INVESTING IN COMMUNITY RESPONSES

A CASE FOR FUNDING NON-SERVICE DELIVERY COMMUNITY ACTIONS TO END AIDS

2016

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ARASA AIDS & Rights Alliance for Southern Africa

SUMMARY

Greater investment in community responses is needed to end AIDS. UNAIDS suggests that investments in community mobilization should increase threefold to 3%, and spending on social enablers should reach 8% of total expenditure by 2020. However, a recent survey showed that 40% of organizations tasked with implementing community activities reported a funding decrease since 2013. Two thirds expected flat or declining funding in the future. PEPFAR[1] reduced its investments in community-based care, treatment and support by 12.6% from 2013 to 2014. The Global Fund's Technical Review Panel has expressed concern that the majority of concept notes are not including funding requests for the community systems strengthening module at all. An investment case for community responses is needed to motivate the necessary levels of funding.

To make the investment case, a review of the peer-reviewed and grey literature was conducted and complemented by case examples. The findings were categorized in terms of evidence of impact and return on investment in three areas of community responses: (1) networks and linkages; (2) advocacy and influence; and (3) monitoring and accountability. Service delivery components of community responses were excluded from this analysis.

A significant return on investment was found in all three areas of community responses examined. Community networks of key populations were found to increase coverage of services and improve health outcomes for these groups. Linkages at community level, such as adherence clubs and anti-retroviral treatment (ART) refill groups, produced cost-savings in ART provision, as well as reduced total HIV program costs overall. Community advocacy was found to bring additional funding to the response as well as reduce the prices of medicines. Indicators on open and inclusive dialogue spaces were statistically significant predictors of how responsive HIV and TB funding decisions are to the needs of affected communities. In case law, law reform, and policy, developments came about directly as a result of community advocacy. Lastly, community-based monitoring increased accountability, and boosted uptake and quality of services, as well as increased domestic investments in HIV. This investment case presents compelling evidence that there are both allocative and technical efficiencies to be realized by investing more money in strengthening community responses.

A NOTE ON TERMINOLOGY: This paper prefers the use of the term "community responses" over "community systems" as an important recognition that communities address HIV with a wide and diverse range of efforts and activities that are not always formally linked or associated with health or health systems. Where community systems or community systems strengthening (CSS) are referred to, it is to maintain fidelity with the term used in a specific document or by a specific organization or institution. A glossary of terms is provided in Annex 2 for further clarity.

1. The United States President's Emergency Plan for AIDS Relief (PEPFAR)

INTRODUCTION

We know that greater emphasis on community responses is necessary if we are to end AIDS as a public health threat by 2030. A loud chorus of stakeholders agree on this. UNAIDS says strong civil society engagement is critical for the implementation of its 2016-2021 strategy. The strategy recognizes civil society's role in the AIDS response as a global public good, with mounting evidence of its positive impact, which requires legal and social space, as well as financial resources to ensure its effectiveness.[2] PEPFAR's strategy from 2013 to the present, PEPFAR 3.0, has a strong community systems focus under its Human Rights Action Agenda. This Agenda prioritizes increasing civil society capacity to advocate for and create enabling environments, including non-discriminatory services for lesbian, gay, bisexual and transgender (LGBT) populations, promoting gender equality, and reducing gender-based violence.[3] The Global Fund's new strategy for the period 2017-2022 also has a heavy focus on community systems and responses, as well as gender and human rights. The Fund intends to maximize impact among key populations[4] by focusing on data systems, strengthening community systems for increased advocacy, monitoring and service delivery capacity, and addressing human rights policy and barriers.[5] Additionally, the Global Fund's strategy has the building of resilient and sustainable systems for health as one of its four core objectives, with the aim to ensure well-functioning and responsive health and community systems.

To achieve these objectives, there is consensus that we need to increase our investments in community responses. UNAIDS suggests that community systems strengthening, which aims to bolster the role of key populations, communities and community-based organizations at all levels, will become a larger part of the AIDS response going forward. Modelling shows that resources for community mobilization will need to increase from 1% of global resource needs in 2014 (US $216 million) to 3% by 2020, and 4% by 2030.[6] Further, spending on social enablers (including advocacy, political mobilization, law and policy reform, human rights, public communication and stigma reduction) should reach 8% of total expenditure in low-and middle-income countries by 2020. [7] The UNAIDS–Lancet Commission has called on the global community to "invest in activism as a global public good."[8]

PEPFAR, too acknowledges the need to strengthen its commitment to inclusiveness and building a stronger civil society by supporting and building the capacity of global and regional civil society networks.[9] Through PEPFAR 3.0, the U.S. government will also implement civil society and human rights frameworks in all their priority countries.[10]

The Global Fund's investment case for the 2017-2019 replenishment, recognizes the importance of increasing funding for community responses. The Investment Case costing builds in assumptions of shifting more care from facility to community level.

2.UNAIDS (2016). On the Fast-Track to end AIDS – UNAIDS 2016–2021 Strategy. Page 49. Online at http://www.unaids.org/sites/default/files/media_asset/20151027_UNAIDS_PCB37_15_18_EN_rev1.pdf
3. PEPFAR (2013). PEPFAR 3.0 – Controlling the Epidemic: Delivering on the Promise of an AIDS-free Generation. Page 24. Online at http://www.pepfar.gov/documents/organization/234744.pdf
4. Key populations include women and girls, men who have sex with men, sex workers, people who use drugs, transgender and youth.
5. The Global Fund Strategy 2017-2022: Investing to End Epidemics. Page 16 of Board paper GF/B35/02 presented to the Global Fund Board at The Global Fund 35th Board Meeting, 26-27 April 2016, Abidjan, Côte d'Ivoire. Not online at the time of writing but should be available online soon at http://www.theglobalfund.org/en/board/meetings/35/
6. UNAIDS (2015) Fast-Track: Ending the AIDS Epidemic by 2030. Page 21. Online at http://www.unaids.org/en/resources/documents/2014/JC2686_WAD2014report. These figures have been updated and informed based on the UNAIDS (2016). Fast-Track: Update on Investments Needed in the AIDS Response. Page 10. Online at http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Reference_FastTrack_Update_on_investments_en.pdf
7. UNAIDS (2016). Fast-Track: Update on Investments Needed in the AIDS Response. Page 7. Online at http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Reference_FastTrack_Update_on_investments_en.pdf
8. Piot, P., Karim, S. S. A., Hecht, R., Legido-Quigley, H., Buse, K., Stover, J., ... & Møgedal, S. (2015). A UNAIDS–Lancet Commission on Defeating AIDS—Advancing Global Health Defeating AIDS—advancing global health. Lancet, 386, 171-218.
9. Birx, D. (2015). Building a Stronger Civil Society to Achieve an AIDS-Free Generation. Online at https://blogs.state.gov/stories/2015/09/29/building-stronger-civil-society-achieve-aids-free-generation
10. PEPFAR (2013). PEPFAR 3.0 – Controlling the Epidemic: Delivering on the Promise of an AIDS-free Generation. Page 27. Online at http://www.pepfar.gov/documents/organization/234744.pdf

Increasingly channeling more money towards strengthening community delivery models is both more efficient, in that it is cost-saving, but also more effective, improving the uptake of services by bringing them closer to the people who need them.[11]

Alongside international funding partners, countries are also increasingly highlighting the importance of community responses in their national investment cases. South Africa's HIV and TB Investment Case says that spending on community mobilization and other enablers needs to increase significantly.[12] To achieve the TB 90-90-90 targets that South Africa has set[13], the South African Investment Case shows that investments in community systems strengthening for TB responses need to grow each year for the next five years, increasing from ZAR 9.2m in 2015/2016 (approximately US $646,812) to ZAR 12.3m by 2020/2021 (approximately US $864,760).[14]

Similarly, the Philippines' HIV Investment Case notes that investing in strengthening community systems' capacity for care and support, and maximizing synergies between the public, private and community sectors ,can reduce the burden on the public sector, while contributing to more efficient and higher quality service delivery.[15] The Philippines Investment Case calls specifically for scale-up of community-led prevention interventions to reach 90% of men who have sex with men (MSM) and people who use drugs (PUD), while sustaining present coverage for sex workers, with a total annual resource need of US $51 million between 2015 and 2030.[16]

Despite this consensus that we need to increase global spending on community responses to HIV, evidence suggests that these budget lines may be going down rather than up.

11. The Global Fund (2015). Investment Case for the Global Fund's 2017-2019 Replenishment: The Right Side of the Tipping Point For AIDS, Tuberculosis and Malaria. Presented on 17 December 2015 at the Global Fund's Fifth Replenishment Preparatory Meeting in Tokyo, Japan. Page 17. Online at http://www.theglobalfund.org/documents/publications/other/Publication_InvestmentCase_Report_en/.
12. Department of Health, South Africa, and South African National AIDS Council: South African HIV and TB Investment Case - Summary Report Phase 1. March 2016. Page 285. Online at http://sanac.org.za/2016/03/22/summary-report/
13. The 90-90-90 strategy has also been adapted for TB in South Africa, so that by 2020, 90% of vulnerable groups should have been screened for TB, 90% of people with TB are diagnosed and started on treatment, and 90% of those treated for TB are cured.
14. Department of Health, South Africa, and South African National AIDS Council: South African HIV and TB Investment Case - Summary Report Phase 1. March 2016. Page 28. Online at http://sanac.org.za/2016/03/22/summary-report/
15. Investment Options for Ending AIDS in the Philippines by 2022 Modelling different HIV Investment Scenarios in the Philippines from 2015 to 2030. A paper commissioned by UNAIDS Philippines January 2015. Page 14. Online at http://www.aidsdatahub.org/sites/default/files/publication/Investment_Options_for_Ending_AIDS_in_the_Philippines_by_2022.pdf
16. Ibid, page 8 and 13.

DECLINING FUNDING FOR COMMUNITY RESPONSES

Signs of insufficient or declining investments in community responses are emerging from a number of different places across several different sources of funding. Recent data from PEPFAR suggests declining investments in community responses. From 2013 to 2014, PEPFAR funding for community-based care, treatment and support fell by 12.6% - more than $23.3 million (from $184,695,195 in 2013 to $161,393,173 in 2014).[17] This drop in spending for community-based interventions occurred within the context of increased PEPFAR spending overall – from $3.12 billion in 2013 to $3.23 billion in 2014. This expenditure data reflects a de-prioritization of community responses from the largest bilateral funding partner for HIV programs.

In a recent survey conducted by UNAIDS, 40% of civil society organizations and community groups reported that their funding had decreased since 2013.[18] Two thirds expected flat or reduced funding in the future. While it is important not to entirely conflate funding for civil society with funding for community responses, civil society organizations are often tasked with implementing community activities. This reported funding crisis is therefore likely to have an impact on support for community responses.

In another UNAIDS survey focused more specifically on funding for HIV and human rights, even more drastic funding decreases were reported. Of the 123 organizations that responded to the survey, 59% reported that their funding for HIV and human rights work had decreased in the previous two years (Figure 1). Of note, this survey found that organizations that did service delivery work, such as providing legal services related to HIV, suffered less dramatic funding cuts than those which focused more on human rights advocacy, legislative reform or strategic litigation.

FIGURE 1: CHANGES IN FUNDING FOR HUMAN RIGHTS-RELATED HIV WORK[19]

The costs of inaction to fund community responses are dire. Previous analyses showed that the flat-lining of total HIV funding over the 2014-2016 period might have led to 3.9 million HIV infections that would not have occurred if scale-up was achieved.[20] The total lifetime treatment costs for those 3.9 million people are approximately $47 billion.

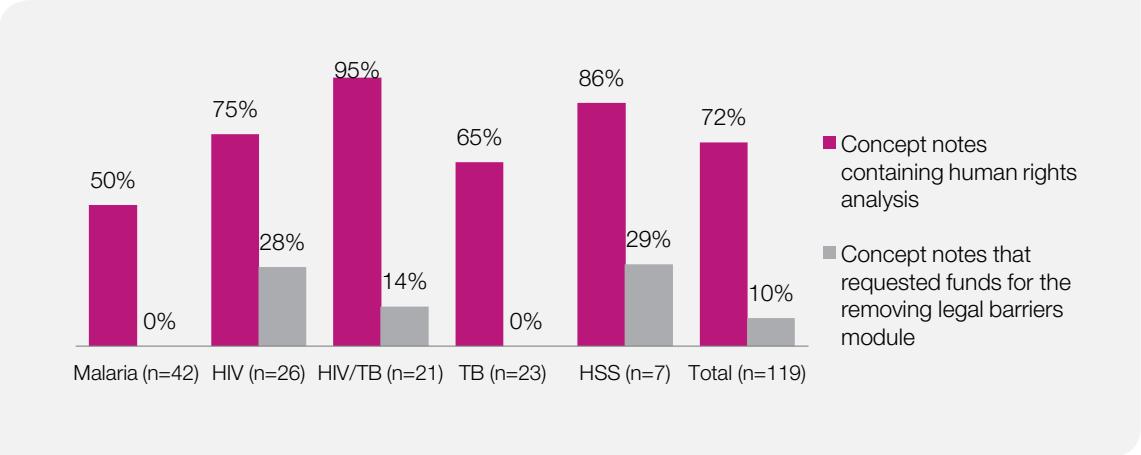
Decreasing funding for community responses, especially those that are delivered by civil society, has a clear detrimental impact on the epidemic. In Romania, there was a spike in HIV infections among people who use drugs after the Global

17. Computed from PEPFAR Dashboard online at https://data.pepfar.net
18. UNAIDS (2016, April 4). Investing in community advocacy and services to end the AIDS epidemic. UNAIDS. Online at http://www.unaids.org/en/resources/presscentre/featurestories/2016/april/20160404_community_advocacy
19. UNAIDS (2015). Sustaining the Human Rights Response to HIV: An Analysis of the Funding Landscape and Voices from Community. Page 18. Online at http://www.unaids.org/sites/default/files/media_asset/JC2769_humanrights_en.pdf
20. International Civil Society Support (2013). Cost of Inaction: A report on how inadequate investment in the Global Fund to Fight AIDS, Tuberculosis and Malaria will affect millions of lives. Page 12. Online at http://icssupport.org/wp-content/uploads/2010/04/COST-OF-INACTION-Sep-12th-2013.pdf

Fund departed in 2010, cutting off funding to civil society's outreach and harm reduction. As a result, in 2013, about 30% of new HIV cases were linked to injecting drug use compared with 3% in 2010.[21] Similarly, many civil society organizations in the northern part of Mexico – where drug use is a common risk factor for HIV – report that distribution of needles and syringes for people who inject drugs fell by 60-90% after a major donor left the country in 2013 and their funding ceased. [22] The organizations also report that their outreach has been sharply reduced, leading many to fear a resurgence in the epidemic among people who use drugs.

Part of this reported decline in funding for community responses can be linked with community systems strengthening programming being deprioritized in funding requests from countries. Human rights advocacy for legal and policy change is an essential pillar of community responses and considered a social enabler. In Global Fund concept notes, the module for this is called "Removing Legal Barriers." An analysis of 119 concept notes submitted to the Global Fund in the first five windows of submission, showed that 72% of them identified human rights barriers to access, even as only 10% actually requested funds for the removing legal barriers module (Figure 2).[23]

FIGURE 2: PROPORTION OF GLOBAL FUND CONCEPT NOTES (WINDOWS 1-5) THAT CONTAIN HUMAN RIGHTS ANALYSIS COMPARED TO THOSE WHICH REQUEST FUNDING FOR THE REMOVING LEGAL BARRIERS MODULE[24]



According to the Global Fund's Technical Review Panel (TRP), this trend is part of a pattern of noticeable absences of requests for community responses, overall. The TRP says that funding requests within the community systems strengthening (CSS) module was limited and that many did not include CSS at all. The CSS module is the broad category of funding requests for community responses. Other concept notes referenced CSS but without an appropriate budget. The TRP was also concerned to see CSS deprioritized and placed in the above allocation request in many concept notes.[25]

21. Open Society Foundations (2014). Undermining the Global Fight: The Disconnect Between the Global Fund's Strategy and the Real-life Implications of the New Funding Model. Online at https://www.opensocietyfoundations.org/sites/default/files/undermining-global-fight-20141201.pdf
22. Open Society Foundations (2015). Ready, Willing, and Able? Challenges Faced by Countries Losing Global Fund Support. Online at https://www.opensocietyfoundations.org/sites/default/files/ready-willing-and-able-20160403.pdf
23. Global Fund Presentation at Community, Rights and Gender Special Initiative Partners Forum. Bangkok, Thailand, 18 August 2015. Also available online via Oberth, G. (2015). Upcoming human rights grant will tackle barriers to access in Africa. Global Fund Observer, Issue 273. Online at http://www.aidspan.org/gfo_article/upcoming-human-rights-grant-will-tackle-barriers-access-africa
24. Global Fund Presentation at Community, Rights and Gender Special Initiative Partners Forum. Bangkok, Thailand, 18 August 2015.
25. Technical Review Panel to the Global Fund (2015). Report of the Technical Review Panel on the Concept Notes Submitted in the Third and Fourth Windows of the Funding Model. Page 7.

Community monitoring is a vital part of community responses, particularly for accountability and watchdogging efforts, but also for data collection and knowledge production on the impact of community-level interventions. For these activities, funding requests to the Global Fund have also been limited. In its recent report to the Global Fund Board, the Fund's Community, Rights and Gender (CRG) department pointed out that less than 20% of country concept notes submitted in windows 1 to 7 of the new funding model requested funding to support community monitoring.[26] Leaving community monitoring out of funding requests can have a damaging effect on the evidence base for community responses. The TRP emphasizes that many concept notes lack "a strong community-based monitoring system and thus an evidence base for the scale up of innovative CSS approaches, as well as efforts to measure impact and effectiveness of interventions."[27]

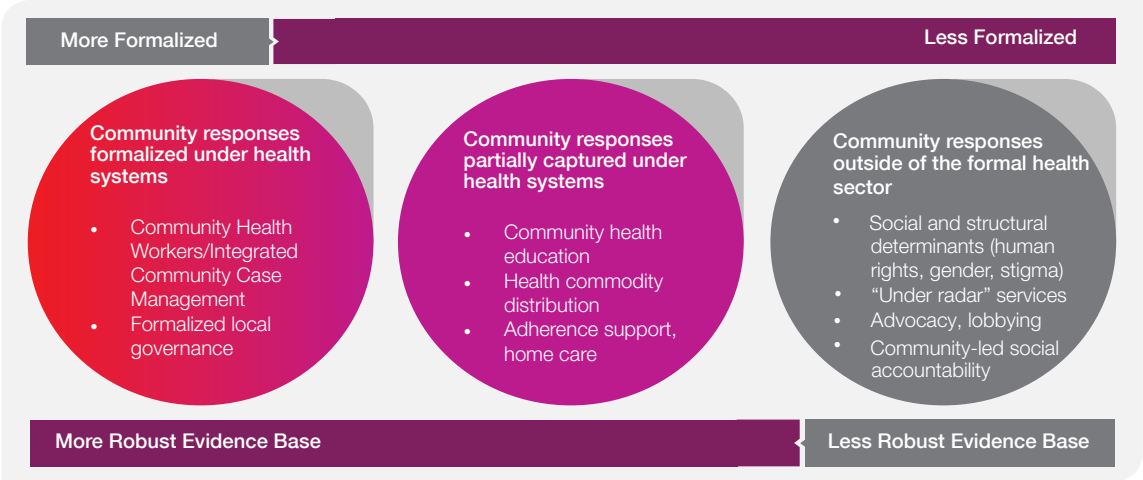
Our ability to demonstrate evidence of impact is critical for motivating sufficient funding for community responses. This is not always straightforward, especially for community responses that are harder to measure and which exist further outside of formal health systems.

THE COMMUNITY RESPONSES CONTINUUM AND THE ISSUE OF EVIDENCE

Community-based service delivery has been well-documented to increase demand and uptake of for instance condom use, HIV testing, voluntary medical male circumcision, treatment enrolment and retention in care.[28,29,30,31] Service delivery elements of community responses are often more formalized and integrated within health systems. For example, community health workers may be on the government payroll, and information they record is more likely to be captured into national data systems. However, there are elements of community responses that are far less formalized. This includes dialogue and engagement, community mobilization, advocacy, community monitoring and efforts to improve social and structural determinants of health such as human rights and gender equality. Unlike community-based service delivery, these less formalized components of community responses often enjoy a less robust evidence base. When it comes to investing in these vital aspects of the response, these less formalized components of community response can then have a damaging effect on the political will of governments and funding partners.

26. Community, Rights and Gender Report 2016. Page 21 of Board paper GF/B35/15 presented to the Global Fund Board at The Global Fund 35th Board Meeting, 26-27 April 2016, Abidjan, Côte d'Ivoire. Not online at the time of writing but should be available online soon at http://www.theglobalfund.org/en/board/meetings/35
27. Technical Review Panel to the Global Fund (2015). Report of the Technical Review Panel on the Concept Notes Submitted in the Third and Fourth Windows of the Funding Model. Page 7.
28. Barr, D., Odetoyinbo, M., Mworeko, L., & Greenberg, J. (2015). The leadership of communities in HIV service delivery. AIDS, 29, S121-S127.
29. UNAIDS & Médecins sans Frontières (2015). Community-based Antiretroviral Therapy Delivery. Online at http://www.unaids.org/sites/default/files/media_asset/20150420_MSF_UNAIDS_JC2707.pdf
30. UNAIDS & Stop AIDS Alliance (2015). Communities Deliver. The Critical Role of Communities in Reaching Global Targets to End the AIDS Epidemic. Online at http://www.unaids.org/sites/default/files/media_asset/UNAIDS_JC2725_CommunitiesDeliver_en.pdf
31. Salam, R. A., Haroon, S., Ahmed, H. H., Das, J. K., & Bhutta, Z. A. (2014). Impact of community-based interventions on HIV knowledge, attitudes, and transmission. Infect Dis Poverty, 3(6).

FIGURE 3: THE COMMUNITY RESPONSES CONTINUUM[32]



Community responses that tend towards the grey bubble on the far-right hand side (see Figure 3), are often undervalued, overlooked or not given enough isolated attention. The contribution that strong community responses make – particularly those which sit outside the formal health sector – is not always recognized and supported.[33] These diverse community contributions remain seriously under-appreciated and under-resourced.[34]

The less formalized side of community responses is also often overlooked because of a perceived lack of scientific evidence supporting its effectiveness (or its reliance on anecdotal evidence). There is also often difficulty in attributing results directly to these kinds of activities.[35] However, scientific evidence is showing that community empowerment and advocacy programs can in fact result in reduced HIV incidence.[36,37] It is also clear that a comprehensive package to address HIV must include community empowerment and advocacy.[38] In 2013, The Global Forum on MSM and HIV (MSMGF) developed a community systems strengthening research agenda to try and drive improved evidence gathering for community responses, particularly those that are more challenging to document.

The recent CRG report to the Global Fund Board shows that there is evidence of greater inclusiveness in country dialogue, and some evidence of improved concept note content as a result. However, work is needed to show how this translates into more effective programs at country level. It is especially necessary to demonstrate how having communities engaged in these issues results in greater impact against the three diseases.[39]

The Global Fund recently commissioned a review of the Fund's Gender Equality Strategy and Sexual Orientation and Gender Identities Strategy, which expressed similar issues with evidence of impact for community responses and activities.

The review found that while the Global Fund Secretariat has led or mobilized significant progress in terms of policies, processes, portfolio analyses and coordination on CRG issues, there remain concerns about the extent to which these

32. Adapted from Thomson, K. (2016, April 21). Strengthening community systems and responses. Presentation at High Impact Africa 2 Regional Meeting. Maputo, Mozambique.
33. International Council of AIDS Service Organisations (ICASO) and International HIV/AIDS Alliance. (2013). Community Systems Strengthening Questions and Answers. Online at http://www.icaso.org/media/files/23931-ECSSQuestionandAnswersNov2013FINALfordistribution.pdf.
34. Collins, C. et al. 2016. 'Time for full inclusion of community actions in the response to AIDS'. Journal of the International AIDS Society, 19(20712): 1-3.
35. UNAIDS and Stop AIDS Alliance. 2015. Communities Deliver: The critical role of communities in reaching global targets to end the AIDS epidemic. UNAIDS: Geneva. Online at http://www.unaids.org/sites/default/files/media_asset/UNAIDS_JC2725_CommunitiesDeliver_en.pdf
36. UNAIDS (2016). Invest in Advocacy. Online at http://www.unaids.org/sites/default/files/media_asset/JC2830_invest_in_advocacy_en.pdf.
37. Grossman, C. and Stangl, A. (2013). 'Global Action to reduce HIV stigma and discrimination'. Journal of the International AIDS Society, 16(Supplement 2): 1-6.
38. UNAIDS (2016). Invest in Advocacy. Online at http://www.unaids.org/sites/default/files/media_asset/JC2830_invest_in_advocacy_en.pdf.
39. Community, Rights and Gender Report 2016. Page 3 of Board paper GF/B35/15 presented to the Global Fund Board at The Global Fund 35th Board Meeting, 26-27 April 2016, Abidjan, Côte d'Ivoire. Not online at the time of writing but should be available online soon at http://www.theglobalfund.org/en/board/meetings/35/

efforts have translated into more and better investments in key populations and gender equality at country level.

National investment cases have also struggled with this limited evidence base for less formalized community responses. From the South African HIV and TB Investment Case:

> [T]here are few evaluations of holistic/comprehensive communication programmes. The majority of rigorous impact evaluations have focused on mass media. Far fewer studies have evaluated community mobilisation programmes, and even fewer have assessed integrated campaigns comprising mass media, social mobilisation and advocacy. As the majority of campaigns are designed using all of these approaches, this is a major gap in the evidence.[40]

WHY AN INVESTMENT CASE FOR COMMUNITY RESPONSES?

This policy paper is intended to be read as an investment case for non-service delivery community responses to HIV. The body of evidence presented here strategically bolsters the rationale for funding activities and interventions that fall outside of the formal health sector (those within or nearing the grey bubble on the far-right hand side in Figure 3). A more systematic approach is needed to ensure that less formalized community responses are adequately funded. This is particularly critical now, as funding appears to be falling for these activities at the exact moment when increased investments are needed the most.

This paper takes its point of departure from the premise that it is important to disentangle more formalized and less formalized service delivery and non-service delivery community responses for several reasons. First, as stated above, motivating investments for non-service delivery community responses can be especially challenging, given the less robust evidence base for impact. As a result, these activities are often neglected, overlooked, and marginalized when it comes to funding, policy, and programming for community responses. Indeed, community service delivery aspects of community responses are comparably well-captured in existing investment cases. The Secretary General's Report leading up to the June 2016 UN High Level Meeting on AIDS emphasizes the need to invest greater resources in community-based service delivery, but it neglects to mention the need for funding other aspects of community response, such as mobilization, advocacy and accountability.

Second, the message is aimed at different audiences: those who should be funding community service delivery are not necessarily the same as those who should be funding non-service delivery community responses. For example, activities that fall in and around the red bubble to the far left in Figure 3 should increasingly be supported by governments, but those that lie in and towards the grey bubble on the far-right hand side – particularly those which involve monitoring, accountability, or advocacy – should receive funding from external partners.

40. Department of Health, South Africa, and South African National AIDS Council: South African HIV and TB Investment Case – Reference Report. Phase 1. March 2016. Page 303. Online at http://sanac.org.za/wp-content/uploads/2016/03/1603-Investment-Case-Report-LowRes-18-Mar.pdf

This paper synthesizes the existing evidence on how non-service delivery community responses can lead to greater efficiency and efficacy in ending AIDS. The paper focuses on documenting evidence of impact for the following areas:[41]

PART I	Networks and Linkages
PART II	Advocacy and Influence
PART III	Monitoring and Accountability

The specific aim of this paper is to showcase the return on investment that can be realized by funding the Network and Linkages (Part I), Advocacy and Influence (Part II), and Monitoring and Accountability (Part III) of community responses. Return on investment is understood as documented links between community responses and their impact on health outcomes. In other words, the aim is to show that networks, advocacy and monitoring matter for the HIV response, because they impact the bottom line – improvements in health. Examples of impact are drawn from community responses in a broad range of fields, as long as they were deemed potentially replicable for the HIV response. Each section is complemented by an in-depth case example to highlight impact at a more detailed level.

EVIDENCE OF IMPACT FOR NON-SERVICE DELIVERY COMMUNITY ACTIONS

PART I	Networks And Linkages

The unity and cohesion of communities have been shown to relate to improved health outcomes in several settings. Networking contributes to building social capital, which is an important determinant of health in many contexts. Membership in community organizations, including religious groups, burial groups and sports clubs (defined as social support and social networks), is positively associated with HIV counselling and testing (HCT) uptake and adherence for people living with HIV (PLHIV).[42]

In **Zimbabwe**, community group participation increased both take-up of prevention of vertical transmission and HIV counseling and testing.[43] Importantly, this study also links the networks to disease impact; individual women in community groups had lower HIV incidence and more extensive behavior change.

41. While these topics are discussed independently, their overlap is undeniable.
42. Underwood, C., Hendrickson, Z., Van Lith, L. M., Kunda, J. E. L., & Mallalieu, E. C. (2014). Role of community-level factors across the treatment cascade: a critical review. JAIDS Journal of Acquired Immune Deficiency Syndromes, 66, S311-S318.
43. Gregson, S., Mushati, P., Grusin, H., Nhamo, M., Schumacher, C., Skovdal, M., & Campbell, C. (2011). Social capital and women's reduced vulnerability to HIV infection in rural Zimbabwe. Population and development review, 37(2), 333-359.

Group membership and community linkages have also been associated with stigma reduction. Stigma has been shown to be a barrier to seeking prevention education, HIV testing and care. In one study in Chennai, India, all measures of stigma were lower when participants reported membership in formal groups, high levels of collective action toward community goals, and high norms of reciprocity between neighbors and residents in daily life.[44]

Investment cases have previously shown the need to increase evidence-based interventions among key populations.[45,46] The existence of strong networks of key and vulnerable populations is often a critical vehicle for the success and coverage of interventions. For instance, the IMAGE study conducted in South Africa succeeded in leveraging existing women's networks to halve the risk of physical or sexual intimate partner violence experienced by participants.[47] Other research from **Swaziland** suggests that leveraging community networks will support increased access to HIV testing for MSM.[48]

Social networking/networks (Facebook, online dating sites, etc.) have increasingly become extremely popular. Studies have shown that social networks can have a positive influence on members, especially key and vulnerable populations, for instance to request home-based HIV testing and reduce unsafe sexual behavior.[49,50]

Community mobilization is an important part of community responses that relates to networks and linkages. Community mobilization involves bringing together groups of people of various typologies who are scattered and hidden across different geographical areas, to provide them with the space and the opportunity to act together. This is particularly important to reach key and vulnerable populations. Community mobilization is highly cost-effective, with an average cost per person of $6 in Latin America, $4 in East and Southern Africa, and just $2 in other regions.[51]

In Karnataka, **India**, female sex workers with high community mobilization exposure were more likely to have been tested for HIV, and to have used a condom during sex with clients and partners.[52] In another study, also in India, being a member of a sex worker community group was associated with access to social entitlements, reduced violence and reduced police coercion.[53] In yet another example from India, the Calcutta-based Sonagachi Project has been linked to lower HIV rates among sex workers, compared to other urban areas in India.[54] Community dialogue and participation, synonymous in the project with "social relationships" are seen as central to this success.

In ZIMBABWE, individual women who were members of community groups had lower HIV incidence (Gregson et al., 2011).

44. Sivaram, S., Zelaya, C., Srikrishnan, A. K., Latkin, C., Go, V. F., Solomon, S., & Celentano, D. (2009). Associations between social capital and HIV stigma in Chennai, India: considerations for prevention intervention design. AIDS Education and Prevention, 21(3), 233-250.
45. The Global Fund (2015). Investment Case for the Global Fund's 2017-2019 Replenishment: The Right Side of the Tipping Point For AIDS, Tuberculosis and Malaria. Presented on 17 December 2015 at the Global Fund's Fifth Replenishment Preparatory Meeting in Tokyo, Japan. Page 37. Online at http://www.theglobalfund.org/documents/publications/other/Publication_InvestmentCase_Report_en/.
46. Stover, J., Bollinger, L., Izazola, J. A., Loures, L., DeLay, P., Ghys, P. D., & Fast Track modeling working group. (2016). What Is Required to End the AIDS Epidemic as a Public Health Threat by 2030? The Cost and Impact of the Fast-Track Approach. PLOS ONE, 11(5), e0154893.
47. Ogden, J., Morrison, K., & Hardee, K. (2013). Social capital to strengthen health policy and health systems. Health policy and planning, czt087.
48. Baral, S., et al. (2013). A cross-sectional assessment of the burden of HIV and associated individual-and structural-level characteristics among men who have sex with men in Swaziland. Journal of the International AIDS Society,16(4Suppl 3).
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52. Beattie, T. et al. (2014). Community mobilization and empowerment of female sex workers in Karnataka State, South India: associations with HIV and sexually transmitted infection risk. American journal of public health, 104(8), 1516-1525.
53. India Evaluation Report. (2011). Evaluation of Community Mobilization and Empowerment in Relation to HIV Prevention among Female Sex Workers in Karnataka State, South India. Washington, DC: World Bank
54. Jana, S., (2004). The Sonagachi Project: a sustainable community intervention program. AIDS Education and Prevention, 16(5), 405-414.

In **Uganda**, a study examining the role of networked groups of people living with HIV in HIV prevention and care found that community groups and networks assume multiple roles in relation to HIV care and support, contributing to personal care, treatment access and adherence support, financial support, bereavement support, and care of children after the death of their parents.[55]

A recent critical review of the role of communities in access to services found that community-level systems have the potential to either hinder or reinforce care-seeking behavior among key populations.[56] In **Zimbabwe**, local community norms and networks hampered a peer education program aimed at sex workers to the extent that HIV incidence in intervention sites actually rose.[57] This is because the project neglected to engage other women's networks that existed in the community – particularly women's church groups – which was crucial for the community's acceptance of the sex worker program.

Adherence clubs are also a key example of how community-level groupings can create cost-saving efficiencies. **South Africa's** HIV and TB Investment Case found that adherence clubs are the only cost-saving technical efficiency factor or enabler, and that they had the power to reduce the average cost of ART provision per person on ART, as well as the total cost of the HIV program overall. The Investment Case suggests that adherence clubs can lead to a 13% reduction in ART cost.

In the **Eastern Europe and Central Asia (EECA)** region, an example of efficiencies realized through enhanced linkages and coordination can be seen with the EECA Regional Platform.[58] Referred to as the "EECA Consortium", the following partners have come together in an effort to enhance coordination of technical assistance to community responses in the region: Alliance for Public Health, Eurasian Harm Reduction Network, EECA Union of PLHA organizations, Eurasian Network of People who Use Drugs, Sex Workers' Rights Advocacy Network, Eurasian Coalition on Male Health, as well as TB Europe Coalition. This initiative ensures that key technical assistance providers are not competing and wasting scarce resources. The consortium has also demonstrated its ability to integrate HIV and TB issues in decision-making processes. Integration of HIV and TB has been well-documented as leading to improved coverage of services, as well as cost-savings in the process.[59] An estimated 910 000 lives were saved globally over six years by improving collaboration between TB and HIV responses.[60]

In **Peru**, a network of community-based organizations called CLAS (Comites Locales de Administracion de Salud, or Local Committees for Health Administration) was formed to amplify the efforts of its individual members. CLAS is focused on elevating existing community self-help groups, largely led by women, to provide similar support to a much wider community through a network approach. CLAS has been associated with efficiency gains in health, leading to better allocation of resources.[61] Specifically, CLAS identified unmet health needs, and subsequently improved coverage of services by effectively allocating resources to those areas. CLAS also developed a payment system that protected the poorest individuals' right to health.

55. Mburu, G., Oxenham, D., Hodgson, I., Nakiyemba, A., Seeley, J., & Bermejo, A. (2013). Community systems strengthening for HIV care: experiences from Uganda. Journal of social work in end-of-life & palliative care, 9(4), 343-368.
56. Underwood, C., Hendrickson, Z., Van Lith, L. M., Kunda, J. E. L., & Mallalieu, E. C. (2014). Role of Community-Level Factors Across the Treatment Cascade: A Critical Review. JAIDS Journal of Acquired Immune Deficiency Syndromes, 66, S311-S318. Page S314.
57. Campbell, C., Scott, K., Nhamo, M., Nyamukapa, C., Madanhire, C., Skovdal, M., Sherr, L. & Gregson, S. (2013). Social capital and HIV competent communities: the role of community groups in managing HIV/AIDS in rural Zimbabwe. AIDS care, 25(sup1), S114-S122.
58. See http://www.eecaplatform.org/
59. Sweeney, S., Obure, C. D., Maier, C. B., Greener, R., Dehne, K., & Vassall, A. (2011). Costs and efficiency of integrating HIV/AIDS services with other health services: a systematic review of evidence and experience. Sexually Transmitted Infections, sextrans-2011.
60. World Health Organization (WHO). WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders. Online at http://www.who.int/tb/publications/2012/tb_hiv_policy_9789241503006/en/
61. Iwami, M., & Petchey, R. (2002). A CLAS act? Community-based organizations, health service decentralization and primary care development in Peru. Journal of Public Health, 24(4), 246-251.

CASE STUDY 1

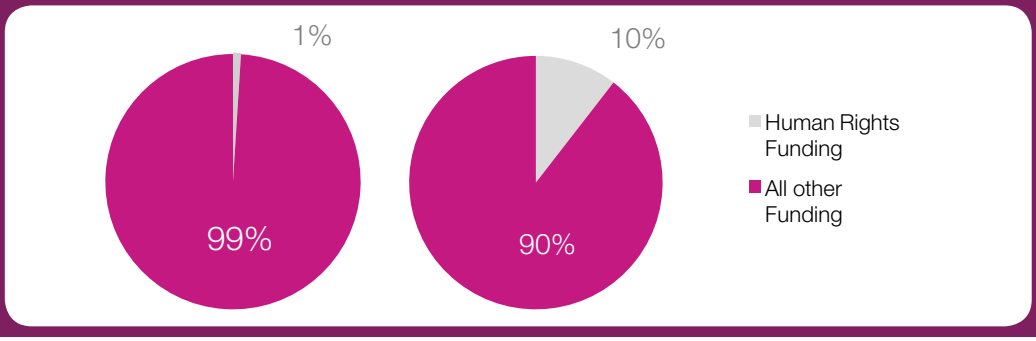
NETWORK STRENGTHENING FOR KEY AND VULNERABLE POPULATIONS IN BELIZE LEADS TO 10X THE AVERAGE GLOBAL FUND INVESTMENT FOR HUMAN RIGHTS WORK TO REMOVING LEGAL BARRIERS TO ACCESS

The Caribbean Vulnerable Communities Coalition (CVC) is a constituency-based regional advocacy coalition of diverse civil society actors, grouping over forty community leaders and non-governmental organizations working with populations who are especially vulnerable to HIV and who are particularly underserved by treatment and health care programs. CVC provides technical assistance and institutional strengthening, including sub-grants through funds received from supporters such as the MAC AIDS Fund and the Robert Carr Civil Society Network Fund (RCNF).

Strong networks and groups of key and vulnerable populations are essential for successful representation in decision-making spaces. In Belize, a key achievement has been the validation of the work of civil society, in particular sub-national HIV committees and the networks of vulnerable populations such as the United Belize Advocacy Movement (UNIBAM) and the Collaborative Network of Persons Living with HIV (CNET+). These organizations received sub-grants from CVC, supporting network strengthening activities, aimed at demanding improved service delivery through effective representation in decision-making spaces.

UNIBAM is an MSM-led policy and advocacy organization, which benefited from technical assistance (TA) and financial support from CVC to engage in Global Fund and other national HIV responses related to key populations, including MSM. The TA and support from this grant contributed to the organization's ability to participate in the national response. UNIBAM's strength in human rights advocacy was recognized by the Belize Country Coordinating Mechanism (CCM), when they were invited to join the technical working group that drafted the human rights section of their latest Global Fund concept note. UNDP also requested that they prepare a human rights brief to help inform their understanding of the human rights situation of key populations in Belize, particularly as it relates to MSM and transgender people. The networking strengthening support provided by CVC had a direct impact on funding for the response, ensuring that Belize was one of the few countries that requested and received Global Fund money to remove legal barriers to accessing services (recall from Figure 2 how uncommon this is). Furthermore, network strengthening of key populations ensured that human rights funding of $363,942 was part of the final signed grant. This amount represents 10.5% of the country's total Global Fund grant, which is more than ten times the average allocation to human rights work across the entire Global Fund portfolio.

Proportion of Global Fund investment in human rights programming overall (left) and proportion secured in Belize as a result of key populations network strengthening (right)



Connected, mobilized and engaged communities also have impact from a sustainability perspective. There is evidence that working through existing community groups, networks and structures can contribute towards greater sustainability in the health response. In **Cambodia**, an equity fund was set up to provide user fee exemptions, structured around existing religious volunteers from the monasteries for Buddhist monks and the temples for Buddhist religious ceremonies (called Pagoda volunteers).[62] This proved a more sustainable mechanism than establishing new networks and groups. The HIV response could be made more sustainable by leveraging existing community networks and groups, both from within and outside the health sector.

There is also evidence that engaged communities create financial sustainability for the response. In **Nigeria**, financial resources of community-based organizations (CBOs) were over three times larger in communities with strong civil society engagement (US $22,500 versus US $6,200) than they were in communities with weaker engagement.[63] In **Kenya**, CBOs in communities with a stronger civil society engagement mobilized nearly three times more resources (US $21,400 versus US $7,500).

PART II Advocacy and Influence

One of the key activities and actions that communities engage in is related to creating an enabling environment through advocacy. This includes fostering dialogue with leaders, creating pressure for legal and policy change, reducing stigma and discrimination, and pushing for increased funding for the response. Effective community responses are those in which community actors are also able to play a systematic, organized role in advocacy, policy and decision-making, and in creating and maintaining enabling environments that support peoples' right to health.[64] Though the impact of advocacy can seem difficult to assess, outcomes related to advocacy can be measured and tools exist to assist in monitoring and evaluating these results (see Recommendations).[65]

Community advocacy has also led to improved rights-based policies, and contributed to challenging religious and cultural barriers.[66] Civil society advocacy has been, and continues to be, essential to fighting HIV criminalization. The evidence is clear that HIV criminalization has a negative effect on both public health and human rights. Important and promising developments in case law, law reform and policy have taken place, largely as a direct result of advocacy from civil society and community groups working to end criminalization of people living with HIV.[67]

There are other convincing cases for why advocacy matters, including the key achievements of the Bridging the Gaps program's global partners.[68] These include improved quality and access to HIV-related services, improved human rights, tailored services that are integrated into mainstream health systems, and strengthened capacity of civil society organizations.

62. Jacobs, B., & Price, N. (2006). Improving access for the poorest to public sector health services: insights from Kirivong Operational Health District in Cambodia. Health policy and planning, 21(1), 27-39.
63. Rodriguez-Garcia R, Bonnel R, Wilson D, N'Jie N. (2013). Investing in communities achieves results: findings from an evaluation of community responses to HIV and AIDS. Washington DC: World Bank. Page 45. Online at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213936/Investing-communities-achieve-results.pdf
64. Mburu, G., Oxenham, D., Hodgson, I., Nakiyemba, A., Seeley, J., & Bermejo, A. (2013). Community systems strengthening for HIV care: experiences from Uganda. Journal of social work in end-of-life & palliative care, 9(4), 343-368.
65. UNAIDS. (2016). Invest in Advocacy. Online at http://www.unaids.org/sites/default/files/media_asset/JC2830_invest_in_advocacy_en.pdf.
66. UNAIDS (2015). '06: The Civil Society Lesson'. In How AIDS Changed Everything – MDG6: 15 years, 15 lessons of hope from the AIDS response. UNAIDS: Geneva.
67. Bernard, E. J., & Cameron, S. (2013). Advancing HIV justice: A progress report on achievements and challenges in global advocacy against HIV criminalisation. Amsterdam, The Netherlands: The Global Network of People Living with HIV (GNP+).
68. Ayala, G. (2014) Global action with local impact. Why advocacy matters. Advocacy achievements of the Bridging the Gaps Global Partners. Amsterdam, Netherlands. Global Forum on MSM and HIV [MSMGF].

In many countries, there are a number of political and legal barriers that limit services for people who use drugs. However, through advocacy, countries such as **China**, **Malaysia**, **Ukraine** and **Vietnam** have taken steps toward policies increasing HIV service coverage for people who use drugs.[69]

An oft-cited example of the potential impact of advocacy is the Treatment Action Campaign (TAC) in South Africa. As an advocacy group, the campaign has mobilized people to pursue the universal right to health. Through its work, the TAC has been able to reduce the price of medicines, prevent hundreds of thousands of HIV-related deaths, and force significant additional resources into the health system and towards the poor.[70] Another example of the impact of advocacy in **South Africa** can be seen with the KwaCele community in Lusikisiki in the Eastern Cape. Supported by the World AIDS Campaign (WAC), the advocacy focus of the community response was around reducing ukuthwala, the practice of "bride abduction" where a young girl (and her family) are encouraged or forced to marry her off to older men. The KwaCele community launched a campaign for collective advocacy, holding meetings with the Chiefs and the King in the area, trying to get people to see that this practice places young girls at risk for HIV. Because of this community advocacy, traditional leaders have taken a leading role in denouncing ukhuthwala and there has been an increase in arrests of perpetrators, and removal of the survivors to places of safety.[71]

Strategic litigation is another form of advocacy which has demonstrated measurable impact on the epidemic. In an August 2014 court victory in **Botswana**, the Botswana Network on Ethics, Law and AIDS (BONELA) and the Southern Africa Litigation Centre (SALC) successfully challenged the government policy of refusing HIV treatment to non-citizen prisoners. The advocacy by BONELA and SALC alongside two foreign prisoners, has direct measurable impact on the 90-90-90 targets for treatment coverage in Botswana, ensuring that non-citizen prisoners have access to treatment. Foreign prisoners make up more than 14% of Botswana's prison population in a country with an adult HIV prevalence of 25.2%.

In BOTSWANA, legal advocacy had a direct contribution towards the 90-90-90 targets, ensuring that non-citizen prisoners would receive ART.

Successful and impactful advocacy has also been recorded in **Zambia** for PEPFAR's 2016 Country Operational Plan (COP). Here, community advocacy was successful in increasing PEPFAR's voluntary medical male circumcision (VMMC) targets for 2016/2017 by 35%.[72] This kind of advocacy is vital for achieving impact. Modelling has shown that scale-up of VMMC in East and Southern Africa has the potential to avert 3.36 million new HIV infections and result in a net savings of US$16.51 billion by 2025.[73]

In the Asia Pacific region, the Global Network of People Living with HIV (GNP+) and the Asia Pacific Network of People Living with HIV (APN+) have worked with networks of people living with HIV from **India**, **Indonesia**, **Myanmar**, **Nepal**, **Pakistan**, **Philippines**, **Thailand**, and **Vietnam** to conduct successful advocacy on access to treatment for Hepatitis C. The networks organized demonstrations and lobbying. This advocacy has resulted in compulsory licenses being issued and new drugs being registered.[74]

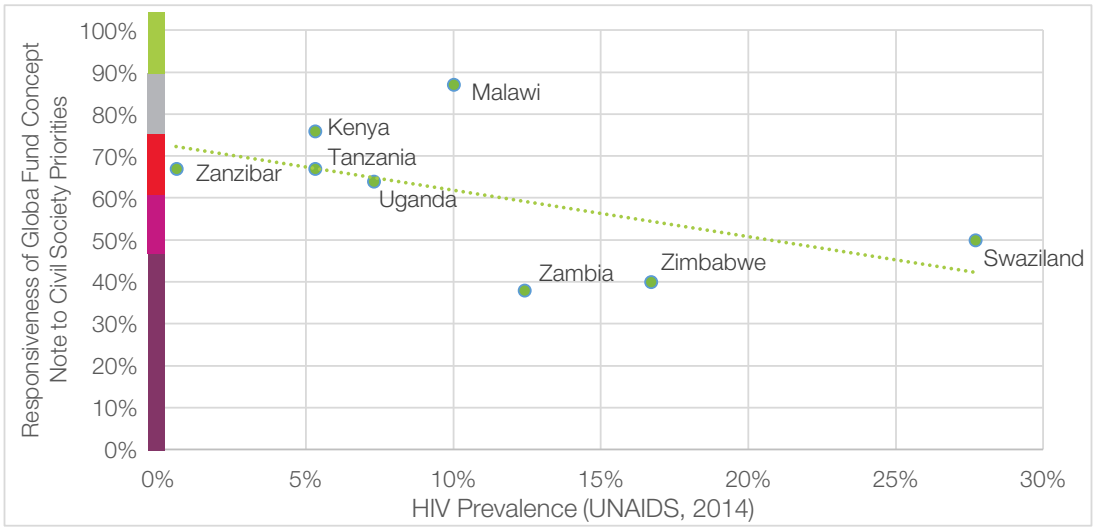
69. International HIV/AIDS Alliance and UNAIDS (2016). Advancing Combination HIV Prevention: An advocacy brief for community-led organisations. International HIV/AIDS Alliance and UNAIDS.
70. Heywood, M. (2009). South Africa's Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health. Journal of Human Rights Practice, 1(1), 14-36.
71. Southern African AIDS Trust (SAT) (2011). Southern Africa CSS Framework. Jacana Media: Johannesburg. Online at http://ow.ly/7q8M300EVby
72. See presentation from AMB Deborah Birx. (May 2016) COP Opening Plenary – Johannesburg. Side 8. Online at http://ow.ly/8U1k300EUzs
73. Njeuhmeli, E. et al. (2011). Voluntary medical male circumcision: Modeling the impact and cost of expanding male circumcision for HIV prevention in eastern and southern Africa. PLoS Med, 8(11), e1001132
74. Global Network of People Living with HIV (GNP+). (2015). Annual Report 2014. GNP+: Amsterdam.

CASE STUDY 2

CIVIL SOCIETY AND COMMUNITY ADVOCACY IN EAST AND SOUTHERN AFRICA ENHANCED BY ENABLING ENVIRONMENTS; LINKED WITH INCREASED LIKELIHOOD OF FUNDING AND LOWER HIV PREVALENCE

In 2013 and 2014, AIDS Accountability International led a process to support civil society and community groups to develop Priorities Charters in East and Southern Africa. Civil society and community groups used these Charters as advocacy roadmaps with an aim to influence their country's Global Fund concept notes for HIV and TB. In an impact assessment of the Charters and the advocacy done around them, the Eastern Africa National Network of AIDS Service Organizations (EANNASO) found significant relationships between enabling advocacy environments and the ability of civil society and community groups to influence Global Fund decisions.

Using Afrobarometer survey data, civil society had greater influence over Global Fund concept notes in countries where people often attend community meetings (CI 95%, P=0.041), often join others to raise an issue (CI 95%, P=0.017) and feel completely free to say what they think (CI 95%, P=0.030). Using World Bank Governance Indicators, civil society had greater influence over Global Fund concept notes in countries where there is more freedom of association and freedom of expression (CI 90%, P=0.083). Further, in countries where civil society and community groups were more successful with their advocacy by getting more of their priorities included in the concept notes, these requests for funding were more likely to be funded without being sent back to be re-worked and re-submitted. In countries where civil society was more effective at influencing Global Fund concept notes, HIV prevalence was lower (CI 95%, P=0.021). This review demonstrates the impact of advocacy not only on resource mobilization but also on the epidemic itself.



Source: Oberth, G., Mumba, O., Bhayani, L. & Daku, M. (2016). Donor Agendas, Community Priorities and the Democracy of International HIV/AIDS Funding. Centre for Social Science Research (CSSR) Working Paper No. 372. ISBN: 978-1-77011-359-6. Published by the University of Cape Town, South Africa. Online at http://www.cssr.uct.ac.za/pub/wp/372

CASE STUDY 3

CIVIL SOCIETY ADVOCACY IN SOUTHERN AFRICA LEADS TO FIRST REGIONAL GRANT TO ADDRESS TUBERCULOSIS IN THE MINING SECTOR

In 2008, ARASA convened a regional meeting on mines, TB/HIV and migrant labor in Southern Africa, attended by representatives from the mining industry, mining unions, public health experts, South African government departments, and various national and international NGOs. The meeting developed concrete policy and programmatic recommendations for interventions to address the increased incidence of TB in labor-sending countries because of migrant workers returning from South African mines. Since then, ARASA has mobilized civil society organizations, the media and networks of ex-miners in labor-sending countries, to demand better conditions for mineworkers in gold mines in South Africa, as well as adequate compensation for miners who contract lung disease. In addition, ARASA's documentation of challenges in the cross-border TB management of migrant workers was used to support litigation for compensation and legislative reform of the compensation parameters governing TB and the mines in South Africa.

In 2011, the TB and mines campaign gained significant momentum after the precedent-setting judgment by the South African Constitutional Court in early 2011. In the compensation case of former miner, Thembekile Mankayi, it was ruled that ex-miners can seek legal redress and compensation from mining companies for contracting occupational lung disease, including silicosis and TB. Also in 2011, the South African government called for an entire overhaul of TB and mines policy with stakeholders within the mining industry to ensure a cross-border management of TB in Southern Africa.

ARASA was invited to participate on the Technical Working Group of the Southern Africa Development Community (SADC) Secretariat for the development of the SADC TB and Mines Declaration and Code of Good Practice in 2012. The SADC TB and the Mines Declaration was endorsed by SADC heads of government and state (except South Africa, Madagascar and Namibia, who were absent) in August 2012. The inclusion of ex-mineworkers as a body in the SADC Technical Working Group ensures that this key population can advocate on issues themselves and present their human rights concerns.

In 2013, with ARASA's support, three national ex-miner bodies from Swaziland, Mozambique and Lesotho registered a regional ex-miners body called the Southern African Miners Association (SAMA). ARASA has worked with SAMA to ensure that their activities are profiled in the media, to mobilize public support for the court cases, as well as push for compensation for ex-miners and widows in labor sending countries in the region.

The media campaign included a press conference held on 20 April 2013 in Johannesburg, ahead of the Anglo American Annual General Meeting (AGM) in the UK, and a co-authored letter delivered to the shareholders of Anglo American during the AGM. In October 2013, ARASA issued a statement to welcome the announcement of a landmark pay-out by Anglo American South Africa to 23 former mine workers. The ex-miners were suing the company for failing to provide protection from dangerous levels of dust created by deep-level gold mining, which resulted in them acquiring occupational lung diseases, including tuberculosis (TB), while in its employment. ARASA also connected the lawyers with experts who were part of the expert witness panel, as well as with other partners in these countries, including ex-mineworker associations. Since 2014, ARASA has worked with stakeholders towards the attainment of the Global Fund's first grant to address TB in the mining sector, through its position as civil society representative on the Regional Coordinating Mechanism (RCM) for the US $ 30 million TB in the mining sector grant, which was awarded in 2016.

Advocacy and influence in national planning and decision-making processes is another critical area where community responses have shown significant impact. In **Belarus**, before the national Universal Access consultation in 2010, UNAIDS shared a preliminary document on indicators and coverage. Based on these, the Belarusian People Living with HIV Community and Belarusian Association of Non-Profit Organizations Countering HIV/AIDS organized a community caucus to reviewed national data, and develop positions on indicators. Because of this caucus, representatives advocated for higher targets for ART, despite resistance from the government.[75] From 2010 to 2013, ART coverage in Belarus increased by more than 70%.

PART III Monitoring and Accountability

There is also evidence of impact from advocacy from outside the health industry. In the United States, an analysis of the level of city expenditures on housing and community found that the political maturity of advocacy organizations has a statistically significant positive effect on local housing and community development expenditures. This suggests that organizations with more experience in advocacy may be more effective in influencing decisions and outcomes. Based on these results, there is a rationale for increasing funding for advocacy – and advocacy organizations – to stimulate other investments.[76]

Strong accountability mechanisms that revolve around the meaningful involvement of community groups, civil society and key populations have been shown to be effective at achieving improved performance. Importantly, community monitoring initiatives, score-carding projects, participatory budgeting, and community research and knowledge production have been clearly and directly linked to improved health outcomes in many places.

The International Treatment Preparedness Coalition (ITPC) has established Community Treatment Observatories in East Africa, West Africa, Central Africa and Latin America. Emerging evidence (since the project began in 2014) is beginning to confirm the impact of this community monitoring approach as a powerful accountability mechanism for leveraging additional domestic resources towards improving treatment access. For example, following ITPC-**Central Africa** (ITPC-CA) meetings with community activists and written memoranda, and public statements and position papers on the negative impacts of stock-outs in Cameroon in 2013, the Presidency of Cameroon and other funders, including the World Bank allocated more than US $24 million to the Ministry of Health for emergency procurement of ARV. Importantly, this also leveraged domestic funds of US $10 million allocated by the Presidency.

Second, ITPC's existing sub-regional community treatment observatory in **West Africa** has successfully prompted the National AIDS Secretariat in The Gambia to dedicate 60% of Global Fund resources to treatment (a proportion far greater than the regional average).

75. ICASO (2015). Working Together: a community-driven guide to meaningful involvement in national responses to HIV. Page 30.
76. Yerena, A. (2015). The Impact of Advocacy Organizations on Low-Income Housing Policy in US Cities. Urban Affairs Review, 51(6), 843-870.

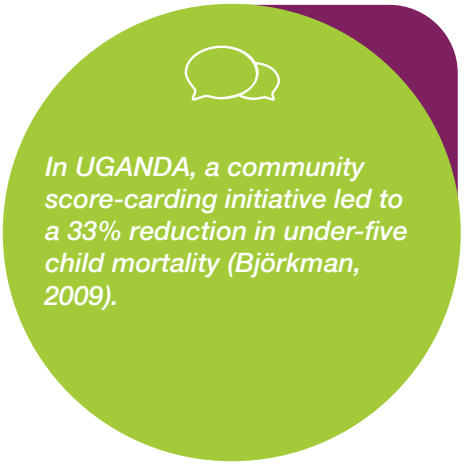
In a third example, ITPC's East African treatment observatory held a media briefing on PLHIV concerns over the looming shortage of TB medications in Kenya in the last quarter of 2014. Immediately following the news coverage, the Government of Kenya allocated US $3.18 million to the Ministry of Health for emergency procurement of first line TB drugs to ensure there would not be any further stock-outs.

In Guatemala, ITPC's community treatment observatory led to CD4 and viral load testing being offered in facilities where they were not previously available. The observatory also led to regular stock of the HIV drug Maraviroc, after nine months without this medicine.

A community monitoring model in Orissa, India, was successful in generating demand for rights and better services among local women. This accountability model was based on public hearings, and included a collaborative effort of local women, intermediary actors (such as public figures), health providers and government.[77] This model involved actors along the entire continuum of community responses (Recall Figure 3). Increasing demand for quality services is necessary to reach the Fast Track targets.

In another example from India, community-based monitoring of health facilities led to significant improvements in service provision. After the first round of surveys, an average 48% of health services were rated as "good" by the community. This increased by 13 percentage points to 61% after the second round of surveys. After the third round, 66% of health services received a "good" rating from the community monitors.[78]

In a Ugandan study, improved child health outcomes and improved performance of health facilities was recorded as the result of a community score-carding initiative.[79] Specifically, this accountability mechanism had direct observable improvements in health, such as a 33% reduction in under-five child mortality and a 0.14 z-score increase in child weight. The community score card also led to a 20% increase in the use of services, with health workers exerting higher efforts to serve the community. This benefit was documented as much as a year after the intervention period. Importantly, the improved service delivery outcomes were said to be related to strong engagement of local CBOs and local health professionals in the community monitoring experiment.



Another community monitoring example with a participatory budgeting approach led by communities is that of Brazil. This model has been linked to improved living conditions and better allocation of resources on health-promoting priorities such as basic sanitation and waste removal.[80] There was a significant reduction in the infant mortality rates among municipalities that adopted participatory budgeting. Based on this example, the study's authors concluded that community-based monitoring can improve both the efficiency and effectiveness of health services, positively impacting how local resources are spent, as well as living standard outcomes.

77. Papp, S. A., Gogoi, A., & Campbell, C. (2013). Improving maternal health through social accountability: A case study from Orissa, India. Global public health, 8(4), 449-464.
78. Kakade, D. (2012, January). Community-based monitoring as an accountability tool: Influence on rural health services in Maharashtra, India. In BMC proceedings (Vol. 6, No. Suppl 1, p. O9). BioMed Central Ltd.
79. Björkman, Martina, and Jakob Svensson (2009). "Power to the People: Evidence from a Randomized Field Experiment on Community-Based Monitoring in Uganda." Quarterly Journal of Economics, 124, 735-769.
80. Gonçalves, S. (2014). The effects of participatory budgeting on municipal expenditures and infant mortality in Brazil. World Development, 53, 94-110.

In the Brazil study, the authors suggest that the significant declines in infant mortality documented in association with the participatory budgeting was likely, because of external changes to sanitation. This indicates that community monitoring and accountability in other sectors can have a positive spillover effect in health. As such, community monitoring of education, inequality, human rights violations, among others – in other words, community responses that lie outside the formal health sector – may also have a positive effect towards reducing the burden of HIV.

In Pakistan, APN+ has created a community-led surveillance program on HIV/hepatitis C co-infection to fill in the gap in data and to use community monitoring to push for better access for treatment. The initiative is focused on the registration of Sofosbuvir, a new hepatitis C drug that represents a major breakthrough in treatment effectiveness and acceptability.[81]

A systematic review of 21 papers on community-led social accountability initiatives highlights the importance of documenting and cataloging evidence of impact for these initiatives.[82] This review concludes that the relationship between groups or committees was linked to the level of impact achieved by community monitoring activities. In other words, the importance of the relationships discussed in Part I of this paper – network and linkages – are also vital for achieving positive results from community monitoring and accountability.

81. Robert Carr Network Fund (RCNF) (2015) Accomplishments and Results: Civil Society Networks Making a Difference with Dedicated Funding. Page 3. Online at http://www.robertcarrfund.org/wp-content/uploads/2015/09/Accomplishments-and-Results.pdf?2d17e2
82. Molyneux, S., Atela, M., Angwenyi, V., & Goodman, C. (2012). Community accountability at peripheral health facilities: a review of the empirical literature and development of a conceptual framework. Health policy and planning, 27(7), 541-554.

CASE STUDY 4

COMMUNITY MONITORING AND PARTICIPATORY BUDGETING LEADS TO IMPROVED ACCESS TO NEEDLE AND SYRINGE PROGRAMS FOR PEOPLE WHO USE DRUGS IN KAZAKHSTAN

In 2014, the community of people who use drugs in the city of Taldykorgan, Kazakhstan, conducted community monitoring on the availability and quality of harm reduction services, particularly needle and syringes programs. This work was supported by the Eurasian Harm Reduction Network (EHRN) under the Regional Program "Harm reduction works - Fund it!" (funded by the Global Fund.)

A first-hand report from Natalya Zholnerova, of the Taldykorgan-based community organization Amelia, reveals just how effective monitoring and accountability work can be when it is led by affected communities:

"We evaluated 9 needle and syringe programs in the Almaty Region, and discovered the low quality of services. Only 4 out of 9 programs were "functioning." The PUD clients were not even aware of the existence of the other 5. Supplies did not meet the needs of the PUD community. The HIV epidemic in the country is at the concentrated stage, which means that it mainly spreads among vulnerable groups. And people who use drugs do not have access to high-quality sterile materials and counselling.

Throughout 2015 we have been working on a goal to include a PUD community representative in the State Working Group developing the budget for the procurement of commodities for the needle and syringe programs, so that we could influence the quality of harm reduction programs. During the supervisory visit of CCM representatives to the Almaty Region, we announced the results of the monitoring of harm reduction programs by the community. As a result of this, as well as other hard advocacy work, including writing letters and making phone calls, local advocacy efforts, various conflicts and compromises, the PUD community representative was included in the State Working Group. Consequently, the materials required for preventing HIV which meet the needs of the community were procured through the latest tender."

There is strong evidence of impact for how needle and syringe programs lead to reduced HIV incidence. A recent cross-national study of 28 countries has shown significant associations between years of NSP implementation and lower incidence rates of HIV among people who use drugs.* Importantly, this study also found that the greater proportion of GDP that was spent on healthcare was associated with a decrease in logged incidence rates of HIV. This provides strong impact backing for Natalya's success story. Community monitoring to ensure the functionality of program sites, and participatory budgeting to ensure funding is directed to the right budget lines, has a clear impact on the health and lives of people who use drugs in Kazakhstan, and other key and vulnerable populations around the world.

**Marotta, P. L., & McCullagh, C. A. (2016). A cross-national analysis of the effects of methadone maintenance and needle and syringe program implementation on incidence rates of HIV in Europe from 1995 to 2011. International Journal of Drug Policy. In press.*

CASE STUDY 5

COMMUNITY MONITORING LEADS TO IMPROVED ACCESS ART FOR PEOPLE LIVING WITH HIV IN MALAWI

Since 2008, the AIDS and Rights Alliance for Southern Africa (ARASA) has provided financial and technical support on a 2-year cycle basis to partner organisations hosting HIV, TB and Human Rights Training and Advocacy Programmes in the Democratic Republic of Congo, Botswana, Swaziland, Lesotho, Mozambique, Zambia, Tanzania and Zimbabwe. The goal is to build a cadre of knowledgeable civil society leaders across the region as the basis of a broad social mobilization around the right to health and accountability of governments and other institutions to their international, regional, and national legal obligations for health and human rights. In each country, ARASA has supported the training of 25 Community Health Advocates (CHAs) from affected communities, to understand, participate and advocate for their health and rights related to HIV and TB. The CHAs receive a monthly stipend and are attached to local clinics, implementing various training and awareness-raising activities, in addition to monitoring access to services and commodities, as well as human rights violations at their local clinics. The findings of the CHAs are fed through to the national level to inform advocacy campaigns on priorities identified by ARASA partners in the country. Good practice documentation on the program in Malawi captured the impact of the CHAs as follows:

Angry communities in Karonga District chase a corrupt health care provider

An uninformed citizenry is dangerous to the nation, they say. This rang true in Karonga, a district in the Northern part of Malawi. Life for most people living with HIV in Kasoba and other surrounding areas was hell as they rarely received their ART drugs as prescribed. The local health facility would always run out of the drugs, despite enough drugs being sent to the facility every month. As a result, HIV and AIDS-related deaths increased in the area. Even worse, those who travelled long distances to other health facilities were being denied access to drugs by health care officials, saying they could only access the drugs at their facility in Kasoba. Clueless, communities simply resigned to their fate.

But all this was before a capacity building training on human rights, HIV/AIDS and TB, facilitated by the CHAs for Kasoba CBO. After the training and subsequent awareness raising campaigns in the area, communities started realising they have rights, including right to health. The activities by Kasoba CBO fired up the community members who decided to do something about the missing drugs at their health facility. Community members investigated the missing of drugs and found out that an official working at the facility was selling the drugs, including ART drugs, to private traders. This infuriated the community members who called for meeting with the Karonga District Health Officer and the accused officer.After thorough discussions, the community members unreservedly demanded the immediate removal of the health care provider. Within a month, the officer was replaced by another. The situation returned to normal at the facility as people living with HIV were able to once again access ART drugs at the facility.

An external evaluation conducted in 2012 found that ARASA partners in the focus countries agreed that the country programs led to positive results in their countries.

CONCLUSIONS

1

STRONG COMMUNITY RESPONSES LEAD TO IMPROVEMENTS IN THE OVERALL HIV RESPONSE, INCLUDING STRENGTHENING SYSTEMS FOR HEALTH.

Communities drive progress towards universal access, raise awareness of the rights of the most vulnerable and marginalized, make use of innovate communications, and motivate other civil society health movements. Evidence has shown that community responses in health have positive spillover impact on the formal health sector, as well as other development sectors.

2

COMMUNITY RESPONSES ARE NECESSARY FOR SCALE-UP, ESPECIALLY TO REACH KEY AND VULNERABLE POPULATIONS.

Effective community responses typically involve members of the community they serve – people living with HIV, young people, gay men and other men who have sex with men, sex workers, people who use drugs and transgender people – in all aspects of programs. Reaching key and vulnerable populations is heavily dependent on well-funded community networks and peer groups.

3

COMMUNITY RESPONSES LEAD TO TECHNICAL AND ALLOCATIVE EFFICIENCY GAINS, REACHING MORE PEOPLE FOR LESS MONEY.

Investing in community responses can be cost saving on several fronts. There is evidence of cost saving from stigma reduction, community adherence and support groups, groups that form to collect medicines, and advocacy for generic medicines among others. There is also evidence of increased resource mobilization as well as more appropriate resource allocation, because of community-led advocacy and monitoring and accountability work.

Ensuring equal access to HIV services also depends on continuing to mobilize and engage people living with HIV and populations left behind as a force for transformation in governing, designing and implementing the response. Community-led networks and organizations (especially of people living with HIV, women, young people and key populations) must be free to self-organize and empowered financially and politically to serve as advocates, accountability watchdogs and full partners.

RECOMMENDATIONS

1

FUND COMMUNITY RESPONSES NOW, TO SECURE THE RETURNS FROM 30 YEARS OF INVESTMENTS ALREADY MADE AND TO SAVE MONEY IN THE FUTURE.

Community responses are currently underfunded at the most critical funding juncture in the AIDS response yet. This can risk reversing the gains made in the epidemic to date, as well as potentially waste 30 years of investments. To harness and leverage existing accomplishments, investment in community responses is necessary. However, such investment needs to be made more strategically, with the role of non-service delivery interventions taken more seriously. Along with money, well-resourced community responses also mean ensuring that these initiatives have sufficient access to human capital, technical assistance, and long-term mentoring and support.

2

PERFORM BETTER RESOURCE TRACKING OF INVESTMENTS IN COMMUNITY RESPONSES.

Because types of community systems and responses vary widely, it is very difficult to track investments in such activities. Accurate and up-to-date resource tracking is an important part of making the case for increased investment. Resource tracking should include donor and government funding, as well as resources from within communities, such as membership based associations, which raise community-level capital. In one good example, an analysis of investment in community responses in 50 Global Fund grants is currently being conducted by the Global Fund Secretariat.

3

CONDUCT MORE FREQUENT AND MORE RIGOROUS IMPACT ASSESSMENTS FOR COMMUNITY RESPONSES.

While there is some evidence of impact for non-service delivery community responses, we need to improve the evidence base to motivate the necessary levels of investment. Tools exist to support documentation and assessment of non-service delivery community responses:

TOOLS FOR MEASURING THE IMPACT OF NETWORKS AND LINKAGES

- Assessing Non-profit Networks Prior to Funding: Tools for Foundations to Determine Life Cycle Phase and Function[83]
- Do Networks Really Work? A Framework for Evaluating Public-Sector Organizational Networks.[84]

TOOLS FOR MEASURING THE IMPACT OF ADVOCACY AND INFLUENCE

- Measuring Up: HIV-related advocacy evaluation training pack (Learner's Guide)[85]
- How to Influence Decision-Making Processes About Health (Video Toolkit)[86]
- Monitoring and Evaluating Advocacy: A Companion to the Advocacy Toolkit[87]

TOOLS FOR MEASURING THE IMPACT OF MONITORING AND ACCOUNTABILITY

- The Community Score Card Toolkit: A generic guide to improve quality of services[88]
- How do you do community monitoring? (Video)[89]
- Toolkit to Increase Accountability on African Health Policies[90]

Draft tools developed in 2015 with the Freemont Center and Southern African AIDS Trust, to track and assess community responses to the three diseases at the country level, are being tested.

The Global Fund Secretariat is also supporting the development and inclusion of tools to assess community responses and services in health facility assessment methodologies. For many non-service delivery elements of community responses, there is a need to develop more robust evaluation designs and carve out credible learning strategies to improve the evidence base with which we can motivate greater levels of investment (Figure 4, Figure 5).

83. Zorounian, P., Shing, J. and Hanni, K. 2011. 'Assessing Nonprofit Networks Prior to Funding: Tools for Foundations to Determine Life Cycle Phase and Function'. The Foundation Review, 3(1): 43-58.
84. Provan, Keith G., and H. Brinton Milward. 2002. Do Networks Really Work? A Framework for Evaluating Public-Sector Organizational Networks. Public Administration Review 61(4): 414-423.
85. Online at http://www.icaso.org/477-measuring-up-a-guide-for-facilitators_original/
86. Online at http://www.eannaso.org/news-centre/eannaso-aai-video-toolkit
87. Online at http://www.unicef.org/evaluation/files/Advocacy_Toolkit_Companion.pdf
88. Online at http://www.care.org/sites/default/files/documents/FP-2013-CARE_CommunityScoreCardToolkit.pdf
89. Online at https://www.youtube.com/watch?v=upc9S0tyYZ0
90. Online at http://www.aidsaccountability.org/?page_id=13582&projectid=13562

FIGURE 4: PATHWAYS FOR IMPROVING EVIDENCE OF IMPACT FOR COMMUNITY RESPONSES[91]

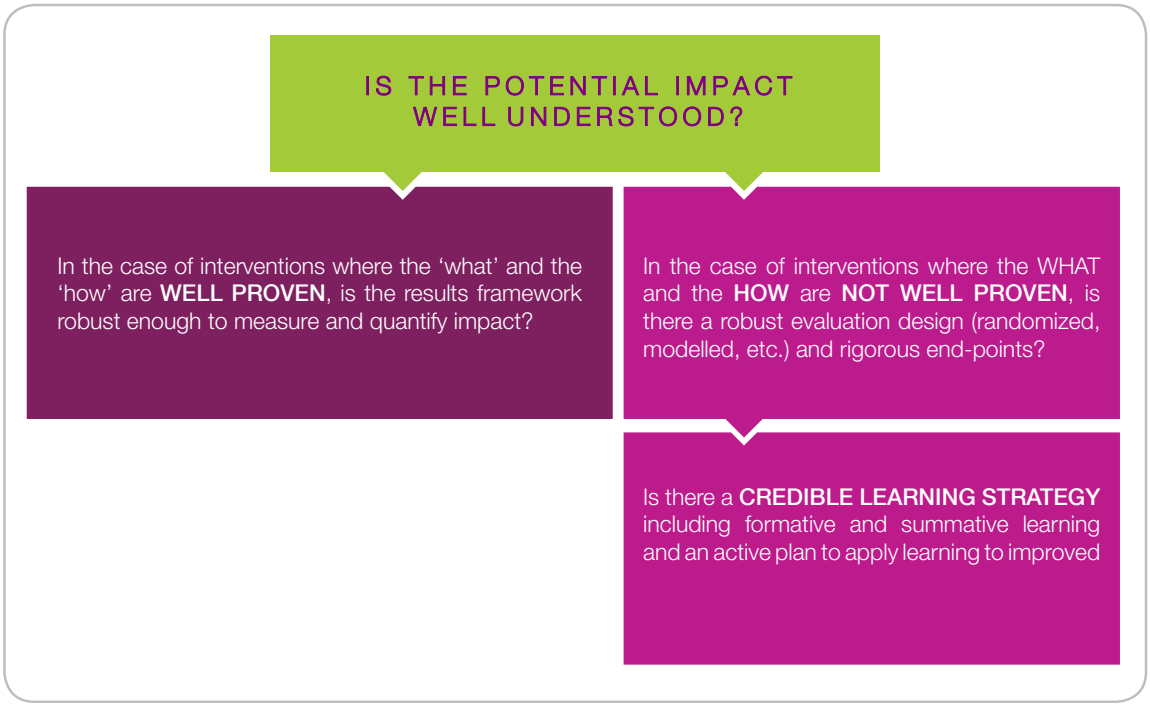
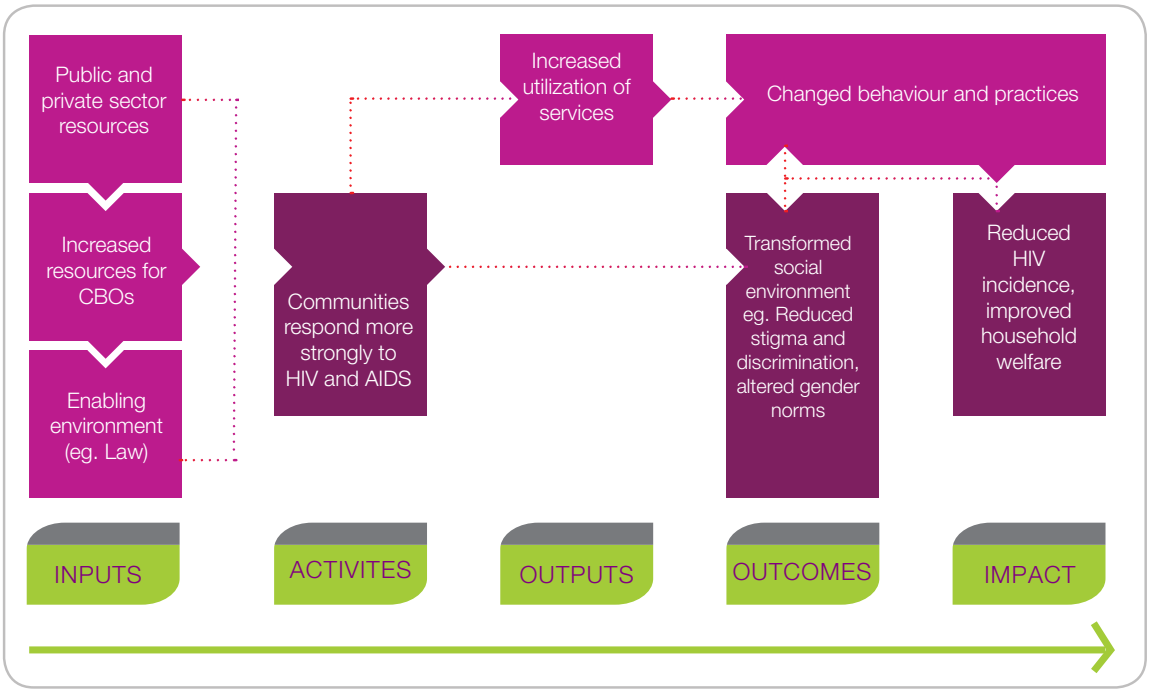


FIGURE 5: A CAUSAL-LOGIC THEORY OF CHANGE LINKING THE COMMUNITY RESPONSE TO IMPROVED HIV AND AIDS-RELATED RESULTS[92]



91. Adapted from the World Bank Group's Decision and Delivery Science model. Presentation given at the UNAIDS/HEARD East and Southern Africa (ESA) Advisory Committee on Investment, Efficiency and Sustainability Meeting, 9-10 March 2016, Durban, South Africa.
92. Rodriguez-Garcia, R. et al. (2011). Investing in Communities Achieves Results: Findings from an Evaluation of Community Responses to HIV and AIDS. World Bank: Washington D.C. Online at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213936/Investing-communities-achieve-results.pdf

ANNEXES

UNAIDS & STOP AIDS ALLIANCE (2015) COMMUNITIES DELIVER

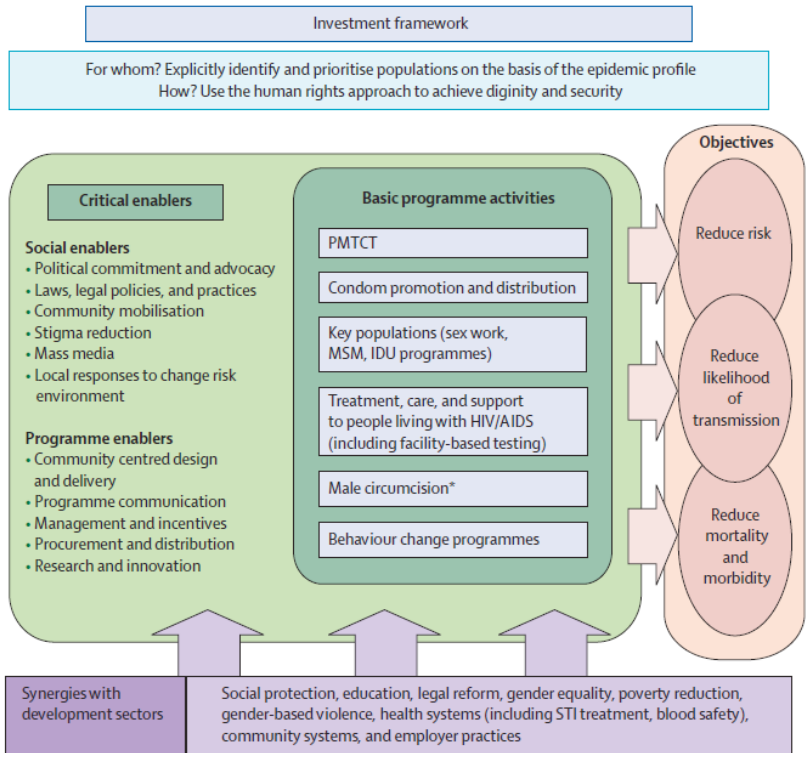
- Participation in decision-making and monitoring mechanisms, including monitoring the enforcement and impact of laws.
- Securing accountability and fulfilling a watchdog role.
- Advocacy and campaigning for HIV-specific issues.
- Advocacy and campaigning on broader human rights.
- Campaigning across society.

- HIV prevention.
- Confidential and voluntary HIV testing and counselling.
- HIV treatment.
- Demand creation and service uptake.
- Care and support.
- Rights and legal services.
- Task shifting and task sharing.
- Training and sensitization of service providers, including health-care personnel, lawmakers and law enforcement officials.

- Evaluation of programmes and services.
- Research on human rights, stigma, and discrimination.
- Improving "know your epidemic" and "know your response".
- Research on new treatment and prevention technologies.
- Research to reach key populations with community and rights-based policies and programmes.

- On-granting (forward granting).
- Resource mobilization.
- Community financing initiatives.

SCHWARTLÄNDER, ET AL. (2011). TOWARDS AN IMPROVED INVESTMENT APPROACH FOR AN EFFECTIVE RESPONSE TO HIV/AIDS



GLOBAL FUND (2014) COMMUNITY SYSTEMS STRENGTHENING FRAMEWORK

ENABLING ENVIRONMENTS AND ADVOCACY – including community engagement and advocacy for improving the policy, legal and governance environments, and affecting the social determinants of health.

COMMUNITY NETWORKS, LINKAGES, PARTNERSHIPS AND COORDINATION – enabling effective activities, service delivery and advocacy, maximizing resources and impacts, and coordinated, collaborative

RESOURCES AND CAPACITY BUILDING – including human resources with appropriate personal, technical and organizational capacities, financing (including operational and core funding) and material resources (infrastructure, information and essential medical and other commodities and technologies).

COMMUNITY ACTIVITIES AND SERVICE DELIVERY – accessible to all who need them, evidence-informed and based on community assessment of resources and needs.

ORGANIZATIONAL AND LEADERSHIP STRENGTHENING – including management, accountability and leadership for organizations and community systems.

MONITORING AND EVALUATION AND PLANNING – including M&E systems, situation assesment, evidence-building and research, learning, planning and knowledge management

UNAIDS 2016-2021 STRATEGY

ANNEX 2: GLOSSARY OF KEY TERMS

This glossary is adapted from definitions in the Global Fund's Community Systems Strengthening Framework and in the UNAIDS & Stop AIDS Alliance 2015 publication "Communities Deliver"

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.

COMMUNITY SYSTEMS are community-led structures and mechanisms used by communities through which community members and community-based organizations and groups interact, coordinate and deliver their responses to the challenges and needs affecting their communities. Many community systems are small-scale or informal. Others are more extensive – they may be networked between several organizations and involve various subsystems. For example, a large care and support system may have distinct subsystems for comprehensive home-based care, providing nutritional support, counseling, advocacy, legal support, and referrals for access to services and follow-up.

COMMUNITY SYSTEMS STRENGTHENING (CSS) is an approach that promotes the development of informed, capable and coordinated communities, and community-based organizations, groups and structures. CSS involves a broad range of community actors, enabling them to contribute as equal partners alongside other actors to the long-term sustainability of health and other interventions at the community level, including an enabling and responsive environment in which these contributions can be effective. The goal of CSS is to achieve improved health outcomes by developing the role of key affected populations and communities and of community-based organizations in the design, delivery, monitoring and evaluation of services and activities related to prevention, treatment, care and support of people affected by HIV, tuberculosis, malaria and other major health challenges.

COMMUNITY RESPONSES (in the context of HIV) are the collective of community-led activities in response to HIV. 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.

COMMUNITY-BASED ORGANIZATIONS (CBOS) are generally those organizations that have arisen within a community in response to particular needs or challenges, and are locally organized by community members. Nongovernmental organizations (NGOs) are generally legal entities, for example registered with local or national authorities. They may operate only at the community level or be part of a larger NGO at the national, regional and international levels. Some groups that start out as community-based organizations register as NGOs when their programs develop, and they need to mobilize resources from partners that will only fund organizations that have legal status.

CIVIL SOCIETY includes not only community organizations and actors, but also other nongovernmental, and non-commercial organizations, such as those working on public policies, processes and resource mobilization at national, regional or global levels.