

RIGHT TO HEALTH



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**THE RIGHT TO
HEALTH IS
THE RIGHT OF
EVERYONE TO
THE ENJOYMENT
OF THE HIGHEST
ATTAINABLE
STANDARD OF
PHYSICAL AND
MENTAL HEALTH.***

* ARTICLE 12 OF THE INTERNATIONAL COVENANT ON
ECONOMIC, SOCIAL AND CULTURAL RIGHTS.

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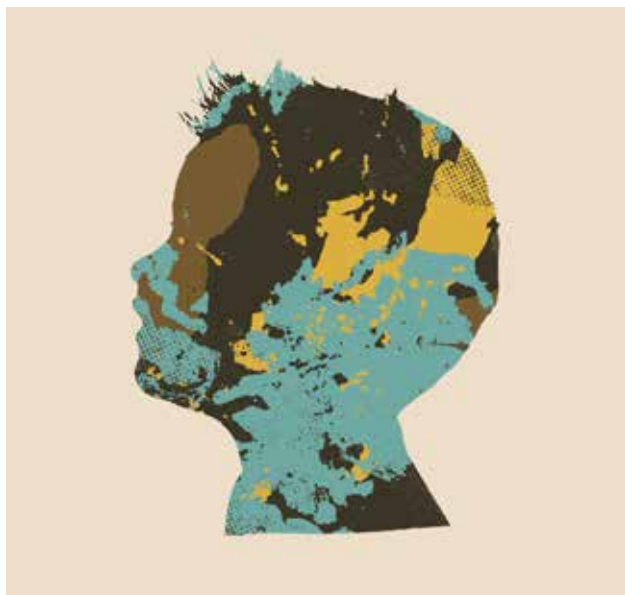
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**MY
MY
HEALTH,
MY
RIGHT.**

MICHEL SIDIBÉ

UNAIDS EXECUTIVE DIRECTOR

The right to health belongs to everyone—no exceptions.

From an early age while growing up in Mali my parents helped me to recognize and respond to inequalities around me. Every day as I returned from school, my friends and I would meet on the street a man called Makan, who was mentally ill. I soon befriended him, but one day he was missing.

With the help of my father, we traced him to where he had been detained. The authorities could not understand why as an 11-year-old I would be asking about him. “He is my friend,” I cried. When I finally saw him, he was in a straitjacket. I could not comprehend why he was being treated that way. He was able to look beyond his tormentors, set aside his anger for those who had mistreated him and smile at me. However, Makan had been denied his right to health and other human rights. Every time I see people being denied their right to health, I think of Makan.

We have come a long way since then. Health services and medicines are reaching more people than imagined even a decade ago. People are living longer. Maternal mortality has declined by nearly half and childhood mortality has decreased by more than half. Hundreds of millions of children have been immunized. Who would have thought 10 years ago that more than 20 million people would be accessing HIV treatment?

But there are millions of people dying each year of preventable diseases. It should not be this way. It need not be this way.

The AIDS response has been a pioneer in the expansion of the right to health. Its hallmark has been giving a voice to people living with HIV and giving affected communities and civil society the means to demand their right to health. People took to the streets, demanded access to life-saving

medicines and for prices to be brought down. They demanded confidentiality and treatment with dignity and without discrimination. They challenged workplace policies, education policies, gender and sexual norms and lack of investment in health systems. They became part of the solution, at the forefront of service delivery.

It is the duty of the state to ensure that everyone has the right to the enjoyment of the highest attainable standard of physical and mental health. The inequities in access to health are not acceptable. Gender inequality, lack of education, sexual violence and harassment, climate change, urbanization, conflict and humanitarian crises all create conditions in which the right to health is denied.

All people, regardless of their age, gender, place of residence, sexual orientation or other status, have one body, one life. It does not matter if someone has HIV or breast cancer, a sexually transmitted infection or diabetes—people, no matter what their health needs, require comprehensive health solutions that are accessible, available, acceptable and of good quality. States have a duty to respect, protect and fulfil the right to health of everyone. And the world has committed to Sustainable Development Goal 3, to ensure good health and well-being for all.

In this spirit, this World AIDS Day we are focusing on the right to health to highlight the gaps in access to health, not just of people living with and affected by HIV, but of everyone. From Baltimore to Bamako, health inequities must be erased.

You have a right to health.

“PEOPLE, NO MATTER WHAT THEIR HEALTH NEEDS, REQUIRE COMPREHENSIVE HEALTH SOLUTIONS THAT ARE ACCESSIBLE, AVAILABLE, ACCEPTABLE AND OF GOOD QUALITY.”

RIGHT TO HEALTH TIMELINE

Good health is a prerequisite for growth and development. States have a responsibility to protect, respect and fulfil human rights. This timeline outlines the history of some of the main obligations defined and guaranteed by international customary law, treaties and United Nations declarations that guide the fulfilment of the right to health.



WORLD HEALTH ORGANIZATION

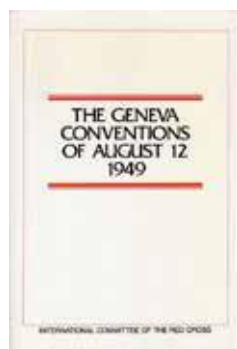
The World Health Organization's constitution, adopted on 22 July 1946, defines health as a fundamental right of all human beings—"The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition."

1948



UNIVERSAL DECLARATION OF HUMAN RIGHTS

Article 25 of the declaration states that everyone has a right to a standard of living adequate for the health and well-being of people and their families.



1949

GENEVA CONVENTIONS

The 1949 Geneva Conventions guarantee the protection of wounded and sick soldiers and prisoners of war and civilians in occupied territory.

1965

INTERNATIONAL CONVENTION ON THE ELIMINATION OF ALL FORMS OF RACIAL DISCRIMINATION

Article 5 of the convention states that, "everyone, without distinction as to race, colour, or national or ethnic origin" has "the right to public health, medical care, social security, and social services."

1966

INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS

Article 12 of the covenant recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.



1979

CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN

Article 12 of the convention calls on state parties to take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health-care services, including those related to family planning.

1989



CONVENTION ON THE RIGHTS OF THE CHILD

The convention calls on states to recognize the right to health of children and to ensure that every child has access to health services and health information.



2001

UNITED NATIONS DECLARATION OF COMMITMENT ON HIV/AIDS

The declaration recognizes that realization of human rights and fundamental freedoms for all is essential to reducing vulnerability to HIV and calls for the respect of all the rights of people living with HIV.

2001



DECLARATION ON THE TRIPS AGREEMENT AND PUBLIC HEALTH

The declaration allows countries to use the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) flexibly in order to access essential medicines to protect public health.

2002

MANDATE CREATED FOR THE UNITED NATIONS SPECIAL RAPPORTEUR ON THE RIGHT OF EVERYONE TO THE ENJOYMENT OF THE HIGHEST ATTAINABLE STANDARD OF PHYSICAL AND MENTAL HEALTH

United Nations Member States create the position of the United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health to monitor implementation of the obligations of states to fulfil the right to health.

2006

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The convention calls on the state to take specific measures to ensure the enjoyment of human rights and fundamental freedoms by people with disabilities. Article 32 recognizes the right to health of persons with disabilities.



2015

JOINT UNITED NATIONS ENTITIES STATEMENT—ENDING VIOLENCE AND DISCRIMINATION AGAINST LESBIAN, GAY, BISEXUAL, TRANSGENDER AND INTERSEX PEOPLE

The joint statement notes that discriminatory laws negatively affect public health by impeding access to health services.



2015

2030 AGENDA FOR SUSTAINABLE DEVELOPMENT

Goal 3 of the Sustainable Development Goals (ensure healthy lives

and promote well-being for all at all ages) sets several health-related targets, including achieving universal health coverage and ending AIDS, tuberculosis and malaria by 2030.

2017

JOINT UNITED NATIONS STATEMENT ON ENDING DISCRIMINATION IN HEALTH CARE SETTINGS

The joint statement calls on states to put in place measures to stop discrimination in health-care settings and to protect the rights of health-care providers.

THE RIGHT TO HEALTH

Everyone. Everywhere.

Fulfilling the right to health enables everyone to
fulfil their promise and their dreams.



Jimson Bhembe is accessing antiretroviral therapy after being referred for treatment by a traditional healer in Mnyatsini village in the Shiselweni region, south Swaziland. Credit: Giorgos Moutafis



**“THE AIDS RESPONSE WAS BOTH
A DRIVER OF AND DRIVEN BY THE
PROGRESS ACHIEVED AT THE
INTERSECTION BETWEEN HEALTH
AND HUMAN RIGHTS.”**



Credit: Giacomo Pirozzi

The right to the highest attainable standard of physical and mental health is a human right. References to the right to health are found in international and regional law, treaties, United Nations declarations, and national laws and constitutions across the globe. The right to health guarantees everyone a system of health protection and the freedom to make decisions about their health regardless of who they are, where they live, what they believe or what they do. Elements of the right to health include access to health services, including access to sexual and reproductive health services. Fulfilling the right to health is inter-related with and interdependent upon other rights including the right to adequate sanitation, food, decent housing, healthy working conditions and a clean environment.

The right to health is supported by, and dependent upon, a wider set of rights. Without the conditions to ensure our right to equality, the right to access, the right to a clean environment, the right to be free from violence or the right to education, for example, we cannot fulfil our right to health. If the air is polluted, people succumb to lung disease. Equally, without the right to health, we cannot realize related rights. For example, a child malnourished and anaemic owing to hookworm would not be able to attend school and fully fulfil his or her right to education. The Sustainable Development Goals (SDGs) provide the framework for leveraging opportunities at intersections between the right to health and other rights.

The right to health is not the same thing as the right to be healthy. Governments are obliged to provide the conditions necessary for good health. However, it is impossible to control factors such as genetics and age that influence our ability to be healthy.

WHY THE RIGHT TO HEALTH?

World AIDS Day provides an opportunity to reflect on the interdependence between progress in ending AIDS and progress towards universal health coverage and the right to health.

Everyone, including people living with or affected by HIV and people at risk of HIV, has the right to health. Without the right to health, people living with HIV and people at risk of HIV lack the services they need to keep themselves and their families healthy. Ensuring accessible, acceptable, available and good quality health services is a core principle of the right to health and is at the centre of the AIDS response.

The AIDS response was, from the outset, built upon the fundamental right to health and well-being. Advocacy for a rights-based health system provided the AIDS community with the leverage points it needed to accelerate efforts to understand HIV and then how to prevent and treat it. The AIDS response was both a driver of and driven by the progress achieved at the intersection between health and human rights.



“ACHIEVING THE
RIGHT TO HEALTH
IS A VERY GOOD
EXAMPLE OF HOW
HUMAN RIGHTS ARE
SO INTERDEPENDENT
ON EACH OTHER
AND YOU ARE NOT
GOING TO ACHIEVE
THE RIGHT TO HEALTH
UNLESS OTHER
HUMAN RIGHTS ARE
ACHIEVED AS WELL.”

Michaela Clayton,
Director, AIDS and Rights Alliance for Southern Africa

The lessons learned from the AIDS response have gone on to inform the expansion and improvement of services across the health system. Experiences from the AIDS response facilitated the expansion of medicines for all, the scale-up of health services through task-shifting and the increased involvement of people living with or affected by illness and has led the way for the integration of health services.

WHAT ARE THE KEY ASPECTS OF THE RIGHT TO HEALTH?

Often when we speak about rights, we speak about complex systems and laws and obligations. While these are critical aspects of ensuring the right to health, it is also important to talk about the concrete aspects of what the right to health looks like in our own community and in our own lives. When we are talking about the right to health, we are referring to the information, services and conditions that we need to be healthy and to stay healthy. This includes ensuring that conditions in laws and policies translate into practice, making a real difference in people's lives.

There are many different aspects to the right to health including health care services, sanitation and vaccinations. All of them are equally important, but some may be more immediate, depending on the context or the environment. Taken together, all the aspects of the right to health reinforce and support one another. They also depend on a wider set of interdependent rights. The right to health is dependent upon access to clean air and the right to live in a healthy environment, for example. It is also dependent upon the right to live in a safe and peaceful society and to be free from harm.

REALIZING THE RIGHT TO HEALTH

A human rights-based health system ensures that everyone has the services and means to achieve the highest attainable standard of physical and mental health. It recognizes that governments may not always be able to provide the most expensive or the most cutting-edge medicines or health technologies. Nevertheless, they must ensure that all health policies, strategies and programmes continuously strive to ensure that everyone has what they need to be healthy and to stay healthy, when and where they need it, and that they feel comfortable using it. All services must always be provided in a non-discriminatory and respectful manner. States must take deliberate and targeted steps towards the realization of the right to health.

**“RIGHT TO
HEALTH MEANS
LEAVING NO
ONE BEHIND”**

Yogan Pillay,
Deputy Director General for
Health, South Africa

“THE RIGHT TO HEALTH MEANS THAT PEOPLE HAVE EVERYTHING THEY NEED IN ORDER TO LEAD A HEALTHY LIFE, WHICH INCLUDES FREEDOM FROM DISCRIMINATION IN HEALTH-CARE SETTINGS, IT INCLUDES GOOD MEDICATION, GOOD ANTIRETROVIRAL MEDICINES, GOOD TESTING, AND IT INCLUDES GOOD SOCIAL SERVICES PEOPLE REQUIRE TO LIVE A HEALTHY LIFE.”

Laurel Sprague,
Executive Director, Global Network of
People Living with HIV

The right to health contains the following inter-related and essential elements: access, availability, acceptability and quality. While there is some overlap between the different elements, collectively the elements provide a robust health system framework:

➔ Accessibility

No one person has more right to health care than anyone else—everyone should be able to access health care. Health care must be affordable or free and comprehensive for everyone. It should be affordable and physically accessible where and when needed. Health services must be available for all, regardless of where they live or what community they represent.

➔ Availability

There must be adequate health-care infrastructure. This includes health buildings and commodities such as clinics and hospitals stocked with sufficient medicines, diagnostics, bed nets, etc. There must be sufficient trained health-care workers available and able to provide health services, including screening, counselling, primary care and mental health services.

➔ Acceptability

Health-care services must be respectful, non-discriminatory, culturally appropriate and treat everyone with dignity. They must take account everyone’s needs, regardless of gender, age, culture, language and HIV status. They must respect medical ethics and protect confidentiality.

➔ Quality

All health care must be medically appropriate and of good quality, which requires trained health-care personnel. It must be provided when it is need in a safe and patient-centred manner. Medicines and commodities must meet quality standards.

VOICES

I am a man who has sex with men and I am a sex worker. My access to health services is blocked because the only health clinic open when I am not working is on the other side of the city. It is my right to have access to the services I need to keep myself healthy and protect myself and my clients from HIV and other sexually transmitted infections.

I am a pregnant woman living with HIV. When I go to the health clinic for an antenatal visit I have to wait hours because there are only two nurses available to provide services to pregnant women living with HIV. Sometimes I have to leave without seeing a health-care worker or getting my antiretroviral medicines because I need to go home to care for my children. It is my right to have sufficient health services available to keep myself and my baby healthy.

I am a transgender woman living with hepatitis C. I only go to the health clinic when I am very sick because the health-care workers refuse to use my chosen female name and insist on calling out my male name in front of everyone else in the clinic. I have a right to be treated with dignity and respect.

I am a 15-year-old girl and I am sexually active. I want to get a human papillomavirus vaccination to keep myself safe from cervical cancer. The health-care worker told me I am too young and I cannot have the vaccination until I am 18. I was too afraid to ask her for condoms. I have the right to quality health services delivered by trained and professional health-care staff.

“PRIORITIZE ACCESS TO SERVICES, HAVING PLENTY OF COMMODITIES, AS WELL AS BEING ABLE TO REACH OUT THROUGH COMMUNITY SERVICES TO THOSE WHO MAY NOT BE ABLE TO ACCESS SERVICES IS FULFILLING THE RIGHT TO HEALTH.”

Nduku Kilonzo,
Executive Director, National AIDS Control Council, Kenya

THE ROLE OF THE STATE

Governments have a responsibility and obligation to create the conditions that enable us to enjoy our right to health. Realizing the right to health means that governments should do the following:

RESPECT

Every state must refrain from interfering with a person's ability to fulfil their right to health.

This includes:

- ▶ Not denying or limiting equal access to health services.
- ▶ Not allowing discriminatory laws, policies or practices.
- ▶ Not imposing discriminatory practices in relation to the health status and needs of women.
- ▶ Refraining from unlawfully polluting air, water and soil.

PROTECT

Every state must act to prevent third parties from interfering with a person's ability to fulfil their right to health. This includes:

- ▶ Ensuring that health sector privatization does not threaten the quality of health facilities, goods or services and that private facilities adhere to human rights.
- ▶ Ensuring that health-care workers meet health-care standards.
- ▶ Ensuring that vulnerable and marginalized groups are protected from violence and harmful practices within their families, schools, workplace and communities.

FULFIL

Every state must adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures to enable everyone to fully realize their right to health and put measures in place to actively inform and promote the fulfilment of the right to health. This includes:

- ▶ Demonstrating leadership for the right to health at all levels of government.
- ▶ Enacting laws to protect and promote health, including laws that protect against gender-based violence.
- ▶ Enacting laws to prohibit discrimination and rescinding discriminatory laws, including harmful and discriminatory criminal laws.
- ▶ Developing and implementing national health policies.
- ▶ Providing quality health-care services.
- ▶ Investing in health systems, including ensuring that health-care workers are appropriately trained and health facilities are in adequate numbers and are resourced and maintained.
- ▶ Ensuring that people have access to justice when they have been denied their right to health.
- ▶ Ensuring effective redress mechanisms when violations of the right to health occur.

AIDS OUT OF ISOLATION— RIGHTS ARE FOR EVERYONE

Issues of human rights have been at the centre of the AIDS response from the outset. Early in the response, people living with or at risk of HIV were denied their right to health because of who they are or what they do—sex workers, people who use drugs, gay men and other men who have sex with men, women and young girls, transgender people—or because of the disease they were affected by. They were denied their right to health services, their right to medicines, their right to protect themselves from infection. In being denied these rights, they were also denied their right to dignity, their right to a voice, their right to justice and their ability to live happy and fulfilling lives.

Rather than standing by and allowing increasing numbers of people to be denied services and dignity, the response of AIDS activists utilized the power of health and human rights frameworks to leverage change. The AIDS response positioned the demand for access to HIV treatment as a right to health, showing that health services are not a privilege for the few but rather the right of everyone, regardless of their HIV status. Activists used laws and the courts to protect individual rights—when sex workers were being criminalized for carrying condoms, they took cases to court to defend the right of women to protect their own health. Communities of people living with HIV and people affected by HIV became very skilled at knowing and using the law to defend

and protect themselves. Groups of people living with HIV were able to use the knowledge of their rights and the law to argue for access to new medicines. The success of the AIDS response established a path for people living with other conditions, such as diabetes, tuberculosis, hepatitis or cervical cancer, to raise their voices and demand services and treatment.

People living with or affected by HIV have led the way in demonstrating the power of the right to health, but also the power of health to realize wider rights. In seeking and securing access to justice in the courts and creating the space to make their voices heard in political and scientific forums, people living with and affected by HIV have also been able to realize their right to fair treatment and their right to participate and contribute to their communities and society. People living with HIV demanded their right to work in a safe and non-discriminatory environment, to earn a decent wage and to contribute to the economy. Building on the foundation established by HIV rights-based arguments, people living with disabilities, migrants and people affected by tuberculosis have been able to make progress in realizing their rights.

Today, a young woman may be focused on her right to a quality education and her right to seek the information and means to protect herself from HIV, sexually transmitted infections and pregnancy. However, her focus

is not just on her current needs, but also on enabling her longer-term hopes and aspirations. Her immediate ability to realize her right to education and health has consequences for her longer-term capacity to realize her right to decent work, her right to form her own opinions and the safety to express them publicly, and when and if she chooses, her right to get married and start her own family.

Similarly, an older man living with HIV will focus on his right to quality health services. In addition to his antiretroviral therapy, he will also have concerns about ensuring that he is able to benefit from the highest attainable standards of treatment and care for older people. He may need services and treatment for hypertension and diabetes. As he is getting older and is not able to work or earn money to pay for food and housing, he will be concerned about his right to be treated with dignity and respect and to be protected from discrimination in his old age. He will be focused on ensuring that his right to safety and security is fulfilled.

People living with or affected by HIV are first and foremost people, with busy and diverse lives and needs. Like all people, their lives change and evolve throughout their life, and with those changes come evolving needs that focus on different aspects of the right to health.

FULFILLING THE RIGHT TO HEALTH

People require access to a range of health services, information and social and economic conditions to realize the right to health. Some of these elements are outlined here.

Health care

Medicines

Information and education

Vaccines and immunizations

Health products and devices

Prevention of disease or illness

Mental health and well-being

Clean air

Sexual and reproductive health services

Safe water

Sanitation

Nutritious food

Adequate shelter

Decision-making about personal health

Healthy working conditions

Freedom from harm and violence

Gender equality

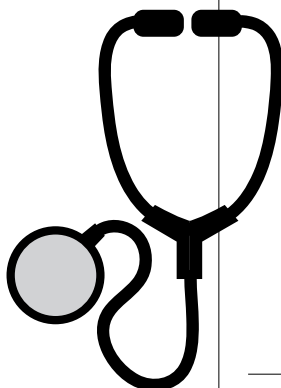
Being treated with respect and dignity

Non-discrimination

Justice

Health care

Health care must be available to all people when and where they need it and in a way that is acceptable to them. This includes ensuring that services are provided in a non-discriminatory and voluntary manner and without coercion. It must meet standards of quality and not impose a financial burden. Health services must be underpinned by a national health policy that provides the vision and commits the resources necessary.



Information and education

Information and education must be available to people to enable them to keep themselves and their families healthy and to seek help when they are unwell. Health information and education must be accurate,

evidence-informed, unbiased and non-discriminatory. Health workers must have the information and tools to be able to explain illness, treatment and the means of prevention to people in a way that they are comfortable with and are able to understand, depending on their age, disability, etc. Health education can take place through different channels. School-based education, including sexuality education, is essential for teaching children about staying healthy and developing respectful relationships based on gender equality and human rights. Social media is an essential channel for sharing health messages.



Medicines

Medicines must be available. People must have access to the medicines they need to keep themselves healthy and to treat diseases or conditions. They must be affordable to everyone, regardless of where they live or their income status. All efforts should be made to invest in the research and development of new medicines for all diseases across the globe. It is not sufficient to focus on diseases affecting only the wealthy.

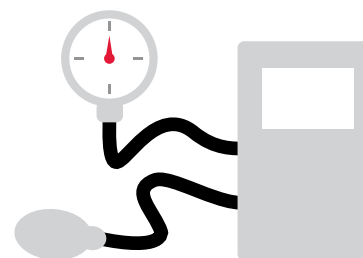


Vaccines and immunizations

Vaccines and immunizations save lives. Everyone—children, young people and adults—should be immunized against preventable diseases. Every effort must be put into developing new and more effective vaccines, including for HIV. Logistics and cold-chain system standards must ensure that the vaccines are procured, delivered and stored safely and effectively.

Health products and devices

Health products and devices, including diagnostics, condoms, contraceptives and voluntary medical male circumcision kits, must be of good quality and available to everyone in need wherever they live. Everyone should have access to products such as condoms or intrauterine devices and other contraceptives without coercion, judgement or discrimination.



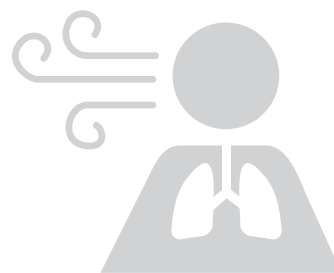


Prevention of disease or illness

Prevention of disease or illness is the cornerstone of primary health care. Whether through immunization, contraceptives, condoms or other prevention measures, people have a right to the knowledge and the means to maintain good health and protect themselves from disease.

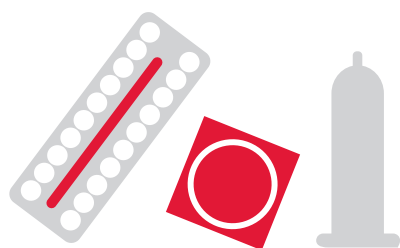
Mental health and well-being

Mental health and well-being services must be made available for everyone who needs them. Mental health is important at every stage of life and is often an additional concern for people living with long term-illnesses or conditions, including HIV, and for the elderly. The services must meet people where they need them, both in health clinics and in the community.



Clean air

Clean air is essential to life and to healthy living. In the absence of clean air, people become unwell. Infants, children and the elderly are particularly vulnerable to respiratory diseases associated with dirty air from, for example, cooking with wood burning stoves or pollution. Everyone has the right to breath clean air.



Sexual and reproductive health services

Sexual and reproductive health services provide women and girls with the means to live healthy lives, including to decide if and when to

have children and how many to have. They have the right to understand and choose the method of contraception that works best for them. Everyone has the right to be informed and aware of how best to protect themselves and their partners from sexually transmitted infections, including HIV.



Nutritious food

Nutritious food is the bedrock of survival, health and development. Without sufficient food, people are unable to participate fully in their communities and economies. Infants and children depend on good nutrition for physical and mental development and are particularly vulnerable to malnourishment. Access to adequate food is also particularly important for people on antiretroviral therapy.

Safe water

Safe water is essential to health and hygiene. Climate change is increasingly playing a role in reducing access to, and the availability of, clean water.

The poor and marginalized are the most vulnerable to the impacts of drought, including lack of potable water, crop failure and insufficient food, and to flooding.



Sanitation

Sanitation is key to the maintenance of a healthy environment. From access to toilets, to the removal of rubbish or availability of soap and disinfectant, good hygiene is a cornerstone of disease prevention.



Adequate shelter

Adequate shelter, including safe and habitable housing, is

essential for maintaining and protecting health. Everyone has the right to be warm and dry, feel secure and be protected from the elements.

Decision-making about personal health

Decision-making about personal health enables

people to take control of their own well-being. When people are empowered to make decisions about their health they are more likely to proactively monitor and protect their health, with a resulting improvement in health outcomes and quality of life.



Being treated with respect and dignity

Being treated with respect and dignity is a fundamental principle of human rights. Health-care workers must always be respectful of people and of their diverse needs, regardless of gender, race, ethnicity, language, age, etc. Equally, health-care staff should never be expected to tolerate dismissive or disrespectful behaviour from people seeking health care.

Healthy working conditions

Healthy working conditions are essential to protecting health. No one should have to risk their health in order to work. A safe workplace not only protects people from injuries and disease, it should also provide support to maintain mental health and provide employees with the information they need to stay healthy and fit.

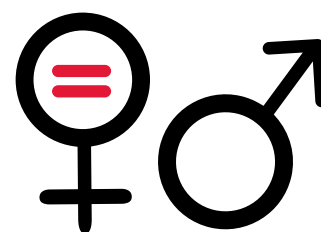


Freedom from harm and violence

Freedom from harm and violence is integral to maintaining health and well-being. Physical and psychological violence, whether real or threatened, has no place in society.

Gender equality

Gender equality ensures that men and women have equal opportunities to access the services and means to keep themselves healthy. Services must fulfil the diverse needs of women and men and be acceptable to them. This includes ensuring access to health services that only women need. Women have the right to seek health care and make choices and decisions regarding their own health, including without third party interference.



Non-discrimination

Non-discrimination ensures that people feel safe and comfortable in seeking health care. No person should ever be discriminated against or denied health care because of their HIV status, age, sex, gender, gender identity, sexual orientation, disability, race, ethnicity, language, geographical location, migrant status, etc.



Justice

Justice ensures that people have a means of challenging people, institutions or systems that are denying their right to health in some way. Governments must provide a legal system that protects the rights of everyone and censures or punishes those who impede or deny the rights of others.



A MOTHER-DAUGHTER CONVERSATION

Q&A WITH Q AND A

Mother and daughter, Quarraisha Abdool Karim (Q), the Associate Scientific Director of the Centre for the AIDS Programme of Research in South Africa, and Aisha Abdool Karim (A), a student at the Columbia University Graduate School of Journalism, spoke about health and what that means for young women in South Africa.



A: For me, growing up I was surrounded by science and it was part of my daily life, but what got you interested in science and health?

Q: Probably for most of my life I thought about science and its application to leaving people better off. So, I wanted to be a scientist and I wanted to do something that would help people.

A: Science continues to be a male-dominated field, like many others, so I feel like you brought an interesting perspective to your research. How do you think your experience as a young woman influenced your research?

Q: My very first study, when I was relatively young, 28, was when I did the first population-based survey in South Africa. The data were very clear, that young women had a four-times higher HIV infection rate than young men and that women acquired HIV about five to seven years earlier than men. And that intrigued me a lot and I spent the next 20-odd years trying to really understand that better. To understand why young women were getting infected but not young men and to understand what some of the factors were that were influencing young women to become sexually active.

A: It's interesting to me that you chose to focus on understanding why women are becoming sexually active, because I feel like my high school education was very focused on abstinence. Even though we did have a version of sex education, it wasn't very informative or useful. Do you feel like there's been a change in education around topics like reproductive health since you were in school?

Q: You know, I grew up in a much more conservative era, where having relationships in high school and being sexually active were much more frowned upon. But I think that teachers still

feel very uncomfortable talking about sexual health and choices and generally about reproductive health issues in South Africa, or, I would go so far as to say, in Africa.

A: I agree, I think there's still this hesitance to discuss sex openly at school. While the topic of sex might not have been off limits in our home, it definitely made some of my friends uncomfortable if I brought it up in conversation.

Q: You're reminding me of something else that I've learned in working with young people, which is that they don't like getting information from adults and people they're familiar with. They're more comfortable getting information from their peers. It shows how knowledge is important, but also how it's viewed in the community and how the society you live in influences your ability to act.

A: Well, you're talking about the role of the community, which extends beyond just education and policies. Nowadays, I think people are becoming more aware of the intersectionality of issues and health is no exception. Young women have been a central part of your research. What are some of the other factors that affect their lives?

Q: I've learned that the vulnerability of young women is very much tied into gender power differences in society and these disparities are very important for perpetuating the vulnerability of young women socially, economically and politically. And that extends way beyond HIV.

A: The reality of gender power dynamics is something I only really began to understand when I was at university, because it wasn't really an issue for me when I was at my girls high school. Do you think that the political landscape of South Africa changing to a democracy has had an impact on these gender dynamics?

Q: Although the politics has changed, that has not been translated to the grass-roots level. Younger women needed to understand that they are now in a different world in South Africa, with many more opportunities.

A: That comes back to the idea of gender dynamics and community. I feel that there's this idea of girls lacking independence and that makes it more difficult, especially for young women, to feel like they can make their own decisions when it comes to their bodies.

Q: So, I think there is this tension, and I think you are in a better position to talk about women of your age or younger. There used to be this thing about how women should be ignorant about their bodies and their partners will be able to tell them everything. Whereas I think to be empowered, you actually need to know about your own body. It's so important for young women to have access to information about health. We need to be encouraging an attitude where young women are no longer ashamed to know about their own bodies. Do you think there's a way we can address this?

Q: Having a social environment that is supportive of those norms is critically important, because young women themselves have very little agency. But in order to create that climate and context, it will necessitate men taking greater responsibility, boys taking more responsibility for themselves and their behaviours.

A: Education is such a key part of creating that environment and addressing the topic of health. Being able to see the impact that your research had on public perceptions gave me a sense of the power that information can have and was part of the reason why I decided to be a journalist. This is something particularly important in this day and age, when we need to combat the spread of misinformation and debunk myths in health care and beyond.

Right to health

ADOLESCENT GIRLS

A CONVERSATION WITH AGNESS CHINDIMBA

Agness Chindimba is deaf and a champion for women and girls living with disabilities. She is the founder and Project Coordinator of the Zimbabwe Deaf Media Trust. She enjoys working with young deaf women and supporting their growth and empowerment. Ms Chindimba is also a member of Deaf Women Included, an organization founded in 2014 that works with deaf women from across Zimbabwe, focusing on the dissemination of information to deaf women on health, education, life skills and being active participants in decisions affecting their lives.

A large, stylized graphic of the letters 'Q&A' in white on a dark green background. The 'Q' is a simple, rounded shape with a vertical bar through its center. The ampersand is a decorative, calligraphic symbol. The 'A' is a simple, blocky shape with a vertical bar through its center. The letters are positioned in the lower half of the page, with the 'Q' on the left and the 'A' on the right.

Stepping up access to health for young women living with disabilities

“THE HIGH NUMBER OF HIV INFECTIONS AMONG YOUNG WOMEN LIVING WITH DISABILITIES SHOWS THEIR VULNERABILITY TO ABUSE AND THEIR LACK OF ACCESS TO THE RIGHT TO HEALTH.”

What does the right to health mean to you?

I see the right to health as a basic human right that should be accessible to all, with accessibility being unrestricted by cost or the physical environment. The right to health also means having choices on health issues that affect our bodies, including sexual and reproductive health, choice about marriage, choosing the number of children to have and safe delivery. The right to health should incorporate economic empowerment to enable girls and women to have nutrition for good health. Ultimately, having control over our bodies is what the right to health means to me.

What is preventing adolescent girls and young women living with disabilities from being able to exercise their right to health?

Adolescent girls and young women living with disabilities are prevented from accessing their right to health by the attitudes of health workers and society when it comes to sexual and reproductive health. Families and society at large do not equip girls living with disabilities with information because it is still believed that women and girls living with disabilities are asexual.

The attitudes of health workers prevent girls and women living with



**“THE RIGHT TO HEALTH ALSO MEANS HAVING CHOICES
ON HEALTH ISSUES THAT AFFECT OUR BODIES.”**

disabilities from accessing health services, even at the times when they need them the most. In Zimbabwe, there is a lack of disability-friendly health information on, for example, cancer, HIV, menstruation and gender based violence. The absence of information in sign language, braille or large print leaves women living with disabilities with huge knowledge gaps. This information gap, combined with general low education and limited access to health information on social media, leaves behind adolescent girls and young women living with disabilities.

What more can be done to make sure that adolescent girls and young women living with disabilities can access services?

There is a need to disseminate information in user-friendly formats, including sign language, braille and, for printed materials, large fonts. I believe that innovative approaches utilizing art, drama, mime, pictures, music, captions and subtitles to develop creative visual and interactive health messages on health education can help to raise health awareness for adolescent girls and young women living with disabilities. There needs to be societal change in attitudes and sentiment around communities living with disabilities.

The health and rights of people living with disabilities need to be mainstreamed. Peer counsellors for adolescent girls and young women living with disabilities should be trained to have a better understanding of the experiences of their peers. Providers should be aware of the impact of gender-based violence on adolescent girls and young women living with disabilities. Empowering adolescent girls and young women with the life skills they need to be

economically independent will increase their independence and increase their access to the right to health.

Do you think the situation has improved at all over the past 20–30 years?

I don't think the situation has improved, and it appears to be getting worse, with many adolescent girls living with disabilities forced into early marriages. These marriages happen despite the law. Girls are unaware and unprotected. The police know little about disabilities and courts have limited resources to give support other than when volunteers help.

The high number of HIV infections among young women living with disabilities shows their vulnerability to abuse and their lack of access to the right to health. Organizations providing family planning and HIV testing and counselling do not use sign language, offer disability-supportive services or have disability-inclusive materials. The situation cannot improve if even government buildings are not wheelchair accessible. I am and will continue to be committed to advocating, speaking up and supporting adolescent girls and young women living with disabilities until a real improvement happens.

“I DON'T THINK THE SITUATION HAS IMPROVED, AND IT APPEARS TO BE GETTING WORSE, WITH MANY ADOLESCENT GIRLS LIVING WITH DISABILITIES FORCED INTO EARLY MARRIAGES.”

BACKGROUND

Deaf Women Included is a grass-roots deaf women organization that aims to empower girls and young women living with disabilities to claim their rights and assist in the development of their own communities. It is a member of the Zimbabwe Feminist Forum, the African Feminist Forum, the Women's Coalition of Zimbabwe and the National Association of Disabled Women Network.

Speaking out

**SONITA
ALIZADEH,
ACTIVIST
AGAINST CHILD
MARRIAGE**





Eliminating child, early and forced marriage is one of the Sustainable Developmental Goals. In developing countries, one in every four girls is married before reaching the age of 18 years. Child marriage threatens the lives and health of girls and limits their prospects. Girls pressed into child marriage often become pregnant while still adolescents, increasing the risk of complications related to pregnancy, unsafe abortion and childbirth. These complications are a leading cause of death among older adolescents (15–19 years old) in developing countries. Although countries around the world have decided that child marriage is a grave violation of human rights, the problem persists.

Growing up in Afghanistan, Sonita Alizadeh was to be a bride at the age of 10. That plan fell through as her family fled to the Islamic Republic of Iran to escape the Taliban, but when she turned 16 her mother told her that a man had offered US\$ 9000 to marry her.

Armed with nothing but passion and perseverance, she found a way out of her situation. She turned her love of music into an opportunity. She has used her rap lyrics and powerful voice to advocate against child marriage and inspire young people.

In 2015, she went to the United States of America, where she is a student and spokesperson for the rights of girls to choose their own destiny.

Why is ending child marriage so important to you?

I personally understand what child marriage really means for children. It is the death of their dreams, the death of their childhood. It is fear and depression, leaving their home and families. It is often abuse. It is having and raising babies while you should still be playing with dolls. It can mean health problems. It is almost always the end of education and the end of hope.

I escaped that fate, but every day I think about all the girls—one every two seconds, 15 million a year—who must face this fate. They are children. It is absolutely devastating. These

things, knowing the personal pain and the greater consequences of child marriage, keep me going.

What is the connection between ending child marriage and the Sustainable Development Goals

Without ending child marriage, we will not achieve at least eight of the 17 Sustainable Development Goals (SDGs). For example, we can't have all boys and girls finish secondary school if girls are dropping out to get married. To end extreme poverty, girls need to finish school and reach their full potential and work together with men for the economic stability of the world.

These are examples of just a few of the SDGs. To achieve these goals, we need to work for achieving gender equality worldwide and specifically aim at eliminating harmful practices, such as child marriage.

How did you get out of marrying at 16?

In response to my impending marriage and the feelings of so many of my friends, I wrote the song "Daughters for sale" and, with the help of a filmmaker who was recording my story, made a music video. We posted it on YouTube and it quickly went viral. The video was seen by the nonprofit organization Strongheart Group, which reached out to me and facilitated my move to the United States for school.

I moved to the United States and eventually my family began to understand my perspective and decided that I didn't need to get married. My music changed my family's mind about my future. It helped them understand something they didn't understand before.

How are you advocating to end child marriage?

I consider myself an advocate and an activist even before a musician and rapper. I want to create change, and I use music to speak out about the injustices I see around me. Music can reach people in a special way.

Now, I also speak with leaders from all over the world about child marriage. By sharing my personal story and giving them a deeper understanding

of the issue I hope to impact thought and policy. I work with the Strongheart Group on all my advocacy and I am a Girls Not Brides Champion.

I speak to students, too! Education and understanding is the first step to change. Together with Robert F. Kennedy Human Rights and Strongheart, I created a curriculum on child's marriage for high school students. I think that working with young people is the key to solving many of the world's biggest problems. I have big plans for this next year!

What are the health effects of child marriage?

Child brides become child mothers. Many girls die in labour, because their bodies aren't ready for childbirth. In fact, in many countries complications from pregnancy and childbirth are the leading cause of death among girls aged 15–19 years.

When girls are too young to be mothers, babies also die. We can prevent millions of babies from dying and from becoming stunted just by ending child marriage. We can also help the health of the girls themselves.

As a result of sexual violence and poor access to health care, girls who are victims of child marriage are also more likely to contract HIV.

What can be done to stop child marriage?

We first need everyone to recognize that child marriage is a problem. That involves education. We need to make sure that countries have laws and policies to forbid child marriage and existing policies can be implemented. Child marriage is a very old tradition. There need to be programmes that support families so that they can make better decisions for their daughters and do something new. Child marriage impacts almost every part of life and many other issues. So, we need everyone to work together: people in education, people in humanitarian response and, of course, people in health. In this way, I am hopeful that we can end child marriage.



Debitu, 14, escaped from her husband after months of abuse. "I didn't want to get pregnant because I was very small. I wanted to wait until I am old enough. Sometimes I think I will die [during child birth]."

All photos, this page and facing:
Stephanie Sinclair / Too Young to Wed

CHILD MARRIAGE IS A HUMAN RIGHTS VIOLATION

Child marriage denies children, particularly girls, the opportunity to make choices regarding their dignity, their life, their health and control over their bodies. It inevitably robs them of their childhood and their education.

Girls who marry in childhood usually become mothers in their teens and carry the entire burden of their household. They are vulnerable to violence, abuse, HIV and ill health.



"Whenever I saw him, I hid. I hated to see him," Tehani (in pink), from Yemen, recalls the early days of her marriage to Majed, who she married when she was 6 and he was 25.



Rajni, 5, was woken up at 4 a.m. and carried by her uncle to be married in a secret wedding ceremony on the Hindu holy day of Akshaya Tritiya in north India.



Sandra, 14, has been married for three years and now has a five-month-old son, Alexander. Her husband, 26, met her in the neighborhood.

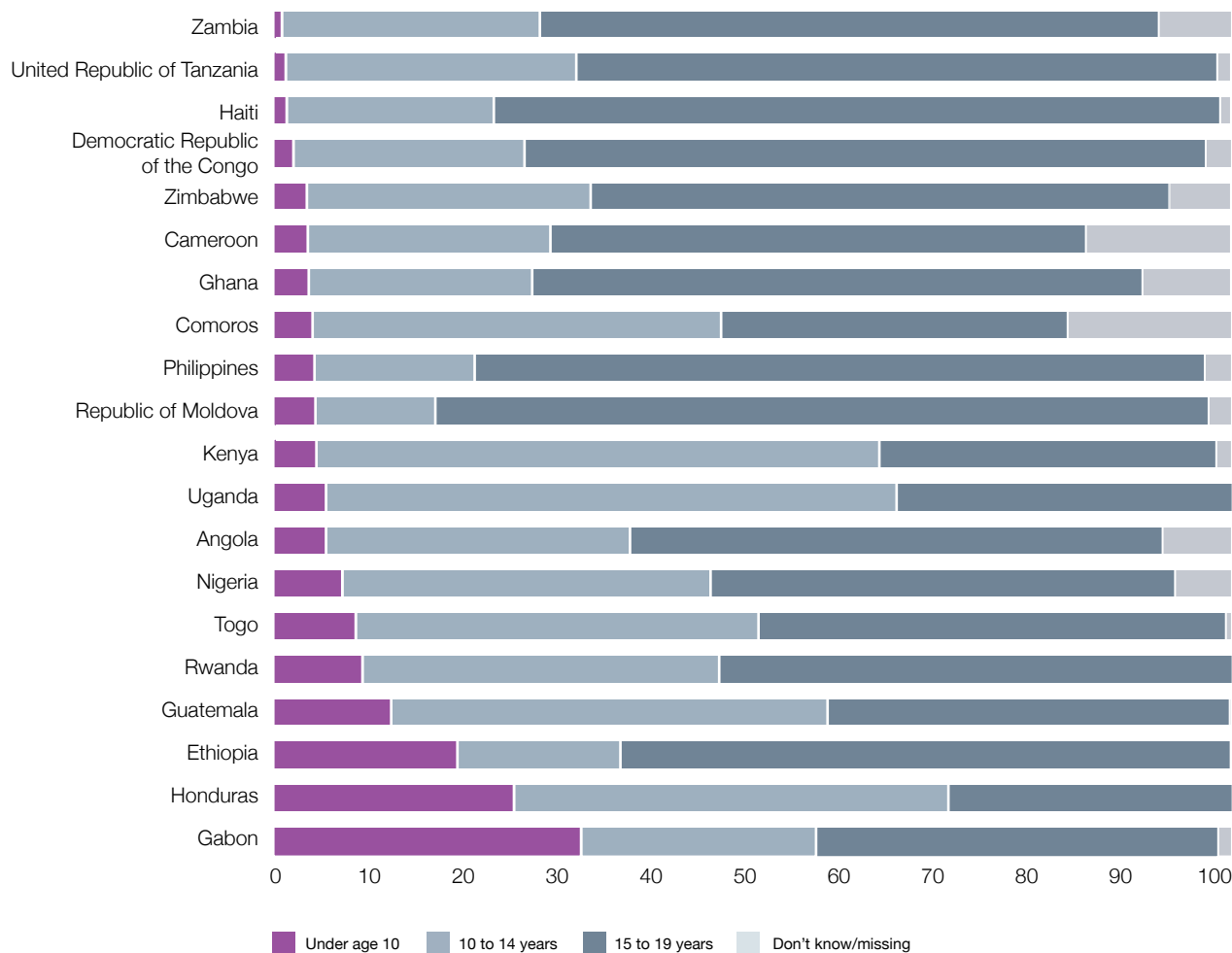
SPOTLIGHT

Protecting children from sexual violence

Children experience violence across all stages of childhood. The violence takes place in multiple settings and is often perpetrated by people who the children know and trust. A United Nations Children’s Fund (UNICEF) study shows that 15 million adolescent girls worldwide aged 15 to 19 years have experienced forced sexual intercourse or other forced sexual acts at some point in their life. Only 1% of adolescent girls who had experienced sexual violence said they had reached out for professional help. Twenty-eight countries reported that 90% of adolescent girls who had experienced forced sex said the perpetrator of the first incident was known to them. Worldwide, 176 million—one in four—children under the age of five years are living with a mother who is a victim of intimate partner violence.

For more details, read the UNICEF report *Violence in the lives of children and adolescents*, https://www.unicef.org/publications/files/Violence_in_the_lives_of_children_and_adolescents.pdf.

Fifteen million adolescent girls have experienced sexual violence

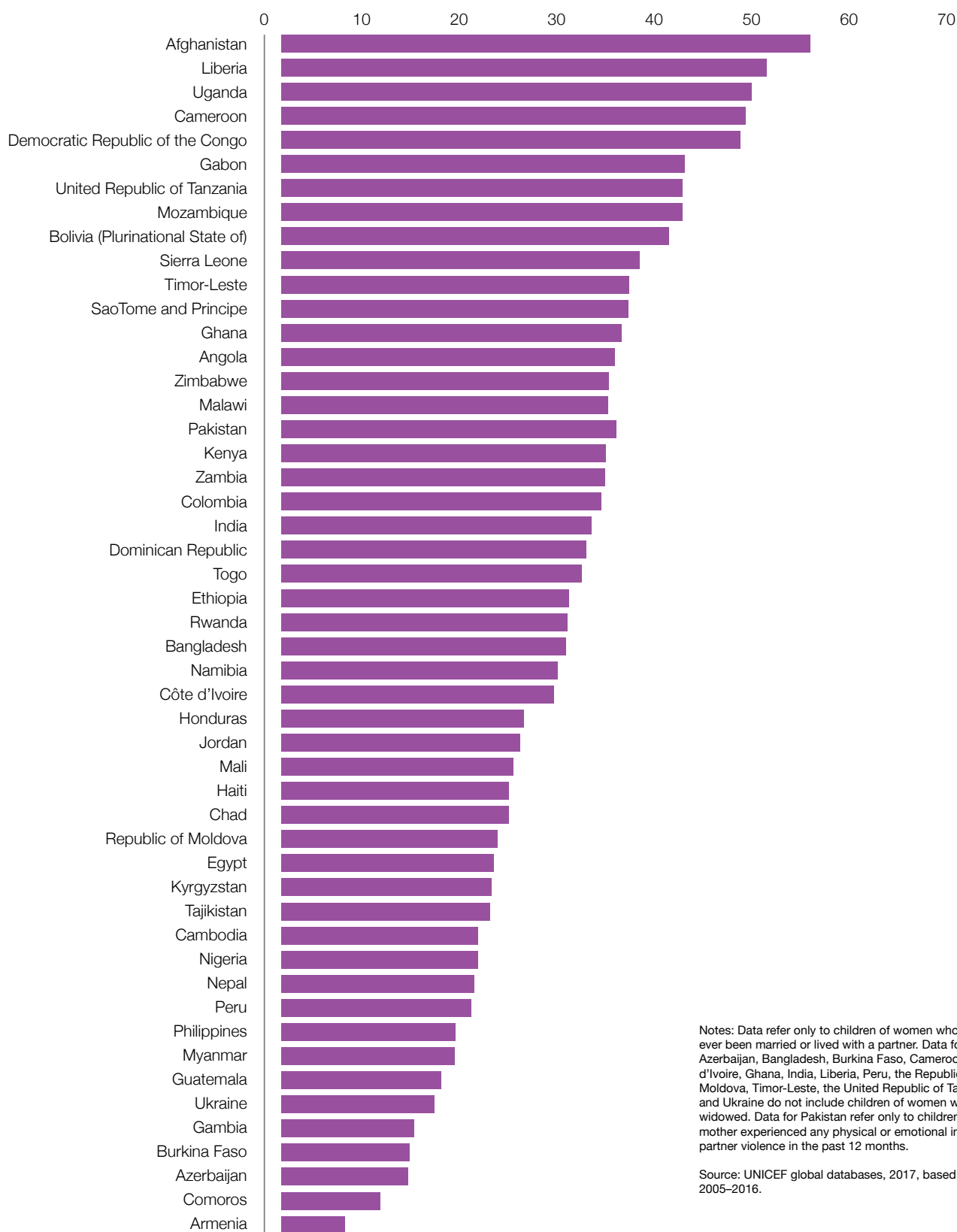


Percentage distribution of girls aged 15 to 19 years who ever experienced forced sex, by age at first incident

Notes: These data need to be interpreted with caution since there are significant proportions of girls who could not recall the exact age at which they first experienced forced sex and of missing data overall in many countries. Only those countries where the proportion of ‘don’t know/missing’ was less than 20% are included in the chart. Data for Comoros, Ethiopia and Kenya are based on 25 to 49 unweighted cases.

Source: UNICEF global databases, 2017, based on DHS, 2005–2016.

Mothers are often victims of intimate partner violence



Notes: Data refer only to children of women who have ever been married or lived with a partner. Data for Azerbaijan, Bangladesh, Burkina Faso, Cameroon, Côte d'Ivoire, Ghana, India, Liberia, Peru, the Republic of Moldova, Timor-Leste, the United Republic of Tanzania and Ukraine do not include children of women who are widowed. Data for Pakistan refer only to children whose mother experienced any physical or emotional intimate partner violence in the past 12 months.

Source: UNICEF global databases, 2017, based on DHS, 2005–2016.

Percentage of children aged 0 to 4 years living with a mother who experienced any physical, sexual or emotional violence committed by a husband or partner during the past 12 months

Right to health CHILDREN

A CONVERSATION WITH CHIP LYONS

Chip Lyons is the President and Chief Executive Officer of the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), the world's leading organization committed to the global elimination of paediatric HIV. EGPAF has been fighting for children's equal rights in the HIV response since 1988. Nearly 30 years after Elizabeth Glaser's own daughter died of an AIDS-related illness, far fewer children are on treatment than adults, and children on treatment are less healthy, leading to higher mortality rates.



Children should come first when it comes to the right to health

“IF 90% OF CHILDREN IN NEED GLOBALLY ARE IMMUNIZED, WHY AREN'T 90% OF HIV-POSITIVE CHILDREN VIRALLY SUPPRESSED?”

What does the right to health mean to you?

EGPAF's message is simple: children living with, or at risk of acquiring, HIV have the same rights as adults, and should benefit equally from innovations in HIV testing, treatment and services.

The right to health is about creating broader circumstances in which health is attainable for everyone. This means erasing disparities that, while technically external to the health-care system, have tremendous impacts on how people enter and interact with that system. Eradicating stigma, promoting gender and educational equity and increasing social protections for vulnerable populations—especially children and adolescents—are all aspects of the right to health. If it's not safe, socially acceptable, convenient or affordable for people to access doctors and medicines, the right to health is an empty promise.

What is preventing children from being able to exercise their right to health?

To date, community and global health leaders have not created the

expectation that children should come first when it comes to exercising their right to health. Such an expectation would open doors to access, treatment and care for children.

There are a number of factors that interfere with children's right to health. Stigma and discrimination can discourage children from seeking medical interventions, social services and education. While stigma is a challenge for all people with HIV, it weighs particularly heavily on children, whose access to health care depends on adults, who may be influenced by discriminatory attitudes. Even when children are connected to care, they are often prioritized below adults, with stock-outs of paediatric antiretroviral formulations occurring more frequently than stock-outs of adult medicines.

Are there additional barriers for girls to exercise their right to health?

Girls do face additional hurdles in exercising their right to health. The risk of acquiring HIV drops the longer girls stay in school, yet persistent societal discrimination against girls contributes



**“CHILDREN LIVING WITH, OR AT RISK OF ACQUIRING,
HIV HAVE THE SAME RIGHTS AS ADULTS.”**

to unequal access to education. Economic pressure to engage in transactional sex, lack of freedom regarding health decisions within families and gender-based violence also contribute to girls' startlingly disproportionate representation among new HIV infections.

Inadequate social protections make these and other barriers to health virtually insurmountable—not just for girls, but for all children. For example, lack of sufficient nutrition and water exacerbates health challenges for children living with HIV, particularly because antiretroviral therapy is extremely difficult to tolerate on an empty stomach.

What more can be done to make sure that children can access services?

Making the right to health a reality for children will require comprehensive action on the part of leaders and policy-makers around the world.

Key stakeholders—global, national and local—must strive to ensure that effective programmes are in place to find children exposed to HIV, test infants early and repeatedly, initiate children on treatment, provide proper counselling to caregivers and older children and use all possible avenues to encourage long-term antiretroviral therapy adherence.

Enactment or amendment of antidiscrimination legislation to prohibit discriminatory acts against people living with HIV is an essential tool in driving health access. Active enforcement of such laws, alongside public political messages against stigma, HIV awareness and advocacy campaigns, health-care worker training and community sensitization programmes, can increase children's access to HIV services by reducing discriminatory actions by members of the community.

Social protection programmes for the most vulnerable children are also effective, particularly those heading their own households or otherwise without legal guardians. These programmes include nutrition assistance for all children, and specific interventions for girls that will reduce their likelihood of being forced into early marriage, relationships with older men, transactional sex or prostitution, which increase their risk of contracting HIV.

Do you think the situation has improved at all over the past 20–30 years?

With the dramatic improvement in the health of children under five years of age over the past 20–30 years, the improvement for children in the HIV context should be more dramatic. If 90% of children in need globally are immunized, why aren't 90% of HIV-positive children virally suppressed?

In 1990, there was no medicine available to prevent mother-to-child transmission of HIV, nor save children born with HIV. Furthermore, the health-care infrastructure in many African states was not sufficient to manage the widespread testing, treatment and care needed for the prevention of mother-to-child transmission of HIV. Twenty-seven years later, the tools exist to eliminate mother-to-child transmission of HIV, and countries have made enormous strides in developing effective health infrastructures. And political support has been strong. Since the 2010 roll-out of the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, the number of new paediatric infections has been reduced by 53% in the 21 priority countries.

In 2016, a successor framework was launched—Start Free, Stay Free, AIDS Free. It focuses on accelerating progress towards ending new HIV

infections among children, finding and treating children, adolescents and mothers living with HIV and preventing new HIV infections among adolescents and young women.

More must be done to uphold children's right to health, especially access to early testing, quick linkage to treatment and long-term support to stay on treatment.

BACKGROUND

EGPAF is the global leader in the response to paediatric HIV and has reached more than 27 million pregnant women with services to prevent transmission of HIV to their babies. Founded in 1988, EGPAF today supports activities in 19 countries and more than 5000 sites to implement prevention, care and treatment services, to further advance innovative research and to execute global advocacy activities that bring dramatic change to the lives of millions of women, children and families worldwide.

“THE RISK OF ACQUIRING HIV DROPS THE LONGER GIRLS STAY IN SCHOOL.”

THE WAY HOME

The rapid political, social and economic changes in eastern Europe and central Asia over the past 20 years have had a deep impact on the well-being of families and children. Confronted with economic hardship, rising unemployment, increasing tensions and conflicts, social pressures and the crumbling of established social safety nets, many families have found themselves unable to cope with the difficulties of socioeconomic change and transition.



Domestic violence, neglect and abuse have pushed children to find a way to adapt to these harsh living conditions. For some children from troubled families, the streets have become their home or source of livelihood. The HIV epidemic has followed closely, and the number of HIV infections among street children has increased rapidly.

The United Nations Children's Fund (UNICEF) has been working with governments and civil society organizations that have been pioneering work on HIV prevention, care and support for vulnerable populations. One such organization, The Way Home, is working to improve the lives of street children in Ukraine.

The Way Home aims to provide a circle of solidarity around the children. This means ensuring that the child has a full range of health and social services available around them for protection, care and support.

Trust points or drop-in centres usually represent the first point of contact with children and adolescents in difficult situations. There, they can build trusting relationships with caring adults, be sure that their immediate needs for food and shelter are met, work together with case managers to assess their life situations and identify the services and sources of support they need to begin their return to more normal lives.

UNICEF supports their work by bringing together community-based organizations and local health and social service providers, including youth-friendly clinics, and policy-

“The street children come to us with a history of maltreatment, substance use and HIV risk. We link them to services that help them stay healthy and build their self-confidence and skills. The needs continue to grow. We have now opened our doors to others, including refugee children coming with the trauma of war. They also need support and services to find a Way Home.”

Sergei Kostin, Director of The Way Home, Odessa, Ukraine

makers to strengthen and build circles of solidarity. These are cooperative networks of service providers at the city or municipal level that work together to facilitate access to protective health and social services so as to meet a variety of the needs of children in difficult circumstances. These also serve to build the resilience and skills among children in difficult life situations in order to increase their options for a better future.

“We have been working on replicating this and similar programmes in other cities and municipalities. What is extraordinary about these HIV prevention programmes is that you start by looking at how to stop a virus, and you end by looking at how to support a life. These programmes work with children and adolescents to build on their strengths and co-create opportunities for a life with dignity. That is why they make a difference,”

said Nina Ferencic, Senior Adviser for HIV and Adolescents' Health, UNICEF.

By reaching out to children with educational, legal, medical, social and psychological support as well as guidance in re-establishing contacts with family members, The Way Home is helping children damaged by involvement with drugs or years of living on the streets to get back on their feet.

“The street children come to us with a history of maltreatment, substance use and HIV risk. We link them to services that help them stay healthy and build their self-confidence and skills. The needs continue to grow. We have now opened our doors to others, including refugee children coming with the trauma of war. They also need support and services to find a Way Home,” said Sergei Kostin, Director of The Way Home, Odessa, Ukraine.

Pictures courtesy of Odessa Charity Foundation “Way Home”



Orphans and their right to health

Orphans are entitled to all their rights, including the right to health. AIDS brought a spotlight on the special circumstances they face. Grandmothers were having to take care of their grandchildren at a time when they themselves needed care. Child-headed households saw children being robbed of their childhood.

In 2016, an estimated 16.6 million children (aged 0–17 years old) had lost one or both parents to AIDS-related illnesses. The total number of children orphaned by AIDS has begun to decrease as increasing numbers of parents are starting on antiretroviral therapy and are living longer. Children who were orphaned in the earlier years of the epidemic are ageing out of childhood and becoming adults. If antiretroviral therapy had not been rolled out on a global scale, however, the number of orphans would have been almost twofold more than today.

Thanks to Africa’s resilience and strong sense of community, an estimated 95% of orphaned children are cared for by other family members or neighbours.

The fear of armed youth orphaned by AIDS, raised without adult supervision and leading civil unrest in the streets has passed unfulfilled. Instead—backed by the resilience of extended families and communities with focused social protection programmes—children orphaned by AIDS have largely been able to go to school and grow up under the care of adults. School bursaries, school uniforms and cash transfers to households with children affected by AIDS are available in countries with a high burden of HIV, reaching as many as 41%¹ of all households with children in Swaziland.

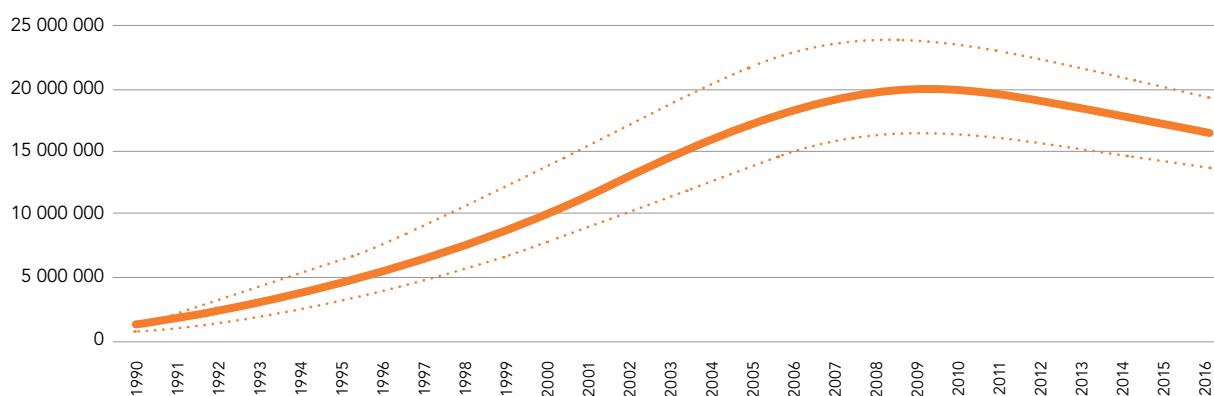
There have been significant strides in mitigating the economic and social impact of HIV on children

and families over the past decade.

In sub-Saharan Africa, the ratio of school attendance of orphans and non-orphans aged 10–14 years has almost reached parity, at 0.96%², a substantial improvement from around 2000, when the ratio was 0.81%³.

However, orphans can face special situations that pose multiple risks to their health and development. They need tailored, context and age-specific support that matches their evolving needs as they grow into adulthood. A study by the United Nations Children’s Fund found that children orphaned by or living with HIV-positive caregivers who are currently ill face an increased risk of physical and emotional abuse compared to other children. They also have higher rates of transactional sex or increased unsafe sexual activity.

Children (ages 0–17 years) orphaned by AIDS, globally, 1990–2016



¹ Source: UNICEF for every child end aids 2016 report.

² Source: UNICEF For Every Child End AIDS 2016 report.

³ Source: State of the world’s children 2005.



Joseline, 81 grandmother raising two grandchildren

GRANDMOTHERS: A CORNERSTONE OF THE COMMUNITY

Kandidah learned traditional Ugandan basket weaving from her parents. She never imagined that her skills would later save her. She had joined a “granny group”, which encouraged her to believe in herself and sell her wares.

At first, she could not believe it when her baskets attracted buyers. In only a matter of months, Kandidah was selling enough baskets to provide for her and her two grandchildren, who had lost their parents to AIDS.

Grandmothers have taken on the responsibility for looking after some of the many children orphaned by AIDS in the country. The

Nyaka Grandmother Programme was designed to empower those grandmothers to provide stable homes for their grandchildren. Started in 2007, the programme is made up of 98 self-formed groups serving more than 7000

grandmothers in the rural southwest districts of Kanungu and Rukungiri. Any grandmother raising children orphaned by AIDS can join a group. Nyaka staff provide each group with support and guidance, but ultimately the grandmothers decide. They determine who among themselves will receive donated items, microfinance funds, homes, pit latrines and smokeless kitchens and who will attend trainings.

The initiative is part of the larger Nyaka AIDS Orphans Project (NAOP). In 1996, Twesigye Jackson Kaguri came face to face with Uganda’s HIV epidemic. His brother and sister both died of AIDS-related illnesses, leaving him to care for their children. His family was not alone. Orphans swelled the ranks of his village. Instead of using his savings to buy a house, he founded NAOP. Two years later, the Nyaka Primary School opened to welcome 55 students—all orphans.

As more students came, additional classrooms were built. Mr Kaguri did not stop there. His project added a water system, a library and a health clinic, along with a secondary school, as well as the grandmother programme.

“The grandmothers are the cornerstones who sustain the community,” said Mr Kaguri. “People don’t give them recognition, but they are unsung heroes.”

As for Kandidah, the 75-year-old is a successful businesswoman and a leader in her community. She trains other women in the traditional arts of their culture and pays for her two grandchildren to go to school.

RECOMMENDED READ:

Read more about the power of grandmothers





Credit: UNICEF Sam Phelps

transmitted infections. Meeting these needs is often unachievable through mainstream health services and the lack of specialized interventions is a major problem.

What more can be done to make sure that orphans can access services?

Realizing the right to health for orphans and other children made vulnerable by AIDS, as with all children, is the responsibility of both the health sector and broader social and economic sectors. Children need multisectoral integrated services tailored to their age and circumstance and delivered in an environment in which laws, policies and attitudes champion the rights of children to access health and other entitlements. There is ample evidence to show that this multifaceted approach is effective and affordable. Building resilience and tackling stigma among communities, families and children is a big part of this. Many orphans and other children made vulnerable by AIDS live in areas with few formal services and are heavily reliant in community-run interventions. Ensuring that orphans and other vulnerable children have access to child protection services and quality family-based care and protection is also vital. It is a foundation for early childhood development as well as for children accessing health and other services necessary for them to survive and thrive. It is essential that we strengthen the links between community social welfare services and facility-based clinical services as well as improve the capacity of the social service workforce.

Background

Corinna Csáky is from the Coalition for Children Affected by AIDS, which consolidates and promotes learning from the latest scientific evidence in order to advocate for better funding, programming, policy and research. It seeks to enable all children affected by HIV to survive and thrive at home, school and in their communities.

THE FORGOTTEN CHILDREN

What does the right to health mean for orphans?

Orphans and other vulnerable children have the same rights that all children have to health. HIV is both a major driver and a consequence of poor health among millions of orphans and other children made vulnerable by AIDS. They are far more likely to experience health problems, many are born with HIV and they are less likely to be diagnosed and accessing treatment. Realizing the right to health for orphans, as with all children, means building the resilience of the “whole child”. Biomedical interventions can only be successful if children have the social and economic means to access and benefit from them. Children lag far behind in the HIV response. Orphans and other children made vulnerable by AIDS deserve more attention and priority.

What is preventing orphans from being able to exercise their right to health?

Stigma, inequality and a lack of resources are critical underlying barriers. Children orphaned by AIDS face the double stigma of being both without one or both parents and being associated with HIV. Many face additional discrimination for being associated with key population

adults or from sections of society that experience broader discrimination. As a result, orphans are often excluded from interventions. Orphans and other children made vulnerable by AIDS face several structural barriers. Without a parent or other adult caregiver, many orphans cannot register for or access health services. The age of consent often prevents underage children from accessing sexual and reproductive health interventions, and the lack of resources in many countries means that health and other services are not widely available, particularly in rural and poor communities, or are not cost-free. Moreover, the use of institutional care continues to be a major threat to orphans and other children made vulnerable by AIDS, since it removes children from the nurturing care and services they need.

What are the special health needs of orphans?

Orphans and other children made vulnerable by AIDS face an increased risk of health problems. They are especially vulnerable to HIV infection, cognitive and developmental delays, stunting, poor psychosocial and mental health and a range of other diseases. Moreover, they are less able to access health services or to remain on health treatment and care. The increased risk of substance abuse, sexual exploitation and gender-based violence for orphans in institutional care, or those outside of any form of care, means that they are at increased risk of infection from HIV as well as other sexually

ALL CHILDREN HAVE A RIGHT TO HEALTH

All children have a right to health—orphans included. In fact, they need more special attention. Some of their special needs are the following:

MEDICINES

Many orphans could also be living with HIV. They need access to HIV testing and treatment, as well as support for adherence and psychosocial issues.

NUTRITIOUS FOOD

Lack of adequate nutrition has a negative impact on the growth and development of children. Special care must be taken to ensure that they are not discriminated against by caregivers and have the necessary nutrition to grow up healthy.

SAFE WATER, CLEAN AIR AND SANITATION

Like all children, orphans must grow up in an environment that is safe.

VACCINES AND IMMUNIZATIONS

Orphans must be immunized against preventable diseases like any other children. Special care must be taken for orphans living with HIV.

HEALTH INFORMATION AND EDUCATION

Orphans must be provided with age-appropriate information to protect themselves from HIV, look after their sexual and reproductive health needs, recognize abuse and know how to seek health care when needed.

DECISION-MAKING ABOUT PERSONAL HEALTH

Children, including orphans, must be able to participate in decision-making about their health. The best interests of the child must be respected by caregivers and health-care providers.

INFORMATION AND EDUCATION

They must be provided with information to protect themselves from HIV, look after their sexual and reproductive health needs, recognise abuse and know how to seek health care when needed.

ADEQUATE SHELTER

Being looked after by family members and communities has a protective effect on orphans. They should be able to live in conditions that keep them safe and healthy. Where there are child-headed households, their property must be safeguarded.

HEALTH CARE

Orphans must have access to health care, as they are more likely to be exposed to communicable diseases and are physically vulnerable. Like all children, they will fall ill from time to time and need to be included in the public health system to protect them from diseases.

BEING TREATED WITH RESPECT AND DIGNITY

Orphans should not be robbed of their dignity and respect. They need to be supported in their efforts to remain healthy at all stages of their life.

HEALTH PRODUCTS

Orphans, as with all children, should have access to essential health products, such as bed nets to protect against malaria or other devices that help them to lead near normal lives.

MENTAL HEALTH AND WELL-BEING

Children orphaned by or living with HIV-positive caregivers who are currently ill face an increased risk of physical and emotional abuse compared to other children. They need support and psychosocial care to understand and manage their life contexts.

GENDER EQUALITY AND NON-DISCRIMINATION

Girls who are orphaned must have the same opportunities as other children. Health-care providers must take special care to detect abuse or lack of access to health services in a child-friendly manner.

JUSTICE

When there are violations of their health and human rights, children should be supported in seeking redressal.

SEXUAL AND REPRODUCTIVE HEALTH SERVICES

A large number of orphans are approaching adolescence and adulthood. As they grow older, they need access to sexual and reproductive health services to protect them from communicable diseases and unwanted pregnancies.

FREEDOM FROM HARM AND VIOLENCE

The likelihood of children orphaned by AIDS facing harm and violence is significant if adequate protection mechanisms are not put in place.

HEALTHY WORKING CONDITIONS

Orphans should not be exploited and should not be subjected to child labour.

Claiming the right to HIV treatment

Since the early days of the HIV epidemic, when it was first recognized that a deadly pathogen was causing what we now call AIDS, the response has been framed by human rights: the right to health, the right to dignity, the right to live free from discrimination and the right to life itself. The courage and determination of people living with HIV to demand and claim their rights—backed up by strong and steady global leadership and financial commitment, and intensive research and development of medicines and the means to deliver them efficiently and affordably—has seen access to effective treatment expand from fewer than 1000 people in 1990 to 20.9 million [18.4 million–21.7 million] people in June 2017.

Progress has been particularly rapid over the past five years, with the number of people accessing antiretroviral therapy nearly doubling since the end of 2012. The pace

of scale-up has been particularly remarkable in eastern and southern Africa, the region most affected by the epidemic. The number of people on treatment in the region surpassed all other regions combined in 2010 and now accounts for 60% of all people on treatment. South Africa is the country with by far the largest number of people on treatment, at 4.2 million, followed by India, Mozambique, Kenya, Zimbabwe, Nigeria and Uganda, which all have more than 1 million people on treatment.

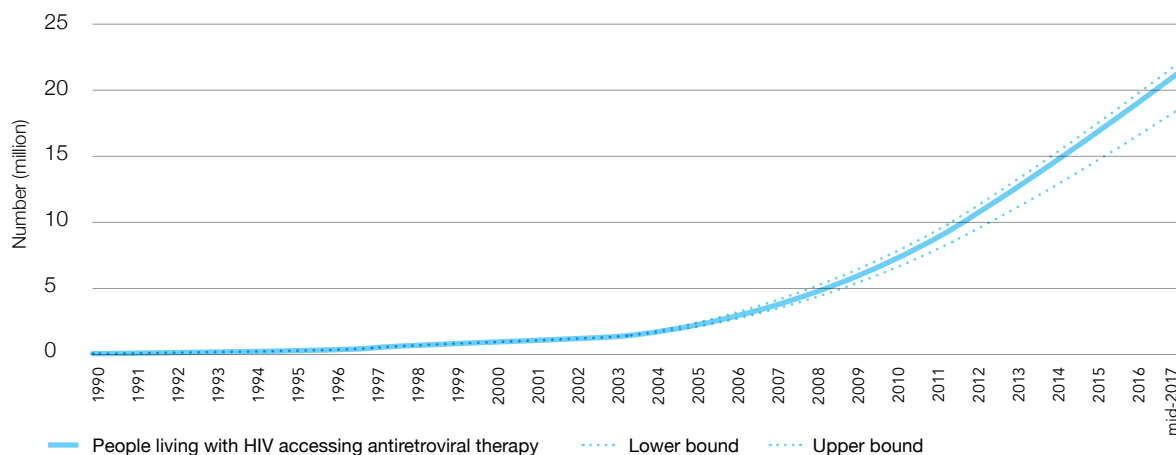
Global scale-up of antiretroviral therapy is the main contributor to a 48% decline in deaths from AIDS-related illnesses, from a peak of 1.9 million [1.7 million–2.2 million] in 2005 to 1.0 million [830 000–1.2 million] in 2016. Despite these gains, AIDS-related illnesses remain the leading cause of death among women of reproductive age (15–49 years) globally, and they are the second

leading cause of death for young women aged 15–24 years in Africa.¹

Fighting for our lives

In the early 1980s, gay communities in the United States of America, Latin America and Europe were among the hardest hit by AIDS. With no effective treatment available at that time, people living with HIV faced not only looming death, but also severe discrimination and human rights violations. Many were summarily dismissed by their employers, turned away from school or refused medical care. Early community-based efforts to provide support and advocate for rights included the San Francisco AIDS Foundation, the AIDS Project Los Angeles, the New York-based Gay Men’s Health Crisis, ACT UP (New York and Paris) and the London-based Terrence Higgins Trust. Among the first public demonstrations were candlelight vigils and marches held under the banner “Fighting for our lives”.

Number of people (all ages) accessing antiretroviral therapy, global, 1990 to mid-2017



Source: Global AIDS Monitoring, 2017.

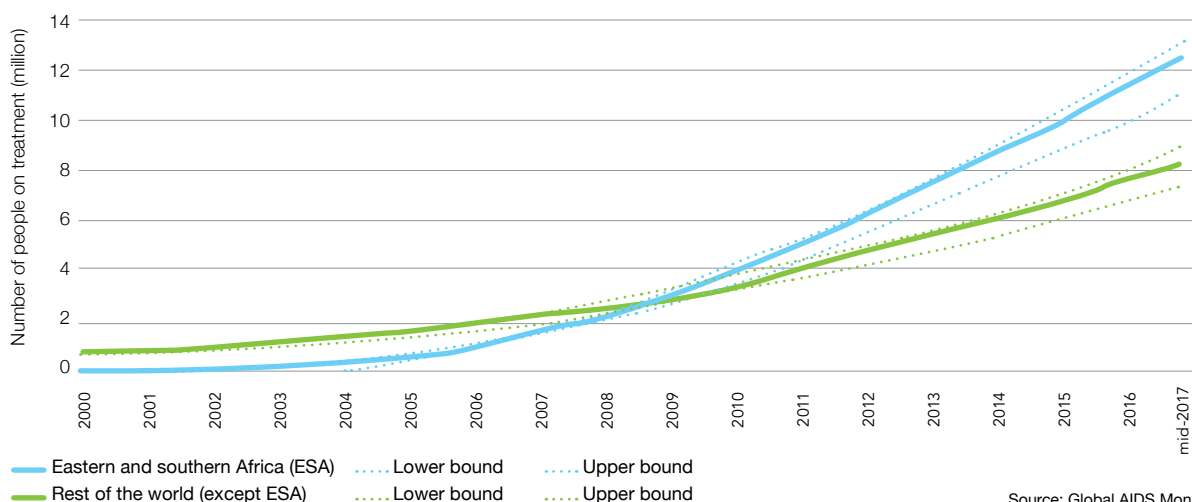
¹ Global health estimates 2015: deaths by cause, age, sex, by country and by region, 2000–2015. Geneva: World Health Organization; 2016.

20.9
MILLION PEOPLE
ON TREATMENT

Mid-2017

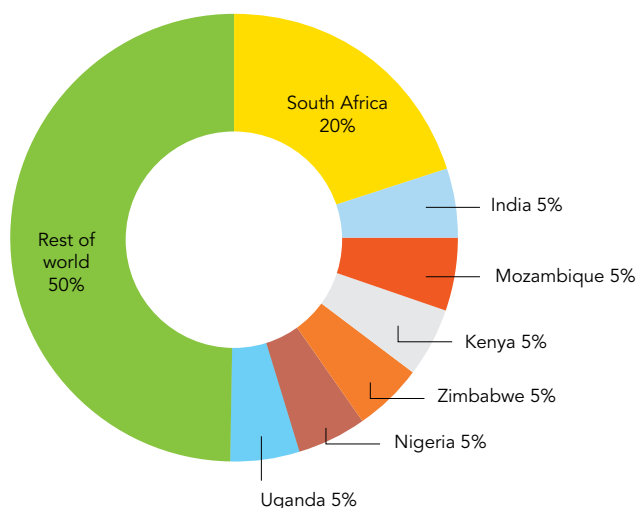
15.8 MILLION PEOPLE STILL
NEED HIV TREATMENT

Number of people living with HIV accessing antiretroviral treatment, mid-2017



Source: Global AIDS Monitoring, 2017.

Distribution of people living with HIV accessing antiretroviral therapy, by country, mid-2017



Source: Global AIDS Monitoring, 2017.

Similar grass-roots movements were emerging in other parts of the world. In Brazil, the country's first government AIDS programme was established in 1983 following advocacy from gay activists, and in 1986 researchers, health professionals and activists in Rio de Janeiro formed the Brazilian Interdisciplinary AIDS Association.² In Uganda, health workers and people living with HIV grappling with the intense stigma and discrimination faced by patients in a Kampala hospital founded the AIDS Service

Organization (TASO) in 1987.³ Initially a small support group, TASO coined the phrase "Living positively with AIDS" and quickly grew into a nationwide provider of community sensitization, care and support.

The first antiretroviral medicine for HIV, zidovudine (AZT) became available in the United States in the mid-1980s, but the side-effects were considerable and serious many patients using AZT in isolation eventually developed resistance to AZT and,

Achieving global treatment coverage targets

By the end of 2016, among people living with HIV, the following countries had reached the current international target of 81% treatment coverage or were approaching the target:⁴ Botswana, Rwanda, Swaziland and Zimbabwe in eastern and southern Africa; Australia, Cambodia, Maldives[†], Samoa[†] and Singapore[†] in Asia and the Pacific; Algeria, Kuwait[†] and Qatar[†] in the Middle East and North Africa; Bosnia and Herzegovina[†] in eastern Europe and central Asia; and Austria^{*†}, Denmark, France^{*†}, Iceland[†], Ireland, Italy^{*†}, Luxembourg[†], the Netherlands[†], Spain^{*}, Sweden[†], Switzerland^{*†} and the United Kingdom of Great Britain and Northern Ireland^{*†} in western and central Europe and North America. In western and central Africa, Gabon had the highest coverage of antiretroviral therapy at the end of 2016, while Argentina and Cuba had the highest coverages for the Latin America and the Caribbean regions, respectively.

* Treatment coverage as of 2016 except for Austria (2013), France (2013), Italy (2012), Spain (2014), Switzerland (2015) and the United Kingdom of Great Britain and Northern Ireland (2015).

† Estimates of people living with HIV that inform progress towards treatment coverage are country-supplied and have not been validated by UNAIDS.

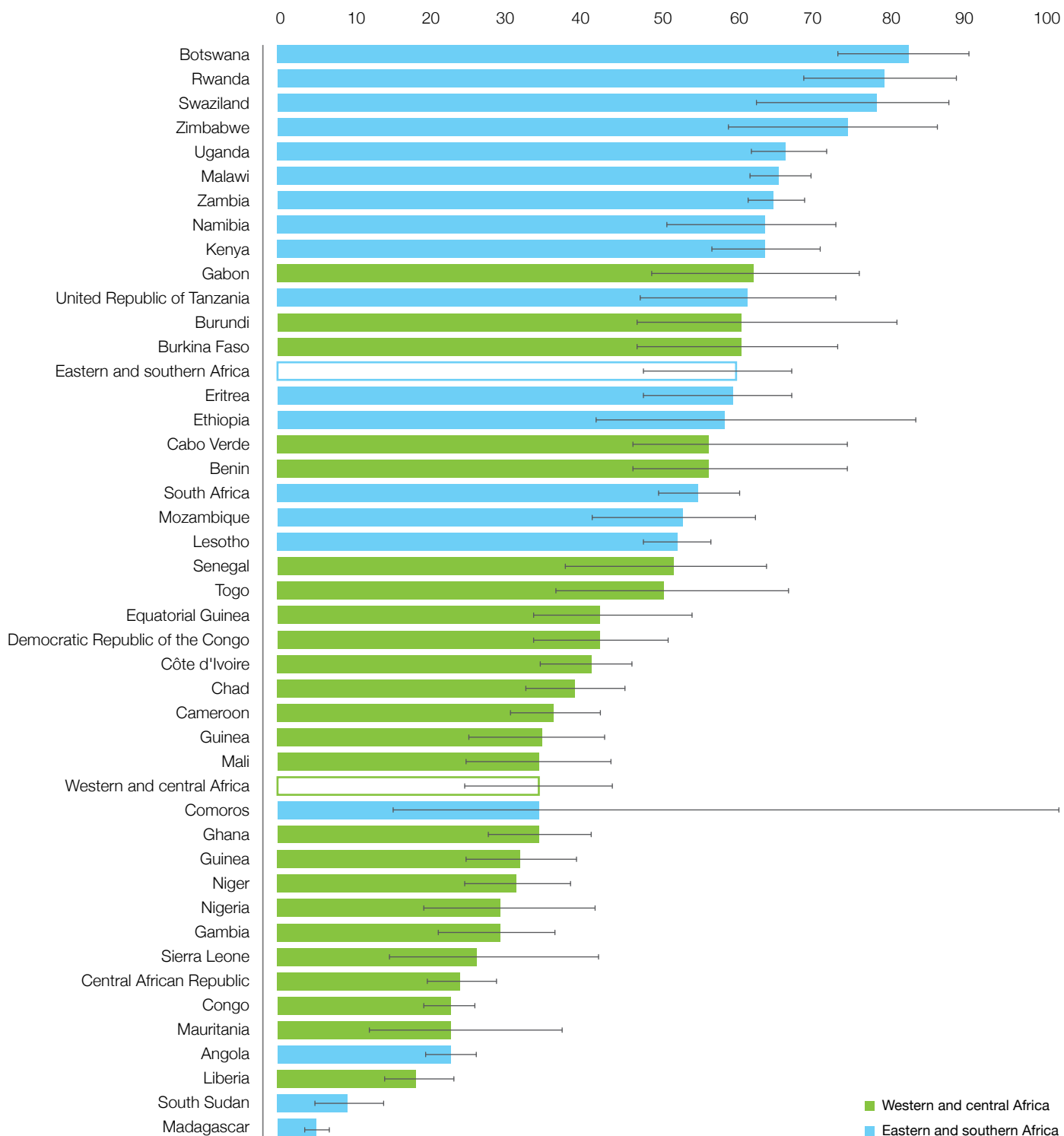
‡ Estimates of people living with HIV are only for citizens of the country.

² Berkman A et al. A Critical Analysis of the Brazilian Response to HIV/AIDS: Lessons Learned for Controlling and Mitigating the Epidemic in Developing Countries. *Am J Pub Health*, July 2005;95, No. 7.

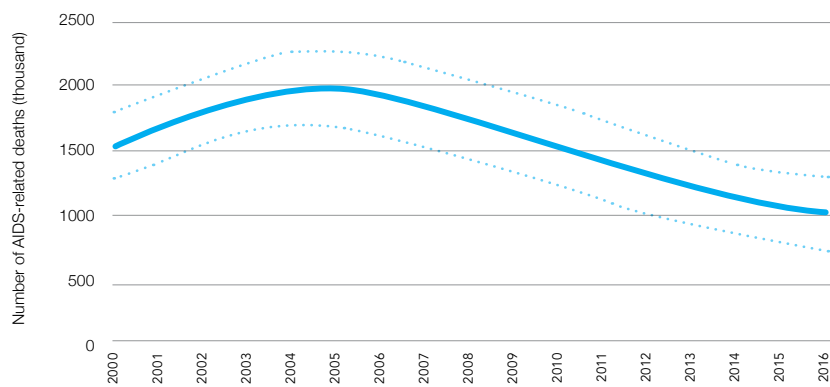
³ Noerine Kaleeba; Sunanda Ray. *We Miss You All* (3rd edn). SAFAIDS.

⁴ Defined as 75–80% coverage or higher.

Antiretroviral treatment coverage among people (all ages) living with HIV, eastern and southern Africa and western and central Africa, 2016



AIDS-related deaths, global, 2000–2016



Source: UNAIDS 2017 estimates.

subsequently, serious opportunistic infections.^{6,7} It was nonetheless a lifeline for people living with HIV, albeit at a cost of more than US\$10 000 per patient per year, well beyond the reach of most in need.⁸ The AIDS Coalition to Unleash Power (ACT UP) was established in 1987 by people living with HIV demanding greater access to HIV treatment and lower costs. ACT UP members staged public demonstrations in New York City, protesting against what they saw as excessive profit margins on AIDS medications that limited access to treatment, and to the slow process of medicine approval that put lives at risk. Following a particularly high-profile ACT UP protest at the New York Stock Exchange in 1989, the pharmaceutical company Burroughs Wellcome lowered the price of AZT to US\$ 6400 per patient per year.⁹

The development of antiretroviral therapies in the mid-1990s that combined two or three medicines greatly improved the efficacy of HIV treatment.¹⁰ Clinical research unveiled at the 11th International AIDS Conference, held in Vancouver, Canada, showcased seemingly miraculous cases of people recovering

from late-stage AIDS thanks to this new, highly active antiretroviral therapy.¹¹ However, the costs of these medicines remained high, and access outside of North America and western Europe remained extremely limited. In 1996, just 1% of the estimated 21.0 million [17.7 million–24.7 million] people living with HIV globally were accessing antiretroviral therapy. In South Africa, where only a handful of wealthy individuals were accessing treatment and an estimated 41 000 [29 000–55 000] people died of AIDS-related causes in 1996, the Treatment Action Campaign began applying the direct action tactics developed during the anti-apartheid struggle to efforts to provide equal access to treatment for all in need (see box).¹²

Momentum gathers after Durban AIDS conference

Efforts to expand access to treatment gathered pace at the 13th International AIDS Conference, held in July 2000 in Durban, South Africa, under the theme “Breaking the silence”, on the urgent need for equal access to treatment, care and a supportive environment for people living with HIV in society.¹³ In 2001, for the first time in its history, the United Nations

The right “to die—and to LIVE—in dignity”: the Denver Principles

In 1983, just a few weeks after HIV was identified as the cause of AIDS, a group of activists, including a dozen men living with HIV, met in Denver as part of a gay and lesbian health conference. Together they drafted a one-page declaration entitled The Denver Principles, which condemned the public portrayal of people living with HIV as victims and scorned those who blamed gay men for the epidemic. The Denver Principles, which was read to participants as the conference drew to a close, also declared that all people living with HIV had rights to full and satisfying sexual and emotional lives, to quality medical treatment and social services without discrimination, to privacy and confidentiality, to respect and “to die—and to LIVE—in dignity”. The declaration also called for people living with HIV “to be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge”—an early statement from the people at the heart of the epidemic that would later grow into an international commitment for the greater involvement of people living with HIV, or GIPA.

General Assembly held a special session on a health issue and world leaders committed to halting and reversing the epidemic. That same year, the Indian generic pharmaceutical manufacturer Cipla announced that it would sell a generic triple-therapy antiretroviral medicine for US\$ 350 per person per year. A few months later, World Trade Organization Member States adopted the Doha Declaration on the TRIPS Agreement and Public Health, which reaffirmed that members of the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) could use various trade flexibilities to produce or import generic versions

⁵ http://bilerico.lgbtqnation.com/2011/09/how_the_denver_principles_changed_aids_and_health.php.

⁶ Moore RD, Chaisson RE. Natural history of opportunistic disease in an HIV-infected urban clinical cohort. *Ann Intern Med*. 1996;124:633–642. doi: 10.7326/0003-4819-124-7-199604010-00003.

⁷ Zidovudine side effects (<https://www.drugs.com/sfx/zidovudine-side-effects.html>).

⁸ An AIDS drug, at a cost, *New York Times*, 25 March 1987 (<http://www.nytimes.com/1987/03/25/opinion/an-aids-drug-at-a-cost.html>).

⁹ ACT UP timeline. <http://www.actupny.org/documents/cron-89.html>.

¹⁰ New findings bring hope to Vancouver AIDS conference. NIAID AIDS Agenda. 1996 Sep.1, 3.

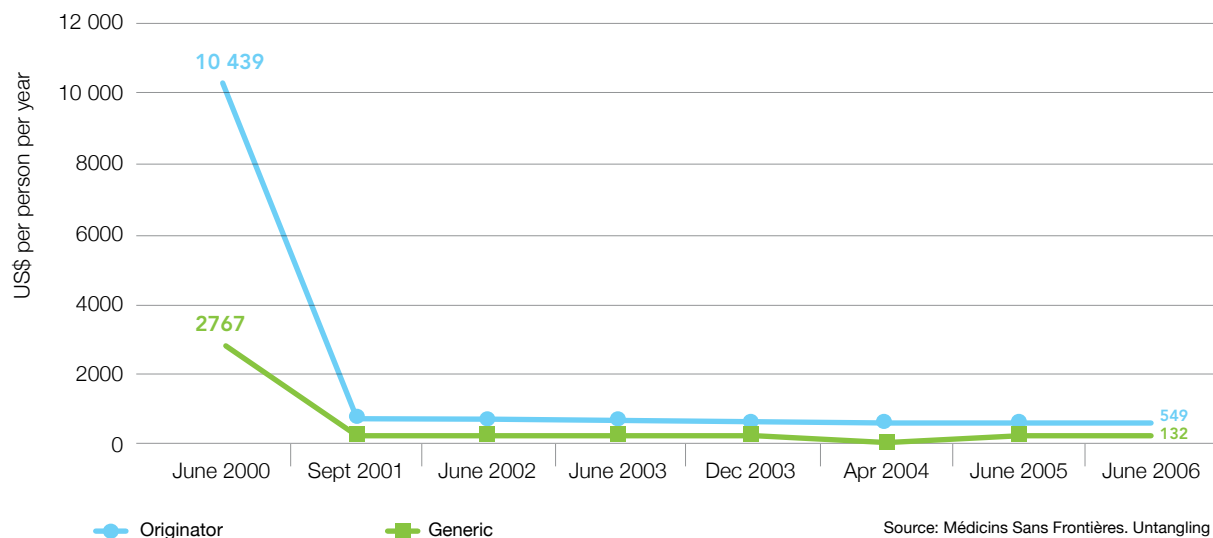
¹¹ A historical perspective on the International AIDS Conference.

Website: HIV.gov. Published 19 July 2012 (<https://www.hiv.gov/blog/a-historical-perspective-on-the-international-aids-conference>).

¹² <https://www.theguardian.com/world/2008/sep/12/matthiasrath.aids>.

¹³ <http://www.thebody.com/content/art16083.html>.

Generic competition as a catalyst for price reduction for first-line regimen



Source: Médecins Sans Frontières. Untangling the web of antiretroviral price reductions, 18th edition, July 2016

of patented medications in response to public health emergencies.

Within the next two years, the Global Fund to Fight AIDS, Tuberculosis and Malaria and the United States President’s Emergency Plan for AIDS Relief were both established, and the World Health Organization launched the “3 by 5” initiative, with the goal of having 3 million people in low- and middle-income countries on antiretroviral therapy by the end of 2005. The target served as an international endorsement of civil society’s call for treatment access and helped build momentum for massive scale-up. World Health Organization technical support was instrumental in the establishment of national treatment programmes in many of the low- and middle-income countries hardest hit by the epidemic. As resources started to flow and the costs of antiretroviral medicines were reduced, the number of people accessing treatment climbed from 914 000 [804 000–950 000] at the end of 2002 to 2.1 million [1.8 million–2.1 million] at the end of 2005. The world ultimately

achieved the “3 by 5” target in 2007, and global ambitions were further raised by subsequent United Nations General Assembly declarations of commitment, which called for universal access to treatment by the end of 2010 and 15 million people to access antiretroviral therapy by the end of 2015. The latter target was achieved by March 2015, the result of a combination of strong and sustained leadership and commitment, community engagement, robust funding, increased knowledge of HIV status, a reliable supply of effective and affordable medicines, improved efficiency and quality of treatment services, innovation and progress in reducing HIV-related stigma and discrimination.

Eliminating mother-to-child transmission and treating children living with HIV

Expansion of the availability of antiretroviral medicines has also been a central pillar of efforts to eliminate mother-to-child transmission of HIV. A significant step forward was made in 2011 by Malawi, the first country to offer immediate and

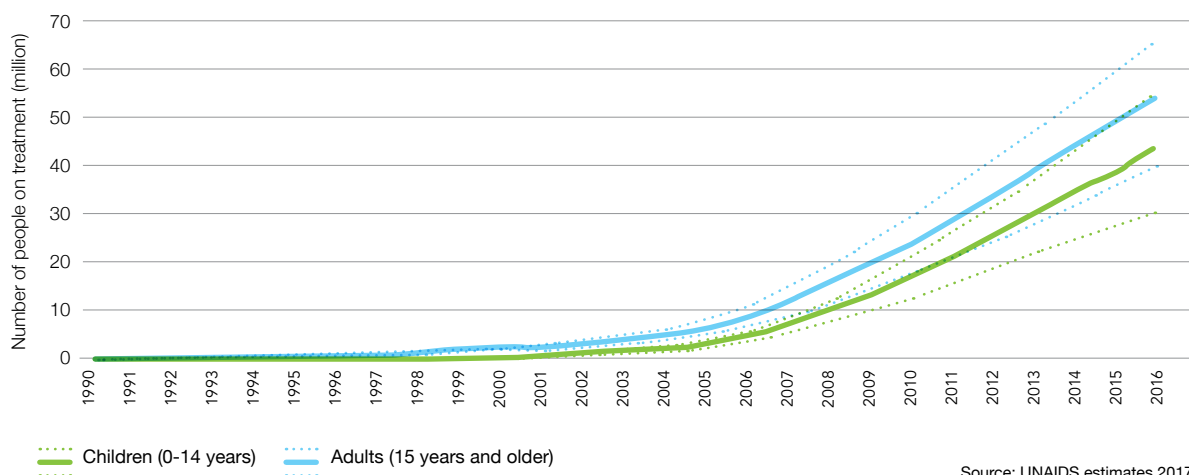
lifelong antiretroviral therapy to all pregnant and breastfeeding women living with HIV regardless of CD4 cell count or clinical stage.¹⁴ The World Health Organization made the Malawi approach its global guidance in 2013, and in 2015 recommended that antiretroviral therapy be initiated for every person living with HIV at any CD4 cell count¹⁵.

New HIV infections among children have declined by 61% since 2006, a considerable achievement. However, about 160 000 [100 000–220 000] children acquired HIV during childbirth or breastfeeding in 2016. Diagnosing and initiating treatment among these children remains a priority and a challenge. A large collaborative study spanning Africa, the Americas and Asia suggests that large proportions of children younger than two years who are living with HIV—as much as two thirds of them—are diagnosed late and start antiretroviral therapy with advanced immunodeficiency. As a result, mortality rates among these children are high.

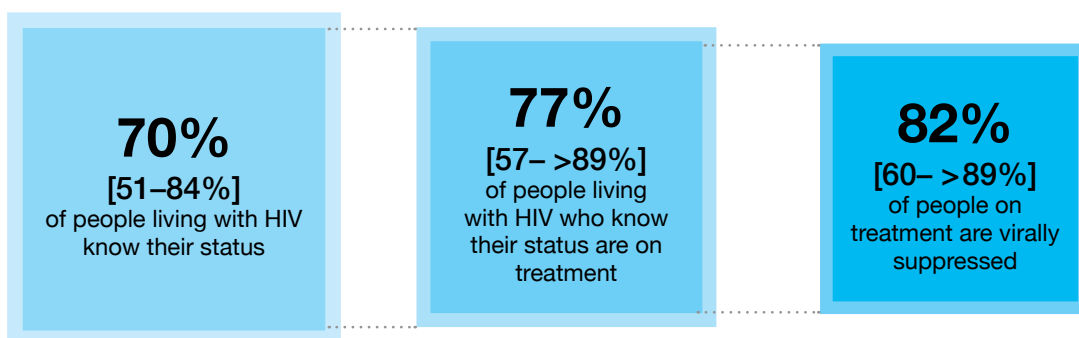
¹⁴ Malawi Ministry of Health. Malawi’s revised policy for PMTCT and ART. Lilongwe, Malawi: Malawi Ministry of Health; 2010.

¹⁵ Guideline on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV. Geneva: World Health Organization; 2015.

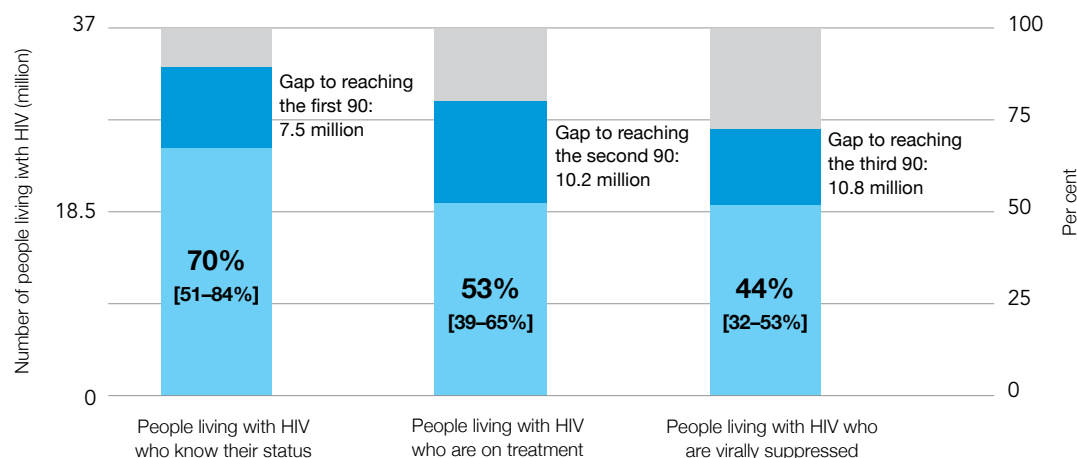
Antiretroviral treatment coverage among children (aged 0–14 years) and adults (aged 15 and older), global, 1990–mid-2017



Progress towards the 90–90–90 targets, global, 2016



Knowledge of HIV status, treatment coverage and viral load suppression, global, 2016



Globally, an estimated 919 000 [810 000–956 000] children (aged 0–14 years) were on antiretroviral therapy in 2016, about 43% [30–54%] of all children living with HIV. Treatment coverage remains lower among children than adults, and the rate of increase in the number of children on treatment has slowed in recent years, falling to an annual increase of 7% in 2016 from an annual increase of more than 10% in previous years. At the current rate of increase, the world risks not reaching the target of providing antiretroviral therapy to 1.6 million children by 2018.

90–90–90: a new emphasis on viral suppression

As evidence mounted that suppressed viral loads achieved through strong adherence to antiretroviral therapy greatly reduces the risk of transmitting the virus to others, and that high coverage of treatment can have a preventive effect within a community, international and national efforts placed additional emphasis on achieving viral suppression¹⁶. At the 20th International AIDS Conference in Melbourne, Australia, in 2014, UNAIDS launched the 90–90–90 targets, whereby, by 2020, 90% of people living with HIV know their HIV status, 90% of people who know their HIV-positive status are accessing treatment and 90% of people on treatment have suppressed viral loads. Fully achieving the 90–90–90 targets translates into 73% of all people living with HIV being virally suppressed.

Remarkable progress has been made towards achieving the 90–90–90 targets. At the end of 2016, more than two thirds of all people living with HIV—an estimated 70% [51–84%]—knew their HIV status. Among those who knew their HIV status, 77% [57–>89%] were accessing antiretroviral therapy and 82% [60–>89%] of people accessing treatment had suppressed viral loads. Seven countries had already

South Africa's roll-out of antiretroviral therapy

South Africa's roll-out of antiretroviral therapy initially lagged behind most other high-prevalence countries as key government officials questioned whether HIV was the cause of AIDS. The Treatment Action Campaign challenged the government's gradual approach in court, arguing that it violated the country's constitution. The South African courts ruled in 2002 that a countrywide roll-out of antiretroviral medicines for the prevention of mother-to-child transmission of HIV was "an ineluctable obligation of the state."¹⁷

In November 2003, the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa was approved, and on 1 April 2004 the provision of antiretroviral therapy was started at several service points across the country. By September 2005, 17 months after roll-out began, 85 000 people were accessing antiretroviral therapy through the public health sector.¹⁸

South Africa's 2007–2011 National Strategic Plan for HIV & AIDS and STIs set a target of providing access to treatment for 80% of those eligible, and the national strategic plan for 2012–2016 included a strong focus on key populations and marginalized groups, including sex workers, men who have sex with men, truckers and adolescents. By mid-2011, nearly 1.8 million people in South Africa were accessing antiretroviral therapy, making South Africa's treatment programme the world's largest. South Africa adopted World Health Organization guidance for all people living with HIV to access antiretroviral therapy, regardless of CD4 count, in May 2016, and in mid-2017, 4.2 million people were accessing treatment, including nearly 279 000 people through the private sector.

achieved or exceeded 73% of viral suppression among all people living with HIV by the end of 2016: Botswana, Cambodia, Denmark, Iceland, Singapore, Sweden and the United Kingdom. An additional 11 countries were near this threshold: Australia, Belgium, France, Germany, Italy, Kuwait, Luxembourg, the Netherlands, Spain, Swaziland and Switzerland. Several cities engaged in the Fast-Track cities initiative have also reached, or are close to reaching, the 90–90–90 targets, including Amsterdam, Melbourne, New York City, Paris and San Francisco.

Viral load testing, which was rarely available in low- and middle-income countries just a few years ago, is rapidly expanding. Nearly half of all people on treatment in countries that reported data to UNAIDS in

2016 receive a routine viral load test, improving the monitoring of treatment outcomes and informing a timely switch to second-line and third-line therapy, when needed.

Moving forward

A major milestone was reached in 2016: for the first time, more than half of all people living with HIV (53% [39–65%]) worldwide were accessing antiretroviral therapy, and by mid-2017 some 20.9 million people were on treatment. However, a considerable gap remains to the 81% coverage called for in the 90–90–90 targets. Achieving those targets and keeping the world on track to achieve the target within the 2030 Agenda for Sustainable Development to end AIDS as a public health threat by 2030 requires addressing the biggest challenges head-on.

¹⁶ Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med*. 2011;365:493–505.

¹⁷ Honermann B, Heywood M. A judgment that saved a million lives. *The Star* 2012, 5 July 2012. <http://www.iol.co.za/the-star/a-judgment-that-saved-a-million-lives-1.1334636#.UmWK8RD6oiQ> (accessed 3 February 2014).

¹⁸ Simelela NP, Venter WDF. A brief history of South Africa's response to AIDS. *SAMJ*. March 2014, Vol. 104, No. 3 (Suppl 1).

“In 2016, more than half of all people living with HIV worldwide were accessing antiretroviral therapy, and by mid-2017 more than 20 million people were on treatment.”

Gaps in knowledge of HIV status

- ▶ *Challenge:* knowledge of HIV status is the first step in the HIV testing and treatment cascade, and also the step in the 90–90–90 targets with the largest gap, especially among children, young people, men and key populations at higher risk of infection.
- ▶ *Way forward:* taking full advantage of new technologies and innovative service strategies, including early infant diagnosis at the point of care, virological testing at birth, community-based HIV testing, HIV self-testing and assisted partner notification.

Late treatment initiation

- ▶ *Challenge:* many newly diagnosed people living with HIV do not immediately initiate treatment owing to national restrictions, fears of stigma and discrimination and the long distances that some must travel to a health facility providing treatment, leaving them vulnerable to tuberculosis and other opportunistic infections.
- ▶ *Way forward:* adoption of a treat all approach and rapid expansion of proven models for linking newly diagnosed people to treatment, including same-day initiation. Increased investment in community-based strategies that use a holistic approach to the entire health needs of the client.

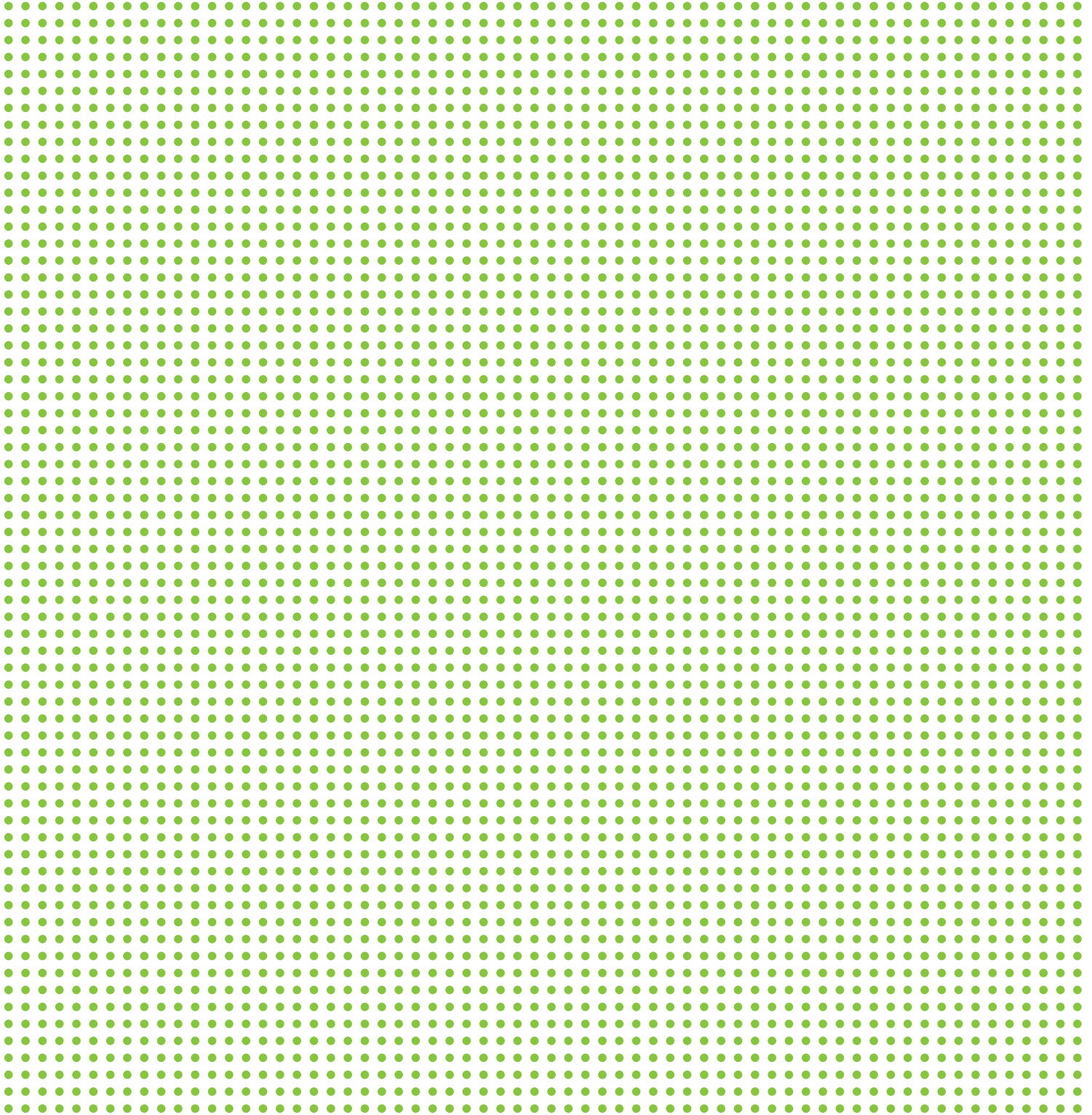
Achieving and sustaining viral suppression

- ▶ *Challenge:* although most people accessing antiretroviral therapy obtain excellent clinical outcomes, treatment failure and the development of drug resistant strains of HIV are a constant concern.

- ▶ *Way forward:* strategies that use peers, peer-support groups and trained community health workers have proven successful at increasing treatment retention among adolescents and young people living with HIV. Intensified development and roll-out of new first-line antiretroviral medicines, such as dolutegravir, can suppress viral loads more quickly, have fewer side-effects, are less prone to resistance and have the potential to lower treatment costs and make treatment programmes more sustainable. Second- and third-line antiretroviral formulations must also be readily available and affordable. Point-of-care viral load testing technologies offer further potential to expand viral load testing to everyone accessing treatment and to achieve more precise monitoring of both individual and community viral loads.

South Africa's treatment journey

● In 2000, 90 people* were
accessing HIV treatment



**By mid-2017, 4.2 million people were receiving antiretroviral treatment in South Africa.
Another 2.9 million need access to HIV treatment.**

● = 100 people

* 90 people were accessing HIV treatment through the public sector

Right to health

PEOPLE LIVING WITH HIV

A CONVERSATION WITH ERIKA CASTELLANOS

Erika Castellanos is a transgender woman living with HIV from Belize engaged in advocacy at the local, regional and international levels. She is currently serving as the Vice-Chair of the Global Network of People Living with HIV (GNP+) and is the Director of Programmes at GATE. Before joining GATE, Erika served as the Executive Director of the Collaborative Network of Persons Living with HIV, Belize. Since 2016, she has been a member of the Communities Delegation to the Board of the Global Fund to Fight AIDS, Tuberculosis and Malaria and a member of the International Group of Trans Women and HIV. She served as a delegate from Latin America and the Caribbean to the UNAIDS Programme Coordinating Board.



The right to life for people living with HIV is the same as for anyone else

“PEOPLE LIVING WITH HIV ARE PREVENTED FROM EXERCISING OUR RIGHT TO HEALTH OWING TO SOCIAL, POLITICAL AND INSTITUTIONAL DISCRIMINATION.”

What does the right to health mean to you?

For me, the right to health is the full enjoyment of the highest possible standard of health. It means to be able to enjoy a state of complete physical, mental and social well-being, which is not just the absence of disease. It is a fundamental right that all people are entitled to, regardless of their sex, sexual orientation, gender identity, economic situation, profession, education or the country they live in.

My right to health includes being able to access services without fear of discrimination—affordable and high-quality services that are client-

centred and based on the needs of the individual. It means that I have access to gender-affirming care, antiretroviral therapy, diagnostic laboratory tests and mental health services, all within an environment free from discrimination and judgement.

What is preventing people living with HIV from being able to exercise their right to health?

People living with HIV are prevented from exercising our right to health owing to social, political and institutional discrimination. Key populations who are also living with HIV experience those barriers much more and with more impact.



**“THE RIGHT TO HEALTH ... IS A FUNDAMENTAL
RIGHT THAT ALL PEOPLE ARE ENTITLED TO.”**

In many parts of the world, we are criminalized and accessing health services can lead to outing ourselves. We are forced to live in an underground world by hate and stigma and fear of the unknown. Health services are designed and geared towards cisgender heterosexual people and are not welcoming for us.

What more can be done to make sure that all people living with HIV can access services?

Many things can be done to improve our access to services. Services should be designed and implemented by our communities and we need evidence-informed services that meet our needs. There needs to be decriminalization of key populations and decriminalization of HIV. Services should be client-driven and client-lead, instead of doctor-led.

In a nutshell, empowered people and communities must be able to demand and deliver services in partnership with nonjudgemental, discrimination-free health systems within a legal and policy environment that sees us as human beings irrespective of our HIV status, sexual orientation, gender identification, drug use or profession.

Do you think the situation has improved at all over the past 20–30 years?

The situation has certainly improved over the past 20–30 years, but in some countries, instead of moving forward, things are going backwards when it comes to the enjoyment of human rights by people living with HIV. This is not the time to celebrate and pat us on the back, it is the time to redouble efforts and make sure that every single person in the world can fully enjoy the right to health. As a transgender woman living with HIV for 22 years, I have seen the changes throughout the years and

“IN SOME COUNTRIES, INSTEAD OF MOVING FORWARD, THINGS ARE GOING BACKWARDS.”

I am happy to say that today we live in a better world. In a world where I do not have to hide my status, in a world where being HIV-positive does not equal death. In a world where I can now plan for a future and in which I have allowed myself to love and be loved.

BACKGROUND

GNP+ is the global network for and by people living with HIV. GNP+ works to improve the quality of life of all people living with HIV by advocating for and supporting fair and equal access to treatment, care and support services for people living with HIV around the world.

GATE is an international organization working on gender identity, sex characteristics and, more broadly, on bodily diversity issues. GATE works on supporting transgender, gender diverse and intersex movements by producing and making available critical knowledge, promoting their access to organizational resources and advocating with them to make human rights a lived reality.

Remembering Prudence Mabele

Prudence Mabele—the voice of the voiceless—refused to be cowed by people who did not understand the right to health, the right to dignity and the right to thrive.

She stood against the people who challenged her, bullied her and told her she was wrong about people living with HIV. She understood that she and other people living with HIV had the right to treatment, the right to have a voice in the policies and programmes designed to respond to the disease she was living with and the right to call out injustice and inequity.

When Ms Mabele became one of the first women living with HIV in South Africa to disclose her status, she said she was tired of the silence and stigma surrounding HIV. In speaking about HIV openly, she brought it out of the shadows and showed what living with HIV really meant. She showed that living with HIV meant that you need access to HIV services and wider comprehensive health services.

The 46-year-old knew from her own experience that the impact of living with HIV went beyond her health. It affected her family, her friends and comrades, her role in the community, her honour and dignity. She wanted to set a precedent and encourage other women living with HIV to speak openly with their loved ones, to live without shame, to seek health care and to lead happy and fulfilled lives.

She was passionate about the need to organize and support women living with HIV and worked tirelessly to amplify the voice of African women living with HIV in regional and global forums. She was a feminist, first and foremost, who fought for gender equality and the empowerment of women living with HIV.

She campaigned tirelessly for the rights of all people living with HIV and championed the cause of the greater involvement of people living with HIV. She was a driving force in addressing issues around stigma and discrimination and fought for the right to have access to treatment. She was part of the driving force behind

treatment scale-up in South Africa, as were those who fought with her.

Her death invoked serious introspection and reflection among her friends and comrades on the daily struggles that people living with HIV go through as they battle with the realities of the loneliness and sometimes lack of support for the often unrecognized consequences of living with long-term treatment. In battling to maintain a semblance of normality in the face of the deep-seated social and psychological challenges associated with living with illness, people living with HIV often struggle with depression, treatment fatigue and coping with adherence to treatment.

Ms Mabele demanded a lot from her community and society. But it was no more than she demanded of herself. People living with HIV have the same right as everyone else in society to access essential health services. People living with HIV have a right to a life of dignity.

“She campaigned tirelessly for the rights of all people living with HIV and championed the cause of the greater involvement of people living with HIV.”



18.8

MILLION WOMEN AND GIRLS
LIVING WITH HIV

NEARLY 870 000 NEW HIV INFECTIONS
AMONG WOMEN AND GIRLS EVERY YEAR

EVERY FOUR MINUTES THREE YOUNG WOMEN
BECOME INFECTED WITH HIV

1.1 BILLION

GIRLS IN THE WORLD TODAY, THE LARGEST GENERATION IN HISTORY

WHAT WOMEN WANT

Nearly 870 000 women are becoming infected with HIV every year and only half of all women living with HIV have access to lifesaving treatment—making AIDS the leading cause of death worldwide among women between the ages of 15 and 49.

Women living with HIV face stigma and discrimination at the hands of family members, in communities, at the workplace and in health-care settings. Health services, including sexual and reproductive health and HIV services, for adolescent girls and women are not yet universally available. Women and their children are still dying during childbirth.

Large numbers of adolescent girls and women all over the world are still not able to take decisions about their own health. The requirement of parental and spousal consent is stopping adolescent girls and women from taking care of their own health and the health of their loved ones.

Violence against women and girls remains a black spot on our social fabric. Every year millions of girls

are being forced into marriage before they are ready and willing.

When girls and women are not served by social, education and health systems, they are not only denied of the human rights, including their right to health, but they are robbed of a future of opportunities to flourish. However, much of this is changing.

Today, we are at the cusp of eliminating new HIV infections among children—a movement led by women. More women are accessing antiretroviral therapy than men, transferring the benefits of their good health to their families and economies. When young women are empowered and have their rights fulfilled, HIV prevalence falls, there are fewer unintended pregnancies, fewer maternal deaths and fewer dropouts from school and more women join the workforce. When young women have access to education, health outcomes dramatically improve.

“MORE WOMEN
ARE ACCESSING
ANTIRETROVIRAL
THERAPY THAN MEN,
TRANSFERRING THE
BENEFITS OF THEIR
GOOD HEALTH TO
THEIR FAMILIES AND
ECONOMIES.”

WOMEN'S HEALTH

ISSUES AND OPPORTUNITIES



0-14

200 children are born with HIV every day

Another 200 children are infected through breastfeeding every day

MATERNAL AND NEWBORN HEALTH

98% new HIV infections among children are preventable

Women with more education tend to marry later, bear children later and exercise greater control over their fertility

CHILD MARRIAGE

47 700 girls marry every day below the age of 18

Providing information on gender and power results in lower rates of sexually transmitted infections and unintended pregnancies

EDUCATION

In Botswana every additional year of school was shown to reduce risk of HIV infection by 11.6% among girls

In sub-Saharan Africa, 7 in 10 young women do not have comprehensive knowledge about HIV




In the least developed countries in the world 6, out of 10 girls do not attend secondary school

Young people require the consent of parents or legal guardians to access sexual and reproductive health services in at least 79 countries

POLICY AND LEGAL BARRIERS

Lowering the age of consent in South Africa increased knowledge of HIV status among young women

20-29

Women living with HIV who are taking antiretroviral therapy can have life expectancies comparable to people who have not acquired HIV

BURDEN OF CARE

Weak health systems and unequal distribution of caregiving responsibilities present a unique challenge for older women living with HIV

50+

Biological changes can put sexually active older women at higher risk of acquiring HIV

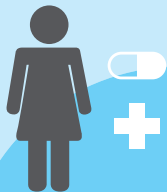


RISK

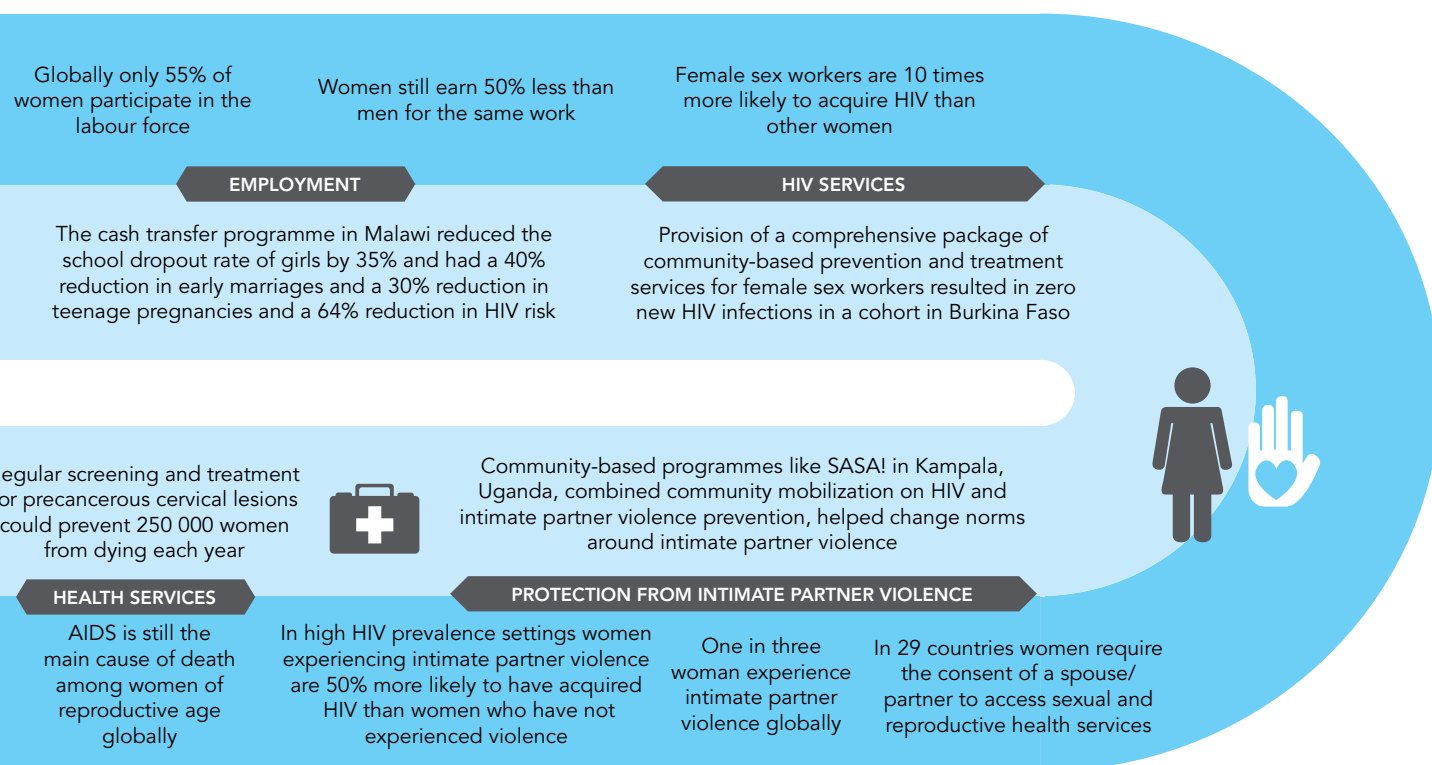
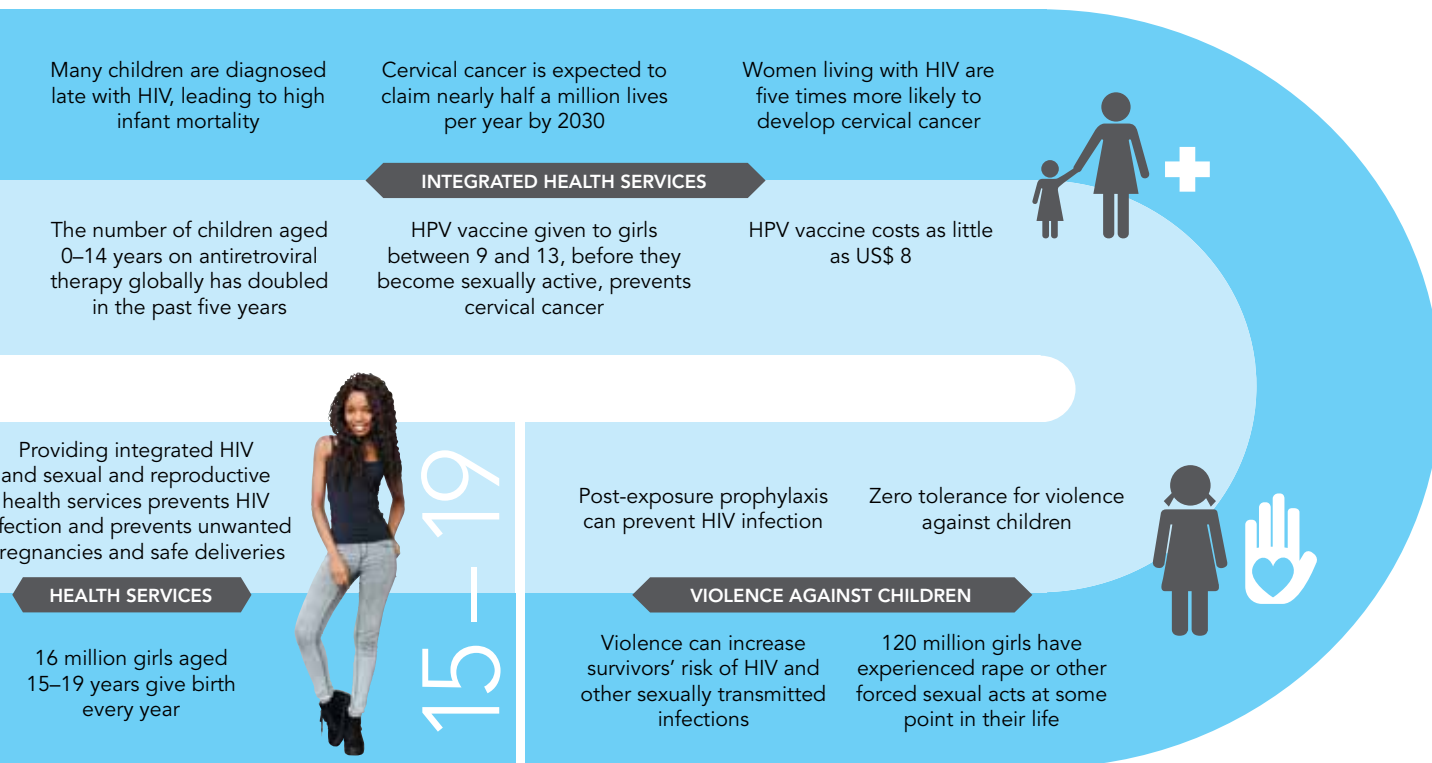
Empowering community health workers can increase access to antiretroviral therapy

HEALTH SERVICES

High mortality due to AIDS among women

30-49



Girls and women are at the centre of the AIDS response. Factors including age, ethnicity, gender inequities, disability, sexual orientation, profession and socioeconomic status compound to influence girls and women's ability to protect themselves from HIV. Programming efforts must recognize the complexity of the every day lives of girls and women as they mature and grow and build the response around their needs. Placing the individual—not the virus—at the centre of all our efforts creates the space for inclusion of the diverse opportunities and needs of girls and women and improves HIV outcomes.

Right to health YOUNG PEOPLE

A CONVERSATION WITH THE PACT

The PACT is a coalition of more than 80 youth organizations working to end AIDS by 2030. It has been building solidarity across youth organizations to ensure the health, well-being and human rights of all young people since 2013. The PACT uses several online coordination platforms to support joint participation and the involvement of young people from across the globe.



Young people working together on the right to health

“ADOLESCENTS AND YOUNG PEOPLE ARE NOT PASSIVE BENEFICIARIES OF ADULT CARE FOR HEALTH, BUT ACTIVE RIGHTS HOLDERS WHOSE PARTICIPATION IS IMPORTANT.”

What does the right to health mean to you?

For us, the right to health means that everyone across the world is able to enjoy the same health outcomes and achieve equal justice in health as any other human being, independent of who they are and where they live. It means that health services for adolescents and young people everywhere are available, non-judgemental, free of charge, physically accessible, take into account the specific needs of adolescents and young people and have the highest possible scientific and medical quality.

It means that adolescents and young people are not passive beneficiaries of adult care for health, but active rights holders whose participation is important when it comes to decision-making that affects our health. It means that everybody is free to access services independent of who they are, their occupation, sexual orientation or gender identity, and that there are no laws or policies that block adolescents and young people from accessing services. It also means that every young woman, everywhere, is free to choose if, when and with whom to have sex, get married and have children and

to live free from violence. The right to health means that each person has access and is able to meaningfully use a comprehensive package of information, services and supplies to ensure a good quality of life. It also means setting the right policies and having the mechanisms to ensure that people can equally access this package of information, services and supplies by respecting every person's autonomy to decide about their own health.

What is preventing adolescents and young people from being able to exercise their right to health?

Some of the main factors that prevent adolescents and young people from exercising their right to health include patriarchy, gender-based violence, inequalities, discrimination and exclusion.

In some settings, laws and policies that require adolescents and young people to have consent from parents or guardians to access health care are also important obstacles to exercising the right to health. Stigma against young people, especially around sexual and reproductive health, and perceptions of adolescents as dependents and needing protection

**“IN SOME SETTINGS, LAWS AND POLICIES ... ARE IMPORTANT
OBSTACLES TO EXERCISING THE RIGHT TO HEALTH.”**



without the autonomy or maturity to decide their own health needs are additional barriers. In many countries, services aren't accessible for reasons that include cost, distance and lack of availability of services or supplies.

In the health-care setting, many services are not friendly to young people and do not address the needs of adolescents and young people in a comprehensive way. Some health-care providers are not well trained in issues relating to young people and can be judgemental.

There can be limited sources of comprehensive knowledge on health-related needs and available services and a lack of quality sexuality education programmes.

Health is interlinked with other issues, such as education, employment, housing and gender equality. Having said that, we find that poverty, lack of urban infrastructure, sexual exploitation and trafficking, lack of decent employment, gender-based violence and bullying are also preventing adolescents and young people from being able to exercise their right to health.

Many young people lack a support system that encourages or facilitates adolescents and young people to access health services and information.

What more can be done to make sure that adolescents and young people can access services?

To ensure that adolescents and young people can access services, we must lift harmful laws, policies and practices that put young people at risk of poor health outcomes, including inequalities, violence, exclusion, discrimination and stigma.

We need to support young people's participation in decision-making that affects their own health, and empower young people to organize, mobilize and participate in the respect,

“MANY SERVICES ARE NOT FRIENDLY TO YOUNG PEOPLE AND DO NOT ADDRESS THE NEEDS OF ADOLESCENTS AND YOUNG PEOPLE.”

protection and promotion of the right to health. We need to ensure the right of adolescents to be an equal party to medical decision-making in line with their evolving capacities, as mentioned in the Convention on the Rights of the Child, at the level of general medical practice at the national level.

We need more research on the maturity and evolving capacities of adolescents. The use of age as a proxy to measure the maturity of adolescents should be addressed through exercising a case-by-case approach whereby adolescents are empowered to demonstrate their maturity to access health services independently.

We should set and promote the differences between services and information focused on adolescents and on young people, both among the users of these services and within the whole health sector.

Do you think the situation has improved at all over the past 20–30 years?

To a certain extent. Although today people seem to live longer lives, this does not necessarily mean that we live better or healthier lives. In terms of HIV, we have seen new infections and AIDS-related deaths beginning to drop. New technologies for prevention and treatment have been developed, but success has been unequal. Young women in Africa and young key populations, including young gay men and other men who have sex with men, young transgender people, young sex workers and young drug

users, still carry a heavy burden of the epidemic, and are criminalized and discriminated against in many parts of the world. In addition, many countries still enforce laws that require adolescents to have the consent of their parents, or spouse in settings where child marriage is endemic, to access sexual and reproductive health services, including HIV. The root causes of poor health outcomes, including inequalities, discrimination, exclusion and violence have not been properly addressed, and they still gravely jeopardize the health of young people.

BACKGROUND

The PACT advocates and promotes youth-led accountability and participation for the integration of HIV and sexual and reproductive health and rights services and policies, including comprehensive sexuality education. It strengthens young people's capacity to change the legal and policy frameworks that prevent young people from accessing services, advocates for young people's participation in decision-making processes and mobilizes young people and engages decision-makers to increase access to evidence-informed HIV prevention and treatment. For more information, visit www.theyouthpact.org.

YOUNG PEOPLE AND HIV:

MISINFORMATION AND DISCRIMINATION

Although new HIV infections and AIDS-related deaths among young people have decreased, in many places knowledge about how to prevent HIV remains worryingly low. Four young people talk about the challenges they face around living HIV.



“YOUNG PEOPLE NEED HIV AND SEXUAL AND REPRODUCTIVE HEALTH SERVICES THAT ARE YOUTH-FRIENDLY, STIGMA-FREE, NONJUDGEMENTAL AND FREE FROM VIOLENCE.”

Resty Nalwanga is from Uganda and has been living with HIV since birth. She volunteers in local health centres and is actively involved in youth HIV advocacy. She believes that gender inequalities and violence must be addressed if we are to end AIDS by 2030, and that more work is needed to provide gender-equitable HIV prevention, treatment, care and support for adolescent girls and young women.



“THE BIGGEST PROBLEM IS RAISING AWARENESS AND GIVING YOUNG PEOPLE AGE-APPROPRIATE INFORMATION.”

Chinmay Modi was born with HIV 23 years ago in India. He thinks that parents are not comfortable talking with their children about sex. As a result, young people are engaging in sex and experimenting, but with little knowledge about the risks involved. He is also frustrated that in India people cannot access stigma-free HIV services at an early age.

“YOUNG PEOPLE CONTINUE TO BE LEFT OUT OF SPACES AND DISCUSSIONS ON ISSUES THAT IMPACT THEIR LIVES. RECOGNIZING YOUTH SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS, FOR EXAMPLE, AND CONTINUING THE CONVERSATION ON HIV WILL GET US CLOSER TO ENDING AIDS BY 2030.”



Lorraine Anyango, a youth health and rights advocate based in Boston, United States of America, works to ensure that young people's voices, specifically around HIV, get heard. In her opinion, young people's participation in decisions that affect their health can contribute to ensuring that programmes are effectively responding to their needs.

“YOUNG PEOPLE ARE STILL AT GREAT RISK OF HIV INFECTION DUE TO A VARIETY OF FACTORS, SUCH AS SOCIAL MARGINALIZATION RELATED TO GENDER AND RACIAL INEQUALITIES. WE SHOULD START TALKING TO YOUNG PEOPLE IN AN OPEN AND RESPONSIBLE WAY ABOUT SEXUALITY, SEXUALLY TRANSMITTED INFECTIONS, TEENAGE PREGNANCY AND LIFE RESPONSIBILITIES.”



Moises Maciel, a 20-year-old activist on lesbian, gay, bisexual, transgender and intersex issues and on HIV, from Brazil, discovered his HIV-positive status two years ago. Since then, he has been on a journey against HIV-related stigma. He has also been motivating his peers to get tested. He said that it baffles him to see how stigma and prejudice still dominate despite people living with HIV living healthy lives with the help of antiretroviral therapy.

WHAT HAPPENS WHEN YOU ARE EMPOWERED TO MAKE DECISIONS ABOUT YOUR OWN HEALTH?



YOU REDUCE COSTS OF HEALTH CARE

YOUR TRUST OF HEALTH-CARE PROVIDERS, CLINICS AND HOSPITALS IS INCREASED



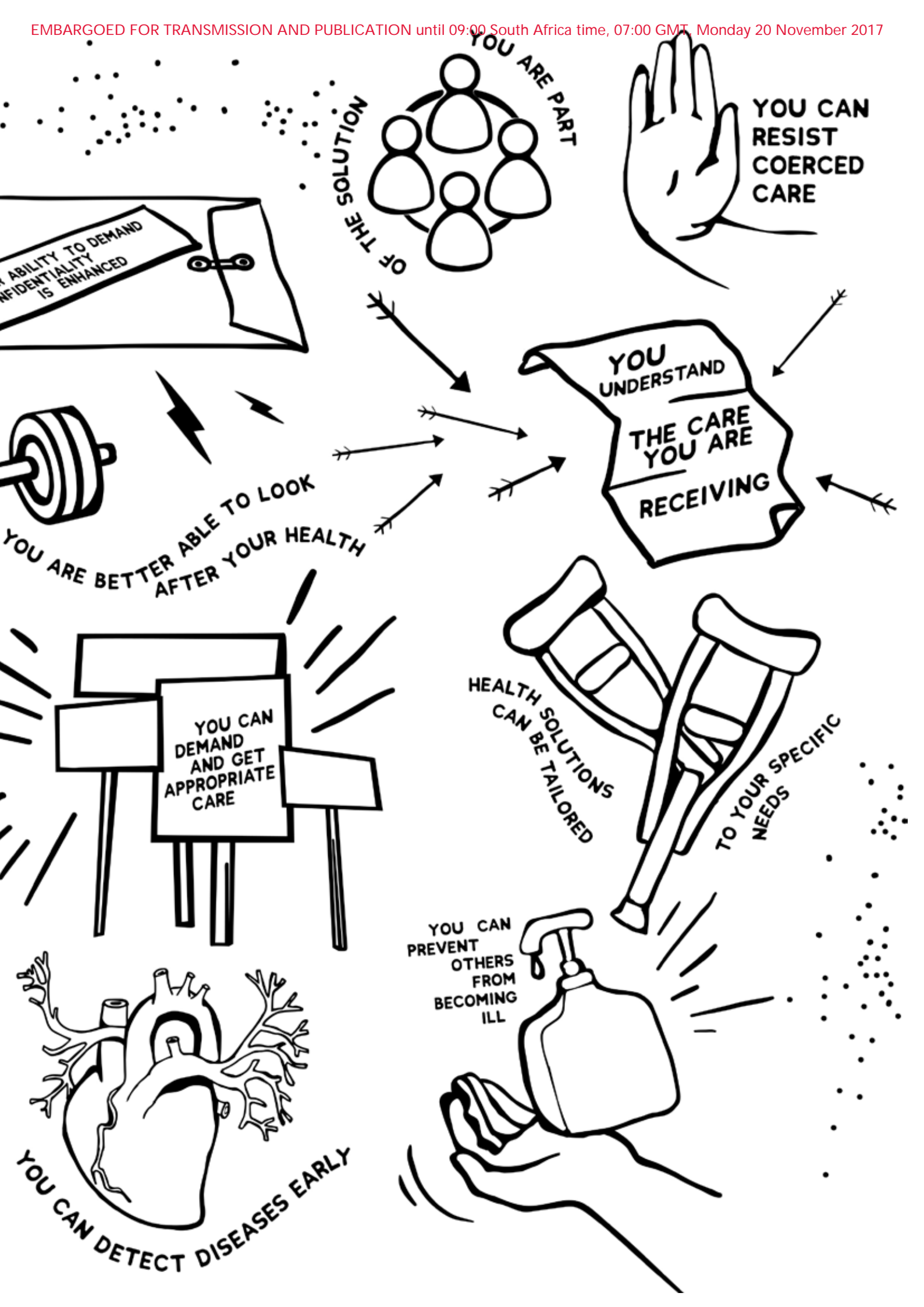
DISCRIMINATION IS REDUCED

YOU CAN PROVIDE SUPPORT TO OTHERS

YOU CAN SEEK THE SUPPORT OF OTHERS

YOU ARE MORE LIKELY TO ADHERE TO PRESCRIBED TREATMENT





Right to health

TRANSGENDER PEOPLE

A CONVERSATION WITH MARCELA ROMERO

Marcela Romero is a recognized Argentine activist for the rights of transgender people. Currently, she serves as the President of FALGBT (the Argentine Lesbian, Gay, Bisexual and Transgender Federation), the President of ATTTA (the Association of Transvestites, Transsexuals and Transgenders of Argentina) and the Regional Coordinator of the Latin American and Caribbean Network of Transgender People (REDLATRANS).



Transgender people demanding the right to health

“A PERSON WHO DOESN'T HAVE AN IDENTITY DOESN'T EXIST, AND WE ARE A PART OF SOCIETY.”

What does the right to health mean to you?

For me, the right to health means equal rights. Without the right to health, HIV prevention, care and treatment don't exist, nor does universal health coverage. When health care is not guaranteed as a human right, poverty and social exclusion increase, and lives are lost. It is the most vulnerable people in the Latin American and Caribbean region who are denied this basic and universal right frequently—people like migrants, mobile populations, prisoners and transgender people. We are dying of preventable and curable diseases, like tuberculosis, pneumonia and hepatitis, which are illnesses that contribute to the circle of poverty and exclusion.

What is preventing transgender people from being able to exercise their right to health?

Violence, stigma, social exclusion and discrimination negatively influence the exercise of the right to health.

They also discourage transgender people and key populations from seeking prevention, treatment, care and support services related to HIV.

The prejudices shown by health professionals and their lack of information are just two examples of obstacles. Also, there are only a few sexual and reproductive health programmes in the region that are addressed to transgender people. It is rare that transgender people have regular access to suitable sexual and reproductive health and HIV services.

What more can be done to make sure that transgender people can access services?

We are changing the indicators of international cooperation agencies and government plans so they invest more in health care and human rights for key populations. We are seeking and facilitating more spaces for dialogue so that transgender people are more visible, participate in decision-making



**"WE ARE NOT ASKING FOR OTHER RIGHTS, WE ARE JUST
ASKING FOR THE SAME RIGHTS."**

and contribute to government public policies. We are also working on reducing stigma and discrimination in society through awareness-raising campaigns with contributions from UNAIDS, the Global Fund to Fight AIDS, Tuberculosis and Malaria and the United Nations Development Programme, as well as other partner organizations.

At the community level, we recently inaugurated the Transgender House, a space where transgender people receive guidance about different issues, including HIV prevention. It is necessary to put an end to gender-based and institutional violence that transgender people suffer from because of having a female gender identity. Through our Documentation Centre for Transgender People from Latin America and the Caribbean, we are monitoring human rights violations against transgender people, and the right to health is one of the main components that we are monitoring.

Finally, there is an urgent need to approve laws and implement policies that facilitate the legal recognition of the gender of transgender people. Gender identity laws recognize transgender people as human beings, as citizens, so they have a right to access public services and be included in government agendas. These laws allow transgender people to access the same benefits and opportunities that any other citizen would have, including access to health services. Without this right, we cannot access HIV prevention, care and treatment.

Do you think the situation has improved at all over the past 20–30 years?

Yes, we can improve the situation that we are living in, but as transgender people we have to step out of the darkness. Our problems have to be included and made visible in political agendas. We have to work

“GENDER IDENTITY LAWS RECOGNIZE TRANSGENDER PEOPLE AS HUMAN BEINGS, AS CITIZENS.”

in a cross-cutting manner so that transgender people are recognized and their human rights are guaranteed, including the right to health. I worry that in some countries in the region we are experiencing setbacks and an increase in gender-based violence. Human rights should be our guiding light. Without a rights-based approach, the 2030 Agenda for Sustainable Development will not be able to prosper and be effective.

We are not asking for other rights, we are just asking for the same rights, just like any other citizen. A person who doesn't have an identity doesn't exist, and we are a part of society.

BACKGROUND

REDLACTRANS is a network of transgender people from Latin America and the Caribbean. It works towards the goal of ensuring the fulfilment of human rights for transgender people in Latin America and the Caribbean through the use of strategies related to political advocacy, social awareness, organizational participation and strengthening of health, education, justice and equality.

CHAMPIONING THE RIGHT TO HEALTH

**“TRANSGENDER PEOPLE HAVE
BEEN SHUT OUT MANY TIMES
BEFORE. WE MUST BE HEARD,
NOT SILENCED OR IGNORED.”**



Phylesha Brown-Acton (second left), from the Asia-Pacific Transgender Network, is a champion for the rights of sexual minorities.

Phylesha Brown-Acton is a champion for the rights of sexual minorities. She works for the Asia-Pacific Transgender Network, volunteers for the Pacific Sexual Diversity Network and is the founder of F'INE (Family, Identity, Navigate & Equality), an organization that supports Pacific lesbian, gay, bisexual, transgender and intersex people and their families.

“Experiencing discrimination on a daily basis and seeing it happen to my peers made me think hard about if I wanted to continue living in a society that defines and restricts me or if I was actually going to do something about it,” said Ms Brown-Acton. “I decided on the latter, and that is why I became an activist for lesbian, gay, bisexual, transgender and intersex rights.”

In her work, Ms Brown-Acton has seen the impact that discrimination in health care can have. “I assisted four

transgender women in understanding their health needs. All of them told me that they had not been to a doctor for several years, because every time they went to see a health-care provider the experiences were bad. So instead of going to see a doctor when not feeling well, they were medicating themselves at home with over-the-counter medicines,” she said. “All of those women were later diagnosed with type 2 diabetes. Their diagnosis was delayed because of discrimination. The same happens to many people living with HIV.”

Despite the persistent stigma and discrimination that transgender people experience, she believes that discrimination in health-care settings can be overcome. “We need to remove bias in thinking and decision-making,” she said. “We need to work with health institutions and practitioners so that they can hear and understand the discriminatory experiences of

transgender people.” Ms Brown-Acton stresses the importance of including zero discrimination training in medical school curriculums and is adamant that people who experience discrimination—including transgender people, people living with HIV, people with disabilities and indigenous communities—must be at the table when decisions are being made.

“Transgender people have been shut out many times before. We have been strategic about getting into the meeting rooms, but there is still a lot of work to be done. We must be heard in those meeting rooms, not silenced or ignored.”

LET YOUR FINGERS DO THE DIALLING TO

0800 Salud Responde is a free hotline in Argentina that fields calls and complaints regarding health. Queries vary from questions about treatment and diagnosis to requests for legal advice.

ACCESS HEALTH RIGHTS IN ARGENTINA

Last year, the Health Answers team had a record number of calls, up 124% from 2014, when they first started. That translates to about 1000 calls a year.

The hotline, part of the National AIDS Programme in Argentina, also answers emails if people prefer communicating online. Based on the input from the hotline, the Argentina AIDS programme works on developing pamphlets on people knowing their rights and training health workers to address stigma and discrimination.

The hotline's main purpose is to address human rights-related issues, but they field all sorts of other calls. The operators help to resolve administrative hiccups or pension payments. If questions involve violations of rights or legal advice, they refer callers to free legal services.

They also suggest so-called safe place—non-biased health-care centres. One such place is the Friendly Services centre in San Martin, Buenos Aires. The centre was founded after a 2010

health study in Argentina pointed out that certain groups were excluded from the health system and not accessing health care. Friendly Services caters to transgender people, sex workers and gay men and men who have sex with men.

At first, the centre had few visitors, but once key populations got involved they rallied their networks and more people came. Now there are 21 Friendly Services centres, functioning mostly in public hospitals.

“IT’S A POSITIVE STEP, MORE AND MORE PEOPLE ARE BECOMING AWARE OF THEIR RIGHTS.”

Sergio Maulen

Director of the National AIDS Programme of the Ministry of Health of Argentina.



Complaints are resolved through administrative means or the hotline refers people to clinics such as Friendly Services and places that provide free legal services.



Fabio Nuñez, Mariela D’Oria and Soledad Sequeira from the human rights and civil society team analyse data that comes from the hotline call centre. Based on the input from the hotline, the team works on capacity-building, developing new materials and training health workers to address stigma and discrimination.



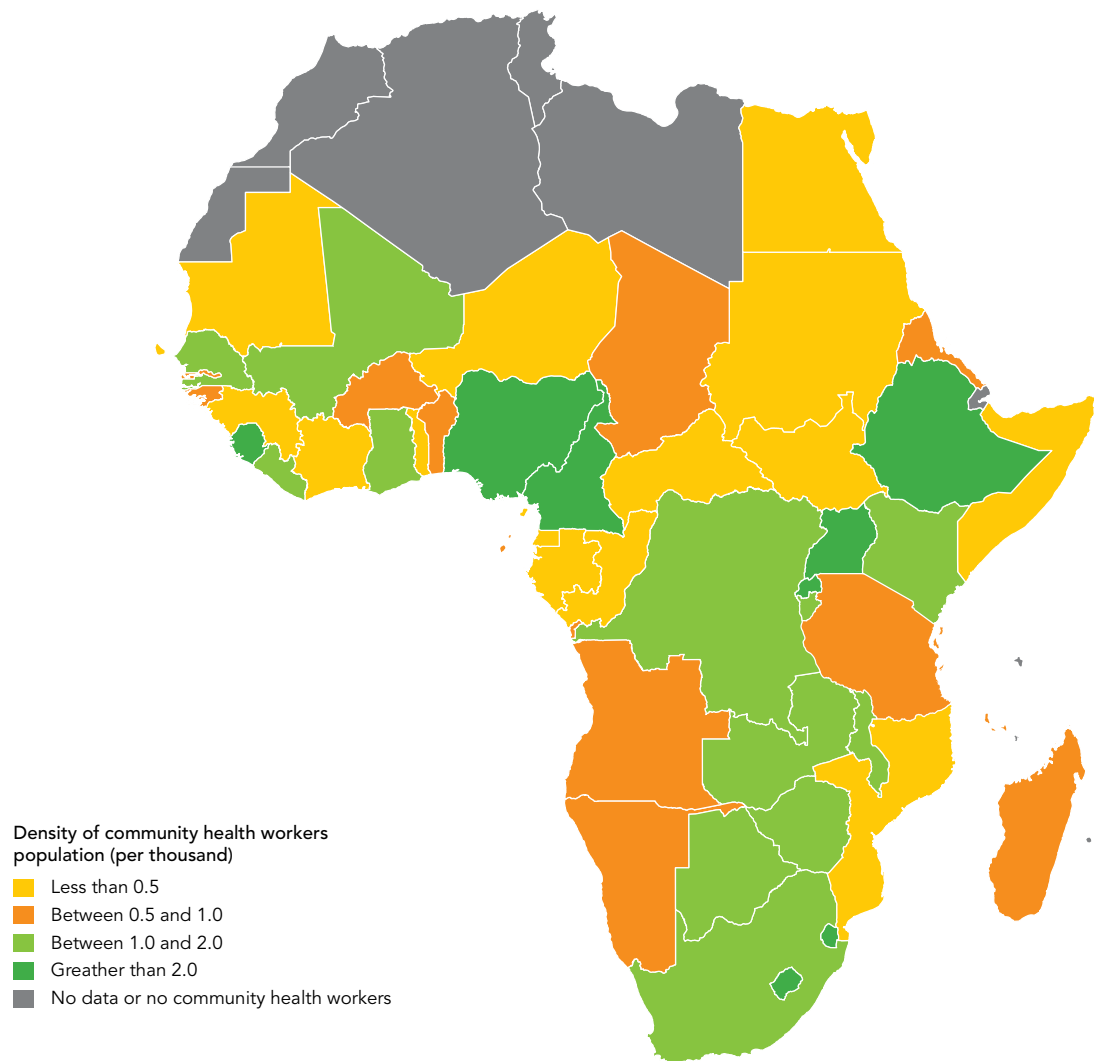
Sebastian Crespo gives health advice to Nicol Rodriguez at the Friendly Services at the Fleming Hospital in San Martin, Buenos Aires.



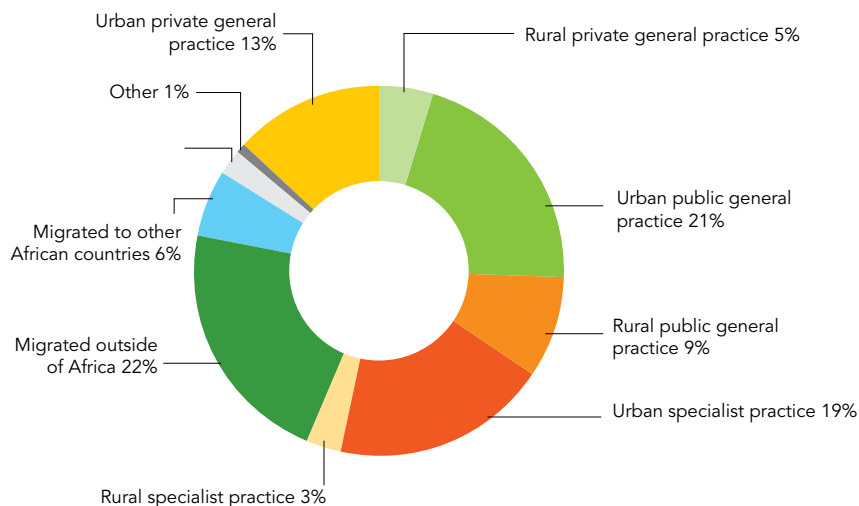
DOOR TO DOOR: the crucial link between communities and health systems

In the small mountainous country of Lesotho, most people live in rural areas. Accessing food and health care is not always easy. With more than half the country's population living below the poverty line and one in four people living with HIV, community health workers are bringing about change.

Population density of community health workers varies considerably across Africa



Location of doctors five years after graduating from medical school in sub-Saharan Africa



Source: The Lancet

Mamokhoplo Motale, donning a Lesotho Network of AIDS Service Organisations polo shirt, makes her rounds visiting her patients. Today she is meeting Mpho Tlabaki.

Greeting him, they sit on the outdoor steps of his home. She takes out a black notebook and asks him about his health. Then she asks him get his medicine to see if he has enough. Jotting down the pill count, she encourages him to stick to his treatment.

“I visit households and teach people about nutrition issues and how to take care of themselves when they are sick,” Ms Motale said. Looking at Mr Tlabaki, she said, “I stress to people how important it is to seek out health services.”

She sees her job as educating people about the basics.

Community health workers, who come from the communities they serve, are key to reaching people in remote areas, often with few resources, to seek out treatment and care. They represent the crucial link between communities and health systems.

Mr Tlabaki is married and has four children. In 2008, he began feeling ill, so he went to a clinic and the nurse advised him to take an HIV test. He found out that he was HIV-positive, but he didn't believe the result. A while later, he went to another clinic for a second diagnosis. Again, he was told he was HIV-positive and he began treatment immediately.

“Treatment changed my life,” he said. “Without it, I would be dead by now.” He says it allowed him to feel strong again and to get back to work.

Community health workers increase the uptake of health services, reduce health inequalities, provide key services and improve overall health outcomes. They receive training that is shorter than that required for doctors, nurses

“Community health workers, who come from the communities they serve, are key to reaching people in remote areas, often with few resources, to seek out treatment and care.”

or other health professionals, but offer essential care. Increasing the number of community health workers provides job opportunities, empowers women, bolsters national and local economies and boosts productivity by improving a nation's health and well-being.

Investing in community health workers in Africa will enable the continent to turn the projected near doubling in its youth population through to 2050 from a potentially perilous so-called youth bulge into a dynamic demographic dividend that drives economic growth and improves living standards. In Mr Tlabaki's case, his community health worker encouraged him to join a group of people living with HIV that she leads. They gather weekly and share their stories.

“Before I knew my status, I drank a lot, but after knowing my status that all changed,” Mr Tlabaki said. “I got counselling, so I was able to concentrate more on taking my medicine daily and eating more healthy.”

The 2 million African community health workers initiative

The 2 million African community health workers initiative aims to accelerate progress towards achieving the 90–90–90 targets by 2020—whereby 90% of all people living with HIV know their HIV status, 90% of people who know their HIV-positive status are accessing treatment and 90% of people on treatment have suppressed viral loads—and to lay the foundation for sustainable health systems. Endorsed by the African Union, the initiative seeks to confront the acute health workforce shortages across Africa and improve access to health services for the most marginalized populations, including people living in rural areas.

Right to health SEX WORKERS

A CONVERSATION WITH RUTH MORGAN THOMAS

Ruth Morgan Thomas has been involved with sex work for nearly 40 years—eight years as a sex worker, two and a half years as an academic researcher at the University of Edinburgh looking at HIV-related risks in the sex industry and 38 years as a sex workers' rights advocate. She is the Global Coordinator of the Global Network of Sex Work Projects (NSWP) and Co-Chair of the UNAIDS Advisory Group on HIV and Sex Work.



“WE’RE TALKING ABOUT SHARING POWER WITH THE COMMUNITY, AND SHIFTING THE POWER TO THE COMMUNITY.”

What does the right to health mean to you?

I am a sex worker rights advocate, but I’ve been a political activist since my teens on issues concerning social justice and rights. For me, the right to health is being able to access services that are non-discriminatory, that meet the needs that I feel I have rather than the needs that others decide or think I have. The right to health is about allowing me to have the highest possible standards of health and care. It goes beyond physical health, it’s about mental health and well-being, as well as physical health and sexual health.

What is preventing sex workers from being able to exercise their right to health?

Today, there are a number of things that create real barriers to being able to access health care. Discrimination that comes from criminalization is a huge barrier. It has enabled health-care providers to treat us differently and to see us as threats to public health rather than as part of the solution.

That kind of treatment drives my diverse community—male, female and transgender sex workers, migrants, both legal and undocumented, and people who use drugs and people living with HIV—away from accessing services. If we’re treated badly we don’t go back to get treated badly again. We need to look at how to address that discrimination and how to address the criminalization that drives our communities away.

There are still countries in which police officers will sit outside drop-in centres in order to catch and arrest people who inject drugs and sex workers. In many countries, the ministry of health will give condoms to sex workers, but then the police will arrest them, confiscate their condoms, use them as evidence and then destroy them. That’s such a hypocritical situation to find ourselves in, where one arm of the government is trying to assist and another arm is taking that assistance away. It’s not a good use of the limited resources we have.

**“IF WE’RE TREATED BADLY WE DON’T GO
BACK TO GET TREATED BADLY AGAIN.”**



We've also seen the closure of health services that are run by sex workers. In the United Republic of Tanzania, for example, a sex worker group has recently had an order to be closed and is under investigation for promoting prostitution; that's such a clear violation of the right to health and the access to the highest attainable standard of health when you close down the very services that are there for our community.

What more can be done to make sure that sex workers can safely access services?

Sex workers need to be involved in the development of both policy and programmes. That means engaging us from the very conceptualization of what needs to be done through to the design and development of the services and meaningfully involving us in their actual implementation and in their management, government and monitoring and evaluation. Doing this will mean that the programmes will be relevant and accessible.

We strongly believe that the ultimate goal is full decriminalization, and it has to be if we are going to create accessible services and equality for all. But we can still do the programming work without decriminalization and we can start that now. We need a paradigm shift in the way that we approach programmes. We're talking about sharing power with the community, and shifting the power to the community, and that's quite difficult for people, because it means that they're working to make themselves redundant, but that will make that paradigm shift happen and will make any marginalized community, not just mine, actually have full access to health and well-being.

Do you think the situation has improved at all over the past 20–30 years?

I think in certain places it has. I first went in to India in 1995 and there has been a huge growth in the number of collectives and networks across India. One example would be the sex workers' collective Ashodaya Samithi in India, where around 15 sex workers from the collective have been trained as nurses or nursing assistants and provide services across the whole community. So, I do think that if we can plant a seed and allow communities to really thrive and grow, and if we don't put glass ceilings or glass walls around them, we can really make phenomenal improvements.

“I AM A SEX WORKER RIGHTS ADVOCATE, BUT I’VE BEEN A POLITICAL ACTIVIST SINCE MY TEENS.”

BACKGROUND

NSWP exists to uphold the voice of sex workers globally and connect regional networks advocating for the rights of female, male, and transgender sex workers. NSWP's work is based on three core values: acceptance of sex work as work; opposition to all forms of criminalization and other legal oppression of sex work (including sex workers, clients, third parties, families, partners and friends); and supporting the self-organization and self-determination of sex workers.

RAY OF HOPE

CARE AND SUPPORT BY THE
COMMUNITY FOR THE COMMUNITY

IN THE SOUTHERN INDIAN STATE OF KARNATAKA LIES THE BUSTLING CITY OF MYSORE, A POPULAR TOURIST DESTINATION WITH A LARGE-SCALE SEX INDUSTRY, WHICH IN THE MID-2000s WAS CONFRONTED WITH HIV.

In 2004, HIV prevalence among sex workers in Mysore was estimated at around 25%. With little knowledge of HIV and little or no access to HIV services, the sex workers of Mysore came together to form their own collective: Ashodaya Samithi or “ray of hope”.

Ashodaya Samithi mobilizes male, female and transgender sex workers to practise and promote consistent condom use and to stand up for their rights. It offers sex workers medical check-ups at Ashodaya clinics in collaboration with government run establishments, which provide HIV prevention, treatment and care services, free from discrimination.

Ashodaya also runs its own academy, the first training and learning site on HIV in the Asia-Pacific region run entirely by sex workers. The academy supports sex workers to

acquire new skills and teaches them ways to assert control over their lives, including managing their finances, addressing violence, knowing their rights and retaining custody of their children. The academy has also supported the training of a number of nursing assistants, who work in clinics across Mysore.

“I expressed interest in assisting at the clinic and seeing my interest the doctor and my community health worker encouraged me to go for training. Not just me but about 15 of us were trained to be nursing assistants. I got the skills to draw blood, do finger prick tests, speculum exams, cervical cancer screening, as well as measuring blood pressure, recording weight and providing pre-exposure prophylaxis and tuberculosis medication to our sisters,” says Ratna, a sex worker and nursing assistant and member of Ashodaya Samiti. “I am proud to be doing all

this because it’s not a job, it’s my responsibility towards my community.”

Research is an integral part of the academy and is conducted by trained sex workers. Based on the research findings, the programme is regularly updated to reflect the latest developments and innovations. Most recently, pre-exposure prophylaxis and community HIV testing have been added to the programme, which has drawn sex workers from across four districts in southern Karnataka.

The mainstay of the work is the volunteer system where, for around four hours a day, female and male sex workers walk around Mysore encouraging people, including sex workers, to get a quick and stigma-free check-up at a government hospital. These workers are called health-care navigators.

“When I see my community members coming into the hospital, I connect with them. I quickly understand their needs and I provide guidance to navigate the system in the government hospital so that they go to the right outpatient department and get the right treatment,” says Vijaya, a sex worker, health-care navigator and member of Ashodaya Samithi, who works at the Krishna Rajendra Hospital. “Today, I am part of the system and the government doctors appreciate our services. I reach out to others who are non-sex workers who are in need too.”

Ashodaya Samithi is an example of how community mobilization and community ownership can enable thousands of sex workers to access and use health and development services. It is a true example of a programme that provides the full spectrum of HIV services, from prevention and treatment to care and support by the community and for the community.



Sex workers trained as health-care navigators discussing strategies for antiretroviral medicine adherence



Top and bottom: Ratna providing health care to her sex work peers

INVESTING

FOR THE RIGHT TO HEALTH

The world wants to end poverty by 2030. For that, people need to be healthy. To be healthy, people need food, adequate shelter, clean air and water, sanitation and access to health services. This costs money. Is there enough? And who should pay for health?

Every year, 100 million people become poor because they had to pay for their health costs out of their own pocket. They join the 767 million people who are living in extreme poverty,¹ whose pockets are already empty.

Half of the world's poor live in sub-Saharan Africa. More than half of all people living with HIV are in sub-Saharan Africa. Half of the world's poor, some 385 million people, are children.

In 106 countries, poverty is 0.65% higher because people have to pay out of their own pocket for health care. In most countries, nearly 30% of spending on health is out of pocket; in low-income countries, it is higher. More than 45% of health expenditures are out of pocket. Many people simply can't afford it.

Let's find the money to pay for the right to health. It is the responsibility of the state to do so.

¹ According to the World Bank, a person is considered to be in extreme poverty if they live on less than US\$ 1.90 per day.

SO, HOW MUCH IS THERE IN THE WORLD?

US\$ 77
900 000
000 000

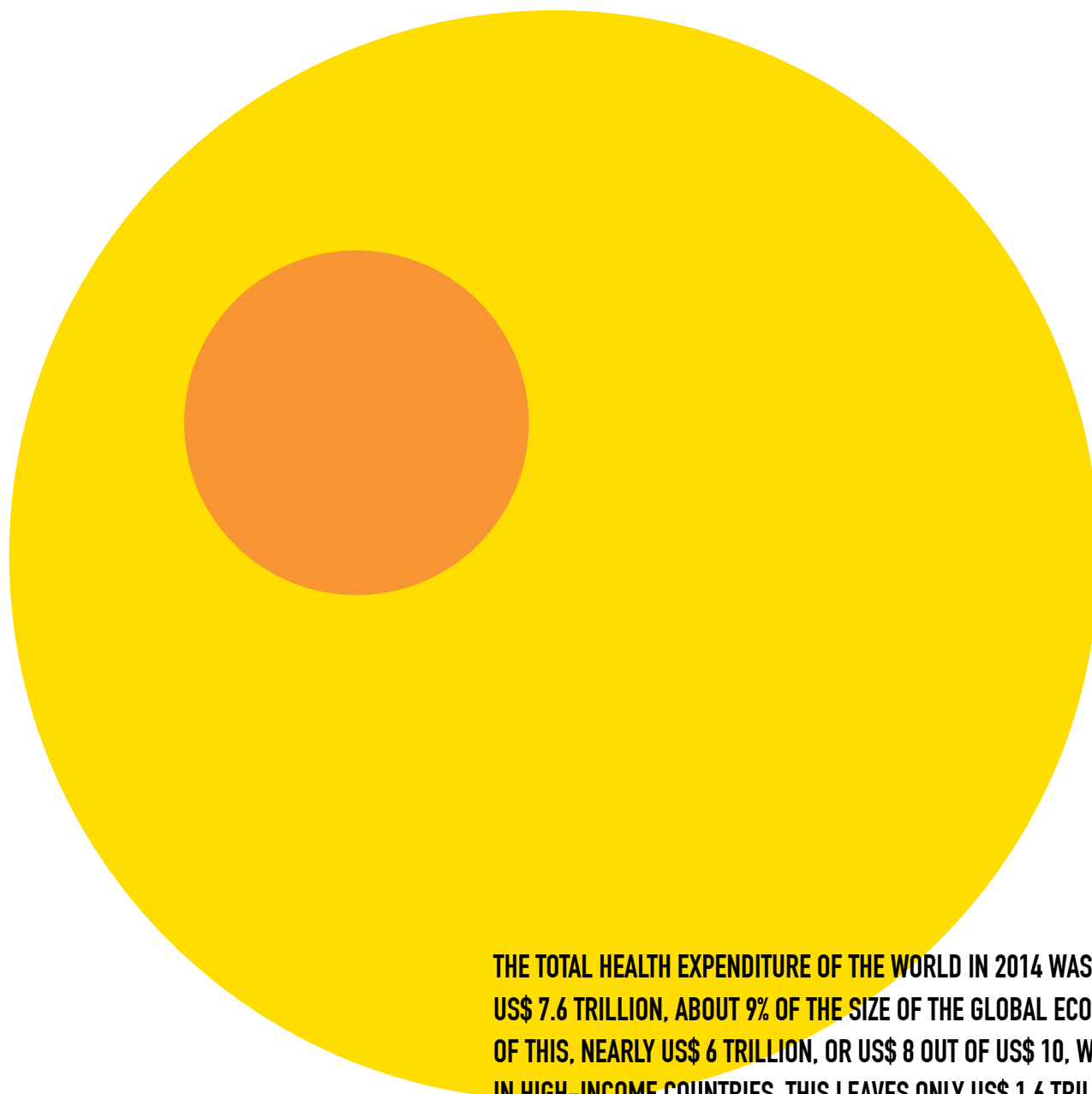
(THAT IS, US\$ 77.9 TRILLION—THE SIZE OF THE GLOBAL ECONOMY²)

SURELY WE CAN FIND US\$ 271 PER PERSON³ TO PAY FOR GLOBAL HEALTH. IN FACT, WE NEED ONLY US\$ 58 MORE PER PERSON THAN IS ALREADY BEING SPENT ON HEALTH.

² World economy in 2014. Constant 2014 in United States dollars.

³ Population weighted mean. Individual costs will vary substantially from country to country and within countries. These are resource needs for 67 low- and middle-income countries where 95% of the world's population live. Source: Stenberg et al, The Lancet, July 2017.

LET'S INVEST IN HEALTH. THERE IS ENOUGH.



THE TOTAL HEALTH EXPENDITURE OF THE WORLD IN 2014 WAS ABOUT US\$ 7.6 TRILLION, ABOUT 9% OF THE SIZE OF THE GLOBAL ECONOMY. OF THIS, NEARLY US\$ 6 TRILLION, OR US\$ 8 OUT OF US\$ 10, WAS SPENT IN HIGH-INCOME COUNTRIES. THIS LEAVES ONLY US\$ 1.6 TRILLION, OR US\$ 2 OUT OF US\$ 10, FOR OTHER COUNTRIES.

- **Size of the world's economy:** US\$ 77.9 trillion (2014)
- **Total health expenditure:** US\$ 7.6 trillion (2014)

TEN TIPS TO INCREASE INVESTMENTS IN HEALTH

For the 67 countries that constitute 95% of the population living in the world, the World Health Organization estimates that an additional US\$ 371 billion is needed annually by 2030. Where can this money come from?

01 Increase the share of health spending as a proportion of the national economy. If all countries increase their health expenditures for health by one to two percentage GDP points, a significant amount of money can be made available to bridge the gap. How? The global economy is growing, so even maintaining the current ratio will add more resources to health, but it will clearly not be enough. A mere 1% increase will generate US\$ 91 per capita and 2% will generate US\$ 105 per capita in low-income countries. This is close to the US\$ 112 cost per person estimated for those countries. A similar increase across all other income categories can meet the need for investments to achieve universal health coverage. However, the transformation of economic growth into increased public health spending is not an automatic process and continuous dialogue with budget officials and ministries of finance is imperative if health is to be reprioritized and to reap the benefits of increased prosperity.

02 Increase and prioritize official development assistance for health for low-income countries. Low-income countries need the most international assistance for health. The current levels of official development assistance for health can be increased to their share in 2013 (i.e. 18%), generating an additional US\$ 4.5 billion, or an additional US\$ 6.9 per capita in low-income countries. On the other hand, better aid effectiveness can lead to more bang for the buck invested. If all high-income countries invest 0.7% of their gross national income on development

assistance and maintained their share of health investments, it would result in a two-fold increase in the official development assistance for health. An increase in the share of health official development assistance to 20% would result in mobilizing an additional US\$ 69 per capita to achieve health system targets in low-income countries.

03 Savings through efficiencies. Getting the most from efficiency gains is one of the most important means of releasing fiscal space for health. Efficient money flows through the system and budget execution are among the strongest arguments to be used in influencing greater public expenditures for health. By better allocation of resources and applying a population–location approach, investments in health can be optimized. Countries will need to fully leverage their negotiating potential, including pooling procurement with other countries and strategically designing commodity tendering processes to bring down the prices of health commodities and services. In addition, the delivery of health services by communities, as shown in tuberculosis and HIV programmes, can lower the cost of health services.

04 Earmarked taxes. Countries can also choose to earmark taxes specifically for health. These taxes can pay a dual role—they can be used to deter unwanted behaviour through resulting price increase of commodities such as tobacco, alcohol and sugar and they can raise additional revenue. Employment-related social health insurance premiums are a type of earmarked tax for health. However, experience so far has been mixed and, in general, earmarked taxes alone can only be an additional source for public health expenditure and will not be able to fill the entire gap on their own.

05 Borrowing. Borrowing can accommodate spikes in health-related costs more gradually in order to avoid sudden disruptions to expenditure in other areas. It also can fund interventions that release fiscal space or it can spread the burden across generations when future generations will reap the benefits of an improved disease environment. Any borrowing, however, should be highly concessional and consistent with national development strategies, and it may not be available

for countries that already have high debt. In such cases, hybrid financing instruments could be explored. Loans might come from the World Bank or regional development banks, facilitated by an international funder that would buy down the interest rate or parts of the principal to terms that are attractive to a ministry of finance.

06 Financial transaction tax. A financial transaction tax can generate billions of dollars of revenue. According to the European Commission, up to €22 billion could be generated annually if such a tax were to be introduced.

07 Partnering with the private sector. Private financing for health can be an important supplement of public health financing. Recent research indicates a growing market for health sector investments, estimating that the total health market for social impact investment could be as large as US\$ 114 billion.

08 Private equity funds. An equity fund, consisting of mostly private equity, makes investments in a geographic mix of projects and investments in the health sector. Equity funds assemble a mixture of funding, the largest part coming from mission-based investors (institutional, sovereign and foundation).

09 National health bonds. A health bond is a frontloaded investment in health programmes that reduces future spending by significantly lowering demand for treatment services and reducing the negative economic impact from ill health sooner rather than later.

10 Philanthropy. Every penny counts. As more corporations, businesses and high net worth individuals are examining their corporate social responsibility and legacies, the opportunities for directing their philanthropy to investing in health is critical. Investments in health can show a measurable and direct return on investment.

INVESTMENT INEQUALITIES IN HEALTH

Low-income countries have the lowest share of health expenditure and often have a high burden of disease. It is clear that the richer a country, the more likely it is to invest more in health. However, health inequities are present in all countries, rich and poor. Even in rich countries, the poor are more likely to fall between the cracks in the health system.

Total investments in the AIDS response have reached nearly US\$ 20 billion each year. Contrary to popular perceptions, HIV expenditures in low- and middle-income countries only account for 1.2% of total health investments. It is estimated that there will be an approximate annual US\$ 6 billion gap for HIV programmes in 2020.

Total health expenditure:

**US\$ 7.6 TRILLION
IN 2014**

High-income countries:

Total health expenditure: **US\$ 6 trillion in 2014**



Per capita health expenditure:
US\$ 4460 per person



19% of the global population

Upper-middle-income countries:

Total health expenditure: **US\$ 1.1 trillion in 2014**

● Total HIV expenditure: US\$ 8.8 Billion⁴
(0.8 % of total health expenditure)



Per capita health expenditure:
US\$ 485 per person



33% of the global population

Lower-middle-income countries:

Total Health expenditure: **US\$ 440 billion in 2014**

● Total HIV expenditure: US\$ 5.2 billion
(1.2% of total health expenditure)



Per capita health expenditure:
US\$ 88 per person



40% of the global population

Lower-income countries:

Total health expenditure : **US\$ 22 billion in 2014**

● Total HIV expenditure: US\$ 4.7 billion
(22% of total health expenditure)



Per capita health expenditure:
US\$ 49 per person

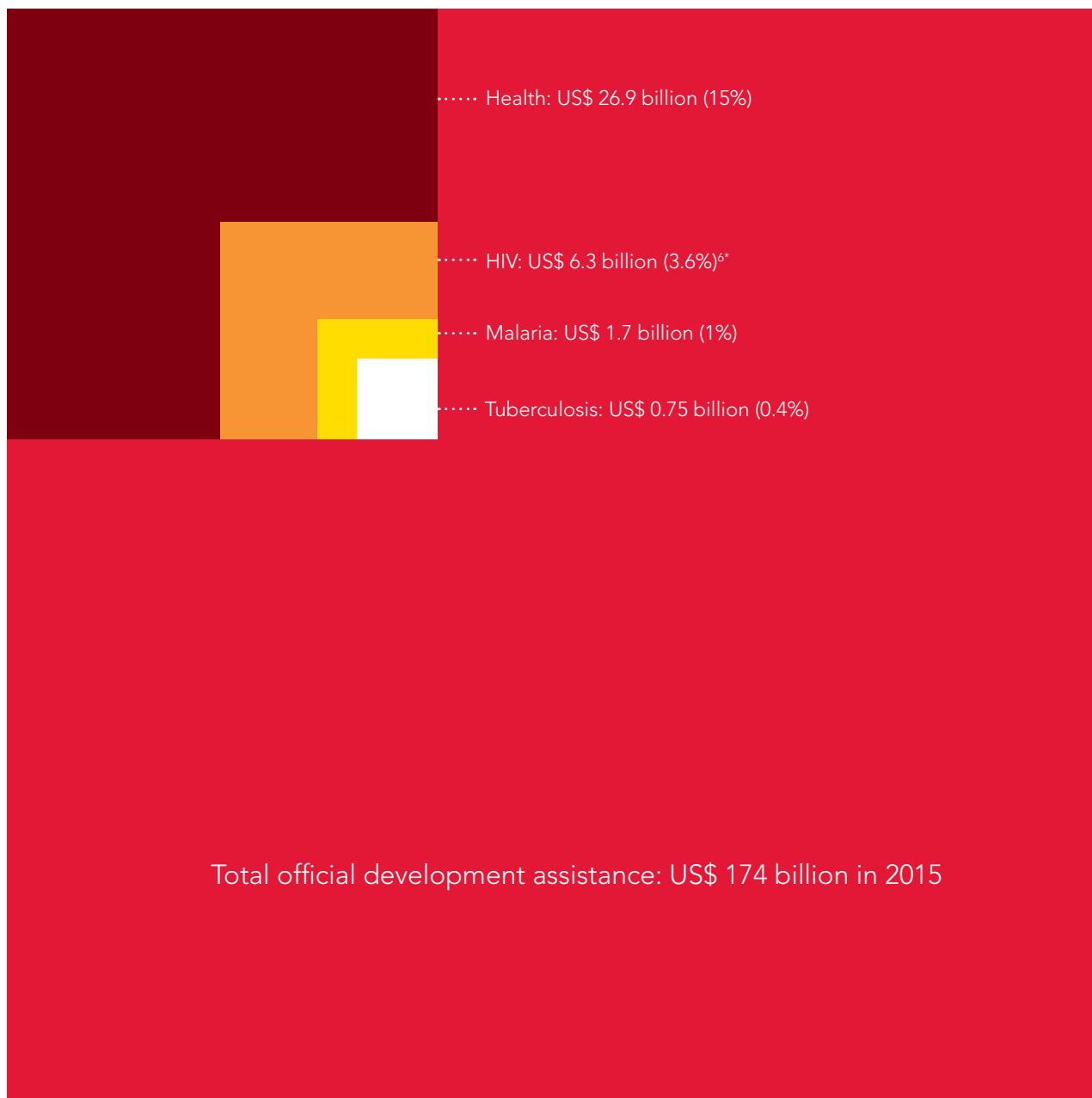


9% of the global population

⁴ These figures are total HIV resources which include international disbursements domestic expenditures. Due to grant cycles, international disbursements may not translate into in-country expenditures in the same year.

FUNDING FOR HEALTH

Global giving reached about US\$ 174 billion in 2015.⁵ But what is it spent on? Only US\$ 26.9 billion, or 15%, is invested in health-related issues. Another 6.2% is invested for education. Within health, about 23% is invested in HIV programmes, 3% for tuberculosis, and 7% for malaria control. International assistance has played a large role in financing HIV programmes, especially in low-income countries. By mid-2017, some 20.9 million people were on antiretroviral therapy, funded in part by donor assistance.



⁵ Total official development assistance obtained from the Organisation for Economic Co-operation and Development creditor reporting system.

⁶ US\$ 8.2 billion when cross-sectoral grants for HIV are included.

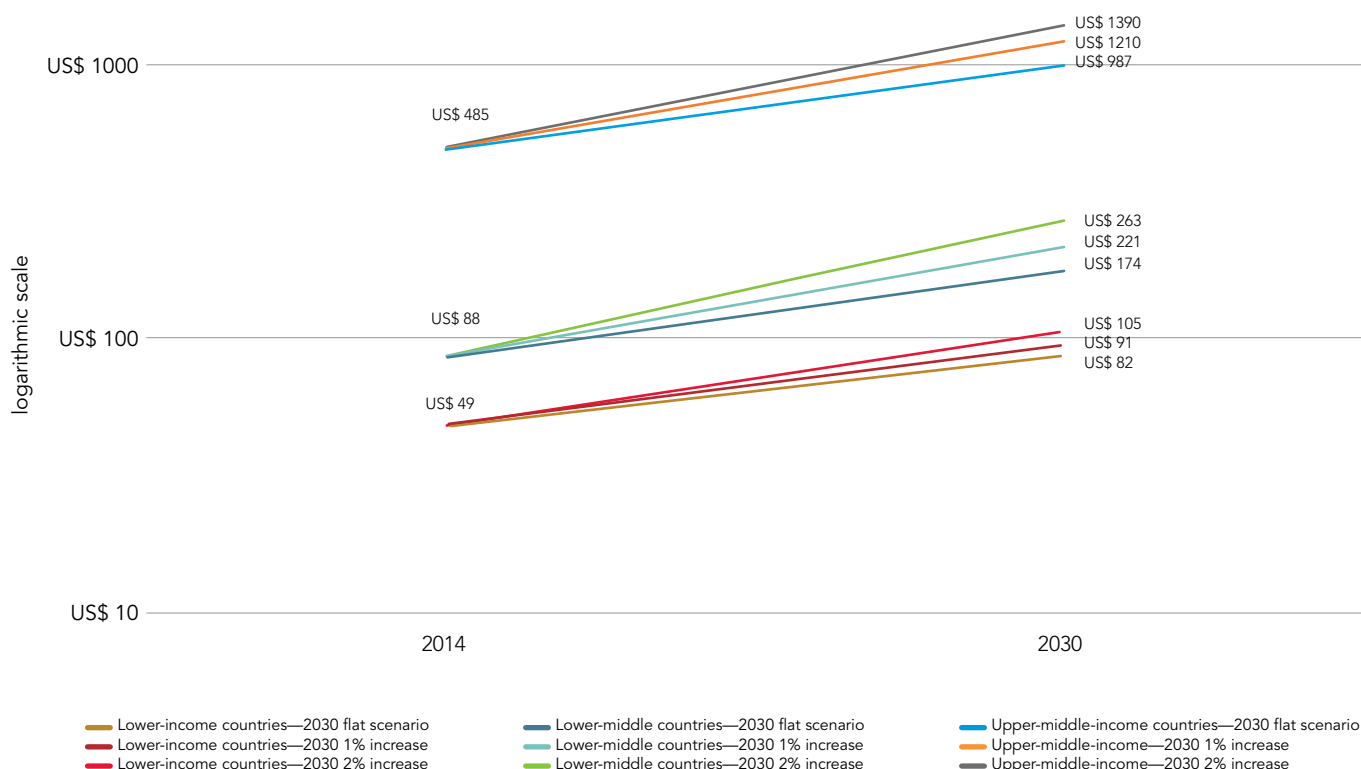
* As per Organisation for Economic Co-operation and Development creditor reporting system under sector codes 13040 and 16064.

NO EXCUSES. THERE IS ENOUGH MONEY TO PAY FOR THE RIGHT TO HEALTH.

LET'S FIND THE MONEY

If countries increase the allocation towards health by a few percentage points, in line with economic growth, it can generate significant new resources towards achieving the 2030 target of universal health coverage. These increases, coupled with targeted international assistance to low-income countries, can close the resource gap for health.

Total health expenditure per capita by country income groups—2014 and 2030
2014 and 2030 in all low- and middle-income countries



Source: World Bank, WHO health expenditure database, UNDP WPP Oct 2016, UNAIDS estimates. L&MICs based on World Bank income level classification 2015, constant 2014 dollars.

Right to health

GAY MEN AND OTHER MEN WHO HAVE SEX WITH MEN

A CONVERSATION WITH ELIE BALLAN

Elie Ballan is a media specialist who has been an activist for the rights of lesbian, gay, bisexual, transgender and intersex (LGBTI) people for more than a decade. He joined M-Coalition in January 2016 as Executive Director, a full-time activist for the rights of LGBTI people and people living with HIV in North Africa and the Middle East. He is also the director of an HIV project in Beirut called Tayf, dedicated to young gay men and other men who have sex with men and HIV. He sits on the Steering Committee of the Global Forum of MSM and HIV and on the Middle East and North Africa Community Advisory Board.



“STIGMA AND DISCRIMINATION AGAINST PEOPLE LIVING WITH HIV, AND SPECIFICALLY GAY MEN AND OTHER MEN WHO HAVE SEX WITH MEN, MAKE IT HARDER TO SEEK HEALTH CARE.”

Mr Ballan came out to his parents, family and friends at the age of 18 and started speaking openly about his HIV status to all who knew him in 2016. He wants to see a Middle East and North Africa region more tolerant for LGBTI people and advancement for the end of AIDS; in other words, he tries to make the world a better place for everyone, one step at a time.

What does the right to health mean to you?

When activists call for rights or advocate for rights, people often mistake them for asking for special rights, when what we actually raise our voices for is equal rights. The right to health means that everyone has access to testing, treatment and the opportunity of a healthy life. It also means that everyone should have the equal opportunity to access amenities to be healthy and thus be productive regardless of their sex, race, religion, gender, sexual orientation, appearance, background or beliefs.

At M-Coalition, the right to health is in the heart of our motto of “Promoting the right to health”. In the Middle East

and North Africa region, where many are denied access to health facilities, treatment or proper medical care for various reasons of accessibility, economy and, sadly, discrimination, M-Coalition’s vision seems more relevant than ever. M-Coalition’s vision is a Middle East and North Africa region in which the right to health and all other rights for gay men and other men who have sex with men are recognized, realized and protected.

Recognizing rights is only one step of the way to achieving a healthy community. Health rights ought to be realized, provided, given to all without bias and most importantly protected to ensure continuity for future generations.

What is preventing gay men and other men who have sex with men from being able to exercise their right to health?

The main reason standing in the way of gay men and other men who have sex with men and their right to health is the criminalization of individuals and their behaviours and wide discrimination against vulnerable populations. All countries in the



**“A COMMUNITY THAT HAS EDUCATION HAS THE
KNOWLEDGE TO CONQUER ILLNESS.”**

Middle East and North Africa region criminalize homosexuality and sexual relations between members of the same sex, with 1–10 years' imprisonment, torture and in some cases the death penalty. Transgender people, people who use drugs, women, refugees and prisoners are all marginalized populations and thus cannot access health rights the same as others.

Socioeconomic situations as well as uneven urban planning deter governments from investment in treatment, especially for key populations. Stigma and discrimination against people living with HIV, and specifically gay men and other men who have sex with men, make it harder to seek health care or, in some cases, get specialized services tailored to their needs.

The culture of seeking health services is not very common, especially among men, where distorted concepts of masculinity dictate that a man should bear the pain or wait for the illness to go away, which only results in advanced cases of infections, which become harder to treat.

What more can be done to make sure that gay men and other men who have sex with men can access services?

For gay men and other men who have sex with men to have access to services, there needs to be a holistic approach for health services and linkage to human rights. Criminalizing laws and legislations should be replaced with protective and inclusive legislation to provide better access for populations to health. Inclusion of gay men and other men who have sex with men in decision-making and strategic planning for services is vital, as it gives people the tools to better plan for their needs.

The inclusion of gay men and other men who have sex with men in national planning is also important

if governments wish to end the AIDS epidemic and move towards healthier, more productive citizens. Services provided in the region need to be more tailored to gay men and other men who have sex with men and speak their language for health care to be effective and individuals to be empowered. Knowledge, education and campaigning should be a constant target of all organizations working on health and other human rights, for those are the key in prevention, early detection and care. A community that has education has the knowledge to conquer illness.

Do you think the situation has improved at all over the past 20–30 years?

In the past 20 years, as medicine improved so did many approaches to health care in the region. In the Middle East and North Africa lie some of the most established bodies of medicine, health and services. The needs are greater than the supply, and most prominent establishments are among the private sector, which monopolizes good health services.

The cost of good health care is unaffordable for many, which is why health care is not accessible by many communities. The treatments are better, the physicians are more experienced, but the services are not distributed, the costs are unfair and the private sector still overpowers the public sector. The public in the past 20–30 years has more knowledge and is not easily led by urban myths, yet with the rise of social media new myths are easy to spread.

The right to health is not a plan to be completed within certain dates—it is a mission, a vision and a way of life to ensure the health of current and future generations.

“THE RIGHT TO HEALTH IS NOT A PLAN TO BE COMPLETED WITHIN CERTAIN DATES.”

BACKGROUND

M-Coalition, based in Beirut, Lebanon, supports the needs of gay men and other men who have sex with men in the region. Founded in 2014 by activists from the region and the Arab Foundation for Freedoms and Equality and the Global Forum on MSM and HIV, M-Coalition works to promote health rights and other rights of gay men and other men who have sex with men, especially around HIV. M-Coalition continues to grow regionally and globally to promote the right to health for vulnerable populations in the Middle East and North Africa region.

PrEP:

new HIV prevention horizon

HIV prevention options come in different forms. The condom has been the standout option for decades, but there are many other ways to protect people from HIV. The latest prevention innovation is pre-exposure prophylaxis (PrEP), in which a person who is HIV-negative takes an antiretroviral medicine before coming into contact with HIV in order to prevent becoming infected.

Depending on a person's situation, including the level of autonomy that they have in choosing and controlling their HIV prevention options, any combination of prevention options could be right for them.

PrEP has been proven to work in research and in real life and the number of new HIV infections has gone down in some populations in some countries after the addition of PrEP to HIV programmes. PrEP uptake has largely been by gay men and other men who have sex with men, who have had strong support from health workers and their peers in some countries.

The challenge now is to make PrEP more widely available. Some people are not always in a position to negotiate the use of condoms or other safer sex for various reasons. For them, taking PrEP can be a discrete and effective HIV prevention method that is under their control. People who were previously anxious and scared about

their uncontrolled risk of HIV infection and who now take PrEP report enjoying more intimacy and improved engagement with their broader sexual health and disease prevention.

The decision to take PrEP should be made, ideally, through discussion between a health worker and someone who considers themselves as having a higher risk of coming into contact with HIV. For example, this might be men or women having condomless sex with multiple partners in a population where there is a high number of people living with HIV, people who lack autonomy in their sexual relationships, people who have had repeat episodes of sexually transmitted infections or people who have used post-exposure prophylaxis after a possible HIV exposure. For couples in which one person is HIV-negative and the other is HIV-positive, PrEP can be used by the HIV-negative partner until HIV treatment brings the level of the virus down so low for the person living with HIV that the virus can no longer be transmitted between them.

Missing too many doses of PrEP can allow HIV infection to occur, so it is important to take the medicine regularly. Taking PrEP requires a commitment to have repeated HIV tests to ensure that infection has not occurred and also to be checked and treated for other sexually transmitted infections. PrEP commonly causes mild side-effects, such as nausea and headache, that pass after a couple of weeks, but it can also occasionally affect the kidneys, so a clinical check-up is necessary before starting PrEP.

Currently, PrEP only exists as a pill that contains the medicine tenofovir, but other methods should become available in the next few years, including a ring that contains the medicine to be put in the vagina, injections that will provide protection from HIV infection for two or maybe three months and possibly products that will go in the rectum.

Even in relatively wealthy countries, many gay men complain of not having



Ratna, a sex worker and health-care navigator, administering PrEP to a young sex worker in Mysore, India

access to PrEP. This is for a number of reasons, according to UNAIDS PrEP expert Rosalind Coleman.

First, she said, spreading information to the communities that could benefit from and choose PrEP and to their health-care providers takes time a long time and political commitment.

Secondly, the cost of PrEP in high-income countries varies greatly, depending on insurance and government support. Low-income countries can buy the medicine for US\$ 5 per month, but staff training and laboratory and other services increase the overall cost. Despite the significant upfront cost, it is believed that PrEP will eventually save governments and people money by reducing the number of new HIV infections and the need for life-long treatment.

Thirdly, there is concern that PrEP will encourage people to ditch condoms and have unsafe sex. Ms Coleman, while

acknowledging this apprehension, doesn't see it as a reason not to roll out PrEP and says that PrEP programmes are designed to address the concern.

“The number of other sexually transmitted infections has been rising steadily for the past decade with a parallel decrease in the use of condoms,” she said. In her opinion, populations with this sexual risk profile are exactly the group whose prevention needs PrEP responds to.

“It has been shown that in real-life programmes it is the people with the highest likelihood of being sexually exposed to diseases who come to ask for pre-exposure prophylaxis and who use it correctly,” she said.

Ms Coleman agrees that a thorough discussion about sexual behaviour and all sexually transmitted infections should accompany PrEP distribution. In addition, she points out that PrEP programmes involve repeat testing

for sexually transmitted infections, leading to earlier detection. Projections of the impact of PrEP programmes estimate that the number of sexually transmitted infections diagnosed will at first rise with the introduction of PrEP, but with consistent testing and treatment they will then fall.

Treatment alone will not end AIDS, which is why prevention is key. And for people who have a much higher chance of being exposed to HIV than others, PrEP can play a role.

Built by us, for us, with us: ownership key in humanitarian aid

In 1991, at the age of 16, Abraham Leno became a refugee. At the time, he imagined himself becoming an engineer, but instead he had to flee Sierra Leone as civil war raged.

He and his family landed on the banks of the Moa River in neighbouring Guinea. “In the beginning, we stayed close to the border, because, just like millions of refugees, in my mind I thought this wasn’t going to last long,” Mr Leno said.

They then settled in an old school building, which is where the Office of the United Nations High Commissioner for Refugees

(UNHCR) came in and registered them. His life suddenly shifted from focusing on school to survival.

The emergency food rations never seemed enough for his older brothers and himself, so he and his siblings sold fuel in bottles on the street corner and worked as porters to make ends meet.

Having arrived in 1991, the family kept moving within Guinea, in part to avoid rebels crossing the border to recruit men and boys. Mr Leno describes feeling hopeless. He wanted to know when and if he would finish school, have a family of his own and start a career.

Mr Leno grew restless and angry. Angry at feeling like a number with limited opportunities.

From 1992 to 2001, in the lull of the Sierra Leone war, he managed to travel back and forth to Freetown, Sierra Leone, to pursue his studies, but the conflict reignited and he again had to return to Guinea. “Here I was almost living my dream to finally become an engineer and another war chased everybody out,” he said.

Once he graduated from a Guinean university in 2002, he found a job in what seemed to him an obvious choice.

“I went from receiving aid to giving it,” he said, explaining that he understands what both situations feel like.

Over 10 years, Mr Leno has helped refugees in Ethiopia, Liberia, Pakistan and Sudan. In 2012, he landed in the Democratic Republic of the Congo. Today, Mr Leno is the country

SAFE WATER

Some three in 10 people worldwide, or 2.1 billion people, lack access to safe, readily available water at home, and 263 million people have to spend more than 30 minutes per trip collecting water from sources outside the home.

SANITATION

Six in 10 people, or 4.5 billion people, lack safely managed sanitation. Good hygiene is one of the simplest and most effective ways to prevent the spread of disease.





representative for the American Refugee Committee (ARC) in Bukavu, Democratic Republic of the Congo.

Eastern Democratic Republic of the Congo has been beset by conflict for more than 20 years, restricting access to food, water and basic services. Not only have people fled the country, with some returning, but the country has also had an influx of nearly 500 000 refugees, mostly from Burundi, Rwanda and Uganda, according to UNHCR. In 2017, there were more internally displaced people in the Democratic Republic of the Congo than anywhere else in the world.

In the country, only 31% of people in rural areas have access to clean water, and hygiene and sanitation services are low, according to the World Bank. Accessing HIV treatment has been extremely difficult for many people.

“As an aid worker, what struck me was the effort I put in that often would be completely wiped out,” he said. He complained that everything seemed geared for immediate needs, with no long-term vision.

“Perpetual aid leads nowhere,” he said. “And on top of that, it wears you down when you are seen as someone with a constantly outstretched hand, plus you also feel guilty for accepting handouts that often you have no say in.”

Despite states being the main duty bearers to fulfil citizens’ right to health, the ongoing conflict in the Democratic Republic of the Congo led other stakeholders and the private sector to take the lead. This suited Mr Leno. His organization transformed its mindset to think long-term, with the motto, “Built by us, for us, with us.”

In 2013, ARC, USAID and local families started a cluster of community-owned, for-profit businesses, including a health clinic, a clean water distribution system and an agricultural cooperative.

The umbrella group, named Asili, is linked through a monthly membership that allows members access at reduced prices. For example, Asili provides local farmers with resources, tools and training plus a loan for seeds and fertilizer. They then provide a guaranteed market for the goods once harvested.

“Asili is a service provider, not an aid provider programme, and that makes all the difference,” Mr Leno said. By charging fees that reflect one’s own contribution, you create a sense of ownership,” he added. “By turning people into customers, it also raises the level of accountability.”

In the case of water, there are two options. Either you pay US\$ 4 monthly

“In the Democratic Republic of the Congo, only 31% of people in rural areas have access to clean water, and hygiene and sanitation services are low.”

for access to 100 litres a day or you pay as you go for 20 litres of water.

“Dignity is all about giving people options,” Mr Leno said.

Since Asili launched, Mr Leno said that people have benefited from 5.3 million litres of clean water, boosting health and agriculture. He also boasted that their three health clinics have invested heavily in training staff and linking them to reputable medical schools and hospitals for support.

Mr Leno said he finally accomplished one of his dreams.

“I helped build something that will outlive me.”

STREET CREDIBILITY AND RESPECT.

a recipe to help others

What could have been a final blow ended up being an epiphany for Andries Swarts. Ambling around the city streets of Pretoria, South Africa, at 4:30 in the morning, he had a heart attack.

“Before that, I didn’t care about myself, I didn’t want to live anymore,” Mr Swarts said. He realized that he wanted to live, but not that life anymore. That life was heroin addiction, homelessness and fear.

For 14 years, he lived on and off the streets using drugs. “My daily routine involved getting up, making some money, buying a bag, cooking it up and shooting up,” he explained. He points to his arms, baring marks from reusing needles. After a while, he said, his existence became unbearable.

The spark of hope came from peer educators from StepUP, who walked the city streets handing out clean needles and inquiring about his health. “They treated me like a human and said, “You

matter, you’re important,”” he recalled. Pausing, he added, “It blew my mind.”

“As a junkie, I hate that word,” he said, starting his sentence again. “As a drug user,” he said, “everybody treated me like a nuisance, calling me useless. I was harassed and judged by everyone.” The StepUP outreach workers made him a client, giving him sterile needles that he in turn would return.

“They taught me how to take better care of my health and all about the dangers of injecting, which I knew nothing about,” Mr Swarts said.

Slowly, he started believing in himself again. He checked into rehab and two years later applied for a job as a peer educator at StepUP. The programme offers syringes and sterile water as part of its harm reduction outreach, as well as testing for HIV and hepatitis B and C. They also offer HIV counselling and initiate clients on HIV treatment if necessary.

Mr Swarts found his calling. “Fourteen years on the streets would be worth nothing if I did not do this job,” he said. He visits drug users weekly. In his backpack he has kits that he hands out to drug users he calls the guys.

The kits include syringes, sterile water, alcohol swabs and a tiny aluminium cooking pot.

“These guys have a huge amount of respect for us because we are giving them something they’re desperate for,” he said. A sterile syringe at a pharmacy in Pretoria costs about one dollar, which StepUP hands out for free.

“They taught me how to take better care of my health and all about the dangers of injecting.”



Certain days the guys come to the StepUP drop-in centre. They can take a shower, drink coffee, watch movies and get counselling. “We really seek to make them feel like a human being,” he said.

Patting his black baseball cap firmly affixed on his head, he considers himself lucky to be HIV-negative, despite sharing needles.



He has hepatitis C, however, but manages it by living healthily. In South Africa, access to treatment for the disease is limited, owing to patent and cost barriers. Mr Swarts believes more needs to be done to change that, recalling how HIV activism in South Africa brought treatment costs down. He also believes that

his country needs a better support system for people who inject drugs. In his mind, drug policy needs to shift from complete abstinence to harm reduction. “You’ve got to meet the person where they’re at,” he said. “No amount of arguing, fighting or begging will make someone stop if they’re not ready to stop.”

Right to health

PEOPLE WHO USE DRUGS

A CONVERSATION WITH LARISA SOLOVYEVA

Larisa Solovyeva is a member of the Eurasian Network of People Who Use Drugs. She currently lives in Germany and coordinates the Berlin Network of People Who Use Drugs. Ms Solovyeva previously worked in Kaliningrad, Russian Federation, as a case manager for Spinning Top, a nongovernmental organization. For more than seven years she was engaged in social and legal support for people who inject drugs living with HIV following release from their places of detention. She has actively defended the rights of people who use drugs in courts as a public defender.



People who use drugs fighting
for the right to health

**“PEOPLE WHO USE DRUGS ARE
CONSIDERED RESPONSIBLE FOR
THEIR OWN ILL HEALTH ... AND
CONSEQUENTLY PEOPLE THINK THEY
DON'T DESERVE TREATMENT.”**

**What does the right to health
mean to you?**

The right to health for me is a right that is declared in our constitution, but it is rarely observed. And if it is observed, it is often perceived not as a duty of the state, but as a privilege. This is especially true for people from vulnerable groups, including people who use drugs, who are classified as criminals and marginalized.

People who use drugs are considered responsible for their own ill health because they should know how to stop using drugs, and consequently people think they deserve neither treatment nor are deserving of normal relationships. This is not

the opinion of the uninformed, but of well-educated citizens. It is an opinion that is fully supported in society and reflected in the media.

In addition, existing repressive laws and a punitive system give preference to incarceration as a method of treating the disease. Incarceration has practically replaced medical care for people who use drugs.

**What is preventing people who use
drugs from being able to exercise
their right to health?**

A person who uses drugs can seek treatment for his or her illnesses, but before receiving any treatment he or she will be sent to a specialized



**"HARSH LAWS ... HAVE DRIVEN THE PROBLEM OF PEOPLE
WHO USE DRUGS INTO THE SHADOWS."**

hospital, namely a narcological clinic or an AIDS centre. Not only is there no treatment for associated illnesses in the narcology clinic, the treatment of drug dependence itself is outdated, is not effective and requires that you are registered as a drug user and lose your rights to anonymity.

Treatment with opioid substitution therapy is proven to be effective and yet it is legally banned in the Russian Federation. At the AIDS centre, a person living with HIV who uses drugs will be the last among people living with HIV to receive treatment and will be the first to have their treatment interrupted in the event of a shortage or stock-out. This situation has become increasingly frequent in the Russian Federation. People who use drugs have resigned themselves to these negative attitudes, and in some cases consider them deserved. This system prevents people from exercising their right to health.

What more can be done to make sure that people who use drugs can access services?

Over the past 20–40 years, the situation has worsened because of the tightening drug policy of the state and because of government officials’ lack of a clear understanding of the ways to address the health needs of people who use drugs. Increasingly harsh laws and lack of help and treatment have driven the problem of people who use drugs into the shadows, intensified the HIV, hepatitis and tuberculosis epidemics and reduced the number of people seeking help.

Do you think the situation has improved at all over the past 20–30 years?

Thanks to support from the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), it has been possible to unite communities and to work towards counteracting

the approach to the epidemic. It turned out that to improve access to medical services and care for people who use drugs it is necessary to improve information on laws and human rights and how they affect people who use drugs.

“A PERSON LIVING WITH HIV WHO USES DRUGS WILL BE THE LAST AMONG PEOPLE LIVING WITH HIV TO RECEIVE TREATMENT.”

It is important to strengthen training in rights literacy and to provide accessible community-based legal aid. Increasing the awareness of our rights has allowed people who use drugs to seek legal protection, increased the potential for community cohesion and provided an opportunity to monitor prevention, treatment and support programmes. The big question is what awaits the Russian Federation when the Global Fund grant expires.

BACKGROUND

The Eurasian Harm Reduction Network’s mission is to promote humane, evidence-informed harm reduction approaches to drug use with the aim of improving health and protecting human rights at the individual, community and societal levels.

AMONG THE ESKASONI
FIRST NATION IN CANADA

PROMISING PRACTICES





Nestled alongside the beautiful Bras d'Or Lake in eastern Cape Breton Island, Canada, live the Eskasoni First Nation, part of the Mi'kmaq community. The word Eskasoni is derived from a Mi'kmaq word, We'kwistoqnik. Literally translated, this word means "where the fir trees are plentiful", and indeed this part of the world has amazing forests.

In the 1940s, the federal government began a policy of centralization, which involved moving Mi'kmaq families from other reserves to Eskasoni. Prior to centralization, Eskasoni's population was less than 200. Now, Eskasoni is the highest populated reserve in Nova Scotia, with a population of more than 4000.

In 2009, alarm bells went off, owing to a high occurrence of accidental deaths and suicides. Elder Georgina of the Eskasoni community said, "Like many communities, we have our fair share of addictions."

Drug use had affected families, the young, the old and children, triggering community elders and leaders to bring about change.

"We looked at our health services and also the gaps in those services," said Sharon Rudderham, Health Director of the Eskasoni Community Health Centre on Cape Breton Island. "We then talked to youth and elders and the community to see what they needed and where they needed to go."

"Each tribe, each community, has to customize what will work for them, but we failed so many times until we got it right," Eskasoni Chief Leroy Denny said.

He was sceptical at first about setting up a needle-syringe programme and other harm reductions strategies. His wife, a nurse at the time, stressed the benefits and showed him the statistics from other regions.

"Each tribe, each community, has to customize what will work for them, but we failed so many times until we got it right."

A community health nurse, Jasine Bernard, recalled how the community resisted at first. "They claimed we were making people use more," she said. She explained that, in the beginning, only two people came forward to use the harm reduction programme. A poster campaign was then launched publicizing the availability of sterile needles and explaining that a person can contract hepatitis C more than once.

Another nurse, Julie Francis, said that the centre opened doors for people who for once didn't feel judged. "We show them that we care about them," she said.

Since 2015, the Canadian Aboriginal AIDS Network has been filming indigenous communities to highlight responses to HIV and hepatitis C and to show promising harm reduction practices. The latest film, *Promising Practices in Eskasoni—Utilizing Harm Reduction*, demonstrates and highlights the challenges faced by the community. The film highlights how the Eskasoni took ownership over their own health and their story of hope.

For more on the films, see www.promisingpracticesfilms.ca/.

Right to health

TUBERCULOSIS AND HIV

A CONVERSATION WITH DMYTRO SHEREMBEY

Dmytro Sherembey went to prison as a teenager in Ukraine for drug use. At the age of 21 years, he was diagnosed with HIV, and he believes that he contracted tuberculosis while in prison. After his release, he started working with local nongovernmental organizations working in the AIDS response.



Prisoners demand their right to health

“IT GETS BETTER. NOT AS FAST AS I WOULD LIKE, BUT IT GETS BETTER.”

What does the right to health mean to you?

It will sound tacky, but the right to health is one of those universal human rights, and any human is entitled to proper medical care especially tuberculosis treatment, regardless of whether he or she is in prison or of any other reason.

What is preventing prisoners from being able to exercise their right to health?

Stigma and lack of knowledge and understanding are hindering the right to health of prisoners, as do the high prices of medicines and medical services.

What more can be done to make sure that prisoners can access services?

We should talk to prisoners and make them understand that not taking medicines if they are available is not the way out of prison, but taking them properly is. We should work with prison officials and make them understand that proper medical care for prisoners including for

tuberculosis and HIV is as much part of their job as keeping prisoners under control. We should work with health-care systems and make them understand that prisoners are the same as those who are not in prison.

Do you think the situation has improved at all over the past 20–30 years?

Some things have changed. We have antiretroviral therapy in prisons, we have hepatitis C virus and TB treatment and our parliament just approved health-care reform. It gets better. Not as fast as I would like, but it gets better.

BACKGROUND

The All-Ukrainian Network of People Living with HIV works for people living with HIV, as well as people with living with tuberculosis and hepatitis and representatives of key populations. The network represents the interests of people living with HIV in 25 regions of Ukraine and is working towards ensuring that everyone living with HIV has access to HIV treatment.



**"TB DISEASE AND DEATHS CAN BE AVOIDED WITH EARLY
DIAGNOSIS AND TREATMENT OF TB AND HIV."**

UNDERSTANDING TUBERCULOSIS

Tuberculosis (TB) is caused by bacteria called *Mycobacterium tuberculosis*. TB infection occurs when a person breathes in respiratory droplets produced when someone with active TB (TB disease) coughs or sneezes. Respiratory droplets can remain infectious in the air for several hours under certain conditions—damp enclosed spaces with little ventilation or direct sunlight. These conditions are often found in informal settlements, overcrowded housing, prisons and other constrained settings.

TB infection does not always result in active TB; most healthy people are able to contain the TB bacteria, which are captured in the lungs by cells from the immune system. These cells may kill the TB bacteria,

clearing the infection, or the bacteria may remain dormant in the lungs for many years. Overall, a relatively small proportion (5–15%) of the estimated 2–3 billion people infected with *mycobacterium tuberculosis* develop TB disease during their lifetime.¹

However, if a person's immune system becomes weakened, the TB bacteria can multiply, spread and cause damage in the lungs and spread to any part of the body. In this case, asymptomatic TB infection progresses to become active TB. In addition to HIV, risk factors that weaken the immune system and increase the risk of progressing to TB disease include malnutrition, diabetes, drug use, excessive alcohol use, silicosis (miner's lung), cancer or cancer treatment and old age.

TB AMONG PEOPLE LIVING WITH HIV

The strongest risk factor for TB infection progressing to TB disease is underlying HIV infection. In 2016, the risk of developing TB disease among the 36.7 million people living with HIV was around 21 times higher than the risk in the rest of the world population. There were more than one million TB cases among people living with HIV—10% of all global TB cases in 2016. People living with HIV are much more likely to die from TB disease than HIV-negative people, and one in five (22%) TB deaths occurs among people living with HIV. In 2016, there were 374 000 TB deaths among people living with HIV, which represents almost 40% of all AIDS-related deaths.²

TB disease and deaths can be avoided with early diagnosis and treatment of TB and HIV. TB preventive therapy can prevent TB disease and deaths among people living with HIV but most people who can benefit are not receiving it. In 2016, fewer than 1 million people newly enrolled in HIV care were started on TB preventive treatment.² The global burden of drug-resistant tuberculosis continues to rise with an estimated 600,000 cases requiring treatment but only one in five were enrolled on treatment in 2016.²

**“THE STRONGEST
RISK FACTOR
FOR TB
INFECTION
PROGRESSING
TO TB DISEASE
IS UNDERLYING
HIV INFECTION.”**

¹ Global tuberculosis report 2016. Geneva: World Health Organization; 2016.

² Global tuberculosis report 2016. Geneva: World Health Organization; 2017.

MAKING THE LAW WORK FOR HEALTH



RIGHT TO ACCESS HIV TREATMENT

BOLIVARIAN REPUBLIC OF VENEZUELA, 1999

People living with HIV filed an action against the Ministry of Health on its refusal to deliver antiretroviral medicines. The people who filed the case had no social security and lacked the resources to pay for the life-saving medicines.

The Tribunal Supremo de Venezuela (Supreme Court) ordered the Ministry of Health to supply to the applicants the medicines that make up triple therapy on a regular and reliable basis, as well as any medicines needed to treat opportunistic diseases derived from their HIV-positive status, and all the required medical tests. It asked the President of Venezuela to correct the budgetary allocation known as Task: AIDS Prevention and Control or to provide an additional disbursement for the rest of the fiscal year and to ensure future budget bills include resources for this purpose.



SOUTH AFRICA, 2002

The Treatment Action Campaign launched a constitutional challenge alleging a violation of the right to access health-care services and demanding a programme to make antiretroviral medicines for the prevention of mother-to-child transmission of HIV available throughout the country.

The High Court ruled that such medicines should be made available to pregnant women living with HIV throughout the country. The government appealed to the Constitutional Court, which rejected the appeal. This judgement set the foundation for the widespread availability of HIV treatment throughout the country.

South Africa now has the world's largest HIV treatment programme. The decision established a conceptual and remedial framework for the judicial review and enforcement of the obligation to ensure access to health care. About 5000 people marched to the court in Johannesburg at the opening of the hearing.

PAYING FOR HEALTH

IRELAND, 2005

The President of Ireland asked the Supreme Court for advice on the constitutionality of a bill that authorized the government to charge for in-patient services provided by the public health service, especially for elderly people with limited means. The court pronounced that

the legislation was unconstitutional in part, notwithstanding the fact that such a finding would cost the state an estimated €500 million. It held that in certain circumstances, the constitution may impose an obligation on the state to provide individuals with essential care and services.

RIGHT TO HEALTH

COLOMBIA, 2008

The Colombian Constitutional Court reviewed situations that disregarded the constitutional right to health in Colombia. The review of 22 such cases resulted in the court ordering remedies for the individual cases, but most importantly compelled the authorities to modify regulations that create conditions for not fulfilling the right to health. One decision sparked wide political and academic debate over the health-care system, especially over sustainability issues and the protection of the right to health. The decision also reaffirmed the right to health as a fundamental right.

APPROVAL OF A COMPULSORY LICENCE TO PRODUCE AND MARKET LIFE-SAVING MEDICINES

INDIA, 2013

The Intellectual Property Appellate Board of India upheld the decision to grant a compulsory licence to produce and market a multinational pharmaceutical company's patented cancer medicine. The board validated the decision of the Controller of Patents, Mumbai, to issue a compulsory licence to a generic manufacturer with the sole purpose of reducing the extraordinary price charged by the patentholder. The ruling ordered the payment of a licence fee and fixed the maximum price for the medicine to be marketed by the generic producer.

RIGHT TO CHOOSE AND REFUSE STERILIZATION

INDIA, 2016

Health rights activists challenged the practice of governments of subjecting women and men to sterilization procedures without their informed consent in dangerous and unsanitary conditions. The petitioner claimed before the Supreme Court that such practices were in violation of the Indian constitution. The Supreme Court ruled that the respondents had violated two components of Article 21 of the constitution (protection of life and personal liberty): the rights to health and to reproductive rights.

The court held that the freedom to exercise reproductive rights includes the right to make a choice regarding sterilization on the basis of informed consent and free from any form of coercion. In its deliberations, the court referenced General Comment No. 22, on the right to sexual and reproductive health, issued by the United Nations Committee on Economic, Social and

The right to health can be enforced. Courts and human rights bodies have an important role in upholding health rights. Courts around the world have stepped in and reinforced the right to health. Below are a few cases that highlight the various types of judgements that have helped to enforce health rights worldwide.

Cultural Rights, which observes that reproductive health is an integral part of the right to health.

DATA COLLECTION ON CHILDREN LIVING WITH HIV MUST RESPECT THE RIGHT TO PRIVACY

KENYA, 2016

The President of Kenya, Uhuru Kenyatta, issued a directive ordering the collection of data and the preparation of a report pertaining to schoolchildren, guardians



and expectant and breastfeeding mothers living with HIV. The High Court found the directive unconstitutional on the basis that it constituted a breach of the right to privacy and of the provision on the best interests of the child enshrined in Articles 31 and 53(2), respectively, of Kenya's constitution. The High Court ordered that, within 45 days of the judgement, all the data collected be codified in a manner that does not link an individual's name to their HIV status in a public document.

RIGHT TO CONFIDENTIAL TREATMENT

1986, ENGLAND AND WALES

The House of Lords decided that a mature minor can be entitled to confidential medical treatment without parental consent.

RIGHT TO HEALTH FOR INDIGENOUS COMMUNITY



1985, BRAZIL

A petition was filed with the Inter-American Commission on Human Rights against Brazil for not taking care of an indigenous community's well-being while undertaking a construction project in their area. The construction project led to an influx of migrants, the displacement of the community and the emergence of epidemics. The commission found that the state was responsible for failing to take timely and effective action to protect the indigenous community's human rights, including their right to health, and ordered them to take measures to protect the life and health of the community.

RIGHT TO HEALTH FOR MIGRANTS

2004, FRANCE

A petition opposing the ending of exemptions of poor illegal immigrants from charges for medical and hospital treatment in France was filed by the International Federation of Human Rights Leagues at the European Committee on Social Rights.

The complainant alleged that the rights of children to protection were contravened by the restricted access to medical services for the children of immigrants. The committee found that France had acted contrary to the rights of children. The committee held that any "legislation or practice which denies entitlement to medical assistance to foreign nationals, within the territory of a State party, even if they are there illegally, is contrary to the European Social Charter."

2015, BOTSWANA

Two cases involved three foreign nationals who acquired HIV while in prison and for whom the national authorities refused to

provide antiretroviral therapy, despite it being available for citizens. A lower court ordered that HIV treatment be provided to the prisoners. The government appealed, and the Court of Appeals dismissed the appeal.

The Appellate Court held that denial of testing, assessment and antiretroviral therapy to foreign prisoners, while affording it freely to citizens, discriminated unlawfully against non-citizens. The court held that the directive could not be justified by public interest concerns owing to resource constraints, because a statement from the government, absent evidence showing statistics and cost analyses, did not adequately demonstrate that providing antiretroviral therapy to non-citizens was unaffordable. The court stated that a lack of funds could not, in the normal course, justify non-compliance with laws protecting human rights and freedoms.

NON-DISCRIMINATION AND RIGHT TO FAMILY LIFE

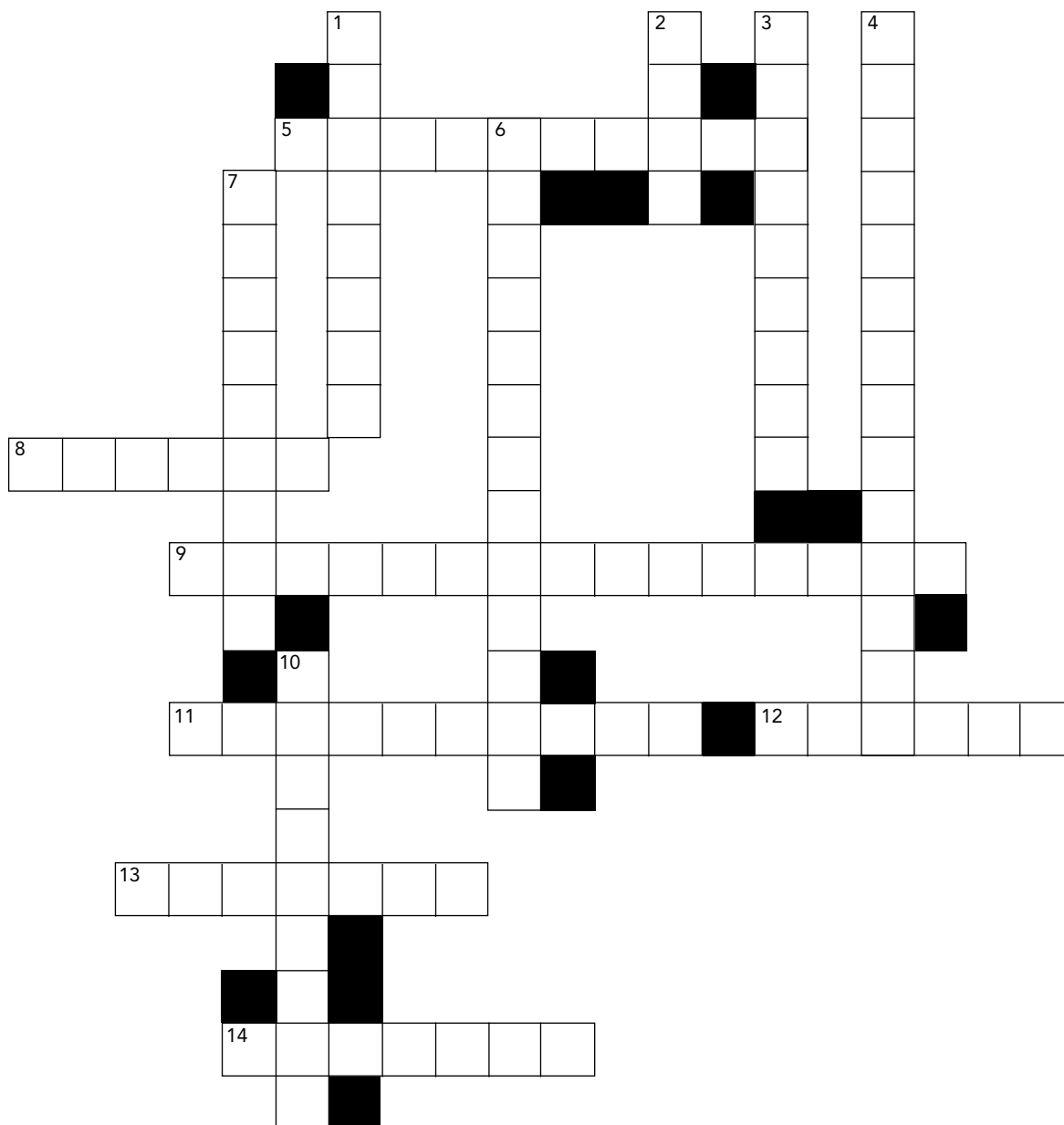
RUSSIAN FEDERATION, 2011

An Uzbek national married to a Russian national was denied a residence permit to stay in the Russian Federation, as he was found to be living with HIV. The European Court of Human Rights held that the Russian Federation had violated Article 14 of the charter, which called for the prohibition of discrimination, and Article 8, which enshrines the right to family life. The decision was in line with UNAIDS' call to lift travel restrictions for people living with HIV.

For more information on how law has been used to secure health and other human rights, visit www.eschr-net.org and www.globalhealthrights.org.

TEST YOURSELF ON THE RIGHT TO HEALTH

CROSSWORD



ACROSS

5. Responsible for ensuring and protecting the right to health.
8. Fair and equal treatment.
9. Crucial to build trust between patients and health-care providers.
11. How to reduce new HIV infections.
12. An effective and affordable health product to help prevent HIV infection.
13. Improves immunity to diseases.
14. Key to knowing your HIV status.

DOWN

1. Must be eliminated to lower new HIV infections among women and girls.
2. An effective treatment to lower the risk of HIV infection.
3. Vital for our bodies to function properly and stay healthy.
4. A barrier to HIV services, support and care.
6. Something we all have, but only few enjoy (three words, no spaces).
7. The acquisition of knowledge and skills.
10. Used to treat or prevent illness.

WORD SEARCH

M N X M F P J N D I K V E H P H B A M J
 P O L M Y O K A O I V V K P I I B R Y S
 P I S A N I T A T I O N E K A W X G J C
 O T P Y D Q B I P M T R Z Q X J K K X V
 V A W J Z B P H C D P P C Q R W Y H J E
 A Z F N E Y Z T A Z L W E J Z Q A Y P C
 Z I Y T I L A U Q E H X E C Z Z D V J W
 O N P S Z O A S K M F P O T A O Q S O C
 Z U M R M W A Y X B X G N C P R W V Y G
 Y M T E W O N A B Q F J D H V W T S Q V
 V M B V D S D I O A Q L Z Q C D T N S A
 H I W G B I O N N I H X H E V V O E O K
 O O H E C N C U O X E P T Q U I C D P C
 R T C C Z W T I Y C L R L W T C S U Y C
 K Y W O T R C D N D E R A N G I Y C G Z
 B I S X I P E C I E B Z E J L W F A X S
 T R P T O O L W D V S V H V L P G T O P
 J M I K Q X I W N M E X G Z K L Y I N K
 N O I T A N I M I R C S I D W T A O E A
 N Z J K A E J V P T N C O S H H Z N B R

CONDOMS
 EDUCATION
 IMMUNIZATION
 PREP

CONTRACEPTION
 EQUALITY
 MEDICINES
 PREVENTION

DISCRIMINATION
 HEALTH
 NUTRITION
 SANITATION

ANSWERS: 1. Violence; 2. PREP; 3. Nutrition; 4. Discrimination; 5. Government; 6. Right to health; 7. Education; 8. Equity; 9. Confidentiality; 10. Medicine; 11. Prevention; 12. Condom; 13. Vaccine; 14. Testing

THE LAST WORD

Dainius Pūras
Special Rapporteur for health



Dainius Pūras, United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, explains some key concepts of the right to health in a conversation with UNAIDS.

The right to health

The right to health does not mean the right to be healthy, but that everyone has a right to access good quality health-care services and to environments in society and communities that promote, and not worsen, physical and mental health.

The link between the right to health and other human rights

All rights are indivisible. If some rights for any reason are violated or undermined, this will sooner or later have negative impacts on the realization of the right to health.

The right to health should leave no one behind

There are certain groups that are vulnerable and may experience higher risks. They should be provided with access to health-care without discrimination.

The responsibility of the state for realizing a person's right to health

States are the main duty bearers and are obliged to respect, protect and fulfil the right to health. However, other stakeholders, such as the private sector, also should be responsible and accountable.

Progressive realization of the right to health

Progressive realization means that, in reality, poorer countries may not perform as well as developed countries, but they still need to realize the right to health.

Monitoring the implementation of the right to health

There are many ways to monitor the right to health. One example is a health impact assessment of any important measures and investments undertaken in the health and non-health sectors. It is important that monitoring is done in an independent way, and in this regard the role of civil society is of the utmost importance.

Let us not forget mental health

Mental health deserves to be addressed in parity with physical health. My mandate is on the right to physical and mental health. There is still so much discrimination of people with mental health conditions globally, which is why I always, in all my country missions and other activities, urge states to integrate mental health into general health and community health services and to abandon putting children and adults with psychosocial and intellectual disabilities in segregated institutions.

When I started working as a medical doctor and researcher 36 years ago, my first clients were children with

intellectual disabilities and autism and their families. Since then, I have come to realize that science and the practice of medicine are only worth something if human rights are seriously addressed, otherwise they may be harmful.

Recommendations on measures that promote and protect the right to health

I have three recommendations. The first is to ensure the meaningful participation of everyone. The second is to prioritize health promotion and primary care so that health systems are rational, equitable and do not waste resources on unnecessary interventions. The third is to reach zero discrimination in all health-care services. This can be reached if a human rights-based approach is seriously applied.

About

Appointed in 2014, Dainius Pūras, from Lithuania, is a medical doctor with expertise on mental health and the health of children. He is a Professor and the Head of the Centre for Child Psychiatry Social Paediatrics at Vilnius University, Lithuania, and teaches at the Faculty of Medicine, Institute of International Relations and Political Science and the Faculty of Philosophy of Vilnius University.

He is a human rights advocate who has been actively involved during the past 30 years in the process of transforming public health policies and services, with a special focus on the rights of children, people with mental disabilities and other vulnerable groups. Between 2007 and 2011, Mr Pūras served as a member of the United Nations Committee on the Rights of the Child.



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