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Inter-Parliamentary Union 1889

INCREASING CHILDREN'S ACCESS TO HIV TREATMENT

BRIEF FOR PARLIAMENTARIANS

INTRODUCTION

More than 30 years into the AIDS epidemic, we are finally slowing the spread of the disease. Since 2001, more than 26 countries have seen a drop of 50 per cent or more in new infections. In 2012, nearly 10 million people in low- and middle-income countries received necessary HIV treatment.[1] By 2015, 15 million people should be receiving treatment, according to UNAIDS targets.

But these successes are not universal. While 65 per cent of eligible adults living with HIV receive treatment, only 34 per cent of children get it.[2] While HIV treatment, care, and support services give a child with HIV a chance at a long and healthy life, most of the 3.4 million children living with HIV do not have access to the services they need.[3]

Efforts are underway to implement new World Health Organization (WHO) guidelines on using antiretroviral drugs to prevent and treat HIV infections. This will greatly expand the number of children eligible for lifesaving treatment.[4] The guidelines recommend **immediate antiretroviral treatment for all children with HIV younger than five**.[5] However, to do that, countries will need to address the medical, social, systemic and economic barriers that block children living with HIV from accessing treatment and care.

Children are being left behind in the fight against HIV and AIDS. Unless countries take action to make treatment services more available, hundreds of thousands of children will continue to die each year from HIV-related causes.

I. EARLY DETECTION OF HIV INFECTION MUST BE A PRIORITY

Early testing, diagnosis, and treatment for HIV-exposed infants and children are critical. Because HIV-related illnesses progress faster in children than in adults, 50 per cent of children born with HIV who do not receive treatment will die before the age of two. Without treatment, 80 per cent of those children will die by age five.

Under the 2013 WHO guidelines, four to six weeks after an HIV-positive mother gives birth, her baby must be tested for HIV. If positive, the baby must start HIV medication. However, more than 75 per cent of those infants are not tested; many who have HIV are only diagnosed years later when they become ill or die.

About 50 per cent of infants who are tested do not receive their test results and of those children who test positive for HIV, 40 per cent never receive treatment.[6]

A variety of social, economic, and systemic factors influence how and when an HIV-positive child is tested and receives treatment and care. Challenges include:

- Transportation costs—many families cannot afford the multiple visits to health centres needed to determine the HIV-status of babies exposed to HIV.
- Stigma and discrimination—some parents do not want their child tested due to fears about stigma against their child or themselves.
- Facilities—clinics are often far from home and opening hours are not convenient for caregivers. Health workers can be scarce and not trained to help children, and laboratories are often overburdened.
- Supply shortages—countries with high HIV prevalence often face shortages of supplies needed to diagnose and treat children living with HIV.

1., 2., 3. UNAIDS, Global Report, 2013.

4. More than 90% of new HIV infections among infants and young children globally occur through mother-to-child transmission of the virus. While efforts to prevent this mode of transmission are being intensified, many children still become infected this way. For more information about mother-to-child transmission of HIV and how to prevent it, see IPU's Brief for Parliamentarians on HIV and AIDS, *Towards an HIV-free generation: Ending the vertical transmission of HIV* (available at: http://www.ipu.org/pdf/publications/aids12-1-e.pdf).

5. Available at: http://www.who.int/hiv/pub/guidelines/arv2013/en/index.html.

6. Essajee, Shaffiq, *Update on EID testing: Global Progress & Emerging Challenges*, May 2013.

JOSEPHINE NABUKENYA; KAMPALA, UGANDA

"I was 12 years old when I was diagnosed with HIV. I fell sick from time to time. This affected my education—in fact, I was often too sick to attend my classes.

My situation got so bad that at one point my mother prayed I would live long enough to reach my senior year of high school. But I had big dreams: to attend university and graduate.

I did not give up on my dream and today I'm proud to say I just started university and I feel great.

Not only are HIV drugs for children like me needed, but so are other supplements, like good food. We must ensure that families—especially children—deep in villages are cared for with proper food and medication.

I am healthy and lively today because I have had access to proper HIV medication, a good diet, and a loving society. I believe all children living with HIV have a right to proper medication and should be given first priority—after all, they are tomorrow's ministers or members of parliament."

II. INNOVATIONS ARE NEEDED TO HELP IDENTIFY AND TREAT UNDIAGNOSED CHILDREN LIVING WITH HIV

Countries need to consider new ways to expand enrollment and retention into paediatric HIV care and treatment programmes. One way is to integrate testing services into non-HIV health services and community-based programmes. Children have contact with the health system through various services (e.g. immunization clinics, nutrition services, etc.), but most of these entry points do not take steps to identify children with HIV. Countries also need to increase the number of health care providers and community health workers trained to confidently counsel and test children.

The following will help identify and enroll HIV-positive children into care:

- **New HIV testing technologies for children:** While adults can be diagnosed using a simple antibody test, that option is not available for children younger than 18 months. More complex tests are required to determine a young child's status, but these tests are also more expensive and not available at many health facilities. Where these technologies are available, receiving results can take more than a month as the tests must be flown or driven to a central laboratory, processed, and returned to community health centres. Some laboratories have begun sending test results to facilities using mobile technologies, cutting turn-around times in half. New innovations could make it possible to test children for HIV at the time of birth and provide same-day results.
- **Better HIV screening and community-based counselling for children:** Children living with HIV are significantly more likely to visit mother and child health (MCH) clinics than HIV comprehensive care clinics – making the MCH clinic an excellent platform for paediatric HIV screening and treatment enrollment. Offering screening and testing for children during Child Health Days could greatly increase access to vital HIV services. Community-based counselling and testing also significantly increase children's access to HIV treatment. Children exposed to HIV can be reached at early childhood development centres, through religious and sports groups, at centres for orphans and vulnerable children, and in their own homes by community health workers.
- **Better-educated health care providers:** Many health care providers are not comfortable with treatment guidelines and are reluctant to initiate treatment in children because starting a child on a lifetime drug regimen seems daunting, especially if the child appears healthy. Educating those providers about the benefits of counselling, testing and treating children will substantially improve their effectiveness.
- **Improved retention in paediatric HIV treatment programmes:** It is difficult to retain children in care and treatment programmes for many of the same reasons that diagnosing children is a challenge: lack of family resources for travel to clinics, overburdened caregivers, clinics located far from the community, fear of stigma, out-of-stock key HIV drugs, and lack of health care worker training. Inconsistent use of HIV medications can lead to drug resistance—therefore it is crucial to tackle these barriers to ensure adherence and retention of children in treatment.

III. CHILDREN NEED EFFECTIVE HIV DRUGS TO MEET THEIR UNIQUE MEDICAL NEEDS

Lack of treatment options for children contributes to low rates of treatment coverage and ineffective—sometimes dangerous—dosing. Many of the paediatric formulations that are available are unpalatable or difficult for young children to swallow. Some paediatric formulations require refrigeration, a resource unavailable to many caregivers in the developing world. Sometimes, health care providers or parents are forced to cut adult medication into smaller pieces that they estimate to be correct for children, leading to possible under- or over-medication.

These issues are complicated by inadequate funding for paediatric treatment worldwide. Paediatric drugs can be more expensive than those for adults, and purchasing them can be complicated because they need to account for different ages and weights. Many of the countries hardest hit by the epidemic have inadequate levels of domestic funding for health while funding for paediatric treatment has not been a priority.

CHILDREN ELIGIBLE FOR AND RECEIVING HIV TREATMENT (ART), AND HIV TREATMENT (ART) COVERAGE IN THE 22 PRIORITY COUNTRIES, 2011 AND 2012*

Country	Estimated number of children eligible for ART, 2011	Estimated ART coverage among children, December 2011	Estimated number of children eligible for ART, 2012	Estimated ART coverage among children, December 2012
Botswana	10 000	95%	10 000	95%
Namibia	13 000	80%	13 000	87%
South Africa	210 000	71%	210 000	67%
Swaziland	14 000	48%	14 000	54%
Zimbabwe	110 000	35%	100 000	45%
India	81 000	28%	86 000	40%
Kenya	160 000	31%	150 000	38%
Zambia	95 000	32%	90 000	38%
Malawi	110 000	27%	100 000	36%
Chad	20 000	8%	20 000	29%
Uganda	90 000–130 000b	19–27%b	85 000–130 000b	27–42%b
Mozambique	110 000	22%	100 000	27%
United Republic of Tanzania	130 000	14%	130 000	26%
Lesotho	23 000	27%	22 000	25%
Ghana	16 000	16%	14 000	25%
Ethiopia	86 000	19%	78 000	23%
Burundi	11 000	18%	9 900	21%
Côte d'Ivoire	37 000	14%	35 000	16%
Cameroon	34 000	13%	33 000	15%
Angola	22 000	11%	23 000	13%
Nigeria	260 000	14%	260 000	12%
Democratic Republic of the Congo	54 000	12%	53 000	9%
Total	**1 720 000**	**29%**	**1 660 000**	**34%**

* Extracted from WHO and UNAIDS data available here:: http://www.who.int/hiv/data/en. The 22 priority countries are those specified in the UNAIDS Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping Their Mothers Alive.

DR BEVAN GOQWANA, MP, SOUTH AFRICA

"The needs of children living with HIV in our countries are varied and many - as are the barriers they face in accessing treatment. From high prices or lack of availability of appropriate medicines, to lack of trained medical staff and stigma and discrimination--all are challenges that we must tackle if we are to reach the goal of a generation free of AIDS. These barriers can and must be challenged by us as parliamentarians. With national political will and international solidarity, we can and will overcome them, in the interests of our children's futures."

IV. PARLIAMENTS AND THEIR MEMBERS CAN HELP IMPROVE ACCESS TO PAEDIATRIC HIV TREATMENT

Parliamentarians are uniquely positioned to make children living with HIV a priority in national heath and HIV/AIDS programmes. They can dramatically improve paediatric treatment rates and ensure that the WHO guidelines are implemented by following these recommendations:

ACT IN PARLIAMENT

1. Build cross-party support to address the needs of children living with HIV and explore what remedies can be put in place through parliamentary action.
2. Draw up an inventory of laws related to accessing paediatric HIV treatment, making sure that they reflect the 2013 WHO guidelines on paediatric HIV treatment.
3. Advocate for budget allocations to bolster public policy and legislation supporting HIV treatment for all children who need it.
4. Support laws and actions that aim to reduce stigma and discrimination against people living with HIV.
5. Advocate for including HIV testing in MCH and other relevant health programmes.
6. Promote better education of community-based health workers on the specific needs of children living with HIV.
7. Advocate for increased development assistance for purchasing paediatric HIV drugs and increasing children's access to HIV treatment.

PROVIDE STRONG LEADERSHIP

1. Meet with government officials, health care providers and organizations working in your community to get the latest information about the HIV epidemic in your constituency and country.
2. Ask your Ministry of Health about the types of paediatric treatment available and the gaps. Ask your Ministry of Finance about HIV treatment allocations, particularly for infants and children.
3. Visit hospitals and service providers to gather first-hand knowledge of the challenges families face in getting testing and treatment for their children and to gain an understanding of how HIV testing of newborns and children is performed and followed up.
4. Enhance public understanding of paediatric HIV and the barriers facing children in accessing care and treatment, including by holding public meetings to inform your constituents. Educate the public about the commitment of your government to ensuring universal access to HIV treatment by children who need it.
5. Speak out against HIV-related stigma and discrimination affecting children at home, in schools and in the community.

Parliamentary leadership and action: TANZANIA

Tanzania has an exceptionally active parliamentary coalition, the Tanzania Parliamentarians AIDS Coalition (TAPAC), with a unique membership of 75 per cent of current Tanzanian MPs, the country's President and Prime Minister and many other high-level politicians. Over the past decade, TAPAC's actions have contributed to combating stigma against people living with HIV and securing an increased budget for HIV/AIDS. Some of TAPAC's key achievements include the adoption of one of the most progressive pieces of legislation on HIV/ AIDS, and the creation of a Standing Committee on HIV/AIDS Affairs in 2008, which truly mainstreamed HIV into the work of parliament.

For further information about TAPAC, see http://www.ipu.org/pdf/publications/hiv12_en.pdf