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Breaking Taboo through Grassroots Advocacy

Inclusive HIV/AIDS Programming in the MENA Region

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EXECUTIVE SUMMARY

A lack of funding for human rights based HIV/AIDS advocacy programming in the Middle East and North Africa (MENA) has undermined the effectiveness of prevention strategies, leading to an alarming increase in HIV/AIDS cases across the region. This is because a lot of people living with HIV and AIDS (PLWHA) face stigma and taboo as a result of certain gender and sexual norms, which are institutionalised at the state level in legal and penal systems. Such approaches heightened the vulnerability of at-risk group by shifting the burden of responsibility on already marginalised communities such as men who have sex with men (MSM), LGBTQ, women, children and refugees/asylum seekers.

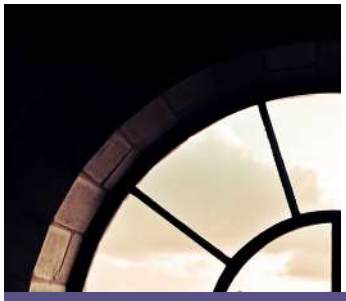
Because of this, we need to prioritise alternatives to state-centric prevention strategies, creating programmes that emphasise human rights-based responses led by PLWHA run community-based organisations (CBOs). In light of the extensive literature on this topic, and CTDC's own research, we believe that mainstreaming such approaches in the MENA region will be able to:

a) More effectively engage marginalised communities in HIV/AIDS prevention projects, leading to more inclusive programming overall.
b) Enhance the sustainability of projects by filling in critical gaps or changing existing narratives about the stigma and discrimination faced by vulnerable groups.
c) Empower communities, and enhance the capacity of PLWHAs to advocate for their rights.
d) Serve as a systematic feedback loop for state-centric approaches to improve their practice at the regional and international level.

CONTENTS

ABBREVIATIONS

ALCS	AIDS Control Association
ATL MST-SIDA	Association Tunisienne de Lutte contre les MST et le SIDA
CBO	Community-based organisation
CSO	Civil society organisation
CTDC	Centre for Transnational Development and Collaboration
GNP+	The Global Network of People Living with HIV/AIDS
INGO	Intergovernmental organisation
LM-LMST	Moroccan League for the Control of Sexually Transmitted Infections
M&E	Monitoring and evaluation
MENA	Middle East and North Africa
MSM	Men who have sex with Men
NGO	Non-governmental organisation
OPALS	Pan African Organisation for the Fight Against AIDS
PLWHA	People living with HIV and AIDS
PrEP	Pre-Exposure Prohylaxis
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Fund for Population Activities
USAID	United States Aid for International Development
WHO	World Health Organisation
WLWHA	Women living with HIV and AIDS



"The organisations have programs that include MSM and MSM sex workers. But no-one goes unless it's an emergency."

— Survey participant from CTDC's research

Statement of Issue

The MENA region receives only a fraction of the total global funds directed toward HIV/AIDS projects.[1] This is despite evidence that HIV/AIDS prevalence is rising in the region at much faster rates than anywhere else in the world, particularly among MSM, LGBT and other vulnerable groups such as women and children.[2] Programmes and strategies that do exist are currently limited in their ability to meet the needs of these populations due to their reliance on state-centric 'prevention strategies' whose focus is primarily on service provision only, lacking a complementary focus on advocacy and human rights. Indeed, in some instances, such approaches have had the unintended effect of exacerbating the stigma faced by key populations, placing the burden of responsibility on those with HIV/AIDS.[3] Subsequently, HIV/AIDS prevention strategies have become a key 'technique for social control'[4] to such an extent that many vulnerable communities are reluctant to seek help from medical professionals:

> *"The organisations have programs that include MSM and MSM sex workers. But no-one goes unless it's an emergency."*[5]

The consequences of this on already marginalised groups are numerous, but can more easily be explained in relation to societal norms and taboos relating to sexuality and gender roles. These roles are often enshrined in laws and in penal codes that punish certain sexual practices as against the 'norm of nature'. Other attitudes relating to gender place certain groups at heightened risk of violence, for example domestic violence, where physical lacerations or sexual exploitation can expose individuals to a heightened risk of HIV/AIDS infection.[6] Another key problem remains a lack of awareness about HIV/AIDS, or access to resources that may help treat or prevent infection, such as the use of PrEP medicines. CTDC research into community knowledge about HIV/AIDS testing among GBT individuals revealed that, even in Lebanon, which showed the highest rates of HIV/AIDS testing, 25% had never been tested/did not know their status.[7]

Ultimately, such taboos—and the ways in which they are informed by a number of prominent homophobic and/or misogynistic power structures—puts key populations at heightened risk of physical and psychological violence, reduces access to services, and undermines the dissemination of legal and medical knowledge. As such, it is the purpose of this policy brief to identify ways in which overcoming taboo through human rights-based and community-led advocacy efforts in the MENA region can and should be prioritised in HIV/AIDS programming. It does so by exploring a range of programme options and the various degrees of success certain approaches have had in the region more generally. It then presents some recommendations for future strategies. Ultimately, a key component that must also be considered is the extent of chronic underfunding both in the region more generally, and of human rights based strategies more specifically, despite evidence that such funding will have a significant impact in developing the HIV/AIDS advocacy campaigns of already active CSOs.[8,9]

In this way, it is essential that more funding is directed toward community-led human rights and advocacy projects so that the structural roots of stigma can be properly challenged. As such, this policy brief points to some of the ways in which such programming is both necessary and feasible in the context of the MENA region.

[1] Setayesh, Hamidreeza, Farzaneh Roudi-Fahimi, Shereen El Feki, and
[2] Ibid.
[3] GNP+ and UNAIDS. 2009. *Technical Consultation Report*. Positive Health, Dignity And Prevention. Amsterdam: GNP+.
[4] Himmich, Hakima. 2015. *The Rise of Harm Reduction in Morocco: Successes and Challenges*. Washington D.C.: Middle East Institute.
[5] CTDC. 2016. "GBT Livelihoods in the MENA Region". In *28th ILGA World Conference*.
[6] UNFPA, Global Forum on MSM & HIV, UNDP, WHO, USAID, and World Bank. 2015. *Implementing Comprehensive HIV and STI Programmes with Men who have Sex with Men: Practical Guidance for Collaborative Interventions*. New York (NY): UNFPA.
[7] CTDC. 2016.
[8] UNAIDS. 2015. *Sustaining the Human Rights to HIV: Funding Landscapes and Community Voices*. Geneva: Switzerland.
[9] 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 D.C.: World Bank.

Programme Options

State-centric prevention strategies

Early implementations of HIV state-centric prevention strategies were criticised for 'medicalising' and 'oversimplifying' the issue by advocating for an individual level of responsibility, resulting in an increased sense of alienation and stigmatisation of PLWHA as potential 'vectors of transmission'.[10,11] In doing so, structural and societal barriers to HIV/AIDS prevention, care, and treatment went unaddressed and the effectiveness of HIV prevention programmes were subsequently compromised. Identified at-risk populations—such as MSM, drug users, and female sex workers—share a "status...effectively criminalised by law", which renders them targets of discriminatory representatives of the state and other public institutions.[12,13]

Today, many HIV prevention strategies incorporate at least elements of human rights-based programming and increasingly recognise fighting against stigma and discrimination as a priority. Some states cooperate with INGOs in spearheading and implementing national strategies targeting legal and policy environments that encourage stigmatisation and criminalisation of PLWHA. One successful case study in the MENA region is exemplified by Morocco and its 2002-2005 National Strategic Plan. In contrast to its predecessors, the National Strategic Plan used a "participation, decentralisation, and a multidisciplinary and multicultural approach", resulting in notable achievements such as the affordability of antiretroviral therapy and the expansion of HIV testing and counselling to the entire population and all regions of the country.[14]

However, the success of this approach is conditional on the political will of states reflected not only on paper, but also in practice. In countries with environments that doubly stigmatise HIV/AIDS and certain groups on the basis of gender or sexual orientation, for instance, such strategies will be less effective.

CBO-led human rights-based strategies

In comparison to state-centric prevention strategies, human rights-based strategies led by CBOs have the primary advantage of acting quickly as "first responders".[15] With a history of implementing human rights-based interventions[16], making cost-effective use of comparatively limited resources, and consistent outreach to local communities, CBOs—often led by the beneficiaries themselves—can fill the vacuum of leadership without capacity issues such as lack of experience or social capital.

[10] GNP+ and AIDS. 2009.
[11] Anderson, Terje. 2004. "Expanding the Boundaries of Positive Prevention Programmes". In *Broadening The HIV Prevention Landscape: 4th Annual CAPS Conference*. San Francisco: University of California, San Francisco.
[12] GNP+. 2007. *Human Rights and HIV/AIDS: Now More than Ever*. New York: Open Society Institute.
[13] UNFPA, et al. 2015.
[14] UNAIDS. 2009. *Morocco: A National AIDS Response (Highlights)*. UNAIDS Best Practice Collection. Geneva: UNAIDS.
[15] UNAIDS and Stop AIDS Alliance. 2015. *Communities Deliver: The Critical Role of Communities in Reaching Global Targets to End the AIDS Epidemic*. Geneva: UNAIDS.
[16] UNAIDS. 2015.

The following subsections briefly outline different, successful approaches taken by CBOs in implementing human rights-based strategies in HIV/AIDS programming:

Filling in critical gaps in service provision

One of the primary goals of Morocco's National Strategic Plan was to extend confidential, voluntary HIV testing and counselling to people living in remote or rural communities. State officials and health authorities, which typically service big cities, partnered with three civil society organisations—ALCS, OPALS, and LM-LMST— to reach these areas. Each CSO chose a different strategy, which also depended on their respective organisational capacity. LM-LMST and OPALS integrated testing and counselling services into existing health facilities under the Ministry of Health "with the constraints that this entails"[17], whereas ALCS operated its own fixed service centres independent of state health facilities to preserve anonymity of service users as well as free mobile testing centres. In certain urban areas, the management of all or a part of the health facility was outsourced to OPALS.[18]

The success of varying strategies, taken by each organisation, underlines the need for a diverse range of human rights-based strategies to achieve a common goal. In other words, each CBO or CSO with their respective set of strategies can fill context-dependent critical gaps in service provision, thus allowing for more efficient targeting. In states where the capacity for service delivery is insufficient, partnership with such groups can prove to be invaluable. However, specialised targeting should not discourage a wider availability of service providers: the ability to *choose* the service provider whose approach best fits their needs and wants (among other options) could be a welcoming change to PLWHA.

Empowering legal, political, or economic literacy

CBOs have stepped in to assist PLWHA with legal, political, or economic literacy, thereby empowering PLWHA to navigate institutional environments hostile to their human rights on the basis of gender, sexual orientation, and so forth. To address the economic insecurity affecting WLWHA in Algeria, El Hayet founded by a woman living with HIV in 1998 started a microfinance programme in the remote and impoverished region of Tamanrasset. The programme consists of different vocational courses taught by respective specialists with a diploma to certify qualification upon completion, business management and marketing advice from national agencies, and the provision of loans of 40,000 to 120,000 Algerian Dinars (US $500-1,500). In addition, beneficiaries are educated on HIV knowledge by health professionals from a local hospital. By 2012, El Hayet trained 150 women in the region to become entrepreneurs, of which 20 have taken out loans.[19,20]

The economic and informational benefits speak for themselves: WLWHA have the potential to gain a more stable form of employment and access to necessary knowledge about their conditions. Less obvious but equally significant is the role CBOs play as a trustworthy intermediary between PLWHA and the public or private sector. This relationship can be characterised by mistrust or fear due to entrenched stigma and discrimination of HIV/AIDS relating to gender, sexual orientation, and other intersectional issues.

Changing narratives through human rights-based advocacy

In Tunisia, a SIDA funded ATL MST project integrated advocacy activities addressing stigma and discrimination faced by MSM into HIV prevention, treatment, and care strategies. The advocacy activities were tailored to the different needs of MSM subgroups, which were determined by the results of a qualitative study carried out by the organisation. In addition to having an on-site psychologist for mental health needs, ATL MST-SIDA opted for peer educators over health professionals to better preserve anonymity, informal safe social spaces for MSM to rely on for mutual support and dialogue, and a telephone hotline for HIV-related knowledge and advice to reach those unable to access their services in-person.[21] Similar to ATL, new community-based organisations, such as Association Tunisienne De Prévention Positive (ATP), have started filling the gender gap in human rights-based advocacy by working with groups other than MSMs, including women and trans people.

Advocacy in the form of lobbying or campaigning has the potential to catalyse transformative social changes, but advocacy in the quieter form of informal peer-to-peer support is also important. The form of advocacy undertaken by ATL MST-SIDA and ATP alleviates the isolation of at-risk populations who are coping with double stigmatisation, both in public and at home, and is able to better specialise in catering to mental health needs of the community. In addition, advocacy and prevention programmes that are both run and used by members of at-risk populations have the potential to effectively inspire community leaders and champions capable of producing long-term and sustainable change.

[17] UNAIDS. 2009.
[18] Ibid.

[19] UNAIDS. 2012. *Standing Up, Speaking Out: Women and HIV in the Middle East and North Africa*. Geneva: UNAIDS.
[20] UNAIDS. 2011. *Middle East and North Africa: Regional Report on AIDS*. Geneva: UNAIDS.
[21] Ibid.

Recommendations

In light of the various benefits and limitations of the different programmes considered above, CTDC recommends that for HIV/AIDS prevention strategies in the MENA region to be effective, the following points should be considered:

Overall framework

- *A cohesive, independent system of CBO-led human rights programming to limit the stigma and discrimination-based vulnerability of PLWHA:* CBO-led human rights-based strategies work effectively as a cohesive system relatively independent from state-centric institutions and entities, particularly in countries where vulnerable groups of PLWHA face stigma and discrimination.
- *Informal alternatives to objectively guarantee vulnerable groups of PLWHA confidentiality and anonymity:* Informal alternatives to HIV/AIDS service provisions should be equally prioritised alongside formal, state-based HIV/AIDS service provision to embolden vulnerable groups to seek out treatment, care, and support. Lack of *objective* guarantees of confidentiality, as opposed to relying on the individual good faith of health professionals, remains a key obstacle to seeking out testing or treatment in a context.
- *Normalisation of HIV/AIDS as an effective counter strategy:* Normalisation of HIV/AIDS should be featured and implemented as a key strategy to counter stigma, discrimination, and de-facto criminalisation of HIV/AIDS. The 'Positive Health' model championed by GNP+, an NGO led by PLWHA, offers a feasible, successful approach.
- *Beneficiaries as equal partners:* Vulnerable groups and the CBOs they lead should be equal partners in the programme design during the run-in period prior to project implementation. This has been proven effective in previous CTDC projects. Involving beneficiaries as leaders has a secondary benefit of acting as a feedback loop.

Specific programmes

- *Community centre:* Community centres serve as a viable, peer-led *informal* alternative to formal, state-centric institutions by offering a safe space for advocacy, education, and peer support. In countries where vulnerable groups face a discriminatory legal and policy environment with respect to HIV/AIDS and other intersectional issues, the services provided by these community centres should be broadly based and relevant to general community concerns.
- *Mental health/psycho-social support service provision and delivery:* Mental health should be given more priority and integrated as a part of HIV/AIDS service provision. In particular, counselling programmes should be led or include PLWHA for more effective treatment, care, and support.
- *Legal, regulatory, and economic empowerment:* Pressuring governments to pass anti-discrimination laws should be supplemented by organisations specialising in the education or training of legal, political (regulatory), and economic literacy of vulnerable groups. HIV/AIDS is an intersectional issue as such many vulnerable groups face double stigmatisation.

Benefits

- *Inclusivity of HIV/AIDS programming:* HIV/AIDS programming should prioritise a community-led approach to strategy development in order to ensure long-term project inclusivity is enhanced. This improves the effectiveness of advocacy campaigns and ensures that no key population is left behind.
- *Capacity of CSOs improved:* HIV/AIDS programming should encourage CSOs to network with one another as a means of enhancing and coordinating advocacy campaigns and improving the overall effectiveness of prevention strategies.
- *Capacity of CSOs improved:* HIV/AIDS programming should also encourage CSOs to compile a database of friendly legal and medical services as part of the networking. This should also be accessible to non-internet and internet users, and done in consultation with both service providers and service users through workshops and training sessions run by CSOs and community champions.
- *Root causes of violence tackled:* HIV/AIDS programming should recognise the important link violence has with risk of HIV/AIDS infection by working to stamp out taboo as part of any effective prevention strategy. This requires strategies to be designed in coordination with at-risk populations, who might otherwise be excluded from

such a process - an outcome which itself is violent, and detrimental to the formation of any long-term and sustainable change.

- *Good governance and institutional accountability improved:* Empowering CSOs and key-populations to advocate for their legal and medical rights will encourage greater degrees of institutional accountability, thus enhancing the effectiveness of pre-existing state-centric prevention strategies, and allowing for a greater degree of good governance in general.
- *Further research completed leading to more sustainable impact:* HIV/AIDS programming in the MENA region should work substantial M&E work into their capacity building curriculums. This will ensure that advocacy projects can build on their successes, and work to improve both knowledge about HIV/AIDS work being done in the region, and develop models of best practice that can be scaled up in future projects.

Outcomes

- *Community champions:* Engaging CSOs in ways recommended by this policy brief will enable community champions to more effectively advocate for their rights, leading to sustainable long-term change, innovation in advocacy techniques, and the fostering of more effective care strategies.
- *Regional level networking of advocacy strategies:* Bottom-up approaches to CSO advocacy within HIV/AIDS programming should encourage organisations to network at the regional level, leading to more effective integration of advocacy strategies, and collaboration between and within key-population groups.

M&E

- *Structural focus mainstreamed into M&E:* Monitoring and evaluation should focus on a broader structural focus in order to study the impact of HIV/AIDS on certain populations otherwise overlooked by specific, project only, evaluations (Garcia et al.)
- *More effective indicators for greater impact:* M&E should be quality-assurance orientated by prioritising the following key indicators: inclusivity, impact, accessibility, extent of community engagement, quality of service, and impact on community connectedness. These will require assessments that extend beyond a project only focus, ensuring that any consideration of a project's impact is considerate of the wider community (those not engaged in the project), and the extent to which the project has encouraged inclusivity.
- *Recognition of unintended consequences:* In order to limit the possibility that projects may enhance taboo, create backlash, or inhibit the effectiveness of overall advocacy strategies, M&E work should prioritise an assessment of unintended consequences through a wider analysis of project impact within non-governmental, governmental, third sector, private sector and community-level circles.