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Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

Joint written statement* submitted by World Vision International, a non-governmental organization in general consultative status, the Elizabeth Glaser Pediatric AIDS Foundation, the International HIV/AIDS Alliance, non-governmental organizations in special consultative status

The Secretary-General has received the following written statement which is circulated in accordance with Economic and Social Council resolution 1996/31.

[8 February 2013]

* This written statement is issued, unedited, in the language(s) received from the submitting non-governmental organization(s).

Children's right to health: Children living with HIV*

The Elizabeth Glaser Pediatric AIDS Foundation welcomes the report of the UN High Commissioner for Human Rights on the right of the child to the enjoyment of the highest attainable standard of health, and the focus of the Human Rights Council's annual full-day meeting on the rights of the child on the same issue. This statement focuses on some key aspects the health rights of children living with HIV with some recommendations for further action by the Human Rights Council.

The International Covenant on Economic, Social and Cultural Rights (ICESCR) calls on States to recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Art. 12(1)). This is even more relevant in the case of children, as the Convention on the Rights of the Child (CRC) requires that States Parties not only recognize the right of the child to the enjoyment of the highest attainable standard of health but also to facilities for the treatment of illness and rehabilitation of health and, *inter alia*, to strive to ensure that no child is deprived of his or her right of access to such health care services (Art. 1, 2(a)).

Despite this, thirty years into the HIV epidemic, children continue to be left behind in the HIV response and attempts to address the problem of access to pediatric HIV treatment are scarce.

Child mortality

An estimated 230,000 children died from AIDS-related illness in 2011 alone—630 every day.[1]

In some of the highest-burden countries, HIV contributes to as much as 28 percent of under-5 deaths – though this figure is likely to be far higher, as many under-5 deaths are attributed to infections related to HIV or affect children not yet diagnosed.[2] The contribution of HIV to mortality of children under age five is continuing to rise.[3]

Children born to HIV-positive mothers require early diagnosis and timely treatment to ensure their survival, due to the rapid disease progression observed in children under two years of age.[4]

In fact, in 2010, the World Health Organization (WHO) recommended that children start anti-retroviral treatment immediately upon diagnosis – regardless of clinical symptoms, immune status, or viral load.[5] Despite this, only 28 percent of infants born to HIV-positive

* Drugs for Neglected Diseases Initiative (DNDi) and Medicines Patent Pool, NGOs without consultative status, also share the views expressed in this statement.

1 EGPAF, "The Global AIDS Pandemic – Key Facts," at: http://www.pedaids.org/Publications/Fact-Sheets---Brochures/fact-sheet-and-issue-brief-updates-(august-2012)/Global-AIDS-Pandemic-Key-Facts-(updated-August-201.

2 UNICEF, Preventing mother-to-child transmission (PMTCT) of HIV, at: http://www.unicef.org/esaro/5482_pmtct.html.

3 WHO, Child mortality, 2011, at: http://www.who.int/pmnch/media/press_materials/fs/fs_mdg4_childmortality/en/index.html.

4 Violari et al., "Early Antiretroviral Therapy and Mortality among HIV-Infected Infants," N Engl J Med. 2008, November 20; 359(21): 2233–2244. See: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2950021/.

5 WHO, Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access-Recommendations for a public health approach, 2010 revision, at: http://whqlibdoc.who.int/publications/2010/9789241599801_eng.pdf.

mothers are tested for HIV within their first two months of life.[6] This lack of testing is one of the very earliest and deadliest points when children fall out of the treatment cascade, and access to early testing and treatment in children exposed to HIV in low- and middle-income countries remains woefully inadequate.

The result is that children are needlessly dying of complications from HIV infection—whether it is because mothers did not have access to services to prevent transmission of HIV to their babies, because children were not identified as HIV positive early enough, or because children did not have access to quality HIV treatment and care.

All of these problems can be addressed with knowledge and equipment that is currently available.

Over the last 15 years, mother-to-child transmission of HIV has been virtually eliminated in developed countries, due largely to HIV testing in pregnancy and widespread use of efficacious antiretroviral (ARV) medication during pregnancy, childbirth, and the post-natal period. However, in the developing world—particularly in sub-Saharan Africa— women and children have challenges accessing these interventions, and every day, more than 900 children are born HIV-positive. Without access to treatment, about half of those children will die before their second birthday, with 80 per cent dying before the age of 5.[7]

The UN's *Global Plan towards the Elimination of New HIV Infections in Children by 2015 and Keeping Their Mothers Alive* has begun to address these problems, bringing much-needed attention to the goal of eliminating pediatric HIV through preventing mother-to-child transmission.

However, although every effort should be made to eliminate new infections in children, we must not forget the millions of children already living with HIV/AIDS, and those who will become infected in the coming years.

Treatment of children living with HIV

The rate of children diagnosed, enrolled, and retained in HIV treatment is lagging far behind that for adults. In 2011, ARVS were available to 57 percent of adults who required them, but only 28 percent of children in need.[8]

There are many barriers that prevent infants and children living with HIV in resource-limited settings from accessing HIV diagnosis, treatment and care, ranging from financial shortages to lack of political will to implementation challenges. All of these barriers contribute to the shortfall in fulfilling children's health rights.

Weak health systems, limited capacity of health care workers, and the need for caregivers to return to a health facility multiple times are just some of the challenges facing children in need of HIV treatment. Availability of supplies that are needed to diagnose and treat children living with HIV can also be a challenge, with "stock-outs" occurring in many countries with high-HIV prevalence. Also, healthcare workers often don't have adequate training to properly treat children living with HIV.

[6] Data from 65 reporting countries. WHO, Global AIDS Response, Epidemic Update and Health Sector Progress Towards Universal Access, 2011, at: http://whqlibdoc.who.int/publications/2011/9789241502986_eng.pdf.

[7] WHO/UNAIDS/UNICEF, Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access, 2011, at: http://www.who.int/hiv/pub/progress_report2011/en/index.html.

[8] UNAIDS, A progress report on the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, 2012, at: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2385_ProgressReportGlobalPlan_en.pdf.

Even when children are tested and linked to treatment, there are several hurdles to overcome to ensure their needs are met so that treatment can be successful. Often, poverty is an impediment; families do not have the funds to cover transport costs for the necessary multiple visits to healthcare centres or adequate nutrition to enable children to take their medication. Mothers may not have disclosed their status to their partners or families, and may fear violence from their partners and stigma and discrimination from their families and communities upon disclosure of an HIV-positive status.

There is also limited medical research of treatment for children living with HIV, with the result that there are few treatment options available for children compared with the variety of options available to adults.

Fear of stigma can also be an enormous challenge, and result in children not being informed of their HIV status, meaning that they are less able to engage in informed behavior that can support their health. Often, parents and guardians of HIV-positive children withhold the information in a bid to protect the child and even themselves from stigma in a society that still discriminates and sometimes criminalizes those living with HIV. Children unaware of their own status often do not fully appreciate the importance of taking their medication regularly, and they can become ill more often than they should.

The international community can and must do more to both prevent children from acquiring HIV, and effectively treat and care for those who do acquire the virus.

Recommendations

The Elizabeth Glaser Pediatric AIDS Foundation urges the Human Rights Council to:

- seize itself of the situation for children living with HIV and monitor the implementation of the CRC and ICCPR with respect to children living with HIV;
- affirm that children should be a priority in all aspects of the HIV response, at a national, regional and international level;
- call on states to prioritize, in their National HIV Action Plans, prevention of mother-to-child transmission of HIV, early infant HIV diagnosis, and treatment and care for children, with clear and measurable objectives;
- urge states and tackle the key barriers, including financial constraints, to effective diagnosis and HIV treatment of children, including stigma and discrimination, gender-based violence and nutritional challenges;
- call on states, UN agencies, multi-lateral organizations to prioritize pediatric HIV treatment as a basic right for the millions of HIV infected children and collect disaggregated HIV data for children;
- urge the pharmaceutical industry to develop less expensive fixed-dose combination drugs (FDCs) suitable for infants and children living in resource-poor settings and make necessary pediatric medicines locally available at the lowest possible cost, including through the licensing of relevant intellectual property rights;
- call on states to implement faithfully the provisions of the ICCPR and the CRC with regard to the diagnosis, care and treatment of children living with HIV.