The children left behind
Inequalities drive epidemics
Contents

Foreword by Mark Vermeulen, executive director, Aidsfonds - Soa Aids Nederland

Summary:
COVID-19 increases the inequalities in the HIV response

HIV in the world
HIV in the world’s regions

Funding the global response to AIDS

Conclusion
Foreword

Now, more than ever before, people have come to understand the importance of health, and how easily it can be endangered by a pandemic. Most of the populations of Europe and North America have been vaccinated against COVID-19. After this winter, we can perhaps look forward to getting back to normal life. And we hope that COVID-19 can even be taken off the list of public health threats in rich countries in the Western world in the not too distant future.

But that won’t happen if we do not tackle the pandemic across all continents. For the COVID pandemic is still devastating the world’s poorest countries and communities. And just 4% of the populations in sub-Saharan African countries have had their first vaccination. Global vaccination levels are alarmingly unequal, and nowhere near what is needed to contain COVID-19 and prevent the emergence of new, dangerous variants that will endanger the whole world once again.

Inequalities in the world are the greatest obstacle to ending a pandemic. That is precisely what the HIV response has shown us for many years now.

**HIV pandemic has run rampant for the past 40 years**

This year, it is 40 years since the first cases of AIDS. Since then, almost 80 million people have become infected with the HIV virus, and there have been over 36 million AIDS-related deaths worldwide. As yet, there is no cure to prevent HIV, and it still cannot be cured, but there is now effective treatment that suppresses HIV to such a degree that the virus can then no longer be passed on. Huge advances have been made: more than 70% of the people living with HIV - 27.5 million people worldwide - are now on life-saving treatment.

But AIDS is not over yet. The number of new HIV infections worldwide, 1.5 million in 2020, is no less than three times higher than the target the world had set itself on its way to ending AIDS. And investments in recent years have been much lower than what is necessary to achieve that ambition. The COVID pandemic has taken us even further off track.

**The children left behind**

It is the most vulnerable people who have been hit the hardest. Two years after the start of the COVID crisis, the youngest generation in poorer countries are the most affected by all the restrictions. Children with HIV are being forgotten. Young people living with HIV are not given priority. Fewer children are being tested than before, and for the first time in 20 years the number of HIV treatments given to babies and very young children has gone down, while the number of AIDS-related deaths among young people has not declined. The future is looking very bleak for the next generations in Africa and Asia.

**Partnering local communities**

Local community groups of people living with HIV have been the most effective in providing help during the COVID pandemic. They know best about what is needed. They took medicines to people’s homes, and brought food to people with no income. They were particularly resilient, able to build on decades of experience in combating viruses. That’s why we should invest in these healthcare heroes. In the past 40 years, and now once again during the COVID crisis, they have been the best partners we could have, both in the AIDS response and in the response to this new COVID-19 epidemic.

**Stop inequalities, stop AIDS**

The COVID-19 pandemic has revealed the world’s vulnerabilities. The pandemic has also shown us what an extra global effort can achieved. That insight and that commitment are both vital for preventing new HIV infections and beating AIDS.

We must now continue on the fast track in our response to HIV. By investing in equal access to HIV prevention and treatment for everyone that needs it. It is also vital that the inequalities that drive the HIV pandemic come to an end. By getting rid of discriminatory laws that exclude people because of their gender identity or sexual orientation. Stop inequalities, stop AIDS.

"The reason why the HIV pandemic needs urgent attention now is simple. During 40 years of the HIV epidemic, 80 million people have been infected; in one year of COVID-19, more than 100 million have been infected. But whereas about 2% of those with COVID-19 have died, 43% of people living with HIV have, predominantly from AIDS-related disease. HIV is the deadliest pandemic."

Dr. Anthony Fauci
director of the National Institute of Allergy and Infectious Diseases, USA
Summary:
COVID-19 increases the inequalities in the HIV response

The COVID-19 pandemic is having a devastating effect on the global response to HIV. In the past year, 22% fewer HIV tests have been done, which means that 30 million people have not been tested for HIV. According to research conducted by the Global Fund to Fight AIDS Malaria and TB, the number of HIV tests went down by no less than 41% in more than 30 countries in Africa and Asia. Over half of the HIV programmes worldwide – from prevention to treatment – are still affected by COVID restrictions.

The children left behind
The first people to suffer are the most vulnerable. There has been a dramatic decline in the number of children (aged 0-14) living with HIV who are on life-saving treatment. For the first time in 20 years, it means that fewer children have been tested for HIV, and started treatment, than the year before. It also means that children who were receiving antiviral drugs, now no longer get them and have been forgotten. Without treatment, half of the children with HIV will not reach the age of two.

Because of the COVID pandemic, there has been much less prenatal care in many countries in Africa and Asia, resulting in far fewer consultations for children under the age of five. At least 1/3 of the babies born to mothers with HIV were not tested. The number of mothers receiving drugs to make sure they do not transmit HIV to their babies also dropped by 4.5%.

Children living with HIV were being left behind, even before the COVID crisis. Almost half of all children with HIV (aged 5-14) are not on HIV treatment, while a quarter of adults are not yet treated with life-saving drugs.

Fewer young people (aged 10-19) who are at risk of HIV have gone to get tested during the COVID pandemic. HIV prevention services available for young people decreased by 12% worldwide. The number of young people in Africa who are not aware of their positive HIV status is growing. In some countries in sub-Saharan Africa, this has increased by an average of 40%. In this region, girls and young women in particular are now even more vulnerable as a result of the COVID crisis. Due to a lack of education and information about HIV, as well as increasing sexual violence, they are at twice as much risk of becoming infected with HIV than boys of the same age. 63% of new HIV infections are found in this group of young women and girls.

Contrary to trends among adults, the number of AIDS-related deaths among children and young people has not further declined. AIDS is still the major cause of death among young women (aged 15-49). They pay the price for global inequalities that have increased because of the COVID pandemic.

Inequalities obstruct HIV response
Numbers of new HIV infections have decreased in many countries, with the Netherlands hoping to be close to reaching the end of the HIV epidemic. But even though life-saving HIV drugs have been available for two decades now, these are still not accessible for all the people living with HIV. Of the 38 million people with HIV worldwide, 74% are now on treatment and can no longer transmit the virus. Over 10 million people are still not getting medicines. In 2020, there were 680,000 AIDS-related deaths that could have been prevented.

The gap between those who have access to the HIV services they need, and those who are excluded, is widening. Every day, there are at least 4,000 new HIV infections worldwide. Two thirds of these are found in countries in sub-Saharan Africa, where it is poverty, taboos and traditions that stand in the way of good HIV healthcare.

At the same time, increasing numbers of countries in the world are introducing repressive legislation that excludes people at risk of HIV from life-saving treatment. Gay men, sex workers, trans people and people who inject drugs are still disproportionately affected by HIV. 65% of the new HIV infections worldwide are among people in these key populations, as well as their sexual partners. In this way, gains in some countries are offset by policy failures elsewhere.

Inequalities drive the HIV epidemic
Inequalities between countries, between rich and poor, gender inequality, discrimination and criminalisation of groups of people are increasingly obstructing progress in the global HIV response.

"Inequalities in power, status, rights and voice are driving the HIV pandemic. Inequalities kill."

Winnie Byanyima
Executive Director of UNAIDS
HIV in COVID-19 times

27.5 million of the 38 million people living with HIV in the world are now on treatment. With antiretroviral therapy, they can live healthy lives and no longer pass on the virus. Millions of people worldwide owe their lives to that treatment. Two thirds of all the people with HIV live in sub-Saharan Africa.

Those countries in particular, with their fragile healthcare systems, have seen the worst disruption of HIV services that has been caused by the COVID pandemic. The Global Fund, that is particularly active in the HIV response in middle and low income countries in Africa and Asia, reports 33% of those countries still in lockdown, and 22% still applying very restrictive measures. This means high levels of disruption to HIV prevention and care services. So people are no longer being tested for HIV, nor receiving the care and treatment they need. And that is life threatening.

More than half of the HIV programmes worldwide, from prevention to treatment, are still being restricted by COVID measures, but it is the HIV testing programmes in particular that have been severely disrupted in the past year. Worldwide, 22% fewer HIV tests have been conducted, even 41% fewer in more than 30 countries in Africa and Asia.

One way of solving problems with the delivery of life-saving HIV drugs during the COVID crisis was to prescribe a six months’ supply of pills for people with HIV, rather than the monthly amount they are usually given. That meant they didn’t have to go back to the clinic very often. Another solution was that many HIV activists brought the HIV drugs to people’s homes in remote areas.

Most local HIV testing locations were simply closed down, or turned into COVID-19 test centres. By not testing, there is an increased risk of the HIV virus being transmitted or diagnosed too late for life-saving treatment. And the first to be badly affected by this: children, girls and young women, plus young people who are at risk of HIV. Stigma, intimidation and discrimination have all increased during the COVID crisis.

There are 1.7 million children (aged 0-14) living with HIV worldwide. Nearly half of those children are not on treatment. So every six minutes, somewhere in the world, a parent loses a child to AIDS. Almost 70% of these forgotten children live in countries in sub-Saharan Africa.

For many years, there has been a huge gap between the number of children with HIV on treatment, 54%, and the number of adults on treatment, 74%. What’s more, the COVID pandemic has had a huge impact on the services available for children and families in the past year. In 24 countries in Africa, there was a 23% drop in the number of medical consultations for children under the age of five. In seven countries in Asia, the number decreased by as much as 74%. There was also less prenatal care given – a reduction of 5% in most African countries, and 66% in the seven Asian countries.

All this has a devastating effect: for the first time in 20 years there are fewer children with HIV on treatment.

Children are forgotten

- 1.7 million children (aged 0-14) living with HIV
- 54% are on treatment, 20% less than adults. In West and Central Africa, only 32% of the children are on life-saving treatment
- 80,000 AIDS-related deaths among children in 2020
“Children with HIV were already being left behind, but with the COVID crisis it’s simply got worse. Yes, fewer children are being tested for HIV, but what’s also extremely worrying is that many children who had already started treatment are no longer getting their drugs. Mothers have to pick up those medicines at the local medical centre, but even though public transport is now working again and you’re allowed to go out, their fear of COVID 19 is so great that they prefer to stay at home.

If a mother with HIV has previously visited a clinic, and she misses an appointment, then her medicines are brought to her by community health volunteers. But babies and children with HIV are not registered. They are completely dependent on their mother taking them to the clinic. If she doesn’t do that, the children don’t get their treatment. That’s how we have lost sight of very many children in the past year. Sometimes a mother decides to share her HIV drugs with her child, but children have trouble digesting these pills. So the mother soon stops doing that.

Because of COVID, more mothers are having babies at home. Those babies are never tested for HIV. So it is the volunteers that bring food to the poorest families who are finding children who are ill and taking them to be tested for HIV. Some circumstances are very distressing. I know families where a child of 13 has to feed her younger brothers and sisters. Where the mother has died of COVID and testing for HIV is simply not a priority.

The same goes for hospitals and local testing locations. Testing for COVID-19 is now taking precedence. You have to wait months for the results of an HIV test at the moment, because the labs are much too busy with COVID-19. And if a mother only hears about her baby having HIV three months after the birth, and the baby hasn’t yet become ill, she is not likely to go to a clinic to pick up medicines. So very many young children are getting life-saving drugs much too late now. We must go out into the community as soon as we can to start testing children for HIV on a large scale.”

Merian Musinguzi
National coordinator of programmes for children with HIV in Uganda
“The World Health Organization has finally approved an HIV medicine for children. We’ve been waiting and campaigning for this for a long time. The strawberry-flavoured medicine doesn’t need to be kept cool – important in Africa – and is easy to prescribe for children up to 20 kg. And young children find it much easier to digest. There is a generic version on the market too. Dolutegravir for children costs just 36 US dollars per child per year. So this paediatric medicine is both cheaper and easier to use. It will make a huge difference. It’s vital that we get the medicine quickly to the children with HIV who need it. And that is what Aidsfonds is doing in Africa, together with national governments and local partners.”

Sabrina Erné
children’s projects coordinator
Aidsfonds
“There is still a 10 p.m. curfew. The police come down hard on you if you’re found outside after that time. They beat you and then arrest you. Public transport is still limited and face coverings are compulsory everywhere. But young people don’t have the money to buy them. It’s particularly hard for girls. From the age of 18 they can live on their own, but because of the COVID crisis many of them have been forced to return home, and their families would rather not have them there. Sexual abuse and rape are occurring more frequently. And the girls don’t dare go to a clinic to be tested for HIV, as they’re afraid of COVID and HIV. Very often they are simply sent away if they do go to a clinic. They are told that their temperature is too high so they may be infected with COVID. When you’ve been walking in the sun through the city for an hour, you get hot but that doesn’t mean you have COVID. Most clinics discriminate and send the girls away. They only let you in if you’re pregnant.

The quality of HIV care really deteriorated. For over six months, we had no HIV drugs. While so many people here are dependent on life-saving drugs. Many of us have had to stop with our HIV treatment. And that came on top of all the problems caused by the COVID crisis: no job, no home, no money for food. Very many young people have been suffering badly from depression. Something we haven’t seen before, and due to COVID. It really got to me sometimes. We couldn’t even go anywhere to talk about it, because getting together was not allowed.

So we started to help each other. We created groups online and via WhatsApp. Now we all pass around information about COVID and HIV. We check whether everyone is OK and provide food if need be. HIV drugs are now available again, but not all my friends have started treatment yet. Things are getting better but life is not yet back to normal.”

Jerop Limo (23)
Ambassador for Youth and Adolescent Reproductive Health Program (AYARHEP) Kenia

Blog Jerop Limo
https://www.lifeandlovetwithiv.ca/dear-miss-corona/

Less testing
There has been much less testing for HIV among adolescents (aged 10-19) as a result of the COVID crisis. Prevention services available for young people were reduced by 12% - particularly in countries in sub-Saharan Africa. It is this region where the younger generation is growing faster than in the rest of the world, and where 60% of all young people with HIV worldwide live. And 1 in 3 of them do not know how to protect themselves against HIV.

Research conducted by Columbia University in Zimbabwe, Malawi, Zambia, Eswatini (formerly Swaziland) and Lesotho shows that the number of young people unaware of their HIV status is growing rapidly. In the countries studied, the average is currently 40%. Zambia has the most undiagnosed young people, approximately 60%. In Eswatini, with its systematic approach to testing the whole population for HIV, that is just 22%.

There are also concerns about the young people who are on treatment, as few of them seem to be able to suppress the virus. That means the HIV drugs are not being taken as they should. And it explains why many young people go on to develop AIDS, and why that number is not declining, as is the case with adults.
Aidsfonds sets up digital platform for young people
In many countries, no education or information on HIV prevention is available. In South Africa, Kenya and Mozambique, Aidsfonds has been building a website specially for young people which gives all kinds of information about HIV. It is based on the Dutch online platform Sense.info. The new South African online platform BWise is where young people can now go with all their questions about HIV and COVID-19. The site gives them tailored advice, and refers them to the right service if they need further help. The Ministry of Health has used the site to introduce HIV self-testing kits that can be ordered free of charge.

Young people under the age of 18 can now make their own decisions about HIV testing. And young women can make their own choices, without anyone else being involved.

BWise https://bwisehealth.com/

All over the world, there are people who are particularly vulnerable to HIV infection. People who inject drugs are 35 times more at risk of HIV infection than people who do not use drugs; trans people have a 34 times higher risk of contracting HIV than other adults; female sex workers have a 26 times greater risk of becoming infected with HIV than other women; and men who have sex with men have a 25 times higher risk of HIV than heterosexual men. Of all people with a new infection, 65% are found in key populations and their sexual partners. The number of infections in these communities has risen in recent years, as discrimination and oppression are seen in more and more countries. In Russia, for example, 99% of the new HIV infections are found in key populations. Repressive legislation increases the inequalities that drive the HIV epidemic. Same-sex relationships are punishable in no less than 73 countries. And in 108 countries, the law states that people who use drugs are criminals. In most countries in the world, sex work is illegal.

Using COVID measures to their advantage
In some countries, governments are using COVID measures to target marginalised populations. Aidsfonds partners say that people in these communities are increasingly oppressed. Crisis centres and safe houses for young people and gay men have been closed by Ugandan and Kenyan authorities. The people who lived there were arrested and held for a long time. In Belarus, AIDS activists fled the country after their organisation was closed down by the authorities and their office raided. This partner coordinated regional HIV projects and provided HIV care for trans people who were not welcome anywhere else.

Many young people living with HIV are forced to go into hiding again, missing medical check-ups and no longer picking up their medicines. And that will lead to an increasing number of new HIV infections and more deaths.
Research done by Aidsfonds and partners among young people in Kenya, Russia, South Africa and Vietnam

In Russia young gay men do not know where to go for HIV testing and HIV care and treatment. Information about homosexuality is forbidden.

In Vietnam young sex workers and drug users know nothing – or not enough – about HIV. Sex work and drug use are forbidden.

In Kenya girls under the age of 18 are not welcome at clinics. Until they reach the age of 18, young people need permission from their parents to have an HIV test. Girls who have been raped hardly dare go to a clinic.

In South Africa, young people under the age of 18 need their parents’ permission for an HIV test, but what really stops them from going to a clinic for a test is that travel costs are much too high.

Young people think their peers, friends and social networks are their most important and most reliable source of information. They think that information given by the government and public health providers is not meant for them, does not answer any of their questions, and is stigmatising too.

Young people call for discriminatory laws to be abolished. They want accessible and low-cost – even free – health services that are adapted to their needs. What they also need is easy to understand information, as well as support, both online and offline.

Young, Wild and Free: https://aidsfonds.org/resource/a-young-key-population-led-needs-assessment

HIV in the world

The global response to AIDS is facing a major setback. In the current situation, the end of AIDS is not feasible in the near future. We are nowhere near achieving the targets set to realise that ambition. Many countries have not taken the action they promised and inequality in access to healthcare is a structural problem.

38 million people living with HIV worldwide
1.5 million new HIV infections this year
27.5 million people have access to life-saving treatment, that is 74% of all people living with HIV
680,000 AIDS-related deaths in the past year

680.000 AIDS-related deaths in 2020
UN target: fewer than 500,000

1.5 million people infected with HIV in 2020
UN target: fewer than 500,000 new HIV infections
The results achieved by the HIV response vary in different parts of the world. The progress made in preventing HIV in some countries is offset by other countries not taking sufficient action.

Numbers of new HIV infections per year have increased significantly in the Middle East and North Africa. But the most alarming increases in the HIV epidemic are in large parts of Eastern Europe and central Asia, particularly Russia. The main reasons for this are the discrimination of gay men and men who have sex with men and the criminalisation of people who inject drugs.
The most progress in reducing the number of new HIV infections has been made in some countries in sub-Saharan Africa, where there are the highest populations of people living with AIDS. But it is clearly the children who continue to be left behind.

Its approach to the HIV epidemic has been so effective that the Netherlands is expected to be one of the first countries in the world to stop HIV transmission. Despite the COVID crisis putting so much pressure on doctors and GGD health centres, all involved are hugely committed to achieving that goal. This does, however, call for priority setting in the national strategy and sufficient funding.

Although 93% of all people living with HIV in the Netherlands are on treatment, and in 95% of them the virus is suppressed and therefore cannot be passed on, there are estimated to be another 1,700 people who are unaware that they have HIV. This greatly delays the start of their HIV treatment.

Key to success is combining a number of actions: making the HIV prevention pill PrEP widely available (which is still not the case), more targeted HIV testing, and earlier treatment. All based on the data available on the last HIV infection hotspots. This means increased use of a tailored approach both in big cities and other regions. And – what is just as important – always taking non-medical factors into account, such as stigma, taboos or no access to health services, as is the case with asylum seekers and immigrants. That is what we have to solve if we are to prevent new HIV infections.
Funding the global response to AIDS

All UN member states agreed to a strategy to end AIDS and the HIV pandemic by 2030 at the latest. UNAIDS calculated the investment required to achieve that, and the World Health Organization developed guidelines for meeting the target. But neither the commitment to increase funding nor the commitment to invest in communities most at risk have been honoured in recent years. Global investment in the AIDS response is nowhere near what it should be. There is now an annual deficit of some 7.3 billion US dollars which is needed to end the HIV epidemic.

National investments in the countries affected have increased in the past 10 years and are now responsible for two thirds of the total AIDS budget worldwide. But these countries can no longer offset the diminishing global support. On top of that, many countries are now in economic crisis because of the COVID pandemic and are reducing their contribution to the AIDS response. It is by no means certain that they will even be able to maintain this funding level.

International donor funding has been fluctuating for 10 years, which was already a setback. The total amount invested by international donors in 2020 was back to the same level as 2010. 10 of the 14 Western donor countries, including the Netherlands, have once again reduced their investments.

The COVID crisis has also had an adverse effect. The Global Fund says it needs another 10 billion US dollars this year to offset and alleviate the impact on healthcare systems in countries in Africa and Asia. There is still a deficit of 6.3 billion US dollars.

An end to the threat of COVID-19 and the end of HIV. Both are a realistic prospect in the Netherlands and something we definitely look forward to. But the picture is very different for the rest of the world.

The efforts of scientists in the Netherlands and elsewhere may lead to a HIV cure being found in the not too distant future. At the same time, the knowledge acquired during the development of vaccines for COVID-19 may well mean that an HIV vaccine is becoming a possibility too. There is at least renewed hope. A cure for HIV, or an HIV vaccine, will really put an end to the HIV pandemic, and that would be fantastic news, especially for younger and next generations.

But that cure and that vaccine must then be available all over the world. And currently the opposite is the case. Many people in the world still have no access to life-saving HIV drugs. The same goes for today’s COVID vaccines: rich countries have supplies while poorer countries are missing out. Meanwhile, it is poor countries who will soon have to face a new wave of COVID, with more infectious variants of the virus. Inequalities drive epidemics.

40 years of responding to HIV have taught us that, to beat the epidemic, no one may be excluded from the prevention and care they need. The Netherlands sets a good example.

But there will only be global success if governments in other countries put an end to discriminatory laws that affect vulnerable people. If we continue to invest in the creativity and resilience of local services and activists and communities - the people who know what they can do to solve their problems. And if we make a global effort to provide universal access to good healthcare, with no discrimination at all.

Conclusion:
Stop inequalities. Stop AIDS.

We must continue until the HIV epidemic has ended all over the world, otherwise it will come back in force. The HIV response has shown that with international support, plus the efforts of the communities affected, it is possible to reach people in all corners of the world with testing and treatment. So continuing to invest in what has already been built up, and has proved to be successful, is the right thing to do. Strengthening what is still vulnerable.

It is the only way to beat old and new epidemics.

Source: UNAIDS

Resource availability for HIV in low- and middle-income countries, 2025 target

Source: UNAIDS
References

1. UNAIDS Global AIDS Update 2021


3. The Global Fund - The impact of COVID-19 on HIV, TB and malaria services and systems for health - A snapshot from 502 health facilities across Africa and Asia

4. The Global Fund - Funding shortage puts future investments at risk

5. The Global Fund – Results report - 2021
   https://www.theglobalfund.org/en/results/

   https://doi.org/10.1093/cid/ciab031

7. UNAIDS/KFF (Kaiser Family Foundation) report: Donor Government funding for HIV in low- and middle-income countries in 2020

8. Aidsfonds onderzoek: Young, wild and free - Do young key populations have access to sexual and reproductive health services?
   https://aidsfonds.org/resource/a-young-key-population-led-needs-assessment