

# FAMILIES AT THE CENTRE

How family-centred care can help reach people being left behind in the global response to HIV

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2018



“We will not end AIDS if we  
don’t go back to the family,  
to the community.”

Michel Sidibé, Executive Director, UNAIDS

## IMPRESSIVE PROGRESS—AND CRITICAL GAPS— IN THE GLOBAL RESPONSE TO HIV

The latest data released by UNAIDS show that great progress has been made against HIV, but the scope of unmet need remains sizeable—there is a lot of work still to do.

Nearly 21 million people living with HIV are accessing antiretroviral therapy—this is more than half of the 36.7 million people living with HIV worldwide.

} BUT {

15.7 million people living with HIV—including 1 million children—don't have access to life-saving medicines.

New HIV infections have declined by 11% among adults and by 47% among children since 2010.

} BUT {

There were still 1.8 million new HIV infections in 2016, 160 000 of which were among children.

AIDS-related deaths have fallen by 48% since the peak in 2005.

} BUT {

One million people still die each year from AIDS-related illnesses.

With 15.7 million men, women and children living with HIV currently unreached, and millions more at risk of contracting the virus, we are a considerable way from achieving the Fast-Track Targets that UNAIDS proposed, and the world embraced, in 2015.

The opportunity to end AIDS is real, but we must quicken the pace of action and reach the people being left behind. The choices made in the next few years will determine whether the AIDS epidemic is ended or whether it continues indefinitely. Involving families in efforts to scale up HIV testing, prevention and treatment will be crucial to success.



Photo credit: UNAIDS/Eric Bondou

## WHAT IS FAMILY-CENTRED CARE?

Family-centred care is a comprehensive coordinated care approach that addresses the health- and social-care needs of adults and children in a family, either directly or indirectly through strategic partnerships, linkages and referrals with other service providers. The approach builds on the understanding that a child's quality of life is interwoven with the life and experience of the family in which they live.

### FOR THE FAMILY

Family-centred care offers HIV prevention, testing and treatment to the whole family simultaneously, during the same visit, in a non-HIV-specific health-care setting. The programmes take a holistic and long-range view of health and involve the entire family in the health and well-being of people at risk of, or living with, HIV.

Family-centred care provides a minimum package of services. Prompt maternal and paediatric HIV diagnosis, antiretroviral prophylaxis, opportunistic infection prophylaxis, testing and long-term antiretroviral therapy for the whole family, nutritional supplementation and optimal infant feeding support are provided in one location. Services also include psychosocial support and access to community-based support groups.

### CARE IN THE COMMUNITY

Often, family-centred care is initiated through outreach done by community health-care workers who contact families thought to be at risk. Community health-care workers are trained to recognize possible signs of HIV within families, including opportunistic infections and malnutrition among children.

When a person takes a home-based test and finds that they are living with HIV, they are linked to family-centred care facilities. Regular home visits allow community health-care workers to establish bonds with all family members and help them to speak openly and honestly about their health concerns and needs.

Community health-care workers are trained in child development and can identify when normal development is impeded. They understand the cognitive and emotional needs of children and recognize signs of abuse. Community health-care workers can provide life skills education to children and encourage parents and caregivers to ensure that children are immunized against preventable diseases.



Photo credit: UNICEF

## TEN ADVANTAGES OF FAMILY-CENTRED CARE

- 1 Earlier detection of HIV infection, including among hard-to-reach populations, leads to **faster treatment initiation**, which results in improved health outcomes.
- 2 **Increased uptake of testing and treatment** for mothers living with HIV, thus preventing transmission of HIV to their babies and reducing HIV-related infant mortality.
- 3 **Increased testing, diagnosis, prevention and linkage to treatment and care** for men and boys.
- 4 **Health for all the family improves**, including improved nutrition among families and increased rates of vaccination for all children. Gender-based violence and violence against children can be identified and addressed.
- 5 **Less loss to follow-up and better compliance** with antiretroviral therapy, which is essential for viral load suppression and prevents new HIV infections.
- 6 **Increased awareness** of HIV treatment, prevention and self-care skills creates an enabling environment for parents to disclose their HIV status to each other and to their children.
- 7 **Reduction of HIV-related fear, stigma and discrimination** within families, which in turn supports the health and emotional well-being of people living with HIV.
- 8 **Simpler, more efficient and less expensive** HIV prevention, testing and treatment for people at risk of and living with HIV.
- 9 **Improved quality and accuracy of data**, especially among hard-to-reach populations.
- 10 Creates a platform for wider **integrated health-care service delivery**.



Photo credit: UNAIDS/Dwayne Senior

## FAMILY-CENTRED CARE REACHES THE UNDERSERVED

Family-centred care draws whole families together into health-care settings or visits families at home and helps reach many of the people who are being left behind.

### CHILDREN

The majority of the 1 million children living with HIV who are not accessing antiretroviral therapy will die before their fifth birthday. In some regions, the need is even more acute. In western and central Africa, four out of five children living with HIV do not have access to the life-saving medicines.

Young people are a concern more broadly. The largest group of adolescents and young adults on the African continent to date is about to come of age. This new generation will soon graduate from childhood and adolescence in the geographic areas where HIV remains prevalent.

### MEN AND BOYS

Men are less likely to take an HIV test, less likely to access antiretroviral therapy and more likely to die of AIDS-related illnesses than women. Less than half of men living with HIV globally are on treatment, compared to 60% of women. Men are more likely than women to start treatment late, to interrupt treatment and to be lost to treatment follow-up. In sub-Saharan Africa, men and boys living with HIV are 20% less likely than women and girls living with HIV to know their HIV status, and 27% less likely to be accessing treatment.

When men access HIV prevention and treatment services, there is a triple dividend: they protect themselves, they protect their sexual partners and they protect their families. Enabling men and boys to stay free from HIV, get tested regularly or start and stay on treatment if HIV-positive improves male health outcomes and reduces new HIV infections among women and girls.

### YOUNG WOMEN AND ADOLESCENT GIRLS

When men do not know their HIV status or are living with HIV and do not know how to protect their partners from HIV infection, women and girls are at increased risk of HIV infection. A disproportionately large number of young women are newly infected with HIV in sub-Saharan Africa, often by older men. Girls aged 15–19 years old are eight times more likely to be living with HIV than boys of the same age. As these young women mature and find partners in their peer group, a second wave of young men are at risk of HIV infection.

## INVESTING IN FAMILY-CENTRED CARE IS ESSENTIAL FOR ENDING AIDS

We can end AIDS as a public health treat by 2030. The first step is achieving the 2020 Fast-Track Targets.

The Fast-Track Targets call for 90% of all people living with HIV being diagnosed, 90% of all people who are diagnosed on treatment and 90% of all people on treatment virally suppressed, and a 75% reduction in new HIV infections, by 2020. Meeting those targets would put the world on track to ending AIDS as a public health threat by 2030.

Family-centred care can have an outsized positive impact on the health of people affected by HIV and the people who live with them. Strengthening the economic security and health of the whole family translates into benefits well beyond the life of the programme.

Family-centred programming offers an opportunity to focus on strengthening the family unit for more sustainable development. Understanding the contexts in which people live, people's social relations and networks and ensuring that whole families are supported when treating anyone for HIV will help achieve better outcomes for HIV programmes.

The health and well-being of vulnerable children can be improved by improving the health and well-being of the families in which they live. A family-centred approach leads to long-term positive impacts for the health of children, education and political development. Healthy families lead to healthy communities, which in turn lead to healthy and stable countries.

Family-centred care requires investment in health systems and human resources, which are time- and resource-intensive. However, while the upfront resource demands of an integrated programme may appear initially to be more expensive than vertical testing or treatment programmes, the outcomes and longer-term benefits of the integrated approach are ultimately cost-effective.

One thing is clear: because of its unique ability to connect the people at higher risk, a family-centred care approach is integral to ending AIDS. It is a cornerstone of the work that needs to be done at the country level to control the epidemic—a critical step on the journey to ending AIDS for good. It can help close the gaps in the response to HIV and in doing so, save millions more lives.



Photo credit: UNICEF

## CASE STUDY 1

### SUNSHINE SMILES CLINIC INITIATIVE, GERTRUDE'S CHILDREN'S HOSPITAL, NAIROBI, KENYA

Recognizing that the families of patients have a significant impact on the treatment outcomes of children living with HIV, Gertrude's Children's Hospital's Sunshine Smiles Clinic Initiative moved from working only with children to offering comprehensive family-centred care and support services.

There are no signboards labelling the site as an HIV clinic. Services are integrated with general clinic services, including outpatient services and mother-and-child antenatal, postnatal and immunization services.

Children with a history or symptoms of HIV are tested for HIV. Routine screening is provided for children previously exposed to HIV. Parents can also be tested for HIV when they accompany children to the hospital.

All children found to be living with HIV are immediately enrolled into care. If family members are diagnosed with HIV, the entire family is enrolled into care and people diagnosed with HIV are started on antiretroviral therapy.

If a parent is found to be HIV-negative, they are enrolled into a family-focused arm of the programme that aims to support the child to adhere to treatment, retain them in care and support the parent to remain HIV-negative. Children over the age of 13 years are matched with a treatment buddy—another person living with HIV—to provide peer support.

Families receive psychosocial support through play therapy, child fun days, treatment literacy, youth forum seminars, life skills training, adolescent–adult transition trainings and caregiver seminars. Mother-to-mother support groups help prevent mother-to-child transmission of HIV. Home visits support antiretroviral therapy adherence and provide home-based care to family members unable to visit the clinic.

The work of the centre has resulted in a reduction of cases lost to follow-up and improved adherence to treatment.

“ALL CHILDREN FOUND TO BE LIVING WITH HIV ARE IMMEDIATELY ENROLLED INTO CARE.”

## CASE STUDY 2

### REACH OUT MBUYA PARISH HIV/AIDS INITIATIVE, KAMPALA, UGANDA

Reach Out Mbuya Parish HIV/AIDS Initiative (ROM) is a community, faith-based non-governmental organization founded in 2001. ROM offers medical, psychosocial, economic and spiritual support to people living with, or affected by, HIV in urban Uganda. Fewer than 10 staff working in four locations serve 3450 people—2000 of whom are on antiretroviral therapy.

The programme aims to reduce transmission of HIV among marginalized populations and enable people living with HIV to live an informed and dignified life. ROM works to achieve these goals by educating people and communities about HIV and providing holistic care to people living with HIV and their families. The holistic model of care relies heavily on community-based approaches that emphasize community ownership. More than 49% of ROM's staff are living with HIV and live locally.

ROM provides counselling, treatment, HIV testing and psychological support to children affected by HIV as well as tuberculosis screening and gives adherence support to people on antiretroviral therapy and tuberculosis medication. In seven years, there has been 0% mother-to-child transmission of HIV among people reached by the programme.

The programme is connected to the Village Savings and Loans Association, which provides subsidized loans to staff, clients and elderly guardians living with or affected by with HIV in order to ensure a level of financial independence. The programme also helps pay for school fees and offers vocational training.

“IN SEVEN YEARS, THERE HAS BEEN 0% MOTHER-TO-CHILD TRANSMISSION OF HIV AMONG PEOPLE REACHED BY THE PROGRAMME.”

## CASE STUDY 3

### **SAINT GABRIEL'S HOSPITAL, NAMITETE, MALAWI**

Saint Gabriel's provides a full spectrum of health care, including adult care, paediatric care, an ambulatory clinic, surgery, maternity services, gynaecology services, internal medicine services, endoscopy and palliative care and has a large family-centred care unit. The family-centred care unit educates patients, families and community health workers about the patient's diagnosis and care. Family preferences are respected and avenues for support in the home are investigated.

The hospital is the region's main clinic and reaches about 600 villages through a network of volunteers and community health workers. Ambulances and bicycle services help to link families in rural areas with health care and a mobile clinic diagnoses and monitors the health of children in remote villages. Community health workers trained in family-centred care communicate with doctors at the hospital via an SMS system, allowing questions to be answered and support to be obtained while out in the field.

Saint Gabriel's efforts in the prevention of mother-to-child transmission of HIV increasingly focus on engaging men, both to encourage the partners and spouses of women who have tested positive for HIV to know their own status and to involve men in self-care as well as the care of partners and children.

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