



Early Diagnosis and Treatment for Children and Adolescentsⁱ Living with HIV: Urgent Call by Religious and Faith-Inspired Organizations for Greater Commitment and Action

As professionals engaged in the response to the continuing and grave challenges posed by the HIV epidemic, at global, national, and local levels, we gathered from Africa, Asia, Europe, Latin America, and North America, to share our knowledge, experience, and good practice models but also our grave concerns, with special attention to the wellbeing and future of children, vulnerable to, or already living with HIV. We were joined in these strategic reflections and discussions by other key stakeholders, including officials of multi-lateral organizations and national governments, non-governmental organizations (NGOs) facilitating provision of services (implementing agencies), and various innovative funding, research, development, and advocacy organizations committed to advance the shared vision to end new infections of HIV among children and keep their mothers healthy, and to end AIDS as a public health threat by 2030. “We need to bring our minds and our hearts together to face the future to take us to the end of AIDS.”ⁱⁱ

Rejoicing in the Signs of Hope and the Grace of God

We grounded our time together in prayer and discernment of Sacred Scripture and the centuries-old traditions of people of faith to

reach out to, and accompany, as part of our mission as people of hope, those sisters and brothers who find themselves most in need, marginalized, rejected, and stigmatized.

Working in the “vineyard” of religious and faith-based action, we deeply appreciated the acknowledgement offered by our international colleagues and partners during this consultation: “You’ve worked tirelessly, often without the resources, long before the Global Fund, long before PEPFAR;” “You were there when all we could do was stand beside bedsides and help people die with dignity”ⁱⁱⁱ; “You are a bridge to bring the science to the people. The data makes that very clear.”^{iv} “ Faith-based organizations are an essential and irreplaceable piece of this puzzle.”^v

On a related note, we celebrated with many others, but most especially with our sisters and brothers living with or affected by HIV, in the scientific, technical, and practical progress made to date:^{vi}

- The number of children who died of AIDS-related causes in 2014 (150 000) is 41% lower than in 2001, when global paediatric HIV mortality peaked;
- Since 2000, new HIV infections among children have declined by 58%. Yet the epidemic continues to have profound effects on the youngest people. In 2014, 2.6 million children under 15 years of age were living with HIV;
- Since 2000, antiretroviral medicines have averted an estimated 1.4 million HIV infections among newborns and infants;
- Approximately 73% of pregnant women living with HIV worldwide have received treatment to stop transmission of HIV to their babies. This is a giant leap from 36% receiving effective regimens in 2009 and from 2000, when only 1% of pregnant women living with HIV had any form of access to prevention of mother-to-child HIV transmission services;
- In 2013 worldwide, only 42% of newborns exposed to HIV received early infant diagnostic services in their first two months of life.

We shared the stories of entire families, and especially of their HIV-positive children, being accompanied by our faith-based programmes and benefitting from education from primary to tertiary levels; entering into value-based and respectful inter-personal friendships with peers; excelling in sports; and developing self-sufficiency skills as they transition from adolescence to young adulthood.

Confronting Persistent and Grave Obstacles

Despite our best efforts, specialized skills, and holistic, person-centered, community-based, and family-centered vision and approach to care, the children and families under our care continue to face serious challenges as they seek universal access to effective, accessible, and acceptable prevention education, treatment, care and support:

- When analyzing overall mortality among children, we note that more than six million children still die, mainly of preventable and treatable diseases, before their fifth birthday each year.
- Four out of every five deaths of children under age five occur in sub-Saharan Africa and Southern Asia.
- Tuberculosis (TB) is common in countries that have a high burden of children living with HIV and high under-five mortality. Yet, TB/HIV co-morbidity among children has been largely overlooked globally and grossly under-reported.
- The proportion of children living with HIV who receive antiretroviral therapy more than doubled between 2010 and 2014 (from 14% to 32%), but coverage remains notably lower than it does for adults (41%). Only 820 000 of 2.6 million children living with HIV have access to treatment.
- Even when services are readily available, stigma can prevent parents from bringing their children forward for test results and for initiation of treatment.
- Long delays in return of EID test results continue to interfere with and timely initiation of treatment.
- Children are still being initiated on anti-retroviral treatment too late; one-half of children living with HIV and who are not receiving anti-retroviral treatment die before the age of two years (UNAIDS), yet, on average, children are not initiated on treatment until 3.8 years of age (UNAIDS/Ideea).
- Impairment of neuro-cognitive development and stunting have been noted among children living with HIV; early initiation of anti-retroviral therapy and adequate nutrition have shown positive impact in this regard.
- Stock-outs of testing supplies and medicines create frustration, defaults, and desperation, among parents and primary caregivers who make great sacrifices of time and meager financial resources

to bring their children to clinics and hospitals in search of testing and treatment.

- Funding often is tied to bio-medical services alone, when there is strong evidence base demonstrating the need and effectiveness of a holistic approach that combines medical, emotional, and spiritual support to child and parents/caregivers: "The HIV epidemic among children and adolescents is defined not only by the virus and medical interventions to control it but also by social, economic and political conditions that they find themselves in. We know that children thrive when they are placed in a supportive and nurturing environment from their earliest days. UNAIDS is committed to increasing attention to social protection, especially for children and adolescents."^{vii}
- Medication distribution and delivery systems remain complicated, and medicines continue to require cold chain storage, even in countries without a reliable electrical supply.
- In many countries and districts HIV, TB, ante-natal, maternal and child health, and other medical services continue to be delivered in “silo” fashion and thus result in missed opportunities for early diagnosis and initiation of treatment.
- Despite strong advocacy and some innovative approaches to issues related to intellectual property, this “progress” has not yet yielded large-scale production of “child friendly” diagnostics and medicines that can be used in low-technology and low-income countries and among poor and marginalized populations in middle- and low-income areas of “rich” countries.
- We also recognize that some faith-based organizations have held attitudes that contributed to the marginalization of people living with and affected by HIV and that, at times, our silence could be linked to the worsening situation of HIV infection.

What do we need from NOW until 2020^{viii}, with specific interim targets and reviews on an annual basis, to address these life-threatening issues?

- Variability and disruption in funding can have catastrophic results for formerly successful projects; we cannot assume programmes will be maintained without adequate and sustainable funding from both international solidarity and domestic sources.
- Invest in programmes to prevent HIV infection in parents;
- Expanding numbers of adolescent youth can result in higher vulnerability to HIV infection among this population, in particular, among girls; we need to better understand their needs and to

develop more effective means to assure that they enter and are maintained in school, which, in itself has been demonstrated as an effective prevention strategy.

- Since there is high mobility among many families and children, especially among the poorer populations, more “portable”, “Smart Card” medical and social records and other information communication technology are needed in order to track their progress and to enable them to stay in care over time and place.
- A multi-pronged approach to HIV must be developed in order to extend past the bio-medical service system in order to include nutritional support, services to children with disabilities, mental health services, spiritual, social, and emotional support, education, and economic empowerment and assistance, and social services, attention to the impact of conflict and other humanitarian crises, and sensitivity to cultural and religious contexts.
- Invest in social services for children and families, including social protection, in order to address the underlying causes that hinder the response to HIV, including poverty, abuse, stigma, and harmful social norms and develop social indicators to demonstrate effectiveness of these interventions.
- Attention must be given to greater involvement of men and boys if we want to reduce HIV vulnerability among women and girls, including elimination of inter-personal and domestic violence.
- Access to, and availability of, timely lab testing, including virologic tests, for early infant diagnosis must be increased through innovative systems and new technologies to allow infected infants to be started on antiretroviral treatment rapidly.
- Testing of children in high yield venues such as index-case based testing and OVC programs, malnutrition and TB clinics, and sick child wards must be intensified to identify children living with HIV. Training on disclosure to children of their HIV status must be provided for health care workers and parents/caregivers.
- Providing effective and well-tolerated drugs for children remains critical to ensuring scale up of paediatric treatment and improved clinical outcomes.
 - Formulations must be palatable, suitable for infants and young children, adaptable for varied weights, and co-formulated as much as possible.
 - Immediate new formulations are needed for children and are more potent, better tolerated and minimally toxic regimen allowing full harmonization with adult treatment strategies.

- Second and third-line treatment regimens must be available in paediatric formulations to allow treatment of children failing initial regimens.
- Innovative strategies for prevention, retention and adherence are needed especially for adolescents, who are at high risk of loss to follow up and onward transmission.
- Serious study and analysis needs be given to integration of HIV Testing and Counseling into immunization programmes
- Strengthen the capacity of, and retaining, paid and volunteer community health workers and facilitate task shifting in order to expand outreach, efficiency, and effectiveness.
- Consistent and broadly accepted targets and sub-targets should be defined for diagnosis, treatment and retention in care of children living with HIV; no target should be accepted if it is based on the assumption that large numbers of children will die before elimination can be reached.
- Inter-sectoral and inter-ministerial cooperation should be formalized within governmental offices engaged in response to HIV.

The unique voice of faith communities and related organizations to save the lives of children living with HIV and their parents, and to accompany the empowerment of affected families

Thus we commit ourselves to:

- Address psycho-social and spiritual needs of children and families;
- Deliver testing and treatment services at local community level;
- Utilize the sermons and other educational services, including pastoral and clergy training and formation programmes, to deliver direct, comprehensive, effective, and understandable messages for individuals, families, and communities, in relation to physical, emotional, behavioral and spiritual health and wholeness;
- Shape positive attitudes that counteract fear and tendencies toward stigma and discrimination;
- Integrate value-based sexual and responsible relationship education into their curricula and into preparation for life-changing transitions (adolescence, marriage, death and mourning, etc.);
- Initiate and sustain effective advocacy approaches to address social justice-related barriers and obstacles to universal access to early and sustained testing and treatment for HIV, TB, and other co-infections

- Increase partnership and collaboration with government and other civil society actors;
- Assume a critical role in implementing, and monitoring progress in achieving, the Sustainable Development Goals (SDGs) and other international commitments and to safeguard respect for human rights;
- Assure access to treatment and provide social, emotional and spiritual support for arriving migrants and refugees;
- Maintain focus and concern on marginalized, low-prevalence, and/or hard-to-reach populations within our respective countries,
- Contribute to ethical and theological reflection, and ecumenical and inter-religious dialogue, on overcoming obstacles and barriers to effective Early Infant Diagnosis and Treatment of Children living with HIV;

ⁱ According to the United Nations Convention on the Rights of the Child, *Article 1*, “a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier”, in this document, it will be presumed that adolescents are included in such references to children.

ⁱⁱ Dr. Luiz Loures, Assistant Secretary-General of the United Nations and Deputy Director of Programmes, UNAIDS, 11 April 2016.

ⁱⁱⁱ H.E. Deborah Birx, Coordinator, U.S. President’s Emergency Plan for AIDS Response and for Global Health Policy, 11 April 2016.

^{iv} Dr. Luiz Loures, 11 April 2016.

^v H.E. Deborah Birx, 11 April 2016.

^{vi} Unless otherwise specified, references are from *UNAIDS: How AIDS Changed Everything: MDG 6: 15 years, 15 lessons of hope from the AIDS response*. Geneva: UNAIDS, 2015

^{vii} Dr. Luiz Loures, **Global Partners Forum: a holistic approach needed to keep children and young people safe from HIV**, 20 July 2014,

<http://www.unaids.org/en/resources/presscentre/featurestories/2014/july/20140720children>

^{viii} “Quickening the pace to achieve the Fast-Track Targets would reverse the AIDS epidemic by 2020. With achievement of these new targets, by 2030 the epidemic would be dwindling. In contrast, with business as usual (keeping service coverage at 2013 levels), the epidemic will have rebounded by 2030, representing an even more serious threat to the world’s future health and well-being and requiring substantial resources for what would then be an uncontrolled epidemic.”

http://www.unaids.org/sites/default/files/media_asset/JC2686_WAD2014report_en.pdf, page 12