children under 15 years of age. If access to PMTCT services were increased, not only the number of children newly infected

with HIV would be decrease, but also the immediate initiation of ART among children born to HIV-positive mothers would delay the onset of HIV-related illnesses. Indeed, mother-to-child transmission of HIV can be reduced to less than 2 percent through increased access to and uptake of effective prevention of mother-to-child transmission programmes.

The Need for More and Better Treatment and Care for Children Living with HIV

Without adequate care and treatment, up to one third of all children born with HIV die before their first birthday, and half of them will die before they are two years old. Yet 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 developing resistance to a single drug, and therefore to prevent the further progression of HIV disease. These medicines must be formulated differently than those for adults, and in a way that takes into consideration the climatic 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, and a continuous supply of electricity are not always available and can therefore further jeopardize the quality of treatment that a child can access. Indeed, an insufficient variety of formulations of antiretroviral medicines are available for specific use among children, "*largely because the HIV medicine market for children was judged too small to warrant investments in such research*" [5]. As a consequence, caregivers have to halve or crush adult tablets, with the risk of under- or over-dosing, which means that at best the treatment will not yield its full benefits, and, at worst, may actually cause harm. Therefore, the lack of child-friendly fixed-dose combinations (FDCs) (3 pills in one) that are adapted to the climactic and other conditions of resource-limited settings is a major challenge to treating HIV in children. Paediatricians often have only liquid formulations available for use since tablets need to be taken with food and water, which can be scarce in remote settings or urban slums.

The poor state of health systems in many countries most seriously affected by the pandemic, and the shortage of skilled healthcare workers, in particular of paediatricians and nurses familiar with treating children, also negatively affects children's access to ARVs. Unlike adults, children taking ARVs require constant check-ups and advice from trained personnel in order to receive maximum benefit from and to adhere to their 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, particularly as treatment recommendations vary based on age of the child and previous exposure to ARVs during PMTCT.

The Obligation to Uphold Right to Health of Children Living with HIV

The above-mentioned barriers thwart the child's Right to the Highest Attainable Standard of Physical and Mental Health recognized, *inter alia*, in the Convention on the Rights of the Child (CRC). 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.

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, and when they do not invest in research and development of much needed medications to treat HIV in children or advocate 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*" [6].

Proposals for Action for Governments and Pharmaceutical Companies, Including Generic Companies

Governments and pharmaceutical companies play a major role in ensuring 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, the co-signing NGOs urge the United Nations Human Rights Council to call upon its Members to:

- **Invest in innovative financing mechanisms that promote research and development of paediatric testing and medicines, in particular paediatric triple fixed-dose combinations (FDCs) adapted for infants and children living in resource-limited settings, and 2nd and 3rd line paediatric ARVs and FDCs;**
- **Support and promote negotiations toward development of a binding convention on research and development to deliver products focused on priority health needs of developing countries, including children in those countries;**
- **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, especially among poor and vulnerable populations;**
- **Develop National Essential Medicines Lists for children that include paediatric FDCs for both HIV and TB;**
- **Negotiate with the pharmaceutical industry to make necessary paediatric medicines locally available at the lowest cost possible, including, for example, by taking part in initiatives such as the Medicines Patent Pool;**
- **Take measures to increase food security by children as part of a comprehensive response to HIV/AIDS, since 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 in the broader context of the Social Determinants of Health;**

- Fulfill governmental obligations to provide international assistance and cooperation to facilitate access to medicines by children;
- 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;
- 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 outside the clinic settings;
- 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.

Moreover, the co-signing NGOs recommend to the United Nations Human Rights Council to call upon its Members to urge pharmaceutical companies and generic companies to:

- Develop less expensive fixed-dose combination drugs (FDCs) suitable for babies and children living in low-income settings, and 2nd and 3rd line paediatric ARVs and FDCs, and explore ways of doing so collaboratively, such as by joining the Medicines Patent Pool;
- 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.

[1] UNAIDS, *Report on the Global AIDS Epidemic*, 2012.

[2] UNAIDS Report *Together We Will End AIDS*, July 2012.

[3] 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.

[4] UNAIDS, *Together We Will End AIDS*.

[5] *Paediatric HIV: From a Human Rights Lens*, Caritas Internationalis HAART for Children Newsletter, Issue 2, June 2012, Interview with Prof. Daniel Tarantola.

[6] *Ibid.*

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