Children being forgotten in the AIDS response
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AIDS and inequality always go hand in hand. What has changed over the years is the people affected by the AIDS epidemic. 30 years ago it was mostly young men who got seriously ill and died. Now it is children, young women and vulnerable people who are hit disproportionately hard by AIDS. Treatment for a whole new generation is lagging behind and the youngest ones are simply being forgotten. It is this that endangers all the progress made so far.

We know what has to be done to respond to AIDS, so it is crucial that we reach everyone affected. Responding to AIDS is all about a person’s right to treatment, and about the political choice to fight structural inequalities. The end of AIDS is now, in 2019, largely in the hands of the world’s political leaders.

We know exactly what we need to do to end AIDS. We need to make all prevention methods accessible – including the HIV prevention pill PrEP – and we need to test and immediately treat people with life-saving drugs. Because when people living with HIV are on treatment, they remain healthy and cannot pass on the virus. Treating HIV brings the epidemic to a halt. We can end AIDS. Responding to AIDS is a choice.

The global response to AIDS is not on track. It is shocking that so many new HIV infections are still being diagnosed every year, and that the decline seen in recent years has not continued. In some countries the epidemic is worse than ever before. That is unacceptable, as it means that goals that seemed achievable will not be met. Progress is slowing down, while at the same time funding is being cut. All of us made the commitment to end AIDS. We must honour that commitment. To do so, we need a change of course. And that calls for leadership.

I call on everyone to continue to support the fight against AIDS. And I call on the Netherlands to continue to fulfil its unique role in the world, supporting those people who are most affected by HIV. We are the generation who can end AIDS. We must adopt an approach to the epidemic in which we focus on children, young women and everyone who is at risk, and where no one is excluded or forgotten. That is the only way to end the AIDS epidemic. Yes, we can put an end to AIDS.
“Our united effort can make the difference between life and death. This year I was privileged to meet some very brave children in Zimbabwe. I met Chido and Rumbi, whose mother had contracted AIDS and died, something that happens to so many children. For years now, Rumbi has been making sure that her younger brother takes his daily HIV medication. Rumbi herself had not been tested because she never said she felt ill. One of our community health workers discovered that she too has HIV. This was diagnosed in time, fortunately, so she is now on treatment.”

Mark Vermeulen,
Executive Director Aidsfonds
World AIDS Day, 1 December 2019
Executive Summary

Over 24 million people living with HIV worldwide are now on treatment. That is more than ever before. But 1.7 million new infections means yet more people living with HIV who need lifelong, life-saving treatment. There are fewer and fewer AIDS-related deaths, but every 40 seconds a child, woman or man somewhere in the world dies due to AIDS-related illness. And 14 million people living with HIV worldwide are still not on treatment. Although the crisis is not over, funding is already being cut. The commitment to end AIDS worldwide by 2030 will not be met. The end of AIDS is not yet in sight.

Children missing and forgotten
Children with HIV are in crisis. Every 5 minutes, a child (aged 0-14) somewhere in the world dies due to AIDS-related illness. Even though the number of AIDS-related deaths among children and adolescents (aged 0-19) is gradually declining year on year, it is still double that of 2000. The annual number of deaths among adults is declining much faster.

Every day, more than 400 children (aged 0-14) in the world become infected with HIV. But fewer of these children are receiving treatment than adults with HIV. An average of only 54% are on life-saving treatment. That is almost 10% less than adults living with HIV. In West and Central Africa, only a quarter of the children are reached. Research conducted by Aidsfonds in six African countries shows that there is a lack of adequate medical care for babies and children, healthcare providers are not properly equipped to treat children, and the medicines available are not paediatric formulations.

Whether or not a child with HIV will survive depends on whether they are rich or poor, live in an urban or rural area, and how well educated the mother is. Too many children living with HIV are missing and simply forgotten. They need to be traced quickly and given the right kind of medication, because otherwise they will die and we will miss the opportunity to end AIDS among the youngest generation.

Young women and key populations affected
There are noticeable differences between countries. The success of effective action in one country is undone by policy failures in another country. In places where stigma and discrimination predominate, the HIV epidemic hits hard

Young women (aged 15-24) are disproportionately affected. More than 60 young women die every day due to AIDS-related illnesses.
Worldwide, AIDS is the leading cause of death for women. Inequality and violence make young women in Central and Southern Africa twice more likely to become infected with HIV than men of the same age.

Worldwide, just over half of all new HIV infections are found among marginalised groups such as gay and bisexual men, transgender people, sex workers and people who use drugs. In more and more countries, vulnerable populations are discriminated by laws and excluded from HIV prevention and care. In Russia, for example, where no less than 95% of the new HIV infections are found among these groups.

**Inadequate response from political leaders**

1.7 million people became infected with HIV in 2018. That is slightly less than in 2017 and a 16% decline since 2010. Yet this number is nowhere near the commitments made by the world’s political leaders that are necessary to end AIDS. Their pledge was that in 2020 there would be fewer than 500,000 new HIV infections. It is a UN target which cannot possibly be achieved.

Meanwhile, funding for the AIDS response is being cut. Global funding declined by almost $1 billion in 2018. National investments in the affected countries have not grown rapidly enough to offset the drop in international resources. Because of this, there is now a funding gap of some $7.2 billion for the global AIDS response.

“While the Global Fund partnership continues to have huge impact, saving 32 million lives since 2002, the world is not on track to meet the target of ending the AIDS epidemic by 2030. We need a sharp change of trajectory”.

Peter Sands, Executive Director of The Global Fund to fight Aids, tuberculosis and malaria.
HIV in the world in 2019

37.9 million people living with HIV worldwide

24.5 million people have access to life-saving treatment

1.7 million new HIV infections

770,000 AIDS-related deaths

Children

• 1.7 million children (aged 0-14) living with HIV

• An average of 54% are on treatment, almost 10% less than adults with HIV

Women

• Every day, there are 60 AIDS-related deaths among young women (aged 15-24)

• Every day, there are almost 1000 new HIV infections among women aged 15-49

Key populations

• 54% of new HIV infections within key populations

• More than 95% of new HIV infections among these vulnerable populations in Russia

• 95% of new HIV infections among these populations in the Middle East and North Africa
No further decline in new HIV infections

Declines in new HIV infections in Eastern and Southern Africa, but stagnation and even increases in other regions
AIDS-related deaths

UN target for 2020: fewer than 500,000 new HIV infections

AIDS is not over yet

1.7 million people infected with HIV
UN target for 2020: fewer than 500,000 new HIV infections

770,000 AIDS-related deaths
UN target for 2020: fewer than 500,000 AIDS-related deaths
Children with HIV are in crisis

Aidsfonds Research into paediatric HIV treatment in Kenya, Mozambique, Nigeria, Zuid-Afrika, Oeganda and Zimbabwe.

Rumbi(9) and Chido(6) both have HIV and are taking medication.
Without treatment, a third of the children with HIV will die before they reach the age of one, half of the children living with HIV die before they reach the age of two.

Every 5 minutes a child dies of AIDS

About half of them receive life-saving treatment. In some countries only a quarter of them do. The standard of HIV care for children is sub-optimal in many countries. Whether or not you can live a healthy life with HIV depends on where you were born.

Every day, more than 400 children worldwide become infected with HIV

Almost half of all children who became infected with HIV in the past year live in 6 African countries: Kenia, Mozambique, Nigeria, Zuid-Afrika, Oeganda en in Tanzania.

Two-thirds of all children with a new HIV infection are found in 15 African countries (the countries mentioned above plus the Democratic Republic of Congo, Angola, Zambia, Zimbabwe, Cameroon, Malawi, Ghana, Ivory Coast and Ethiopia)

Shortfalls in paediatric HIV treatment

Almost all babies with HIV were infected by their mothers during pregnancy, birth or breastfeeding. Every child with HIV could live a long, healthy life if the correct diagnosis was given in time, and if they were guaranteed treatment and care for the rest of their life. But only a little over half of these children, on average, currently have access to life-saving drugs.

World map: Children living with HIV
Children represent 15% of all AIDS-related deaths. There are shortfalls in paediatric HIV treatment when compared to treatment for adults. Even though the number of AIDS-related deaths among children and adolescents (aged 0-19) is gradually declining year on year, it is still double that of 2000.
**United global effort**

Three years ago, it was agreed at the United Nations that children with HIV would be made a priority. There would be a global “fast-track strategy”. By 2020, there would be fewer than 20,000 new HIV infections among children. According to the latest figures we are nowhere near that, with another 160,000 children infected with HIV in 2018. The main reason for this is a lack of adequate medical care for babies and children in many countries.

**Mothers**

In recent years, there have been huge efforts to prevent HIV transmission from mother to baby. Successful prevention programmes received international funding. 80% of all pregnant women with HIV are now on treatment. To compare: only 62% of all people living with HIV worldwide are receiving treatment.

It is not surprising that the World Health Organization (WHO) calls this a great success. But HIV transmission is also possible after birth, i.e. through breastfeeding. So daily medication for a mother living with HIV is crucial, both for herself and for her baby.

**Rapid testing**

WHO guidelines state that children of HIV-positive mothers should be tested for HIV between four and six weeks after birth. If the result is positive, treatment should begin immediately. The sooner treatment starts, the greater the child’s chances of survival. Early infant diagnosis using diagnostic devices for HIV testing is therefore crucial – the difference between life and death.

It takes 55 days before conventional laboratory-based HIV testing services can provide a diagnosis, while point-of-care diagnostic devices for rapid testing give a result the same day. The Aidsfonds research shows that when a baby’s diagnosis takes longer, their HIV treatment also starts much later. On average, they are over three months of age and quite ill already. While babies with an early diagnosis can also be given antiretroviral drugs immediately; usually at the age of six to eight weeks.

Rapid testing equipment is not available everywhere because it is more expensive and also calls for specially trained personnel. Aidsfonds believes that a lot could be achieved in African countries in a short time by providing suitable testing devices and training personnel to use them.
Missing children

According to Aidsfonds research, if there is a long waiting time between testing and diagnosis, babies with HIV disappear. Mothers with newborn babies cannot wait around for days to get the result of a test. The long journey to the clinic is too expensive, and the fear of stigma and discrimination often means they do not go back to hear their child’s diagnosis. Many other children with HIV are not even tested at birth, for example because the mothers have their babies at home. And these ‘missing’ children need antiretroviral drugs. Without treatment they will die.

In Kenya, Mozambique, Nigeria, Uganda, Zimbabwe and South Africa, Aidsfonds actively searches for missing children with HIV. To do this, it trains community health workers. They go to all the villages in the area to test children for HIV, and then make sure the children take their life-saving medication. In these countries, there is a lack of funding and political will to make HIV care for children a priority. Nigeria and Mozambique have the worst shortfalls, with no specific policies for tracing children with HIV and treating them.
Child-friendly medication
For children living with HIV, the medication available is far from ideal: the pills are big and therefore difficult to swallow and they have an unpleasant taste. Sometimes, children have to take more than one pill at the same time. Other treatment is available as a medicine, but the oral liquid contains alcohol and is therefore unsuitable for children. 40% of the children living with HIV in the six countries where the research was done are given medication actually meant for adults.

Most countries only have antiretroviral drugs for adults. These tablets contain 50 mg of active ingredient. Children are often given a half dosage. But even those 25 mg are too strong for children and often have nasty side effects.

HIV medication specially formulated for children is available, for example tablets with 5 or 10 mg of the active ingredient, but low production volumes make it less profitable. Aidsfonds is in discussions with the pharmaceutical companies ViiV and Gilead, hoping to convince them to speed up the availability of special paediatric formulations.

Increasing resistance
Using HIV medication that is not specially formulated for them makes it very hard for children to stay on the treatment. And children do stop taking their medication, according to the Aidsfonds research.

A doctor or nurse is too far away to keep an eye on the children. And in more and more children the HIV virus is becoming resistant to mainstream, life-saving treatment because they stop taking the medication. That means they are becoming increasingly difficult to treat. In Uganda, for example, growing numbers of children have developed resistance to antiretroviral drugs: 10% of the children in the research have a drug-resistant HIV virus.

"It is high time we begin prioritizing children. We know there are children out there who have fallen through the cracks and have not been found. We fully support the initiative to find the missing children who are living with HIV".

Dr. Angela Mushavi of the Zimbabwean Ministry of Health and Childcare
**Kenya**

- **120,000** children living with HIV, **61%** receiving treatment
- **7,600** new HIV infections among children in 2018
- **5,200** children in 2018
- **850,000** children (under the age of 17) have lost their parents due to AIDS

Funding for the HIV response doubled between 2006 and 2012, thanks to Western donors. That international support will stop in 2020. There is no budget for children living with HIV.

**Mozambique**

- **140,000** children living with HIV, **51%** receiving treatment
- **16,000** new HIV infections among children in 2018
- **8,700** children in 2018
- **1,1 mln** million children (under the age of 17) have lost their parents due to AIDS

Mozambique spends **7.8%** of its total national budget on health. Western donors contribute **3%** to the HIV response budget. There is no budget for children living with HIV.

**Nigeria**

- **140,000** children living with HIV, **26%** receiving treatment
- **24,000** new HIV infections among children in 2018
- **14,000** children in 2018
- **1 mln** million children (under the age of 17) have lost their parents due to AIDS

The budget for healthcare is **0.5 - 1%** of the total national budget. **95%** of the national HIV budget comes from Western donors. There is no budget for children living with HIV.
Zuid-Afrika

- 280,000 children living with HIV, **58%** receiving treatment
- 14,000 new HIV infections among children in 2018
- 4,400 children in 2018
- 1.2 mln million children (under the age of 17) have lost their parents due to AIDS

13% of the budget for the HIV response comes from Western donors. There is no budget for children living with HIV.

Uganda

- 95,000 children living with HIV, **68%** receiving treatment
- 7,600 new HIV infections among children in 2018
- 5,500 children in 2018
- 950,000 children (under the age of 17) have lost their parents due to AIDS

90% of the budget for the HIV response comes from Western donors. There is no budget for children living with HIV.

Zimbabwe

- 84,000 children living with HIV, **89%** receiving treatment
- 4,800 new HIV infections among children in 2018
- 3,300 children in 2018
- 580,000 children (under the age of 17) have lost their parents due to AIDS

86% of the budget for the HIV response comes from Western donors. There is no budget for children living with HIV.
“Every 5 minutes a child dies of AIDS. Children living with HIV are simply forgotten about. Treatment for a whole new generation has been neglected. We must now give top priority to effectively tracing and treating children. We must not wait any longer with the production of child-friendly medication that is affordable too.”

Mark Vermeulen, Executive Director, Aidsfonds

“Stalling HIV progress is a wake-up call to the world. Progress in stopping new HIV infections among children has stagnated, missing global targets by a wide margin. Countries have to look at why this is happening if 2020 targets are to be met.”

Shannon Hader, Deputy Executive Director, UNAIDS
AIDS is not over yet

Investments
Last year, fewer resources were available for the global response to AIDS: a total of $19 billion. This has led to a deficit of more than $7 billion on the funding calculated to be needed for 2020 to end AIDS.

Contribution
It is the Western donors who are cutting back on funding (three lower parts of the bars). Last year, their joint contribution was $8 billion. The funding provided by the affected countries themselves has stabilised (top part of bar).

"We need more. The commitment is not just to reduce the Aids epidemic; it's to end it. Now is not the time to lose focus."

Dr. Tedros Adhanom Ghebreyesus, Director General of WHO
Contrasts in the world
There are noticeable differences between countries. The success of effective action in one country is undone by policy failures in another country. In places where stigma and discrimination predominate, the HIV epidemic hits hard.

While South Africa has successfully reduced the number of new HIV infections since 2010 by no less than 40%, the epidemic is growing alarmingly in Russia: ‘Russian Federal AIDS Center’ statistics show a 70% increase when 2017 is compared to 2010.

Since the beginning of the HIV epidemic, South Africa has been the worst hit. It is the country with the highest number of people living with HIV in the world. But South Africa is now also a country with a large number of HIV treatment programmes. By contrast, Russia is in the midst of a health crisis, according to the ‘Russian Federal AIDS Center’.
Contrasts on the African continent
Stark contrasts are evident on the African continent.

There is a growing HIV epidemic in countries in North and Central Africa, with a 10% increase in new HIV infections since 2010. But in most countries in Eastern and Southern Africa, where there are still the highest numbers of people living with HIV, there has been a great deal of progress. HIV infections have fallen by a third here, and the number of AIDS-related deaths has halved. But support must continue if AIDS is to be ended.

World map: Africa with Kenya/Botswana - Mozambique/Nigeria

HIV in Kenya
- 1.6 million people living with HIV
- 46,000 new HIV infections, 30% fewer than in 2010
- Two-thirds of the people living with HIV are on treatment
- 68 AIDS-related deaths each day

HIV in Botswana
- 370,000 people living with HIV
- 8,500 new HIV infections, 36% fewer than in 2010
- More than 90% of the people living with HIV are on treatment
- 13 AIDS-related deaths each day

HIV in Mozambique
- 2.2 million people living with HIV
- 150,000 new HIV infections, 7% more than in 2010
- Half of the people living with HIV are on treatment
- 148 AIDS-related deaths each day

HIV in Nigeria
- 2 million people living with HIV
- 130,000 nieuwe hiv-infecties, dat is 5% meer dan in 2010
- Half of the people living with HIV are on treatment
- 145 AIDS-related deaths each day
Contrasts in Europe
Thanks to good and affordable healthcare, the numbers of people living with HIV in Europe are low, but conservative and homophobic policies in some Eastern European countries are leading to a resurgence of the HIV epidemic. People who are at risk of contracting HIV are faced with increasing stigma and discrimination within the borders of Europe, in countries such as Hungary and Poland.

Meanwhile, Ukraine is trying to turn the tide in the country, with international support. And the Netherlands has the best chances of becoming the first country in the world to bring an end to its HIV epidemic.

World map: Europe with the Netherlands - Ukraine

HIV in Ukraine
- 360,000 people living with HIV
- An estimated 19,000 new HIV infections
- A third of the people living with HIV are on treatment
- 40 mensen per dag sterven aan de gevolgen van aids, dat is 22% minder dan in 2010

HIV in the Netherlands
- 23,300 people living with HIV
- 664 mensen met hiv erbij
- Nine out of ten (92%) people living with HIV are on treatment
- 20 AIDS-related deaths each year
The Netherlands towards 0

Each year, the number of new HIV infections in the Netherlands continues to decline, showing the rest of the world that ending the HIV epidemic is possible. The Netherlands could be one of the first countries in the world to reach zero new HIV infections.

**Rapid testing and timely treatment**

Early diagnosis of an infection and timely treatment are crucial. This ensures that people living with HIV can live long, healthy lives and also stops further transmission. People who are treated effectively with antiretroviral drugs cannot pass on the virus. Earlier diagnosis of HIV infection will stop the epidemic.

**PrEP**

PrEP is a drug that prevents HIV. The HIV prevention pill is one of the most effective ways to substantially reduce the number of new HIV infections. In London, the number of new infections was halved after PrEP was introduced. In the Netherlands, PrEP is unfortunately not yet accessible and affordable for everyone. Since the summer of 2019, PrEP has been available at GGD health centres for gay men who are more at risk of HIV. This is a programme for a five-year period. For other people, PrEP is only available through a doctor and they have to pay for it themselves.

Aidsfonds wants PrEP to be made widely available, as that will lead to a substantial reduction of new infections. This could be done, for example, by providing PrEP under basic health insurance cover, as is already the case in Belgium, France, Portugal, Germany, England and Norway.

**The Netherlands towards 0**

Zero new HIV infections in the Netherlands is a realistic and achievable target. The challenge now is how to work more effectively and efficiently, using all the knowledge and tools available to reach the right people in the right places. We will need to provide fresh impetus to trace those last infections. Political will and more cooperation between regions and large cities are also vital. PrEP must be made widely available. At the same time, the damaging stigma surrounding HIV must be dispelled, so that HIV becomes something you can easily talk about. If all this can be achieved, then we can end the epidemic.

Aidsfonds has taken the initiative to work together with healthcare providers and scientists, plus the people living with HIV, on this ambitious response to HIV in the Netherlands.
Conclusion

Despite the huge progress made in the global response to AIDS, the latest HIV data is alarming. At the end of 2019, it is obvious that the end of AIDS is not yet in sight. So millions of people all over the world will still die unnecessarily and there will continue to be new HIV infections. First, that is an enormous amount of suffering. What’s more, not all countries will be able to bear the cost of this continuing epidemic.

It looks like one of the main commitments – to end the HIV epidemic for the next generation – will not be met. The ‘missing’ children living with HIV are being forgotten. And this will have a devastating effect.

**Aidsfonds is investing in the youngest generation**

This situation can still be turned around if we act fast and effectively. But we can only reduce the number of new HIV infections if we focus on the populations and regions with the most problems. Aidsfonds is working closely with local communities and small organisations of people living with HIV to make their voices heard and to mobilise political will for providing sustainable healthcare with respect for the individual living with HIV.

Aidsfonds believes that children should now be given top priority. If we want to end AIDS, then we must start with the youngest generation. In the coming three years, Aidsfonds wants to find 40,000 missing children with HIV in Africa and to make sure they receive treatment before it is too late. Aidsfonds trains community health workers in six countries. They, in turn, ensure that children living with HIV are found and tested and given the medication they need for a healthy future. Both UNAIDS and WHO call this a very promising approach.
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Colophon

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