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## THIRTY-EIGHTH MEETING

Date: 28-30 June 2016

Venue: Executive Board Room, WHO, Geneva

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## Agenda item 8

The role of communities in ending AIDS by 2030

## **BACKGROUND NOTE**

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## I. INTRODUCTION

- 1. The 37th UNAIDS Programme Coordinating Board (PCB) meeting agreed that the theme for the Thematic Segment of the 38th meeting to be held in June 2016 would be: The role of communities in ending AIDS by 2030.
- 2. Communities have been at the forefront of HIV responses since the beginning of the epidemic and, in almost every country, the first response to the AIDS epidemic came from people living with HIV, their families and communities, by organizing themselves to care for those in need and to push for an expanded response to the epidemic. In most countries, these early civil society initiatives were the foundations on which national responses were built [1,2].
- 3. It has been widely recognised that when communities are proactively involved in ensuring their own well-being, success is more likely and more sustainable. The Greater Involvement of People Living with HIV (GIPA) is a principle first voiced by people living with HIV in Denver in 1983. It was formalised at the 1994 Paris AIDS Summit and subsequently endorsed by 189 United Nations member states as part of the 2001 UNGASS Declaration of Commitment and reaffirmed by 192 member states at the 2006 High Level meeting on AIDS. GIPA aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives [3]. People living with HIV have direct experience with what makes communities vulnerable to HIV, first-hand knowledge of what works in managing their illness and ideas to inform policy and programming to improve HIV prevention and treatment. The involvement of people living with HIV in programme development and implementation, as well as policymaking, improves the acceptability and effectiveness of programmes and policies. GIPA is a central part of community responses to HIV and, when effectively applied, contributes to good practice and effective services. This principle of meaningful involvement in health can be seen more broadly as outlined by the 1978 Alma Ata Declaration stating that full and functioning health care systems require communities' full participation in planning, organisation and control of primary health care along with the capacity to do so [4].
- 4. Over 30 years of community actions have resulted in substantial achievements it is now well understood that communities, including civil society organizations, people living with HIV and other key populations networks such as networks of women living with HIV and indigenous communities, have played a crucial role in: the activism and advocacy that mobilized political will and resources for equitable national HIV responses; serving as equal partners in designing and implementing HIV-related policies and programmes; delivering services in partnership with health and social state service providers; and reducing stigma and discrimination associated with HIV and tackling human rights violations and gender inequalities [2]. It is now understood that community-based service delivery can result in positive health outcomes, reach scale, and expand access to life-saving services, including for populations that are hard to reach by state services [2]: "No response to HIV can be effective without community involvement, as the people that make up communities are the very reason we all work tirelessly to end AIDS - they are the people living with HIV, the people affected by HIV - the people who have the most to lose and the most to gain" (Professor Peter Piot in [1]). The role of communities has also been well recognised in humanitarian contexts for their ability to adapt, move quickly, promote resilience and develop solutions that reach those most affected to promote change, preparedness, response and recovery.

- 5. However, it is important to note that community responses are just one part, an essential part, of the larger response to HIV. The responsibility to ensure that services are delivered remains with governments. Community responses, including service delivery, can help share the workload but cannot replace public health services; they can reach people government services may not be able to reach, create demand, and provide support in making services more accessible and acceptable.
- 6. Although 30 years have passed since the beginning of the global AIDS response, national programmes and global partners are only now beginning to integrate community responses into national strategic AIDS plans—making the shift from stand-alone responses that function aside state actions, to actions that work in partnership and together with state systems. Evidence of effectiveness and impact is clear, and notions that community-based responses are too costly, complicated or indirect must be dispelled. Equally, notions that community-based responses can be alternate points of service to state services simply because they are less costly need to be dispelled. Community services complement state services. Both are needed and both need to work better together. Moreover, beyond service delivery, community engagement and activism is "a global public good" and as such requires legal, social and financial support to optimize impact [5].
- 7. Working alongside public health and other systems, community responses are critical to the success and sustainability of the global response to HIV [2] and will be critical in reaching the Sustainable Development Goals and Fast-Track targets by 2030<sup>1</sup>. A particular strength of civil society lies in its diversity, very often representing and providing services to those hardest-to-reach or marginalized communities [6].
- 8. Community has a key role to play in at least four areas (see Figure 1, from [2]):
  - a. advocacy, campaigning and participation in accountability;
  - b. direct participation in service delivery, including mobilizing demand;
  - c. participatory, community-based research; and
  - d. community financing.

<sup>&</sup>lt;sup>1</sup> The Fast-Track approach is an agenda for quickening the pace of implementation, focus and change at the global, regional, country, province, district and city levels. It involves setting ambitious targets and accelerating the delivery of high-impact HIV prevention and treatment services



- 9. Community responses are often innovative and civil society is skilled at finding concrete solutions that negotiate the complex social, political and cultural contexts that directly affect local HIV epidemics. However, civil society continues to face serious challenges that impede its ability to fully contribute, including systemic, political, cultural, legal and funding challenges. Limited technical and organisational capacity, including chronic underfunding leading to unmet needs of community organisations and networks including advocacy organizations and service providers, also pose real challenges to the ability of communities to deliver quality services and act as equal partners in delivering national responses.
- 10. The Sustainable Development Goals (SDGs) aim to end AIDS by 2030. In order to achieve this ambitious goal, the annual HIV incidence rate will need to be reduced by 90% (relative to 2010 levels). Having led on prevention efforts since the beginning of the epidemic, working with governments, communities can contribute to changes in behaviour, help create demand for, and deliver, prevention interventions, and challenge social cultural norms and attitudes to improve prevention outcomes. AIDS-related deaths must be reduced by 90% that means reaching people living with HIV with testing services, antiretroviral therapy and innovative, holistic and accessible programmes that meet their needs as productive members of their countries. Of particular importance is reaching those populations hardest to reach young girls, migrants, indigenous people, children and older people as well as key populations such as sex workers, gay men and other men who have sex with men, people

who inject drugs, and transgender people; communities are often best placed to reach these groups, particularly populations whose behaviour is criminalised. There should be zero HIV-related discrimination – treatment and prevention targets will not be reached unless people who need these services are free from discrimination in accessing services. Communities are best placed to lead and complement state actions to drive down discrimination. Collaboration by all stakeholders for global collective action to address the determinants of vulnerability, and meet the holistic needs of people living with and at risk of HIV, will be a central feature of success in ending AIDS and delivering on other SDGs [7].

- 11. The UNAIDS Strategic Investment Framework identifies community mobilisation, community empowerment and community-led services as critical to effective responses. Investments in community responses to HIV are strategic investments, as community mobilization and service delivery leads to improved uptake of HIV programmes and promotes local-level transparency and accountability. Strengthening and expanding community responses to HIV as well as creatively ensuring meaningful involvement and empowerment of affected populations will increase the likelihood that national systems are responsive to the needs of people living with and at risk of HIV (Piot, P. et al., 2015[5]). The need for greater investment in civil society and community-based service delivery was reiterated as critical to the Fast-Track approach in a 2016 UNAIDS update on progress [8].
- 12. Much of the fundamental work needed to advance the response to HIV and implement a Fast-Track approach will only be achieved with a strong community voice and presence. This includes broadening the reach of services to those in greatest need, being innovative in community-based service delivery (in particular for testing and treatment, linkage to care, harm reduction and in creating demand), monitoring quality, expanding scale and reach of prevention services, advancing human rights, reducing gender inequalities and stigma and discrimination [2].
- 13. It is essential that community and health systems are integrated into sustainable. comprehensive and resilient systems for health. Community-based services are a vital part of the broader health system and as such can support health systems and achieve quality and concrete health outcomes [9]. The unique strengths of communities, working in partnership with government, must be recognised, measured, resourced, and utilised in creating resilient and sustainable systems for health for HIV and broader health services. This means including community responses to HIV as integral components of national health and AIDS plans from the planning phase to budget allocations, and coordination mechanisms. Support for community responses and communities also have sector-wide effects that can positively affect health, human rights and other services. For example, evidence has shown that fully engaging and supporting community responses to HIV leads to increased success in immunization coverage, family planning, and child survival programmes [9]. Community responses have an important role in achieving universal health coverage and ensuring people-centred integrated health services. It is also imperative that community health workers are recognised as an integral part of the health workforce and seen as part of the solution when considering the health workforce crisis and the much needed investment in this area.

#### Case Study #47 Nepal: HIVision 2020: Ending AIDS in Nepal by 2030: A collective response

The HIV response in Nepal depends largely on foreign assistance (with external donors accounting for as much as 80 percent of national AIDS expenditure in 2015). External funding is declining rapidly, and it is more important than ever that actions and strategic allocation of resources for reducing the country's HIV burden are prioritized though wise, evidence-informed investment choices. In 2015, the development of Nepal's National Health Strategic Plan (NHSP) 2016-2021 was initiated through consultations led by the Ministry of Health's National Centre for AIDS and STD Control. A number of governing and coordination structures were established including a high level steering committee, chaired by the Secretary of Health that included members of other sector Ministries, civil society, UN and other partners. Six thematic groups were created and supported by UNAIDS, focusing respectively on key populations, systems for health, evidence and strategic information, governance, human rights and emerging issues/innovation. As a result of full community engagement and leadership in its formulation, commitment in the implementation of the NHSP from civil society, government and all stakeholders is high. Roles and responsibilities of civil society, as accountable actors in Nepal's response towards ending its AIDS epidemic by 2030, are now specifically articulated in formalized divisions of labour, through public-private partnerships. The plan emphasizes the integration of government and community level services; community-based actions to prevent HIV; 'case finding' and 'case management' a prevention-treatment continuum; the introduction of innovative approaches to task-sharing and community testing, supported by both public, private and community health facilities.

#### Case Study #43 Iran: National AIDS Control Programme (Community-based components)

In Iran, the number of registered cases of HIV is only a fraction of the country's estimated population of people living with HIV. To achieve the 2030 goal of ending the epidemic, it has been recognized that a deeper community reach is needed. The 4<sup>th</sup> iteration of Iran's National AIDS Control Programme was endorsed by the country's Council of Ministers in March 2015, and was formulated with input from stakeholders, including NGOs and community-based organisations. It includes strategies to improve synergies between programme pillars, including the integration of HIV-related services within the healthcare system, and the outsourcing of service delivery to CBOs and NGOs. Examples of this model include the "AIDS Bus" – a voluntary counseling and testing (VCT) campaign led by the Ministry of Health, the Municipality of Tehran, and a CBO – which aimed to help reach individuals with VCT who would not normally attend facility-based services.

In 2006, "Positive Clubs" were created, to provide psychosocial support for people living with HIV (PLHIV), and to promote the "Positive Health, Dignity, and Prevention" approach. The Positive Clubs link with local Universities of Medical Science or Welfare Organisations to help close the prevention gap and increase access to services. In addition, the Positive Clubs also provide direct policy input through representation at the Annual General Meeting of the National AIDS Control Programme.

Local community-based organizations (CBOs), under supervision of nearby medical universities, also run Vulnerable Women's Centres. These provide a range of services to aid control of sexual transmission of HIV among women, including prevention, harm reduction, VCT, and specialist care. These services have benefitted from strong, sustained political support, and have largely been funded through the national budget with overseas assistance in areas such as knowledge transfer, capacity development, and procurement of strategic commodities such as rapid diagnostic kits and second-line antiretroviral medicines. Together, these community-based components have helped the National AIDS Control Programme reach and serve groups who previously would have had limited access to care.

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14. This is a remarkable moment in the history of the response to HIV. The tools and knowledge needed to end AIDS as a public health threat by 2030 exist and the Fast-Track approach provides the framework for strategic and coordinated action [10]. Community engagement and community-led responses are required to tackle specific challenges in reaching treatment, prevention and non-discrimination Fast-Track targets: review and revision of laws and policies; mobilizing and ensuring accountability for increased investments and needed programming and research; advancing human rights of people living with HIV and other key populations; understanding social, cultural and other determinants of health; supporting adherence; creating demand for utilisation of services; addressing stigma and

discrimination; delivering accessible and acceptable services; and facilitating collaboration and linkage of multi-sectoral public systems and government Ministries.

15. This background paper outlines the evidence for the critical role of communities as part of national responses to HIV and describes the opportunity for renewed commitment on the role of communities in bolstering efforts to end AIDS as a public health threat by 2030. The paper also highlights key funding gaps and demonstrates how political support for the integration of community responses in national health and AIDS plans are critical to leverage the full potential of communities. Lastly, this paper makes a number of recommendations for policy and action [1,9–12].

# II. COMMUNITY RESPONSES, A CRITICAL PART OF STRATEGIC NATIONAL RESPONSES TO HIV

#### Definitions

**Community** is a widely used term that has no single or fixed definition. Broadly, communities are formed by people who are connected to each other in distinct and varied ways. Communities are diverse and dynamic. One person may be part of more than one community. Community members may be connected by living in the same area or by shared experiences, health and other challenges, living situations, culture, religion, identity or values [10].

The term "Communities" (in relation to HIV) covers a wide range of people, groups and organizations. It is a collection of different interests, opinions, capacities, resources and priorities. These groups may focus on HIV or they may focus on related areas, such as sexual and reproductive health, maternal and child health, women's health, human rights, food and nutrition, economic development and harm reduction for people who inject drugs [11].

Communities refer to:

- People living with HIV and people at higher risk of HIV infection, their groups and networks.
- Community networks and community-based organizations, including those that are run by and/or for people living with HIV and other key populations.
- Local, national and international NGOs.
- Civil society organizations, including AIDS-service non-governmental organizations and faith-based organizations.

Communities of people most affected by, or at higher risk of, HIV include women and girls in sub-Saharan Africa and people living with HIV and other key populations, such as men who have sex with men, sex workers, people who inject drugs, people in prisons and other closed settings, sex workers and transgender people.

**Civil society** refers to the arena of uncoerced collective action around shared interests, purposed and values. It is the sphere of autonomous associations that are independent of the public and for-profit sectors and designed to advance collective interests and ideas [12]. Civil society is made up of ordinary citizens who organize themselves outside of government and the public service to deal with specific issues and concerns that the normal governmental process cannot address by itself [1].

A community response to HIV is the collective of community-led activities in response to HIV that take place at country, regional and international levels. These activities include: (1) advocacy, campaigning and participation of civil society in decision-making, monitoring and reporting on progress made in delivering HIV responses; (2) direct participation in service delivery; (3) participatory community-based research; and (4) community financing [9].

**Community systems**: There is no singular understanding of community systems. In this report, community systems are defined as community-led structures and mechanisms used by communities that enable community members and CBOs and groups to interact, coordinate and deliver their responses to the challenges and needs affecting their communities. Community systems can be informal and small in scale, or they can be extensive networks of organizations. Community systems should not exist in isolation; rather they should serve as a critical component of the overall system that aims to protect and promote health and human rights. These broader systems include government or public health systems (such as, public health facilities, regulatory and governance bodies, and state-employed health-care professionals).

**Community systems strengthening** (CSS): promotes the development of informed, capable and coordinated communities and CBOs, groups and structures. In other words, it is the capacity building needed to ensure that "community responses" can be delivered through "community systems". It should reach a broad range of community actors and enable them to contribute to the long-term sustainability of health and other interventions at the community level, including the creation of an enabling and responsive environment in which these contributions can be effective.

16. In 2012, the World Bank published results from 17 evaluation studies examining the impact of the community response to HIV on knowledge and behaviour, use of services, social transformation and HIV incidence. The studies spanned a three-year timeframe and included country studies in Burkina Faso, India, Kenya, Lesotho, Nigeria, Senegal, South Africa and Zimbabwe. This evaluation found that investments in communities have produced significant results, including improved knowledge and safer behaviour, increased use of health services, and, importantly, decreased incidence of HIV and other sexually transmitted infections (STIs) [13].

- 17. Research and experience has shown that where there is collaboration between health systems, NGOs and members of civil society, a reduction in HIV incidence and mortality can be achieved, alongside an increase in linking groups that are typically hard to reach with quality services [9].
- 18. Studies from countries as diverse as Cambodia, South Africa, the United Republic of Tanzania and Zimbabwe have shown the effectiveness and cost efficiency of communitybased HIV services [13]. Engagement of CBOs adds value to the national response by increasing awareness, availability and utilization of HIV-related services.
- 19. In Nigeria, community responses were found to increase use of existing HIV services illustrated by a 50% increase in participation in prevention services and a 64% increase in treatment care and support services [14]. In Zimbabwe, community group participation was found to increase both uptake of prevention of mother-to-child transmission and HIV counselling and testing [13]. In Senegal, peer mentoring increased the number of individuals participating in counselling and testing by 50% and increased the number of tests taken by the partners of people living with HIV [15].

#### Case Study#23 Malawi: Mother2Mother (M2M)

Estimates indicate that 1.1 million Malawians were living with HIV in 2014, with over half a million (585,660) currently on antiretroviral therapy. In 2011, Malawi pioneered Option B+, a prevention of mother-to-child transmission of HIV (PMTCT)-focused "test-and-treat" strategy that makes treatment initiation easier and more available, and addresses the needs of HIV-positive women throughout their reproductive years. m2m is a programme delivering non-clinical complementary care and support services through its Mentor Mother Model, a widely supported, scalable, evidence-based peer intervention that ensures mother-baby pairs access the full cascade of reproductive, maternal, newborn, and child health (RMNCH) and PMTCT services. The programme trains, employs, and empowers HIV-positive women who have been through PMTCT to work as peer Mentor Mothers in health centers and communities. Mentor Mother services include: group pre-test education; health education talks; individual peer education and support; adherence monitoring and support; retention services including mother-baby pair follow-up; family support groups; and improved linkages and referrals between the facility and community, as well as integrated service uptake within the health facility. m2m operates in 14 districts in Malawi and employs 305 Mentor Mothers and 115 Community Mentor Mothers in 94 high-volume and hard to reach facilities and 25 traditional authority areas. In 2015 23,943 new clients were enrolled in m2m services; 146 486 women received group pre-HIV test education and 328,388 women had one-on-one interactions with m2m in antenatal and postnatal clinics.

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20. To meet the Fast-Track targets to end the AIDS epidemic by 2030, adapting antiretroviral therapy delivery systems to meaningfully include community-based services will be essential. These community systems must be adequately resourced and scaled up. Achieving scale can be complex and challenging, and requires more attention from the outset. Expandnet, in collaboration with WHO, has developed a number of useful tools to support expanding service delivery reach, including a guide outlining 12 steps for scaling up pilot interventions that includes planning, adapting, developing strategic partnerships, advocacy and collecting evidence [16]. Scale-up also demands a transformation in how community-based services are linked and integrated with health systems. In addition, where health systems face a shortage of clinical staff, community-based service delivery can

expand the reach, share the load and create increased efficiency through improved linkages and synergies, including by transferring tasks to community health workers and volunteers [2,9,17–19]. A recent Meeting of a High Level Commission on Health Employment and Economic Growth heard evidence projecting a shortage of 18 million health workers to achieve the Sustainable Development Goals, mostly in low- and lower-middle income countries. The Commission, which includes WHO, called for a change in the way policymakers look at health workers, not as a drain on resources but as a source of opportunities. This is particularly important in the context of investing in community health workers and volunteers supporting HIV responses [20].

#### Case Study #22 Malawi: Community ART Groups

In spite of progress in addressing the high prevalence of HIV in Malawi, further gains are impeded by the lack of human resources to provide a high standard of care to PLHIV. Furthermore, in rural areas the distance between communities and facilities in combination with the frequency of visits to collect medication may also hamper adherence both from the patient and provider side. National moves towards increasing testing, and subsequent increases in numbers of individuals starting antiretroviral therapy, underscore the critical importance of adherence and retention in care. These challenges are being addressed by the creation of Community ART Groups to actively recruit communities of PLHIV. These groups are self-forming units of 4-8 PLHIV who are on ARV, are stable, and are living in the same communities. Each Community Art Group elects a leader, who receives supportive supervision from a Health Surveillance Assistant. The district ART coordinator oversees implementation of Community Art GroupAGs, and liaises with the District Health Management Team. Community Art Group members take turns collecting antiretroviral medicines for their group from the distribution facility thus reducing the total number of visits, and also disseminate health information among their group, thus reducing burden on formal health system workers. The implementation of Community Art Group led to a 59% decrease in the number of antiretroviral refill visits per person per year, and qualitative research indicated acceptability of the Community Art Group model. Other benefits of the model cited include the improvements in HIV literacy through information sharing within the groups, and promotion of autonomy of PLHIV in their own care. Currently a major challenge to the scale-up of the model is concern at the government level that the approach of empowering Community Art Group members to collect and distribute antiretroviral medicines may lead to theft or loss of the drugs. No such incident has been recorded to date, and the pill count among PLHIV improves significantly when individuals are a part of a Community Art Group due to the collective documentation and reporting of adherence, yet this misconception remains a barrier to the expansion of the model.

#### Case Study #31 Swaziland: Maximizing ART for better health and zero new infections (MaxART)

With a population of 1.1 million, the Kingdom of Swaziland has a HIV prevalence of 31% among young adults ages 18-49. Prevalence among young women of 18-19 years of age is 14 times higher than that of young men. A stakeholder consultation initiated by STOP AIDS NOW, with Swaziland's Ministry of Health, the Clinton Health Access Initiative (CHAI), and other community partners led to the creation of the MaxART strategy. It is led by the Ministry of Health and implemented by a consortium of partners from national and international NGOs and academic institutions. The focus of MaxART is on service delivery, implementation research and advocacy. Its first phase (between 2011 -2014) focused on countrywide scale up and implementation of innovative, comprehensive, evidence-informed, inclusive and rights-based interventions along the continuum of care, aligned with national HIV treatment guidelines. During the second phase (2014-2017) the consortium is implementing an effectiveness trial testing the feasibility, acceptability, clinical outcomes, affordability, and scalability of offering ART to all in a government-managed health system. The programme has been successful in reaching communities and increasing demand for services. It also fostered stronger engagement among local leaders in the HIV response, and has increased the number of individuals who know their HIV status and access treatment. Current challenges include the lack of paid health workers at the community level in Swaziland, and there is need to further strengthen community health systems and linkages between community and health services to further enhance sustainability. Furthermore, some health facilities face limitations in available human resources, physical space, and logistics. Despite such challenges, Ministry of Health statistics revealed that MaxART's original targets were met and exceeded. By June 2015, annually 284 680 people were tested for HIV, 134 803 were receiving ART, and from patients in 2013 there was a 10% loss to follow-up.

## Case Study #71 Ecuador: Analysis of social behaviour, sexual practices and HIV prevalence on HIV testing services of the Fundacion Ecuatoriana Equididad Community Centre

The general HIV prevalence in Ecuador is 2%, whilst a concentrated epidemic exists in men who have sex with men, with a prevalence between 11 and 19%, and 34% among transgender and transsexual people. According to the Ministry of Public Health, 41 375 people had been diagnosed with HIV through 2014, but only 13 300 people were undergoing treatment. The Fundacion Ecuatoriana Equididad operates an HIV testing service, which is complemented by a wide range of health services at affordable prices for the key populations, which include medical, psychological, and legal components, the latter being free of charge. During 2015, the HIV testing service conducted 987 HIV tests, 728 of which were administered to men who have sex with men. To better understand behaviours and practices, the Foundation commenced an analysis to establish the epidemiological profile of service users. This will delve into the most relevant aspects related to sexual behaviors, discrimination, and knowledge about HIV among the most affected populations, to compare the national prevalence among men who have sex with men with the prevalence among members of this population diagnosed by the Foundation. The objective of the analysis is to improve outcomes within the national response to HIV, and data generated will help create better communication strategies for campaigns created by the Foundation as well as national efforts.

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21. Community responses to HIV support health systems strengthening and sharing the workload by health systems, making important linkages between communities and multisectoral systems, and improving acceptability and accessibility of services. WHO guidelines increasingly point to task-shifting and task-sharing as important components of systems for health. Community health-care workers work both within and alongside health-care systems. Task-shifting and task-sharing are now a crucial part of HIV testing and treatment programmes, engaging communities in treatment literacy, prevention, adherence, peer support and distribution programmes. Community health workers provide services to their communities and act as the link between health systems and communities on health issues such as HIV, sexual and reproductive health and rights, and many others issues [2]. A recent Lancet review on faith and health care has shown that faith-based providers contribute to service delivery through their facilities and broader community initiatives, and are particularly important where health systems are fragile or weakened [21]. Communitybased responses contribute to sustainability of national HIV responses and scaling up access to prevention, treatment, care and support when they are seen as effective and cost efficient service providers for governments and are engaged through social contracting. [22]

#### Faith-based approach to prevention of mother-to-child transmission, Kenya

A PMTCT project in Kenya collaborated with 20 health facilities and the Kenya Council of Imams and Ulamaa, a longstanding local faith-based organizations. The project trained 25 Imams (mosque prayer leaders) and 85 Maalimat (female religious instructors) in PMTCT to address Muslim women's low use of health facilities. The Imams integrated this information into their Friday sermons and other social gatherings while the Maalimat introduced it through focus group discussions. In total, the project reached 76 000 individuals with PMTCT messages. In one year (May 2013-April 2014), the number of pregnant women tested for HIV increased more than 50 per cent from 770 to 1 183. The proportion of women who tested positive and initiated ART increased from 63 per cent in the first quarter to 93 per cent in the third quarter. Testing of male partners and skilled deliveries also increased during this period. Lessons learnt included the importance of integrating religious perspectives and teachings, involving men and engaging multisectoral community stakeholders. [22]

22. Civil society and community networks play an essential role in advocacy, campaigning, participation in decision-making, and monitoring and reporting on progress. Community advocates are central drivers of investment in HIV services and ambition for service delivery and human rights targets. Community-based advocacy and participation in accountability takes place at global, regional, national and local levels. Stakeholders from different geographic levels work together to ensure community-based responses are a strong pillar in supporting national responses to HIV that reach individual people and societies. [23]

#### Case Study #50 Viet Nam: Asia Action: community advocacy for harm reduction in Viet Nam

There are an estimated 256 000 PLHIV in Viet Nam. In 2013, the greatest proportion of new infections occurred among men who share needles while injecting drugs - 45%. Before 2013, drug control laws in Viet Nam stipulated that people who use drugs who failed to quit could be sent for compulsory rehabilitation in a closed setting for up to four years, but this approach had limited success and encouraged drug users to avoid harm reduction programmes. As a result, the government created the Renovation Plan for Addiction Treatment, which aimed to scale down compulsory rehabilitation from 63% of cases in 2013 to 6% of cases in 2020, along with a concomitant scale-up of voluntary services. From 2013-2015, the Centre for Supporting Community Development Initiatives (SCDI) - a local NGO whose mission is to improve the lives of marginalized populations worked alongside government departments and the drug user community to realize the Renovation Plan. A major aim was to contribute to improving the policy environment regarding drug use and HIV, and to achieve an increased commitment by the government of Viet Nam to evidence- and rights-based policy on drug use and HIV. Bac Giang province, which had a committed local government structure, was selected to pilot the development of a voluntary drug treatment system - consisting of a facility with residential capacity and several community sites - to provide a wide range of services and supports. SCDI subsequently provided key input to the government to develop guidelines for community-based addiction treatment. From the beginning of 2014 until now, there have been no cases of compulsory rehabilitation in Bac Giang province, and the new government guidelines developed by SCDI for voluntary treatment centres and satellite facilities released in 2016 (after the programme ended) will contribute to supporting the commitment by the government to scale up voluntary services so that 90% of drug users are getting treatment by 2020.

## Case Study #84 Latin America and Caribbean: Advocacy in the defence and promotion of human rights of female sex workers (RedTraSex)

Female sex workers are one of the populations most affected by HIV. In Latin America, HIV prevalence among female sex workers is 2.57% - over six times greater than the regional prevalence of the general population at 0.4%. RedTraSex was established in 1997, with the aim of strengthening the National Organisations of female sex workers in the defence and promotion of human rights, operating under the motto "sex workers are not the problem, but part of the solution". RedTraSex promotes training, and seeks to make the voice of sex workers heard in decision-making spaces regarding policies that affect them. From 2012 until the end of 2016, the RedTraSex network is implementing a regional Global Fund grant aimed at decreasing HIV prevalence among sex workers in Latin America and the Caribbean through the strengthening of sex workers' organisations and an increased participation of sex workers' in the political debate about sex work and the stigma and discrimination that surrounds it. The network spans 15 Spanish-speaking countries across Latin America and the Carribbean, and its work is shared across 32 countries in partnership with the International HIV/AIDS Alliance. In 2013, RedTraSex reached

over 17 306 FSW for the first time, and 13 950 for the first time in 2014. From late 2013 to early 2014, RedTraSex held seven national workshops covering financial and technical capacity building among female sex worker organisations, which brought together 225 women, and during 2014, six national workshops were held which reached 117 women. RedTraSex also holds workshops for sensitization for health and security officials, which by January 2015 had reached 1 062 people, surpassing their original target number of 700.

#### Case Study #76 Canada: Canadian Positive People Network (CPPN)

At the end of 2014, there were approximately 71,300 PLHIV in Canada. Among marginalized populations such as resource-poor indigenous communities and refugees, the ability to access healthcare fell between 2006 and 2015, and HIV rates increased. Prior to 2015, Canada lacked a national PLHIV network to represent the needs of individuals and communities living with HIV. To close this gap, CPPN was created as an independent national grassroots network with support of a number of AIDS service organisations. CPPN has a national reach, and has grown to include over 125 members across Canada. A key activity of CPPN is advocacy on national and international levels, and to date it had several achievements in advocacy, campaigning and participation in accountability. These include the creation of an online petition during the federal election in 2015 and a community press conference to ask candidates to commit to placing PLHIV at the forefront of the HIV response. CPPN also led a group of PLHIV activists at 2015 conference of the International AIDS Society to craft the Canadian Declaration by Persons living with HIV to highlight the human rights considerations needed in the expanded testing, treatment and use of new prevention technologies approach. The organization also co-hosts an HIV, Aging and Income Security Think Tank with a national partner, and participates in national consultations and working groups including the Canadian Consensus Statement on the Health and Prevention Benefits of HIV ARVs & HIV testing; the National Coalition Working Group on the development of a new communitydriven HIV strategy; and the national CanPrEP working group to provide perspectives of PLHIVs on pre-exposure antiretroviral prophylaxis (PrEP) to facilitate the listing of PrEP on drug formularies. Additionally, working with partners including the Youth HIV Disclosure Project, CPPN has worked on programme development, and is involved in planning of "HIV is Not a Crime" trainings for PLHIV in Canada. As part of its activities to better represent the needs of PLHIV and civil society, CPPN made an intervention on GIPA at the UN Civil Society Hearing in April 2016, and also participates in consultations on the UNAIDS Programme Coordinating Board thematic working groups and Canadian consultations for the High Level Meeting on Ending AIDS (HLM).

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#### The People Living with HIV Global Advocacy Agenda 2013–2015

The People Living with HIV Global Advocacy Agenda (GAA) is a tool that has been used since 1999 to articulate the issues of most importance to the community of PLHIV, based on broad consultations. It has been used to guide and inform the advocacy efforts of activists, networks of PLHIV and other organizations. It is updated and revised on a regular basis to keep up to date with trends and changing needs within the community.

The People Living with HIV Global Advocacy Agenda 2013–2015 aims to guide and inform actions and programmes of networks of PLHIV and other stakeholders through an evidence-informed advocacy strategy by and for people living with HIV. Building on the knowledge and first-hand experiences of people living with HIV is a necessary and strategic approach to take as part of efforts towards achieving the targets set out in the 2011 Political Declaration on HIV and AIDS, and the Sustainable Development Goals.

The People living with HIV Global Advocacy Agenda is an example on how community networks connect from the grass-roots to global levels to develop a unified advocacy agenda that can mobilize and galvanize action by and for people living with HIV networks wherever they are. To develop the agenda, GNP+ leads a step-wise process. Starting from consulting individual people living with HIV throughout the world, using modern technologies and grass-root networks, areas of concern are analyzed and grouped. Those groups then form priority thematic areas that are further consulted on and analyzed to turn into advocacy action plans. The final GAA is then used by networks of people living with HIV throughout the globe to inform their local responses and actions with their partners and governments. *[23]* 

- 23. Community-led advocacy actions are often innovative and adaptable to navigate the complex social and political contexts surrounding the response to bring about positive change. For example, in Namibia, Positive Vibes and other civil society organizations were successful in using the UNAIDS Strategic Investment Framework to engage in dialogue with the government, resulting in full civil society inclusion in the design and delivery of the national HIV response including the review process of the National Strategic Framework [2] Similarly, successful, sustained and coordinated advocacy led by the East Europe and Central Asia Union of People Living with HIV (ECUO) has resulted in increases and other new commitments in the national budget allocation for antiretroviral therapy in countries across the region.
- 24. Evidence shows that community services can achieve impact, in terms of better access and wider coverage [13]. Not only can community-based service delivery lead to positive health outcomes [24] but also to rapid scale-up of interventions through demand creation. Services include medical interventions, social care or legal and human rights programmes. [22]

#### Case Study #83 Latin America and Caribbean: Advocacy to challenge impunity and violence against transgender people

The average life expectancy of transgender women in Latin America is 35 years. Due to a dynamic of rejection and transphobia, transgender women are often limited in job opportunities, and, as a result, are frequently pushed into sex work. REDLACTRANS works to highlight the vulnerability and inequality of transgender women in Latin America, encouraging countries to take immediate action to rectify this situation, and that they contribute to creating a political and legal environment that favours the inclusion of transgender women in society. The network focuses on advocating for transgender rights, and its activities support development of the network and its focal points. By improving recognition of transgender jeople, and to drive the formulation of inclusive HIV and health policies that meet their needs. In addition, noting the difficulty in reaching judicial authorities with sensitization training towards transgender issues, REDLACTRANS has highlighted the need for strong advocacy for such training to take place. Activities include regional workshops and meetings to provide guidance on steps to take when reporting abuses and crimes including gender-based violence, human rights violations, and hate-crimes. REDLACTRANS also carries out training within the Inter-American human rights system. The network has focal points in 15 countries in the Latin American and Caribbean region, and a major achievement to-date is their instrumental role in the introduction of legislation in Argentina, which seeks to reduce discrimination by guaranteeing equal rights and dignity of transgender people. The work of REDLACTRANS is also shared across 32 countries via their partnership with the International HIV/AIDS Alliance.

## Case Study #5 Burundi: Improving access to prevention and treatment of HIV/AIDS and hepatitis in Africa by defending the human rights of the most vulnerable populations (MSM, IDU, SW, transgender people)

This project by ANSS Burundi aims to strengthen capacity of various actors to challenge the exclusion of vulnerable groups from programmes for the prevention and treatment of HIV. ANSS Burundi recognized that in parallel to working to improve access to prevention and treatment among those most vulnerable to HIV, it also is critical to sensitize and educate the general population to change their perceptions and attitudes towards vulnerable groups. Since the start of the project, 75 sex workers, 35 men who have sex with men and transgender people, 50 health facilitators, 33 legal workers, 20 civil society actors, and 23 drug users have been reached with information and sensitized regarding the links between the human rights of vulnerable groups and the struggle against HIV. Additionally, many government and non-government actors working in the areas of HIV and protection of human rights have been approached to become involved in advocacy activities. The project is being conducted throughout the territories of the country, but until now the activities have been led from Bujumbura and in 3 provinces where ANSS has branches (Makamba, Gitega and Kirundo). The project's main impact is that it has been able to approach a taboo subject by sensitizing stakeholders to generate a change of attitudes towards vulnerable groups.

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#### Network Support Agents, Uganda

The network support agent (NSA) project, described in the 2012 UNAIDS case study on community engagement, was implemented by 420 PLHIV groups, organized into 55 network clusters with one group identified as the lead. At the end of the three year project cycle, 1 302 people living with HIV were trained as NSAs and were working with 643 health facilities and their surrounding communities, providing HIV prevention education, client tracking, promoting male involvement and communication for income generating activities. During one year, the number of people living with HIV on antiretroviral therapy reached with adherence counselling increased tenfold from 17 000 to 170 000. Referrals to state and community-based facilities increased from 5 000 to 115 000. Qualitative evidence of decreased stigma, increased levels of disclosure, reduced client waiting times and improved tracking of client outcomes was also documented. *[22]* 

25. Community service delivery is not limited to health services. Studies show that integrating legal literacy, human rights advocacy, and legal services into health care is an effective strategy for empowerment of vulnerable population groups and for addressing underlying determinants of health. Legal empowerment programmes can increase access to health services, promote accountability, reduce gender inequalities, mitigate stigma and discrimination, and contribute to positive change of discriminatory structures and systems [25–27]. [2]

Community-based services overcome legal challenges to deliver health services for marginalized populations, Nigeria

Heartland Alliance in Nigeria is a partnership between five local key population organizations that works to ensure sustainable access to HIV services for key populations – particularly gay men and other men who have sex with men – in a legal environment where sexual orientation and gender identity may pose a barrier to access treatment, prevention, care and support.

Heartland Alliance in Nigeria is now a strong organization of 34 outreach staff and 255 peer educators who have been trained and employed in five states in Nigeria. Over 62 000 people have been reached through its integrated HIV prevention programme for gay men and other men who have sex with men, and at least 21,000 people from most-at- risk-populations and their partners have been provided with palliative care and support. [2]

In collaboration with local hospitals and other partners, Heartland Alliance in Nigeria has established specialized clinics across the country to deliver HIV services in a safe environment to most-at-risk populations, in particular gay men and other men who have sex with men. Working at the intersection of health and human rights, Heartland Alliance in Nigeria also provides legal aid to those whose rights have been violated because of their sexual orientation and gender identity. *[2]* 

26. HIV stigma and discrimination adversely affect all aspects of life for PLHIV and their families. Discrimination that denies people living with HIV access to health, sexual and reproductive health services, employment, education and participation in family and community settings denies PLHIV their human rights. Moreover, such discrimination limits the ability of people living with HIV to know their HIV status, access and remain in treatment. In other words, it impacts people's lives and reduces the effectiveness of responses to HIV. Self- (internal) stigma also negatively affects a person's ability to access HIV testing, and access care and

adherence to treatment. To reduce stigma and eliminate discrimination it is essential to engage and involve communities and service providers where discrimination occurs. [2, 28]

#### Stigma reduction

In India, the evidence-based global stigma reduction framework was successfully piloted, as part of the national AIDS response stigma reduction activities, addressing the drivers of stigma - lack of awareness of stigma and its harmful consequences, social judgment and fear of infection through casual contact (ICRW, 2013). In Zimbabwe, ZNNP+ with support from partners developed an evidence-based community-based intervention that showed reduction of self (internal) stigma and improvements in self-agency, depression and overall quality of life [2, 28]. In Namibia, Positive Vibes developed the 'From Victims to Victors' programme that focuses on self-stigma and facilitates meaningful participation of PLHIV. (UNAIDS/PCB (38)/16.14 CRP1)

27. There are many challenges that impede the ability of communities to participate and to be effective. These include systemic, political, cultural and funding challenges (see Box 1 for some examples in terms of participation in accountability processes). [12] It can be particularly challenging for community and grassroots organizations to be fully effective as they often rely on volunteer resources and are not appropriately recognised and valued. In addition, unsuitable systems for monitoring and reporting may be imposed by donors and receiving and accounting for funding is not always easy. To address these challenges, modes of providing financial support need to be examined, national funding channels to facilitate access for these CBOs should be strengthened, and -- recognising the lack of capacity to respond to demanding monitoring and reporting requirements -- investment needs to be made in capacity building on data collection and reporting. Investment in building staff capacity and skills for general management and coordination and provision of support for caregivers and volunteers is also necessary [13]. Issues of quality control and appropriate training of community health workers also need to be considered. These challenges need to be addressed by both civil society and government.

#### Box 1: Challenges to effective participation in accountability processes faced by civil society

- Lack of acceptance—where civil society is not recognized or accepted as an equal and valued member in the response.
- Legal and political barriers—where civil society groups and representatives are directly or indirectly barred from effective service and representation activities, as well as from fundraising.
- Exclusion and discrimination and/or criminalization of certain population groups—where there is the denial of existence of certain groups, people, identities, behaviours or practices, or they are criminalized so that coming together to form a representative organization is difficult, illegal and/or dangerous.
- Token representation in processes—where representatives do not have the power to negotiate or speak in a meaningful way.
- Inauthentic processes of consultation—where civil society input is not carried into decision- making processes.
- Inauthentic representation—where civil society representatives are not afforded sufficient legitimacy to represent a specific or general community group or nongovernmental organization. In such situations, key populations may not be represented directly, but through intermediaries who claim to speak on their behalf.
- 'Cherry picking'—where particular civil society representatives are invited to participate because they are easy to work with while controversial individuals, who may be more willing to raise challenging viewpoints, are excluded.
- Undue influence or pressure—where civil society representatives are influenced by other partners (e.g., governments or even the UN), or at the most extreme, coerced in their opinions, or co-opted into decisions.
- Inadequate support and resources—where civil society representatives cannot participate in processes authentically because they lack human or financial resources, information or preparation time.
- Limited capacity in terms of skill sets—where civil society representatives do not have the ability to access information and actively participate on a long-term basis in (for example) meetings and consultations. [12]
- 28. Gaps in capacity exist among some community networks and organisations. To promote community responses, particular attention needs to be given to community empowerment, an intervention in itself essential to effective programme management, planning, implementation and monitoring. For example, in 2013, the WHO, UNFPA, UNAIDS, NWSP and The World Bank came together and developed the Sex Worker Implementation Tool (SWIT). This document provides recommendations for implementing HIV and STI testing, treatment and prevention strategies that are directed by and empower sex workers themselves. It is intended for use by public- health officials; managers of HIV, AIDS and STI programmes; and NGOs, including sex worker led organisations and health workers, and covers broad topics such as community empowerment, community-led services, clinical support services and programme management and organisational capacity building [29].

## Case Study #49 Thailand: Comprehensive HIV Prevention Among Most-at-risk populations by Promoting Integrated Outreach and Networking (CHAMPION) IDU (2009-2014)

Although progress has been made in reducing the HIV burden among the general population in Thailand, the estimated HIV prevalence among drug users was 25-50% in 1989-2009. A focus on law enforcement and public security when dealing with drug issues led to mass incarcerations, forced detentions, human rights violations, and public health barriers. To help address service delivery gaps through community empowerment, CHAMPION-IDU was designed as a community-led, peer-based HIV prevention project, almost exclusively implemented by civil society, to improve the lives of people who inject drugs, and operated between 2009 and the end of 2014. In spite of a hostile operating environment and challenges with retention of staff and peer supporters, the strategy was successful in recruiting people who inject drugs and facilitating access to health services because of the innate trust that exists between peers. Government drug treatment centers saw up to a fourfold increase in inand out-patient admissions since the initiation of the CHAMPION-IDU project. Approximately 80% of the 350 CHAMPION-IDU workers hired were active and/or recovering from drug use and participation was seen as means for PWID to build their capacity to become productive members of society. The project provided skills, salaries, and support to these workers over 5 years, and as a result of regular work and social support, many of the CHAMPION-IDU workers were able to reduce their drug use. Peer workers operated drop-in center based activities as well as outreach based activities, including behavior change communication to reduce risks, education, sterile injecting equipment, condoms distribution, overdose prevention with naloxone, and referrals to services. Over the project life cycle (2009-2014), over 13 000 of the country's estimated 40 300 people who inject drugs were reached by CHAMPION-IDU project services, across 19 of the Kingdom's 76 provinces. However, the project faced difficulties including lack of political support, skepticism in the harm reduction strategy, and lack of funding support.

#### Case Study #46 Myanmar: Increasing access to HIV treatment through a community-supported public-private partnership

Myanmar has experienced an increase in the numbers of people living with HIV, and in response the Ministry of Health has moved to rapidly scale up provision of treatment to help reduce HIV-related illness and deaths. The government aims to provide antiretroviral therapy to 106 058 people by the end of 2016, although to achieve this target the already-stretched health system required innovation to ensure that antiretroviral therapy could be provided close to communities without compromising quality. To assist in the decentralization of antiretroviral therapy delivery, Alliance Myanmar has operated a partnership with private sector general practitioners. Under this partnership the Alliance contracted general practitioners to provide services such as HIV testing, assessment and WHO staging, diagnosis and treatment of opportunistic infections and other aspects of clinical management of sexually transmitted infections and tuberculosis. The Alliance also supports treatment literacy, adherence support, support with disclosure, home-based care, and tracing of lost-to-follow-up patients through community based activities. These activities have been implemented through outreach workers deployed from a network of CBOs and key population networks in Yangon. Subsequently, Alliance Myanmar has become the third-largest provider of HIV treatment services, contributing significantly to the national response. Between March 2009 and April 2015, 2119 patients were provided with antiretroviral therapy, and only 3.3% had been lost to follow-up. The partnership helped maintain HIV knowledge and expertise among private general practitioners in line with national guidelines, and also helped decentralize HIV treatment delivery, thereby relieving the already-overburdened health services and demonstrating the effectiveness of using existing community and private sector health infrastructure to increase coverage without the need for creation of new facilities.

#### Case Study #73 Paraguay: SOMOSGAY - Health and social services by, and for, men who have sex with men

HIV prevalence in Paraguay is 0.4%, with 17 000 people living with HIV. Prevalence among men who have sex with men is estimated to be as high as 13%; however, a culture of homophobia and discrimination, even within the health system, historically meant that there was no safe space for men who have sex with men to access sexual health services. In response, SOMOSGAY Community Centre was conceptualized, and implemented by members of the men who have sex with men and PLHIV communities, providing a range of social and health services and advocating for public health, education and other public policies. It also provides an incubator for grassroots groups to meet and two networks have already emerged to help support the lesbian and young people's PLHIV communities. In 2009, SOMOSGAY opened the Kuimba'e clinic, offering free clinical care, testing, treatment vaccines and referrals, with particular emphasis on HIV and STI prevention. In its first year of operations, 1,915 people visited the SOMOSGAY Centre, rising to 4,020 in 2015. That year, 8,326 clients visited the Kuimba'e clinic. Another closely linked programme 'Community Agents of Human Rights and Health' runs a cycle of workshops focused on training and empowerment of young lesbian, gay, bisexual and transgender people, providing basic information, prevention packages, counselling, leadership and networking training. Currently there are more than 200 Community Agents across the country who work with Kuimba'e on different activities, in particular providing information, prevention packages and referrals to the Kuimba'e Clinic and other public health services. The clinic also runs mass HIV testing programmes and campaigns in public

places to reach large numbers of people with information, prevention supplies, testing, counselling and onward referrals and linkage to care. Kuimba'e works closely with PRONASIDA (the National Programme for AIDS and STI control) and the Ministry of Public Health to ensure efficient linkage to care. In 2016, SOMOSGAY began to replicate its service model in other regions around the country, with support of the Ministry of Public Health and the AIDS Healthcare Foundation. SOMOSGAY maintains a particular emphasis on research, advocacy, and communications as key elements of programme activities.

#### Case Study #53 Georgia: Harm reduction programme – Provision of HIV prevention services to people who inject drugs

The number of new cases of HIV in Georgia is growing, and the rate of transmission via injecting drug use, although declining, remains proportionally high. There are an estimated 50 000 people who inject drugs in Georgia, and this number is also increasing. A number of factors have contributed to this increase, including a strict legal environment regarding drugs, and a lack of treatment, rehabilitation, and resocialization programmes. The Georgian Harm Reduction Network (GHRN) is implementing a needle and syringe programme in 11 cities and 14 harm reduction sites, with service delivery for people who inject drugs, incorporating NGOs and community led organisations. The programme has two main components: HIV Service provision and Advocacy. Through emphasizing the community's role in HIV service delivery, the coverage of the need and syringe programme with a minimal HIV package increased four-fold in comparison to 2012. Community involvement also facilitated access to hidden populations, among them sub-populations such as young PWID or female PWID, and in particular peer based support helped deliver life-saving services at outreach locations. Community mobilization to defend rights and demand better access to health and social services was also a success, and PWID became more prominent in discussions of their problems and needs in the general media such as on TV and radio programmes, and participating in street protests and action for solidarity. In 2015, over 31 000 people who inject drugs were reached with HIV services, and over 22 000 were tested for HIV, hepatitis B and syphilis, representing a 10-fold increase over 2012. The provision of female-specific services and greater involvement of female outreach workers also helped in uptake among female people who inject drugs. In 2016, GHRN aims to further expand coverage via adoption of new strategies such as working via mobile ambulances.

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29. In regions such as Eastern Europe and Central Asia and Asia-Pacific that are experiencing HIV epidemics concentrated in certain key populations, even greater barriers exist to successfully working with communities, as the behaviours driving the epidemic, such as drug use and sex work, are often criminalised. The double stigma and discrimination of living with HIV and being a member of a marginalized population create barriers to accessing services. Politicians are also often less inclined to support programmes for criminalised communities, especially during times of constrained national spending and competing public service needs [30]. Changing punitive laws and abusive law enforcement practices that affect access to services, treatment and information in particular for people who inject drugs, gay men and other men who have sex with men, transgender people and sex workers is key to enabling greater collaboration between government and key populations.

#### Case Study #55 Russia: Street Lawyers Project

Strict anti-drug legislation and lack of official support for HIV prevention and psychosocial support has led to a shortfall in service access by drug users in Russia. There are over 830 000 officially registered cases of HIV in the country, and in approximately 70% of cases, transmission was linked to use of injecting drugs. Among Russia's people who inject drugs, approximately 37.2% are living with HIV, and in some cities, as many as 90% are infected with Hepatitis C. Since 2013, the Andrey Rylkov Foundation for Health and Social Justice (ARF) has implemented its Street Lawyers Project as part of a broader harm reduction strategy in Moscow, with the aim of teaching legal defence skills to people who have no formal legal education, such as social workers and representatives of key populations affected by HIV. The project's outreach workers help provide people who use drugs with brief and timely consultations addressing basic legal issues. Core activities include: Information and awareness generation; Mediation; Official requests; Formal complaints; and judicial protection. In 2015, the project prepared 167 legal documents (including appeals, requests to public authorities, statements of claim, and statements challenging the actions of public authorities), as well as approximately 20 court appeals. The project's social workers also took part in approximately 20 court hearings. Key topics for the project's legal work in 2014-2015 were protection in drug-related criminal cases, and protection of the right to health, including access to antiretroviral therapy, and protection of people who inject drugs

living with HIV and hepatitis C against discrimination. One of the key achievements of the project is the improvement of service access among the people who use drugs, and it has also helped in enforcing human rights laws through taking on cases where the rights of people who inject drugs have been violated, representing their cases in the judicial system, and creating public awareness. In situations where such legal challenges fail, the project brings the cases to national and international courts. Three such cases are currently under review with the European Court of Human Rights.

## Case Study#16 Ghana: Stigma and discrimination reduction among PLHIV and Key Populations using online and SMS reporting

HIV prevalence in the general adult population in Ghana is 1.5%; however, prevalence among men who have sex with men and female sex workers is much higher, at 17.5% and 11%, respectively. This has been driven by stigma, discrimination, poor health services access, and health and human rights violations. Although structures are ostensibly in place to ensure that everyone in Ghana has access to means for justice, the daily stigma and discrimination makes it difficult for people living with HIV and key populations to access these systems in practice. In response, the Commission on Human Rights and Administrative Justice (CHRAJ) created the Discrimination Reporting System (DRS) in 2013. The DRS uses online web-based and SMS reporting modules, to facilitate the reporting and tracking of cases online and also send text message via the phone to CHRAJ whilst reducing the need for in-person contact. The CHRAJ also trained national facilitators to carry out further trainings for their staff, and the programme operates using a Privacy and Confidentiality Policy developed by the CHRAJ, which is the first of its kind at the CHRAJ since its establishment 23 years ago. The implementation of the programme has made justice more accessible for people living with HIV and key populations by strengthening legal support services for redress. It has also empowered people living with HIV and key populations to fight against social barriers that impede the right to health. Between 2013 and 2015, the CHRAJ trained approximately 200 staff on stigma and non-discriminatory practices, across seven regions of Ghana identified as areas of high HIV prevalence. Initially, the CHRAJ noticed that uptake was low, with only 22 cases being reported. Identifying this as due to a knowledge gap on stigma, discrimination and human rights issues, the CHRAJ quickly worked with civil society organizations to bridge the gap and generate demand, to train approximately 464 PLHIVs, members of key populations and service providers during 2015 in six regions of the country, and developing social marketing materials including brochures, cards and fliers. These were distributed nationwide along with anti-stigma and discrimination posters over 200 sites, and a targeted radio advert aimed towards PLHIV was aired over a period of two weeks. The DRS provides data on discrimination for advocates and policy makers in Ghana.

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#### Case Study #54 Moldova: Community-Based HIV prevention services in prisons

The HIV epidemic in Moldova is fuelled primarily by transmission during injecting drug use, and is concentrated in prisons. Commencing in 2000, CBOs and NGOs began leading in the development of policies and services to prevent HIV and TB for the country's inmates. Currently, 12 out of 15 interventions recommended within the UNODC/ILO/UNDP/WHO/UNAIDS comprehensive package of HIV services for prisons are being implemented in Moldova, and the CBOs and NGOs are essential facilitators of prevention, treatment, care, and support for PLHIV and those with co-infections. These actors include the CBO, "New Life" - a key population led organisation, consisting of people who inject drugs and former inmates providing support to PLHIV and people who inject drugs in prisons. Participation of the key affected population in the process of planning, development, implementation and evaluation has been a major factor in the programme's specificity and effectiveness. A team of 25 peer-to-peer consultants, social workers, psychologists and coordinators now work across 17 prisons in Moldova, covering a population of nearly 8000 inmates - both women and men. Activities include advocacy, campaigning and participation in accountability as well as community-based service delivery in prisons, including testing, prevention, treatment, legal services, and training of health workers and community financing. The programme has been critical in the scale-up of opioid substitution therapy, needle syringe programmes, antiretroviral therapy and other essential services in prisons. As a result of interventions by multiple stakeholders including prison and health authorities, CBOs, United Nations agencies, and others, the proportion of inmates living with HIV receiving antiretroviral therapy increased from 2% in 2005 to 62% in 2013, and the programme has also helped reduce the number of deaths due to HIV in prisons from 23% in 2007 to 8.6% in 2013. Rates of blood-borne illnesses in general have also been reduced among the prison population, including Hepatitis C, the prevalence of which has fallen from 21% in 2007 to 8.6% in 2012. The programme was additionally successful in creating a culture of openness among prison authorities towards collaboration and implementation of innovative and evidence-based approaches, and furthermore was instrumental in increasing the level of tolerance towards inmates and vulnerable groups by prison personnel.

#### Case Study #18 Kenya: The Omari Project at Malindi GK Prison

Among the 850 inmates at Malindi GK Prison, it emerged that 50% were experiencing drug use problems. In response, the Omari Project was founded, to help prevent drug addiction among inmates, and protect them against related harm, through rehabilitation and harm reduction. The Omari Project conducts two visits to Malindi prison per week, attending the male wing on Wednesdays, and the female wing on Fridays. To date, over 300 inmates have received HIV testing services, and group counselling has been conducted, hosting 25-40 clients per session. The Omari Project's activities have also included one-to-one addiction counselling sessions and human rights education programming, and the project's harm reduction services are accessed by over 300 inmates each year. Furthermore, the Project has also acted as a link between inmates and their families, for example to ease transition upon their release from prison, and it has also collaborated with Malindi Sub-County Hospital to provide TB, STI, and Hepatitis B screening. This strong partnership between an NGO and prison services has been presented nationally as a best practice, and this collaboration has fostered the mainstreaming of the Omari Project's services among day to day prison activities.

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30. Community-led research has a critical role to play and results in essential and insightful evidence for communities, policy-makers and programme planners. It ensures that policymakers and programme planners understand the needs of the communities and the impact of their policies and programmes. Community-based research empowers communities to play an active role in informing policies and drive the generation of evidence to inform the design and delivery of services [2]. For community-based research to happen, particular attention and resources need to be allocated to building research capacity of community based organizations. For example, the People Living with HIV Stigma Index is a community-based research methodology that has taken place in over 60 countries around the world based firmly on the GIPA principle. In each country, research capacity is built among networks of people living with HIV who then carry out the research. They work closely with governments, academic institutions, civil society and other development partners as a team. Along with generating robust evidence of the levels and forms of stigma experienced by people living with HIV being used to inform policy and practice, the process itself has been empowering, both for the community-based researchers and participants who take part [32]

Case Study #57 Ukraine: Women-led and community based research: Sexual and reproductive health, gender equality and human rights, gender-based violence, economic and political opportunities of women living with HIV

Ukraine has among the heaviest HIV burden in Europe and Central Asia, with a prevalence of 0.62% in the 15-49 age group. There is also an increase in the registration of female cases compared to male cases and a lack of gender-sensitive HIV responses in general. Qualitative research was carried out by women living with HIV to gather evidence in support of the development of gender-based approaches to address HIV in Ukraine. Data was collected on the challenges and needs of women living with HIV in relation to sexual and reproductive health, gender equality, human rights, gender-based violence and economic and political opportunities. The challenges confronted by women living with HIV are exacerbated by the overall worsening of the economic, social and political situation in Ukraine and the deterioration of human rights relating to the ongoing armed conflict and humanitarian crisis. Over 100 women were interviewed through community consultations and focus groups. The results highlighted a number of issues including lack of commitment of the National TB/HIV Council as well as the regional and municipal Councils, small percentage of women in leadership positions within regional administrations, lack of satisfaction in the state's support of people living with HIV and high levels of gender-based violence and violations of women's rights. The community-led research has led to the creation of a discussion platform for women as well as evidence upon which advocacy is now being developed at national and regional levels.

Case Study #64 Bolivia: Body mapping gender-based violence and HIV among women with HIV, transgender women and sex workers in 3 cities in Bolivia

Women living with HIV, transgender women, and sex workers in Bolivia consistently report multiple forms of gender-based violence, but to date, these experiences have not been captured in any official report. The Bolivian Network of People Living with HIV, with technical support of Cayetano Heredia University and the financial support of UNAIDS, implemented a qualitative and quantitative study to explore the linkages between HIV and gender based violence among women living with HIV, transgender women and sex workers in La Paz, Cochabamba and Santa Cruz. The project also included an advocacy strategy targeted towards local authorities. The study accessed 340 women via survey, and 100 women via focus groups and individual interviews, who were able to speak up about their experience of gender-based violence - in most cases, for the first time. These women were able to meet with local authorities and relate their life experiences of HIV and gender based violence, and gathering the different groups of women enabled empowerment regardless of their specific gender identities or vulnerabilities. The programme generated data to help build a picture of the linkages between HIV and gender-based violence in the three targeted groups of women, as well as offering psychological support to those who had never spoken about violence before. It also helped mobilize support from local authorities and sectors that had not traditionally engaged with HIV programmes, such as churches and women's and youth associations. The project was successful in facilitating strategic alliances between different groups of women who already face stigma and discrimination, and helped create awareness of laws aimed at protecting women's rights, access to justice, and protecting against the negative impact of the stereotypically male-oriented culture in Bolivia. High levels of gender-based violence in the country remain a challenge, and next steps include a follow-up project to provide ongoing psychological support.

#### Case Study #71 Ecuador: Mapping of the encounter places of the most exposed populations (MAPLE – PEMAR)

In Ecuador, the limited scope of data regarding the HIV epidemic has made it difficult to design intervention programmes that target key populations such as men who have sex with men, transgender women and female sex workers. Past research carried out by the public health sector, NGOs, and universities has not generally included community participation, which could otherwise provide useful data regarding the relationship between these key populations and HIV. The main objective of the MAPLE – PEMAR study carried out across 11 cities was to provide strategic information to support the design and improvement of focused prevention programmes. The programme's technical committee included participation of representatives of the three targeted communities, who worked together with the scientific members to approve the protocol and the data collection tools, as well as review and discuss the results. Members of these communities participated in focus groups in order to prepare the questionnaire and map the field study. Subsequently, they created maps with 924 places located in the eleven cities studied. The maps that were generated included information such as which of the most exposed populations visit which locations, sexual practices in those places, availability of condoms, and the predisposition to carry out prevention programmes. Other characteristics identified related to schedules of attendance, days of more affluence and mobility of clients, average use of services, and services offered. Individual interviews also helped characterize users of these locations and their own access to HIV prevention services. The results were used to plan activities for peer education, and also for community-based testing. Due to the evident utility of programmatic mapping, there is a demand for transfer of the MAPLE methodology, both from governmental as from non-governmental institutions, and it is now being applied to other cities in Ecuador.

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- 31. Community financing initiatives, such as health insurance and voucher schemes and microcredit, are becoming more common as an accepted strategy where state-funded social protection schemes are unable to reach certain population groups due to limited capacity or because there are legal or policy barriers to access for certain key populations. [33] For example, in Katete district, Zambia, the Katete District Women Development Association developed an economic empowerment programme that combines information and skills on how women can reduce HIV risky behaviours and address gender-based violence in their households with business training and micro-credit to start new businesses [34].
- 32. More than four out of ten new infections among women aged 15 years and over are among young women (15–24) [30]. In eastern and southern Africa, adolescent girls in Mozambique had HIV prevalence of 7%, doubling to 15% by the time they reached 25 years of age. In Lesotho, adolescent girls had HIV prevalence of 4%, increasing to 24% among young women aged 20–24 years. Young women and adolescent girls face multiple vulnerabilities that hinder their ability to protect themselves from HIV or to access antiretroviral therapy,

such as gender-based violence, including intimate partner and sexual abuse, lack of access to education, health and social protection services [30].

33. Community-based responses to improve access to education have proven effective in the response to HIV. Education, the "social vaccine" for HIV - has long since been recognised as a key structural intervention in combating HIV [35]. Some of the most powerful structural interventions for HIV risk reduction among adolescent girls across Africa are those that aim to keep girls in school [36,37]. Education leads to increased knowledge about HIV and

#### A voucher for health: Enabling young people in Uganda to access quality SRHR services

Link Up, which seeks to improve the sexual and reproductive health and rights of young people most affected by HIV, implemented a youth voucher scheme in March 2014 to address these issues. The project was led by Marie Stopes International Uganda, the International HIV/AIDS Alliance and partners and operated in 11 Districts in Central and Eastern Uganda.

#### The voucher scheme

Based on the budget and the ethos of integrating HIV and sexual health and reproductive rights, each voucher allowed for two visits for HIV testing, three visits for family planning, and three visits for STI management. All services were provided for free.

Colourful designs with positive, inclusive messaging were tested among young people before the final voucher was produced. Marie Stopes International Uganda trained 80 clinical officers and nurses from 40 health facilities and clinics. The majority had limited experience working with young people who sell sex and young men who have sex with men. They were trained on the use of encouraging language when counselling and communicating with young people, the vulnerabilities of young people, the entry points for integrating HIV and STI management with family planning, and how to use partnerships to refer young people to additional services including for anti-retroviral treatment, gender-based violence support and the prevention of vertical transmission. Providers were then monitored for the quality of services provided to those young people accessing services using a Link Up voucher. To give out the vouchers, 70 people aged 17 to 26 were trained as community-based distributors. They received three days of training on basic knowledge of HIV and sexual health and reproductive rights, enabling them to provide health education while speaking with peers as well as distributing vouchers, condoms, and written sexual and reproductive rights materials. They were also trained on how to accompany young people to access HIV and sexual and reproductive health services. Two community-based distributors were then assigned to each BlueStar facility and were paid by their facility for every voucher redeemed. Quarterly client verification exercises and spot checks were conducted to ensure the authenticity of clients reported and services provided versus the services claimed.

Additionally, 44 young people from key population groups (those living with HIV, selling sex and teenage mothers), ages 15-24 years, were trained then stationed at each health facility. Their role was to help create a friendly environment at facilities in order to attract more young people from key population groups to take up services.

<u>Results:</u> Between March 2014 and March 2015, the Link Up voucher scheme extended sexual health and reproductive rights and HIV services to nearly 30,000 young people in Uganda. Of those receiving services, 27,002 were aged 10 to 24 while 671 were above 24. The greatest uptake of services was for HIV counselling and testing (92%), STI management (75%) and family planning (37%). Eighty percent received safer sex counselling, which promoted dual protection against STIs and unplanned pregnancies. There was a noticeable shift in family planning uptake, with 51% receiving long-term family planning services and 49% receiving short-term family planning services. A total of 18 996 Couples' Years of Protection were generated. In relation to reaching the most vulnerable young people with HIV and SRHR services, 1 438 sex workers, 4 188 slum dwellers, 225 young people living with HIV, three young transgender people, 537 fisher folk, 19 073 vulnerable youth, and 2 217 truck and boda-boda drivers accessed services.

Findings from the project's 'mystery shopper' exercise indicate that 78% of providers displayed a good attitude and 89% displayed good or very good levels of courtesy towards young people using their services. Good or very good levels of privacy were displayed by 78% or providers. [32][33] UNAIDS/PCB (38)/16.14 CRP1

broader sexual and reproductive health and rights, and leads to better health outcomes for young women and adolescent girls. Keeping girls in school to enable them to receive an education is key to helping them cope with negative gender norms and protect themselves against the risk of HIV and other sexual and reproductive health risks [36]. School feeding programmes may help children enter school and stay in school, increasing enrolment and reducing absenteeism. Recent evidence shows the positive impact of school feeding programmes on school enrolment with different modalities, such as onsite meals and receiving take-home rations, showing stronger effects for girls [38]. Mixed models of implementation, where governments work alongside communities ensure feeding programmes, provide sustainable and of high quality [39].

34. Interventions implemented at the community level to address intimate partner violence are critical to reducing women's, and in particular young women's and adolescent girls', vulnerability to HIV and to empowering them [40]. Innovative community mobilisation approaches are yielding promising evidence of effectiveness in reducing violence, and, HIV risk and positively influencing power dynamics between men and women. For example, recipients of the SASA community mobilisation intervention in Uganda (both women and men) were significantly less likely to accept intimate partner violence, and there was also greater acceptance that women could refuse sex and evidence of decreased incidence of experienced intimate partner, physical and sexual violence [41]. SASA also positively affected HIV-related risk behaviours and relationship dynamics at a community level, especially among men [42]. Another study in Uganda showed significant decreases in both intimate partner violence and HIV incidence by implementing the Safe Homes and Respect for Everyone (SHARE) community-based mobilisation strategy to change attitudes and social norms regarding violence and HIV risk [43]. WHO recently outlined 16 programming ideas to address violence against women in HIV programmes, including in national AIDS plans, programmes and policies [44]. Community empowerment and mobilisation is a key feature of many of the programmes.

# As I Am 'Zvandiri' – a community-based treatment, care and support programme for children and young people living with HIV, Zimbabwe

"Zvandiri" meaning "As I am" in Shona was founded in 2004 by six young adolescents living with HIV. Zvandiri is a youthinitiated community-based HIV treatment, care and support programme for children, adolescents and young people aged 5-24 years. It aims to equip children and young people living with HIV with the knowledge, skills and confidence to cope with their HIV status and to live happy, healthy, fulfilled lives. Services include integrated adolescent-sensitive clinical, psychosocial support and protection services that address their complex, evolving physical, social, developmental, mental and sexual reproductive health needs.

A community-based multidisciplinary team works directly with children, young people and their families through a combination of community support groups, community outreach services including training and skills development, and through child and adolescent-focused Zvandiri Centres. Peer counsellors known as 'Community Adolescent Treatment Supporters' (CATS) work in teams to directly influence children and young people's experience of HIV testing and counselling, diagnosis and linkage to care, disclosure, treatment access, adherence and retention in HIV care. CATS work in their own communities to promote health and psychosocial outcomes among their peers. They are 17-23 year-old adolescents and young people living with HIV who are trained and mentored as peer counsellors by Zvandiri in partnership with the Ministry of Health and Child Care. Integral to this is intensive ongoing support for adolescent and young people's psychosocial well-being and mental health, wider sexual and reproductive health, economic empowerment and linkage to education and child protection services.

In 2014 alone, 5 009 children and young people living with HIV were reached with direct services and 2 730 children accessed Zvandiri Centres. A study of Zvandiri published in 2015 showed statistically significant improvements in adherence from 44.2% at baseline to 71.8% at endline for 10-15 year olds who received CATS services and a monthly Zvandiri support group. Data also showed a statistically significant increase in confidence, self-esteem, self-worth and quality of life and a decline in stigma. At the beginning of 2016, Zvandiri is being integrated in 36 districts of Zimbabwe and there are 240 CATS across the country [40]

35. The meaningful participation and leadership of women, particularly those most affected by HIV, is an essential component of an effective response to HIV. Equally ensuring that women living with and affected by HIV are meaningfully involved in the decision making regarding policies and programmes and in the defining and implementing of solutions at the community, national and global level are crucial to empower women as agents of change rather than just recipients of services. However, this has yet to be mainstreamed as a cross-cutting strategy. Barriers to active and full participation of women living with and affected by HIV include gender norms, gender inequalities, stigma and discrimination, lack of access to resources, the burden of care and multiple responsibilities in the home, lack of access to information, lack of gender-sensitive services, especially for women key populations such as injecting drug users, lack of gender disaggregated data, lack of formal education and training, poor self-esteem, and gender-based violence [45].

#### Case Study #85 Global: ATHENA Network Young Women's Leadership Initiative (YWLI)

While it is widely known that young women are disproportionately affected by HIV, their needs have been historically underrecognized, and their voices under-represented, as research agendas, policies, and programmes are being developed. In response to this, ATHENA developed an evolving leadership strategy for young women living with HIV in all of their diversity. Launched in partnership with the Global Coalition on Women and AIDS and UNAIDS at the International AIDS Society's 2011 Conference on HIV Pathogenesis, Treatment and Prevention, ATHENA's YWLI is a leadership, advocacy and mentoring programme that aims to: increase the visibility of young women living with HIV, supporting them to claim spaces within key policy fora; define priority issues affecting young women living with HIV, and also showcase leadership and community-driven solutions; and increase their knowledge, skills and advocacy experience, particularly with regard to achieving sexual and reproductive rights in the context of HIV. To-date, 75 young women living with, and most affected by, HIV, from all regions of the world, are 'graduates' of, and peer mentors within ATHENA's YWLI. The programme has developed spaces and strategies facilitating meaningful engagement in the HIV response, by providing girls and young women opportunities and support. Past participants have emerged as powerful leaders in their own right, prominently addressing high-level international meetings, and contributing towards country coordination. They are also engaging in critical international dialogues, as well as leading participatory research and advocacy in their own countries and communities, whilst also mentoring other young women to become spokespersons, advocates and leaders for human rights and gender equality. To help build the success of the programme, ATHENA has served as an on-going platform and resource for young women to be integrated within a broader community of practice, so that the knowledge sharing, mentorship, and inter-generational exchange is ongoing and not limited to one workshop or one political moment.

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36. It is clear from the Fast-Track strategy that ending the AIDS epidemic will not be possible without greatly increased efforts to reduce new infections, prevent AIDS-related deaths and eliminate HIV-related discrimination. Community members can be highly effective in understanding the needs of their specific populations and providing services to their peers. Key populations – people living with HIV, gay men and other men who have sex with men, sex workers, people who inject drugs and transgender people – are disproportionately vulnerable to HIV in all parts of the world. HIV prevalence is 28 times higher among people who inject drugs [30], 19 times higher among men who have sex with men and 13.5 times higher among female sex workers (compared to women of reproductive age) than the general population [46,47]. A systematic review including studies from 15 countries shows that 19% of transgender women are living with HIV [48]. Although the epidemic's burden on key population is growing, typically HIV prevention and treatment efforts neglect or under-prioritize key populations [49]. Coverage and reach of interventions for key populations as well as children and adolescents remain alarmingly low; stigma and discrimination, including

gender-based violence, remain high and access to services is extremely low due to structural, social and cultural factors [50].

37. Effective communityresponses typically involve members of the community they serve women and girls, people living with HIV, gay men and other men who have sex with men. sex workers, people who inject drugs and transgender people – in all aspects of programmes. It is also understood that without active engagement and involvement of community members in the design, research, implementation, monitoring and evaluation of policies and programmes that affect their lives, HIV prevention, treatment, care and support programmes and policies will not be optimally effective [51]. Barriers to effective empowerment and

#### Tangerine Community Heath Centre, Thailand

The Tangerine Community Health Centre, located within the Thai Red Cross AIDS Research Centre (TRCARC) aims to provide a comprehensive, non-judgmental clinical services for transgender people. The model was designed together with transgender people from diverse communities and backgrounds, including sex worker, health, HIV, private sector, entertainment, human rights and young transgender people. Along with the model of care itself, the name and slogan for the Centre were co-developed: Tangerine: 'Where transition fulfills identities'. The Centre is co-funded by the United States Agency for International Development and TRCARC.

Tangerine is managed and run by trained transgender personnel and gender-sensitive medical professionals. It offers comprehensive and holistic services that aretailored to respond to the unique needs of transgender people. Transgender-specific endocrinology and metabolic services, including gender-affirming hormone therapy, testing of hormone, lipid, liver and kidney profiles have been used as an entry point. These services are not generally provided and not subsidized by government-run health facilities. Tangerine has also integrated HIV and STI testing and counseling, along with cancer screening services for the anus, neovagina and cervix, using pap smears and detailed examination of these areas by a high-resolution magnifying instrument. In addition, Tangerine provides pre-exposure prophylaxis (PEP) and post-exposure prophylaxis (PEP) as additional HIV prevention choices and harm reduction interventions for safe injection to reduce the risk of infection from HIV and viral hepatitis B and C. Data collection forms and the database system used to collect information have been revised to ensure gender identity is appropriately and sensitively recorded and all data feeds into the national health management information system.

As the clinic has only been operating since November 2015, it is too early to assess its long-term impact. However, Tangerine aims to have 600 transgender clients in year one and 1000 transgender clients by year two. Early indications show strong uptake. In the first two months of operations, the clinic has welcomed 32 male-to-female clients and 17 female-to-male clients who have availed of a number of services including HIV testing, syphilis testing, pap smear, hormone therapy and PEP [40]

engagement need careful attention including ensuring gender responsive and enabling legal and policy environments. [40]

38. Community responses cannot and should not become a substitute for a national response. Evidence has shown that communities are extremely effective in delivering specific results as part of evidence-informed national implementation plans. Importantly, the impact of community responses is particularly strong in increasing uptake of services provided by other actors [13]. In this regard, civil society complements government efforts by promoting available services among communities. Integrated community responses must ensure that the capacity and skills of community organizations are built to ensure quality. Evidence-informed policy and programming may support the meaningful and effective integration of community responses by: 1) ensuring targeted services match the needs of the community, 2) better aligning community-based activities with the HIV epidemic, and 3) strengthening the linkages and complementarity between community responses and national programmes, such as for HIV prevention [13].

Case Study #42 India: Pehchan – a community systems strengthening programme for men who have sex with men, transgender and hijra communities to increase reach, scope and quality of HIV prevention and other services responsive to their needs

India has a concentrated epidemic of HIV, where HIV prevalence is highest among key populations, including men who have sex with men, transgender, and Hijra. Social taboo and punitive laws criminalising homosexuality have further made it difficult for members of these communities to access of services, thereby increasing their vulnerability, and their risk of exploitation, threats, extortion and violence. Pehchan was set up to strengthen community systems, in order to match the needs of these marginalised communities. Named after the Hindi word meaning 'identity', 'recognition', or 'acknowledgement', Pehchan has strengthened and built the capacity of 201 CBOs to provide effective, inclusive and sustainable HIV prevention programming to clients within these populations in 18 states across India. To-date, Pehchan has registered and served more than 435 000 clients from the communities of men who have sex with men, providing nearly 340 000 with HIV prevention services for the first time. Fourteen exclusive transgender and hijra CBOs were established and strengthened, and a total of 169 MTH community members and leaders were trained as master trainers, among whom 80 were transgender women or hijras. More than 228 000 of these communities were tested for HIV with nearly 2% testing HIV positivite, and over 95% of these were linked to care and treatment services. As a result of Pehchan, clients were able to avail themselves of previously difficult-to-access services including STI treatment, community-friendly HIV counselling and linkages to testing, as well as counselling on partner violence, family support, disclosure, sex reassignment, pyscho-social support, legal aid, and general health concerns. Pehchan also raised the issue of gender violence as a barrier to accessing services, and subsequent data reflected increased reporting of violence and a decrease in these incidents against MTH. Pehchan also worked with the National AIDS Control Organisation to map transgender people in all 18 programme states, as well as providing support in consultations to advocate against Section 377, India's anti-homosexuality law, and for protecting the rights of the Third Gender. Throughout this, community organisations proved to be the best vehicles not only for advocacy but also for service provision to their communities, and Pehchan's success was largely based on community involvement and leadership among men who have sex with men, transgender and hijra communities at all levels of implementation, including in national and state-level programme leadership and management.

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39. Unstable political situations alongside outbreaks of diseases such as Ebola in regions already heavily affected by recurrent humanitarian emergencies (natural disasters and conflicts) deeply affect and threaten the response to HIV and further exacerbate inequalities [7]. In 2013, it was estimated that 1.6 million of the 314 million people affected by humanitarian emergencies, were living with HIV, accounting for 1 of every 22 people living with HIV globally. Humanitarian emergencies cause disruption of services, including HIV-related services; increased food insecurity; destruction of livelihoods; and higher levels of extreme poverty. Women and girls are often targets of gender-based violence in the context

of emergencies [52]. UNAIDS has stated that focused and accelerated efforts are especially needed in 35 Fast-Track countries that together account for more than 90% of people acquiring HIV infection. Of these 35, nineteen (more than half) are considered among the top 50 most fragile states globally.

## Case Study#30 Sierra Leone: Making patients happy and healthy: Caring for people living with HIV during the Ebola outbreak in Sierra Leone

The outbreak of Ebola virus disease in Sierra Leone in 2014 severely disrupted general health services and reduced access to care. The epidemic rapidly spread to all districts in the country, with varying levels of intensity. A rapid assessment of health facilities conducted by the Ministry of Health and Sanitation with support from UNICEF found a significant decline in the uptake of maternal and child health services in October 2014, with a 23% decline in the number of visits for prevention of mother-tochild HIV transmission, a 50% decline in HIV testing and a 21% increase in patients lost to follow-up most likely as a consequence of the Ebola outbreak. HAPPY (HIV Prevention Project for Youth) is a national non-governmental organization supported by UNICEF, aiming to mitigate the impact of HIV on the lives of children and adolescents infected and affected by HIV through ensuring access to quality care, treatment and support. During the Ebola outbreak HAPPY recognized the need to proactively reach out to people living with HIV who were not able to access health services and had thus defaulted from their treatment. A programme was created to trace people living with HIV, with the aim of re-engaging the 1 444 pregnant and lactating women and 541 HIV-exposed and-infected children in the districts where HAPPY operated, including districts that were most affected by Ebola at the start of the outbreak. By the end of the project, 60% of children and 84% of pregnant women who were lost to follow-up were re-initiated on treatment. Improvements in access and retention were achieved by triangulating the existing facility data with the information obtained from outreach to patients lost to follow-up. As a result of this experience, the national programme increased its focus on retention monitoring. Peer outreach and proactive follow-up were adopted by the National AIDS Control Programme to address persistent challenges retaining people living with HIV in care. Likewise, building on existing mechanisms such as support groups and a trained pool of counsellors accelerated the pace of implementation. This model was replicated and adapted in the five districts with the highest HIV burden under the leadership of the National AIDS Secretariat, with support from UNICEF, UNFPA, UNAIDS and the World Food Programme.

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40. Preparedness and risk management needs to be integrated into development programming whereby HIV programmes are risk-informed, and continued and reliable HIV prevention, care and treatment services are available, including for tuberculosis, STIs, opportunistic infections, malnutrition and violence prevention and care. Communities are the first line of defence in both preparedness and response, possessing needed knowledge and skills and the ability to identify the needs of those affected and the capacity to quickly mobilise support. A key lesson from the West African Ebola epidemic is that local community engagement is crucial for response, and may have played a role in the decline in transmission rates [53,54]. Although the diseases or crises may be different, the communities at the forefront are often the same. Community organisations providing HIV services and advocacy are already operational when humanitarian crises emerge and need to be considered as a vital part of a national, coordinated response, led by government. Recognising the importance of community responses, community engagement has been identified as a cross-cutting priority in WHO's Emergency Reform Agenda [55].

## **III. FINANCING, CAPACITY AND POLITICAL SUPPORT**

- 41. Recognising that community activism is crucial, it follows that investment in communitybased advocacy should be commensurate with the part it plays in improving health outcomes [5]. To meet the Fast Track targets, UNAIDS estimates that US\$ 26 billion will be needed per year by 2020 to address the epidemic in low- and middle-income countries with resource needs declining modestly beginning in 2021. UNAIDS estimates that a threefold increase in investments in community mobilisation is needed between by 2020 and an additional increase needed from 2020 to 2030. [5]. Increasing reliance on community-based service delivery models will be essential to Fast-Track. Investments are needed for both community-based advocacy and service delivery programmes.
- 42. Investment in civil society advocacy and community mobilization programmes in general will support uptake of services. AIDS-related advocacy has been called "a global public good" by the UNAIDS-Lancet Commission to End the AIDS Epidemic. Investment in community mobilization at country level should increase to 3% of global HIV resources by 2020 to help civil society represent the interests of all fragile communities, drive ambition, financing and equity in the AIDS response. The actual need in investments for regional and global advocacy is not known. The Robert Carr civil society Networks Fund has proven to be a strong mechanism to mobilize resources from different donors that can be accessed through a competitive process by advocacy organizations that have impact through global and regional action [56]. Overall investment in social enablers -- including advocacy, political mobilization, law and policy reform, human rights, public communication and stigma reduction -- should reach 6% of all global AIDS resources [8].
- 43. Investment in community-led service delivery is critical. The evidence shows that community-based services can reach populations left behind, attain wide scale and demonstrate impact. By 2020, about 12% of antiretroviral therapy services should be delivered through community-based services representing about 3.8% of the total global investment in responding to HIV. Outreach to key populations in low- and middle-income countries should account for about 7.2% of global investments by 2020 [8].
- 44. Although community responses have been recognised as a cornerstone of an effective HIV response, this has not translated into the systematic inclusion in systems for health or AIDS programme planning and financing. While global and private funders have provided the majority of funding for community responses to HIV until now, the growing trend towards increased country ownership and the recognition of the need to reach all populations, including those most vulnerable, makes it more important than ever to find ways to increase domestic funding for community responses. Shifting from stand-alone community responses that are mainly funded through international resources to community responses that are fully integrated into national plans, including budgeting, will require strong political leadership. It will require leadership in bringing in civil society actors as partners, and it will require political leadership in making systemic changes that will allow resources and information between community and state systems to work together. While this transition is underway, it will be important to ensure continued financial support from global and private funders so as not to negatively affect current responses to HIV.

45. Though the Fast-Track approach calls for increases in investment in communities, many community-based organizations are experiencing cuts in funding. Late last year, UNAIDS used an electronic survey to ask community organizations working at the local, national, regional and global levels about their financing. Over 480 organizations responded: 68% said that their budgets had decreased or remained the same since 2013, and 42% reported a budget decrease over this time. Smaller organizations suffered the most from funding cuts. Only organizations with annual budgets of over \$2 million saw an increase in funding since 2013. Funding decreased or was flat in every activity category, with those organizations focused on advocacy hit the hardest.

#### Case Study #41 China: China AIDS Fund for NGOs – CAFNGO

In China, NGOs have played an important role in HIV prevention and control. Under the support of governments and international cooperation projects, the number of NGOs participating in HIV prevention and treatment has significantly increased, although NGOs now face a shortage of funding with the end access to assistance from the Global Fund and other international cooperation projects. In response, the China AIDS Fund for NGOs was established jointly by the National Health and Family Planning Commission, the Ministry of Finance and the Ministry of Civil Affairs as a national public welfare special fund in June 2015. CAFNGO aims to support NGOs to undertake education and communication activities, prevention interventions, testing and counselling among high risk groups, as well as care and support for people living with HIV in accordance with national and local HIV response plans and policies. More than 750 projects from 467 NGOs, covering 30 provinces in China, were funded by the CAFNGO during 2015, representing a total amount of funding of 45.21 million CNY (~US\$6.92 million). Applications for funding are reviewed by the Fund Management Committee Office and subjected to expert evaluation. The CAFNGO has played a positive role in promoting NGOs' participation on AIDS prevention and control work, as well as aiding their growth and development. CAFNGO has facilitated implementation of government policy of purchasing social services, as well as promoted multi-cooperation, especially among NGOs, hospitals, and centres for disease control. Additionally, CAFNGO's work helped reveal gaps in provision, identifying the need for improvements in NGOs' capacity to participate in HIV prevention and control.

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46. To achieve the SDG target to end AIDS by 2030, emphasis needs to be placed on sustainable programmes with smooth transitioning to domestic funding of essential HIV services and continued, significant external support for numerous countries. Communities are a key part of these services [19] and must be an equal partner in the response to HIV. While domestic funding is increasing in many countries, there still remains an imbalance. For instance, in countries such as Thailand, while about 90% of resources financing national HIV and TB responses come from domestic sources, the proportion of external funding of HIV prevention programmes remains high, jeopardizing the sustainability of prevention efforts[57]. As Thailand became an upper-middle income country in 2011, the Global Fund support is set to finish in 2017, and it will be imperative to ensure a sustainable transition that includes adequate domestic resources for prevention, particularly for key populations.

#### Case Study #63 Bolivia: Political incidence plan for the allocation of resources for the HIV/AIDS Response in Bolivia

Bolivia has HIV prevalence of 0.05% with 14 312 cases (1984 - June2015). In 2010, Bolivia was declared a middle income country, and as a consequence the level of international assistance fell. Currently, 70% of all HIV care and prevention services in Bolivia are paid by the Global Fund. With the goal of achieving the sustainability of the AIDS response, the Bolivian Network of People Living with HIV/AIDS developed a plan for the allocation of resources for the HIV response in Bolivia, aiming to insert budget lines for HIV in five municipalities, departments or in the national government for HIV, independent of international cooperation. The project was implemented in nine departments of Bolivia and the cities of El Alto and Llallagua, and included advocacy for resources oriented for HIV care and prevention. The strategy included the revision of local laws (HIV, autonomies and the Constitution) that guarantee the right to health, and incorporated social mobilization with mass media. Ultimately, the project was instrumental in increasing resources allocated for HIV, which started at the amount of 1 million BOB (~US\$14,6,628) in 2012, rising to 8 million BOB (~US\$1,173,020) in 2015 at the end of the programme. Additionally, the project also helped clairify information on budgets available for HIV both from national sources and international aid. It also contributed to budget allocation for HIV in the municipalities of El Alto, Cochabamba, Santa Cruz, Sucre, Tarija, and development of local and project laws. The project was also successful in fostering community mobilization among people living with HIV and lesbian, gay, bisexual and transgender communities with the aim of sustainability, as well as building visibility of people living with HIV as actors in political incidence.

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- 47. Increasingly governments are recognizing the benefit of partnering with non-state actors to deliver essential HIV services. Even when political will is there, ensuring mechanisms for funding to reach community organisations is often a practical barrier. In order for communities to work alongside governments to provide much needed services as part of the health system, established "social contracting" systems are required. As with all public funding, social contracting requires oversight that ensures fair competition, transparency and accountability along with measurement of service quality [58]. In Ukraine the practice of financing of NGOs from local budgets through social procurement contracts has been in place for more than ten years. For example, Light of Hope, a local civil society organisation, has succeeded in having local policies and regulations amended to allow them to receive local funding to work with people who use drugs and ex-prisoners. The organization receives more than US\$120 000 annually to support activities such as harm reduction, early tuberculosis, case management of HIV within a social hostel (shelter). The funds are used for social workers' salaries, maintenance and utilities, food for clients, and also to create temporary jobs for vulnerable groups (OSI email communication, 2016).
- 48. A series of factsheets from 10 countries across Eastern Europe highlight some of the common challenges inherent with social contracting and make concrete recommendations for overcoming them [59]. These recommendations outline the importance of strong legal and policy frameworks, strengthening capacity and ensuring good practice, and more specifically suggest:
  - a. The simplification and affordability of NGO registration procedures and the explicit recognition of NGOs as partners and service providers in laws and policies and legal frameworks that enable social contracting at both national and sub-national levels.
  - b. The need to strengthen capacity of NGOs to access public funding, and of State bodies in social contracting at national and sub-national levels.
  - c. The importance of good practice in tendering processes and budgetary process aligned with legislation and policies to ensure allocations for social contracting.

- d. Ensuring social contracting opportunities are made publically available and easily accessible to NGOs.
- 49. The evidence-based Handbook of Non-State Social Service Delivery Models, produced by UNDP, is a useful example for policy makers and practitioners that outlines recommendations, challenges and opportunities of social contracting [58].
- 50. Community-based services are generating data that feeds into the health management information systems at a country level [40]. Granular data drive a location-population approach that is particularly effective in understanding the changing nature of HIV. It is vital that communities are involved as partners in the design of information systems that include gender and age-disaggregated data to ensure the capturing of data on experiences and the needs of service recipients as well as actual numbers and costs. In addition, community-based research, essential for informing policy-makers and programmers about the needs and impact of policies and programmes, needs to be fully valued and financially supported.

#### Case Study #79 Portugal: Checkpoint LX

There are an estimated 20 000-25 000 people living with HIV in Portugal who remain undiagnosed, and there is a concentrated epidemic among men who have sex with men , with cross-sectional studies indicating a prevalence among this population of 10-17%. In high-prevalence settings such as Lisbon, men frequently enter care late or delay linkage to prevention, care and support. WHO has recommended that countries with concentrated HIV epidemics should prioritize and focus on tailored community-based HIV testing approaches for those who remain undiagnosed and are at greatest ongoing risk for HIV infection. In 2011, GAT opened the first community-based HIV testing site in Portugal tailored to men who have sex with men: CheckpointLX. The centre offers anonymous, confidential and free screening of HIV and other STIs), sexual counselling and referral to health care, delivered by a team made up exclusively of men who have sex with men, supported by scientific medical supervision. Between April 2011 and December 2015, 10 002 HIV tests were performed. The centre has had a transformative impact on HIV testing and surveillance nationwide - according to official data, per civil year, on national level, CheckpointLX found 8.71% (2011), 15.27% (2012), 19.95% (2013) and 26.29% (2014) of all new HIV infections among men who have sex with men. Linkage to care was 79.49% (2011), 73.97% (2012), 78.05% (2013), 83.33% (2014) and 74.78% (2015). CheckpointLX has made a significant contribution to early diagnosis and linkage to care for men who have sex with men at both local and national levels, has been recognized by the European Centre for Disease Prevention and Control as a new and innovative service, and was selected by WHO as an example of good practice reflecting the new HIV testing service recommendations.

## Case Study #81 Eastern Europe and Central Asia: Eastern Europe Regional programme, entitled "Harm Reduction Works – Fund it!"

For over a decade, the Eastern Europe and Central Asia region has been home to the world's fastest growing HIV epidemic. With US\$679.5 million designated for HIV and TB programming in the region in 2014-2016, the Global Fund is at the front lines of support for harm reduction in many Eastern Europe and Central Asian countries. However, while such investments have ensured that needle/syringe programme and opioid substitution therapy have gained a foothold in the region, national governments in the region supply less than 15% of harm reduction potentially imperilling the long term sustainability or these essential programs. For the purposes of regional advocacy, the Eurasian Harm Reduction Network (EHRN) developed methodologies to: assess the total costs and unit costs of needle and syringe programs and OST programs in a country for two financial years; study the opinions of program clients about accessibility of and demand for services; identify harm reduction funding gaps to develop arguments for advocacy; and demonstrate the efficiency of investments in harm reduction. The assessment was conducted in six sentinel countries of the Regional Program: Belarus, Georgia, Kazakhstan, Lithuania, Moldova and Tajikistan. This community-led assessment of service quality and priorities had dual aims of building the capacity of communities of people who inject drugs, and formally documenting service quality issues that require attention through further investment and greater political will. The assessment generated evidence that could be applied at several levels, for example contributing to the state public health programme for 2016-2020 in Kazakhstan to help cater to the needs of people who use drugs, and helping create an evidence-based budget for harm reduction in Moldova.

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- 51. There is a need for continued and improved monitoring and evaluation of community engagement and service delivery models as well as costing of these models to make the case for inclusion in national strategies, plans and budgets. Presently work in this area is too often weak and ad hoc, which can lead to inefficiencies and gaps in evidence of what works, and how and why these effective approaches work. More evidence is required to support meaningful scale up of the most effective models. This necessitates more evaluation and also the inclusion of indicators that monitor community-based activities in routine information management systems, which is only happening in a very limited way at present.
- 52. The genuine involvement and active participation of civil society in national and global governance mechanisms has been widely acknowledged and has improved enormously over the years. However, civil society needs resources, information, capacity and understanding of governance and funding mechanisms to ensure ongoing engagement and influence is possible. At a country level for example, Global Fund Country Coordinating Mechanisms (CCMs) are the most important country-level decision-making bodies related to sizeable Global Fund grants. Under the Global Fund's New Funding Model, ensuring civil society participation and influence is a key priority [11]. UNAIDS inclusive governance is unique within the United Nations System and the only governing body to have communities as full members of the board. The UNAIDS Programme Coordinating Board (PCB) has representatives of 22 Member States from all geographic regions, 5 representatives of nongovernmental organisations, including people living with HIV and the UNAIDS Cosponsors. The NGO Delegation to the UNAIDS Programme Coordinating Board, with members from each region, actively participates, advocates and strengthens accountability to communities through its role on the Board. UNAIDS supports the effective and transparent functioning of the PCB NGO Delegation through a Communications and Consultation Facility which supports outreach to broader civil society, facilitates selection of new Delegates, supports preparation and participation of the NGO members to the PCB, including regional and thematic consultations with constituencies and with PCB member states, and preparation of the annual PCB NGO reports. The community members on the NGO delegation also participate in the PCB Bureau, the inter-sessional decision making mechanism of the board as well as in all PCB working groups. The outreach to broader civil society is ensured through the independent PCB NGO delegation website. With explicit reference to the inclusive governance of the Joint Programme, ECOSOC in 2015 stressed the value of the lessons learned from the global AIDS response for the post-2015 development agenda, including those learned from the unique approach of the Joint Programme, and also reaffirmed that the Joint Programme offers the United Nations system a useful example, to be considered, as appropriate, of enhanced strategic coherence, coordination, results-based focus, inclusive governance and country-level impact based on national contexts and priorities. The Global Fund has a Community, Rights and Gender Technical Assistance Program that specifically supports civil society and community organisations to meaningfully engage in the funding model during the country dialogue and concept note development stages. The Global Fund also has in place a Gender Equality Strategy [60] and the Sexual Orientation and Gender Identities (SOGI) Strategy [61] to support applicants. Technical support includes situational analysis and planning, engagement in the country dialogue (increasing knowing, writing and participation skills) and programme design and is available to national civil society organisations and other non-governmental organisations [62]. Civil society involvement in the PEPFAR Country Operational Plan has been identified as crucial to ensure better understanding of geographic priorities, service delivery issues, and where bottlenecks might be in achieving program goals [63]. There have been expanding opportunities for civil society engagement in PEPFAR planning in recent years. There is a

need to establish strong accountability mechanisms for the meaningful involvement of civil society and key affected populations in all levels of governance mechanisms.

#### Case Study #87 Global: Robert Carr civil society Networks Fund

The Robert Carr civil society Networks Fund (RCNF) was created to respond to specific trends in the landscape for civil society action on HIV. These included inadequate funding for HIV; a shift in donor funding towards the country level; and a push towards greater coordination among civil society players. These trends occurred against the backdrop of persistent marginalization and human rights abuses against inadequately served populations, known to be central to 'know your epidemic' responses. There exist a number of processes and funding channels to support civil society action at the country level. However, making optimal use of these – and securing the resources, services and political environment that ISPs need – requires the expertise and action that only regional and global networks can mobilise and provide. The RCNF is the first international fund that specifically aims to strengthen global and regional networks across the world, providing them with both programmatic and core funding, in line with four major objectives: 1. To improve global and regional network capacity; 2. To enhance HIV response implementation; 3. To support human rights advocacy; and 4. To increase resource accountability for the HIV response. The RCNF has so far allocated of 38 grants worth US\$18,217,092 to provide a lifeline to some of the most important global and regional civil society actors in the response to HIV. The overall conclusions of a Mid-term review, conducted in 2014, were that the RCNF has identified a unique and strategic niche within the global architecture; has developed effective grant-management policies and processes; and has established appropriate and highly committed governance bodies. RCNF grantees are achieving impressive outputs across the RCNF's four outcomes – with strong indications that, in combination, they are ensuring stronger support to ISPs and more effective responses to HIV at the country, regional and global levels.

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## IV. AREAS FOR ACTION AND THE WAY FORWARD

Community-based advocacy, participation in accountability and service delivery are all crucial to Fast-Track the response to AIDS. It is time for a paradigm shift in how governments and development partners consider the role and financing of community responses as part of creating and sustaining comprehensive systems for health. Based on the analysis presented above, a number of priority areas for action emerge.

### Acknowledgement and inclusion

- 53. To reach the ambitious Fast-Track and Sustainable Development Goal of ending AIDS as a public health threat by 2030, the meaningful inclusion of civil society in support of community-based responses, including those led by key populations, must be <u>recognised</u> <u>and widely acknowledged as essential</u> and integrated into national and global AIDS responses.
- 54. Recognising community engagement and activism as a global public good, people living with HIV and other key populations, young people and women should be <u>included in at all</u> <u>levels of national planning</u> to ensure full involvement, quality participation and influence in the design, implementation and evaluation of policies and programmes.

### Planning and financing

55. Community-based health services and AIDS service organizations should be systematically

and strategically <u>included as part of comprehensive systems for health planning</u>, with appropriate increases in financing for community services, including through domestic funding and through external funding from agencies such as the Global Fund and PEPFAR. This includes investment in community health workers as part of the larger investment in the health workforce. Overall investment in social enablers, such as advocacy, human rights and stigma reduction, must also be financed appropriately so a complete community-based response is attainable.

- 56. Funding modalities and mechanisms that enable government support to community-based service providers as equal partners and that ensure appropriate and equitable gender-responsive programming are needed. In addition, solutions to regulatory and legal barriers preventing this contracting ("social contracting") should be urgently sought, implemented, shared and evaluated.
- 57. Strategies to increase <u>investment in community-led advocacy</u>, empowerment and government accountability should be sought and implemented. Private funders and development partners have a critical role in financing community-based financing and accountability work.

### Evidence, data and knowledge transfer

- 58. While evidence demonstrates the positive impact of community responses, efforts to continue generating an even stronger <u>evidence base</u> for effective community engagement and the cost and health benefits of community engagement should be intensified to ensure continued commitment.
- 59. HIV <u>data systems</u> should be developed with communities, integrated into existing broader systems for health, and should aim to capture the community response, and document successful approaches with the aim to scale-up and inclusion in national health plans.
- 60. Further analysis should be conducted of the <u>barriers to effective funding of community-led</u> responses by global and private funders as well as <u>better understanding of the challenges</u> faced by national governments in increasing funding to community led responses. This analysis should inform decisions regarding transitions to greater domestic resourcing of community responses and also serve to protect against an inadvertent reduction of urgently needed services.
- 61. Identifying and creating opportunities to <u>transfer and use the knowledge</u> and experience of community engagement beyond HIV should be encouraged. This knowledge transfer will help address emerging health challenges and progress on the SDGs. Knowledge sharing could help benefit action on non-communicable diseases, equitable universal health coverage, reducing inequality, and, more broadly, pursuing inclusive and participatory development, which will in turn impact the progress for ending AIDS by 2030 directly or indirectly.

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### **Reference list**

- 1. UNAIDS. 2006 Report on the Global AIDS Epidemic: A UNAIDS Special Edition [Internet]. Geneva, Switzerland: UNAIDS; 2006. Available: http://data.unaids.org/pub/report/2006/2006\_gr\_en.pdf
- 2. UNAIDS, Stop AIDS Alliance. Communities Deliver: The Critical Role of Communities in Reaching Global Targets to End the AIDS Epidemic. Geneva, Switzerland: UNAIDS; 2015.
- UNAIDS. Policy Brief: The Greater Involvement of People Living With HIV (GIPA) [Internet]. Geneva, Switzerland: UNAIDS; 2007. Available: http://data.unaids.org/pub/briefingnote/2007/jc1299\_policy\_brief\_gipa.pdf
- Declaration of Alma Ata, International Conference on Primary Health Care, Alma Ata, USSR, 6-12 September 1978 [Internet]. Alma Ata, USSR: World Health Organization; 1978. Available: http://www.who.int/publications/almaata\_declaration\_en.pdf
- 5. Piot P, Abdool Karim SS, Hecht R, Legido-Quigley H, Buse K, Stover J, et al. Defeating AIDS advancing global health. The Lancet. 2015;386: 171–218. doi:10.1016/S0140-6736(15)60658-4
- UNAIDS. On the Fast-Track to End AIDS: UNAIDS 2016-2021 Strategy [Internet]. Geneva, Switzerland: UNAIDS; 2015. Available: http://www.unaids.org/sites/default/files/media\_asset/20151027\_UNAIDS\_PCB37\_15\_18\_EN\_rev 1.pdf
- 7. UNAIDS. (In press) Funding for Community-Based HIV Responses: Tracking Resources to Measure Progress. Geneva, Switzerland: UNAIDS; 2016.
- UNAIDS. Fast-Track Update on Investments Needed in the AIDS Response [Internet]. Geneva, Switzerland: UNAIDS; 2016. Available: http://www.unaids.org/sites/default/files/media\_asset/UNAIDS\_Reference\_FastTrack\_Update\_on \_investments\_en.pdf
- UNAIDS. Stronger Together: From Health and Community Systems to Systems for Health (2016) [Internet]. Geneva, Switzerland: UNAIDS; 2016. Available: http://www.unaids.org/sites/default/files/media\_asset/JC2788\_stronger\_together\_en.pdf
- Global Fund to Fight AIDS, Tuberculosis and Malaria. Community Systems Strengthening Framework [Internet]. Geneva, Switzerland: Global Fund to Fight AIDS, Tuberculosis and Malaria; 2014. Available: http://www.theglobalfund.org/documents/core/framework/Core\_CSS\_Framework\_en/
- ICASO. Effective CCMs and the Meaningful Involvement of Civil Society and Key Affected Populations [Internet]. Toronto, Canada: ICASO; 2013. Available: http://www.icaso.org/files/effective-ccms-and-the-meaningful-involvement-of-civil-society-andkey-affected-populations
- 12. UNAIDS Guidance for partnerships with civil society, including people living with HIV and key populations [Internet]. Geneva, Switzerland: UNAIDS; 2011. Available:

http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/unaidspubl ication/2012/JC2236\_guidance\_partnership\_civilsociety\_en.pdf

- Rodriguez-García R, Wilson D, York N, Low C, N'Jie N, Bonnel R. Evaluation of the community response to HIV and AIDS: learning from a portfolio approach. AIDS Care. 2013;25 Suppl 1: S7–19. doi:10.1080/09540121.2013.764395
- Rodriguez-Garcia R, Bonnel R, Wilson D, N'Jie N. Investing in Communities Achieves Results: Findings from an Evaluation of Community Responses to HIV and AIDS [Internet]. Washington DC, USA: International Bank for Reconstruction and Development / The World Bank; 2013. Available: https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/213936/Investin g-communities-achieve-results.pdf
- 15. Arcand J-L, Wagner N, Diallo PA, Sakho C. HIV or AIDS sensitization and peer-mentoring: evidence from a randomized experiment in Senegal [Internet]. The World Bank; 2013 Aug pp. 1–2. Report No.: 81364. Available: http://documents.worldbank.org/curated/en/2013/08/18310904/hiv-or-aids-sensitization-peer-mentoring-evidence-randomized-experiment-senegal
- 16. WHO, ExpandNet. Beginning with the end in mind: Planning pilot projects and other programmatic research for successful scaling up. Geneva, Switzerland: World Health Organization; 2011.
- WHO. March 2014 supplement to the 2013 consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection [Internet]. Geneva, Switzerland: World Health Organization; 2014. Available: http://www.who.int/iris/bitstream/10665/104264/1/9789241506830 eng.pdf?ua=1
- World Health Organization. Consolidated guidelines on HIV testing services. Geneva, Switzerland;
  2015 Jul.
- 19. WHO. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: what's new [Internet]. Geneva, Switzerland: World Health Organization; 2015. Available: http://apps.who.int/iris/bitstream/10665/198064/1/9789241509893\_eng.pdf?ua=1
- 20. WHO. Presidents Hollande and Zuma chair the first meeting of the High-Level Commission on Health Employment and Economic Growth. In: WHO [Internet]. [cited 27 Apr 2016]. Available: http://www.who.int/hrh/com-heeg/com-heeg-meeting-chair/en/
- Olivier J, Tsimpo C, Gemignani R, Shojo M, Coulombe H, Dimmock F, et al. Understanding the roles of faith-based health-care providers in Africa: review of the evidence with a focus on magnitude, reach, cost, and satisfaction. The Lancet. 2015;386: 1765–1775. doi:10.1016/S0140-6736(15)60251-3
- 22. Gulaid LA. Community-facility linkages to support the scale up of lifelong ART for pregnant and breastfeeding women living with HIV: A conceptual framework, compendium of promising practices and key operational considerations (PDF Download Available) [Internet]. New York, USA: UNICEF; 2015. Available: https://www.researchgate.net/publication/279806417\_Communityfacility\_linkages\_to\_support\_the\_scale\_up\_of\_lifelong\_ART\_for\_pregnant\_and\_breastfeeding\_wo men\_living\_with\_HIV\_A\_conceptual\_framework\_compendium\_of\_promising\_practices\_and\_key\_ operational\_co

- 23. GNP+. Global Advocacy Agenda GNP+. In: GNP+ [Internet]. [cited 26 Apr 2016]. Available: http://www.gnpplus.net/about-us/global-advocacy-agenda/
- 24. Zachariah R, Ford N, Philips M, Lynch S, Massaquoi M, Janssens V, et al. Task shifting in HIV/AIDS: opportunities, challenges and proposed actions for sub-Saharan Africa. Trans R Soc Trop Med Hyg. 2009;103: 549–558. doi:10.1016/j.trstmh.2008.09.019
- Carey C, Tolopilo A. Tipping the Balance: Why Legal Services Are Essential to Health Care for Drug Users in Ukraine [Internet]. Open Society Institute; 2008. Available: https://www.opensocietyfoundations.org/sites/default/files/tippingthebalance.pdf
- 26. Gruskin S, Safreed-Harmon K, Ezer T, Gathumbi A, Cohen J, Kameri-Mbote P. Access to justice: evaluating law, health and human rights programmes in Kenya. J Int AIDS Soc. 2013;16. doi:10.7448/IAS.16.3.18726
- Open Society Foundations. Bringing Justice to Health: The Impact of Legal Empowerment Projects on Public Health [Internet]. New York, USA: Open Society Foundations; 2013. Available: https://www.opensocietyfoundations.org/sites/default/files/bringing-justice-health-20130923\_0.pdf
- 28. Ferris France N, Macdonald SH-F, Conroy RR, Chiroro P, Ni Cheallaigh D, Nyamucheta M, et al. "We are the change" an Innovative Community-Based Response to Address Self-Stigma: A Pilot Study Focusing on People Living With HIV in Zimbabwe. Pap Submitt Publ.
- 29. WHO, UNFPA, UNAIDS, NSWP, World Bank, UNDP. Implementing comprehensive HIV/STI programmes with sex workers: practical approaches from collaborative interventions. Geneva, Switzerland: World Health Organization; 2013.
- 30. UNAIDS. The Gap Report (2014) [Internet]. Geneva, Switzerland: UNAIDS; 2014. Available: http://www.unaids.org/sites/default/files/media\_asset/UNAIDS\_Gap\_report\_en.pdf
- 31. UNAIDS Programme Coordinating Board (37)/15.21 Agenda item 6: HIV in prisons and other closed settings [Internet]. Geneva, Switzerland: UNAIDS; 2015. Available: http://www.unaids.org/sites/default/files/media\_asset/20151012\_UNAIDS\_PCB37\_15-21\_EN.pdf
- 32. GNP+. People Living with HIV Stigma Index [Internet]. [cited 26 Apr 2016]. Available: http://www.stigmaindex.org/
- 33. International HIV/AIDS Alliance. A Voucher for Health: Enabling young people in Uganda to access quality sexual and reproductive health services [Internet]. Hove, UK: International HIV/AIDS Alliance; 2015. Available: http://www.aidsalliance.org/assets/000/002/148/2015\_Alliance\_Case\_Study\_Link\_Up\_Uganda\_V ouchers\_Full\_online\_original.pdf?1453290568
- 34. ILO. Corridor Economic Empowerment Project Case Studies [Internet]. Pretoria, South Africa: International Labour Organization Decent Work Team; 2015. Available: http://www.ilo.org/wcmsp5/groups/public/---africa/---ro-addis\_ababa/---sroharare/documents/publication/wcms\_350268.pdf

- 35. UNESCO. Final Report: World Economic Forum, Dakar, Senegal, 26-28 April, 2000 [Internet]. Paris, France: UNESCO; 2000. Available: http://unesdoc.unesco.org/images/0012/001211/121117e.pdf
- 36. UNICEF. Girls, HIV/AIDS, and Education [Internet]. New York, USA: UNICEF; 2004. Available: http://www.unicef.org/publications/files/Girls\_HIV\_AIDS\_and\_Education\_(English)\_rev.pdf
- Cluver L, Boyes M, Orkin M, Pantelic M, Molwena T, Sherr L. Child-focused state cash transfers and adolescent risk of HIV infection in South Africa: a propensity-score-matched case-control study. Lancet Glob Health. 2013;1: e362–370. doi:10.1016/S2214-109X(13)70115-3
- Gelli A. School Feeding and Girls'Enrollment: The Effects of Alternative Implementation Modalities in Low-Income Settings in Sub-Saharan Africa. Front Public Health. 2015;3. doi:10.3389/fpubh.2015.00076
- World Bank. What Matters Most for School Health and School Feeding: A Framework Paper: SABER Working Paper Series, Number 3, June 2012 [Internet]. Washington DC, USA: The World Bank; 2012. Available: http://wbgfiles.worldbank.org/documents/hdn/ed/saber/supporting\_doc/Background/SHN/Fram ework\_SABER-School\_Health.pdf
- 40. UNAIDS. (In press) Good Policy and Practice in Community Responses to HIV: Volume 1 Community-Based Testing and Linkage to Care. Geneva, Switzerland: UNAIDS; 2016.
- 41. Abramsky T, Devries K, Kiss L, Nakuti J, Kyegombe N, Starmann E, et al. Findings from the SASA! Study: a cluster randomized controlled trial to assess the impact of a community mobilization intervention to prevent violence against women and reduce HIV risk in Kampala, Uganda. BMC Med. 2014;12. doi:10.1186/s12916-014-0122-5
- 42. Kyegombe N, Abramsky T, Devries KM, Starmann E, Michau L, Nakuti J, et al. The impact of SASA!, a community mobilization intervention, on reported HIV-related risk behaviours and relationship dynamics in Kampala, Uganda. J Int AIDS Soc. 2014;17. doi:10.7448/IAS.17.1.19232
- 43. Wagman JA, Gray RH, Campbell JC, Thoma M, Ndyanabo A, Ssekasanvu J, et al. Effectiveness of an integrated intimate partner violence and HIV prevention intervention in Rakai, Uganda: analysis of an intervention in an existing cluster randomised cohort. Lancet Glob Health. 2015;3: e23–e33. doi:10.1016/S2214-109X(14)70344-4
- 44. WHO. 16 Ideas for addressing violence against women in the context of the HIV epidemic [Internet]. Geneva, Switzerland: World Health Organization; 2013. Available: http://www.who.int/reproductivehealth/publications/violence/vaw\_hiv\_epidemic/en/
- 45. UN Women. Transforming the National AIDS Response: MAINSTREAMING GENDER EQUALITY AND WOMEN'S HUMAN RIGHTS INTO THE "THREE ONES" [Internet]. New York, USA: UN Women; 2012. Available: http://www.unwomen.org/~/media/Headquarters/Attachments/Sections/Library/Publications/20

12/EN-Transforming%20the%20AIDS%20Response-blue%20pdf.pdf

- 46. Baral S, Sifakis F, Cleghorn F, Beyrer C. Elevated risk for HIV infection among men who have sex with men in low- and middle-income countries 2000-2006: a systematic review. PLoS Med. 2007;4: e339. doi:10.1371/journal.pmed.0040339
- 47. Baral S, Beyrer C, Muessig K, Poteat T, Wirtz AL, Decker MR, et al. Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis. Lancet Infect Dis. 2012;12: 538–549. doi:10.1016/S1473-3099(12)70066-X
- 48. Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. Lancet Infect Dis. 2013;13: 214–222. doi:10.1016/S1473-3099(12)70315-8
- 49. AMFAR. Issue Brief: Tackling HIV/AIDS Among Key Populations: Essential to Achieving an AIDS-Free Generation. Washington DC, USA: American Foundation for AIDS Research; 2013.
- 50. Key Populations: Targeted Approaches Toward an AIDS-Free Generation | U.S. Agency for International Development [Internet]. [cited 26 Apr 2016]. Available: https://www.usaid.gov/what-we-do/global-health/hiv-and-aids/technical-areas/key-populationstargeted-approaches-toward#section4
- 51. UNAIDS Guidance Note on HIV and Sex Work (Updated April 2012) [Internet]. Geneva, Switzerland: UNAIDS; 2012. Available: http://www.unaids.org/en/resources/documents/2012/20120402\_UNAIDS-guidance-note-HIVsex-work
- 52. UNAIDS Programme Coordinating Board (36)15.13 Agenda Item 9: HIV in Emergency Contexts -Background Note [Internet]. Geneva, Switzerland: UNAIDS; 2015. Available: http://www.unaids.org/sites/default/files/media\_asset/20150612\_UNAIDS\_PCB36\_15-13\_EN.pdf
- 53. Kutalek R, Wang S, Fallah M, Wesseh CS, Gilbert J. Ebola interventions: listen to communities. Lancet Glob Health. 2015;3: e131. doi:10.1016/S2214-109X(15)70010-0
- 54. Abramowitz SA, McLean KE, McKune SL, Bardosh KL, Fallah M, Monger J, et al. Community-Centered Responses to Ebola in Urban Liberia: The View from Below. Bausch DG, editor. PLoS Negl Trop Dis. 2015;9: e0003706. doi:10.1371/journal.pntd.0003706
- 55. WHO. Follow up to the World Health Assembly Decision on the Ebola Virus Disease Outbreak and the Special Session of the Executive Board on Ebola: Roadmap for Action. Geneva, Switzerland: World Health Organization; 2015.
- 56. Middleton-Lee S. Mid-Term Review: The Robert Carr Civil Society Networks Fund. [Internet]. Amsterdam, The Netherlands: Robert Carr Civil Society Networks Fund; 2014. Available: http://www.robertcarrfund.org/wp-content/uploads/2014/11/Mid-Term-Review-Robert-Carrcivil-society-Networks-Fund.pdf?c866de&2d17e2
- 57. The Global Fund to Fight AIDS, Tuberculosis and Malaria. Grant Portfolio Thailand. In: The Global Fund to fight AIDS, Tuberculosis and Malaria [Internet]. [cited 27 Apr 2016]. Available: http://www.theglobalfund.org/en/portfolio/country/?loc=THA

58. UNDP. Handbook on Non-State Social Service Delivery Models: A Guide for Policy Makers and Practitioners in the CIS region [Internet]. Bratislava, Slovak Republic: UNDP Bratislava Regional Centre; 2012. Available:

http://www.me.undp.org/content/dam/montenegro/docs/publications/si/SWR/Handbook%20on %20non-state%20social%20service%20delivery%20models.pdf?download

- 59. UNDP. Sustainable financing of HIV responses. In: UNDP in Europe and Central Asia [Internet]. [cited 26 Apr 2016]. Available: http://www.eurasia.undp.org/content/rbec/en/home/ourwork/democratic-governance-andpeacebuilding/hiv-and-health/sustainable-financing-of-hiv-responses.html
- 60. The Global Fund Gender Equality Strategy [Internet]. Geneva, Switzerland: Global Fund to Fight AIDS, Tuberculosis and Malaria; 2009. Available: http://www.theglobalfund.org/documents/core/strategies/Core\_GenderEquality\_Strategy\_en/
- 61. The Global Fund Strategy in Relation to Sexual Orientation and Gender Identities [Internet]. Geneva, Switzerland: Global Fund to Fight AIDS, Tuberculosis and Malaria; 2009. Available: http://www.theglobalfund.org/documents/core/strategies/Core\_SexualOrientationAndGenderIde ntities\_Strategy\_en/
- 62. The Global Fund to Fight AIDS, Tuberculosis and Malaria. Community, Rights and Gender Technical Assistance Program. In: The Global Fund to fight AIDS, Tuberculosis and Malaria [Internet]. [cited 26 Apr 2016]. Available: http://www.theglobalfund.org/en/fundingmodel/technicalcooperation/communityrightsgender/
- 63. Zapfel A, Gibbs A. PEPFAR 2015 COP Civil Society Engagement Analysis: Recommendations for Future Engagement [Internet]. Washington DC, USA: Futures Group, Health Policy Project; 2015. Available: http://www.healthpolicyproject.com/pubs/859\_FINALPEPFARCSEngagementReport.pdf