

Community-Initiated  
HIV Testing Services  
in South Asian Cities for  
Men who have Sex with Men  
and Transgender Women

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RAPID ASSESSMENTS OF  
COLOMBO, DHAKA, KATHMANDU, LAHORE, AND MUMBAI

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## Acronyms and Abbreviations

AAS	Ashar Alo Society
AEM	Asian Epidemic Model
AIDS	Acquired Immunodeficiency Syndrome
APCOM	Asia Pacific Coalition on Male Sexual Health
APLHIV	Association of People Living with HIV/AIDS
APN+	Asia Pacific Network of People Living with HIV/AIDS
ART	Antiretroviral therapy
ARV	Antiretroviral
BCC	Behaviour Change Communication
BDS	Blue Diamond Society (Kathmandu)
BMGF	Bill & Melinda Gates Foundation
BRH	Bangkok Regional Hub
BSMMU	Bangabandhu Sheikh Mujib Medical University (Dhaka)
BSWS	Bandu Social Welfare Society (Dhaka)
CBO	Community-based organization
CHW	Community health worker
CSS	Community systems strengthening
DIC	Drop-in centre
DMCH	Dhaka Medical College and Hospital
DMHS	Dostana Male Health Society (Lahore)
ELISA	Enzyme-linked immunosorbent assay
FHI 360	Family Health International 360
FPAN	Family Planning Association of Nepal
GARPR	Global AIDS Response Progress Reporting
GIPA	The Greater Involvement of People Living with HIV
Global Fund	The Global Fund to Fight AIDS, Tuberculosis and Malaria
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
HCP	Healthcare provider

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HRW	Human Rights Watch
HTS	HIV testing services
iccdr,b	International Center for Diarrhoeal Disease Research, Bangladesh
ICTC	Integrated Counselling and Testing Centre
IDAHOT	International Day Against Homophobia and Transphobia
IEC	Information, Education, and Communication
IGLHRC	International Gay and Lesbian Human Rights Commission
IPPF	International Planned Parenthood Foundation
KSS	Khawaja Sara Society (Lahore)
KPK	Khyber Pakhtunkhwa (provincial municipality, Lahore)
MDACS	Mumbai District AIDS Control Society
MOH	Ministry of Health
MOHFW	Ministry of Health and Family Welfare
MSA	Multi-country South Asia
MSF	Médecins Sans Frontières
MSM	Men who have sex with men
MSW	Male sex worker
NACO	National AIDS Control Organisation (India)
NACP	National AIDS Control Programme (India/Pakistan)
NASP	National AIDS/STD Programme (Bangladesh)
NGO	Non-governmental organization
NMC	Nepal Medical Council
NMHA	Naz Male Health Alliance (Lahore)
NSACP	National STD/AIDS Control Programme (Sri Lanka)
NSASC	National Centre for AIDS and STD Control (Nepal)
PEP	Post-exposure prophylaxis (PEP)
PICT	Provider-initiated counselling and testing
PLHIV	People living with HIV
PMTCT	Prevention of mother to child transmission
PR	Principal Recipient
PrEP	Pre-exposure prophylaxis
PWID	People who inject drugs
PWUD	People who use drugs

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RDT	Rapid diagnostic test
RFE/RL	Radio Free Europe / Radio Liberty
SEARO	South-East Area Regional Office
SOGI	Sexual Orientation and Gender Identities
SR	Sub-recipient
STI	Sexually transmitted infection
TG	Transgender
TI	Targeted intervention
TOT	Training-of-trainers
UAI	Unprotected anal intercourse
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing
VMMC	Voluntary medical male circumcision
WHO	World Health Organization
WMA	World Medical Association
WSG	Women Support Group (Sri Lanka)

## **Executive Summary**

The Multi-Country South Asia (MSA) HIV Programme funded by the Global Fund has an overall goal to reduce the impact of, and vulnerability to, HIV among men who have sex with men (MSM) and transgender women by strengthening their community systems. With an estimated 54% of HIV infections remaining undiagnosed in 2014, detecting, treating, and preventing HIV in MSM and transgender women are important components of community systems to improve, as they will lessen the impact and vulnerability of these communities to HIV.

In this respect, Country Sub-Recipients (SRs) of the MSA HIV programme have been implementing community-initiated HIV testing services (HTS) among MSM and transgender women in Mumbai, Lahore and Dhaka. With the aims of increasing HIV testing, treatment and prevention in these key populations, the community-initiated HTS offered include outreach activities that provide HIV prevention information and materials, primarily condoms and lubricants, to their municipal communities. However, the expected increase in HIV testing, providing correct test results, and effective linkage into care of these HTS have been slow to materialize. As a Regional SRs of the programme, Asia Pacific Network of People Living with HIV/AIDS (APN+) conducted this rapid assessment on existing community-initiated HTS in the municipalities of Mumbai, Lahore and Dhaka to shed light on the situation and yield insight on the sustainability of these programmes; as well as explore the feasibility of expanding community-initiated HTS in these cities, and at Kathmandu and Colombo.

Each of the five cities was assessed separately using a bespoke rapid assessment framework that explored how well existing programmes had been fulfilling their core functions as community-initiated HTS, and the moderating factors that impacted their delivery of HTS. In general, the assessment had an overarching aim to seek out enabling environments for municipal HIV responses among MSM and transgender women; with the rationale that certain social conditions were positive moderators of HTS and would be required for HTS to flourish in communities. Findings were then contextualized with data from focus group discussions held in each city, which had reached a total of forty-five MSM and transgender women; twenty-nine of whom were living with HIV. Discussions had been audio recorded with prior informed consent, which were subsequently transcribed and translated into English for analysis.

From the perspective of moderating factors, Mumbai emerged as the most enabling city to sustain community-initiated HTS among MSM and transgender women, and Lahore as the least enabling city. However, of the three HTS programmes that were assessed – comprising the Shakti Clinic (ICTC) in Mumbai, the DMHS and KSS services in Lahore, and the BSWS-AAS collaborative service in Dhaka – only the Dhaka service had fulfilled its core functions as a community-initiated HTS. The service was also the only HTS assessed to feature a synergistic collaboration between a community-based organization for MSM and transgender women, and an association of PLHIV. Unlike the other two programmes, the BSWS-AAS collaborative service had been successful in yielding effective HIV test results as well as linkages into treatment and care by attracting individuals who were infected with HIV to undergo testing and accept treatment; thus, contributing to the reduction of

undiagnosed infections among MSM and transgender women in Dhaka, and putting the notion of treatment as prevention into successful practice.

Subsequent analysis pointed to the inclusion of PLHIV in the BSWS-AAS collaborative HTS as key to their success. Contextualized findings based on cultural theory presented a precarious situation for MSM and transgender women living with HIV in their own communities. It was commonplace for PLHIV in these communities to face HIV-related stigma and discrimination from members of their own communities, as well as from wider society; and included real possibilities of harassment and violence. These situations had underlined the cultures of fear, discrimination, misinformation, and the weaponizing of HIV, which were embedded in these communities. Thus, in the current antagonistic municipal environment, reliance on the strategies of outreach and reciprocity to generate demand for community-initiated HTS would likely not be effective in reaching individuals who were socially vulnerable, and were most in need of care and support. From the foregoing assessment, HIV could remain undiagnosed in certain groups of MSM and transgender women in the cities of South Asia and would likely be the corollary of the failure of current municipal HTS to improve HIV detection in these communities, link HIV-infected individuals effectively into treatment and care, and provide members of these communities who were most at risk of HIV with the full range of evidence-based HIV prevention strategies.

In conclusion, the assessment calls for increased efforts in the creation of more enabling municipal environments as a necessary step in tandem with the provision of HTS to MSM and transgender women communities. To ensure municipal HTS

programmes, including ones that are community-initiated, will be effective, sufficient advocacy must be in place to pressure local governments to prioritize the eradication of institutionalized stigma present in municipalities and instill the cultural value of professionalism among healthcare providers to deter them from discriminatory practices. HTS providers should also adopt the principles of the greater involvement of people living with HIV (GIPA) in their delivery of HTS to ensure the requirements and needs of PLHIV are met, which will undoubtedly generate the necessary demand for these HTS as observed in Dhaka. The assessment closes with five group-level programmatic recommendations, which have been adapted from successful social interventions to fit present contexts. These recommendations have been based on their potential as game-changers in the situations facing current community-initiated HTS in South Asian cities.

## Background

### Multi-Country South Asia HIV Programme

Phase two of the Multi-Country South Asia (MSA) HIV Programme is a regional HIV programme operating in seven countries. These countries are Afghanistan, Bangladesh, Bhutan, India, Nepal, Pakistan and Sri Lanka. The programme is funded by a grant from The Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). The Asia Pacific Network of People Living with HIV/AIDS (APN+) and the Asia Pacific Coalition on Male Sexual Health (APCOM) are the two regional Sub-recipients (SRs) under the United Nations Development Programme Bangkok Regional Hub (UNDP BRH) as interim Principal Recipient (PR). The overall goal of the programme is to reduce the impact of, and vulnerability to, HIV among men who have sex with men (MSM), *hijras*,<sup>1</sup> and transgender women communities through Community Systems Strengthening (CSS).<sup>2</sup>

### HIV testing services

HIV testing services (HTS) comprise the full range of services involved with HIV testing, which include the delivery of pre-test information and post-test counselling,

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<sup>1</sup> *Hijra* is a term used to describe a transwoman in South Asia, India in particular, and *hijras* have been known to define themselves as ‘not-men/not-women’ and as a ‘third-gender’.

<sup>2</sup> CSS is a concept championed by the Global Fund as a means of scaling up HIV responses by systematically engaging community groups and civil society organizations to mobilize in the AIDS response. See Global Fund. (2014, March). Information Note: Community systems strengthening.

HIV testing, quality assurance and correct test results.<sup>3</sup> Key to HTS are its linkages of individuals who test HIV positive to antiretroviral therapy (ART), care and support, and to evidence based prevention strategies among those who test HIV negative but may still be at increased risk of HIV. These strategies include the prevention of mother to child transmission (PMTCT), voluntary medical male circumcision (VMMC), and the offer of pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP).<sup>4</sup> HTS have generally been delivered in clinical settings through provider-initiated testing and counselling (PITC), also known as routine HIV testing. Newer models of community-based and community-initiated HIV testing are HTS that have been organized and implemented by, and within, communities rather than clinically. These newer models are attempts to reach individuals who do not currently participate in routine HIV testing. It is estimated that in 2014, 54% of people infected with HIV remain undiagnosed and unaware of their HIV status.<sup>5</sup>

### Importance of community-initiated HTS

Community-initiated HTS that target key populations have demonstrated to be effective in reaching the men who have sex with men (MSM) and transgender women communities, and particularly those who have never previously had an HIV test. Studies indicated that MSM and transgender women prefer community-based HTS, which include non-judgmental and gay-positive service providers, and offer a high

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<sup>3</sup> WHO. (2015, July). Consolidated guidelines on HIV testing services. Geneva: WHO: p.xvii.

<sup>4</sup> Ibid: p.2.

<sup>5</sup> Ibid: p.3.

degree of confidentiality.<sup>6</sup> Given that early HIV diagnosis and timely initiation of ART are essential in ensuring long-term health and survival of PLHIV, and preventing onward transmission of HIV,<sup>7</sup> the idea of community-initiated HTS for MSM and transgender women seemed to be among the best ways for both communities to achieve universal access to ART. However, recent data suggest that HIV testing levels are still low and less than half of MSM and transgender women have been tested in this region, and hence insufficient to link enough of the populations into treatment and care to halt and reverse the HIV epidemic in both these communities.<sup>8</sup> In order to be effective, community-initiated HTS would need to attend to the major disincentives to HTS uptake: perceptions and feelings of PLHIV stigma, the lack of perceived risk of infection especially among young MSM and transgender women, anxieties about a positive test result, and low levels of knowledge about HIV and AIDS.<sup>9</sup>

### Rapid assessments in five South Asian cities

This report is the result of rapid assessments of MSM and transgender women communities including PLHIV in five South Asian cities conducted by APN+ in its capacity as grant sub-recipient. Focusing on Mumbai in India, Lahore in Pakistan, Dhaka in Bangladesh, Kathmandu in Nepal, and Colombo in Sri Lanka (presented in

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<sup>6</sup> Ibid.

<sup>7</sup> WHO. (2013, June). *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for a public health approach*. Geneva: WHO.

<sup>8</sup> UNAIDS. (2014). *The Gap Report*. Geneva: UNAIDS: pp.209, 226

<sup>9</sup> See e.g. *ibid.*

the order of the narrative), the rapid assessments were meant to identify good practices of community-initiated HTS, and explore how to encourage the practice to take root in South Asia from the perspectives of MSM and transgender women, including PLHIV, in the five cities. As a result of the assessments, a roadmap towards the founding or scale up of replicable models of community-initiated HTS in the five cities is proposed. Two South Asian cities that were part of the MSA HIV Programme had been excluded from the rapid assessment due to security concerns (Kabul, Afghanistan), and budgetary constraints (Thimpu, Bhutan).<sup>10</sup>

### *Employing a cultural lens*

This report offers a perspective through the cultural lens to explore some of the key social organizations and communities in the municipal response to HIV among MSM and transgender women in South Asian cities. To instill a cultural lens, the report draws on the definitions of culture provided by Douglas, an anthropologist,<sup>11</sup> and employs a cultural theory pioneered by Douglas,<sup>12</sup> as well as her typology of municipal culture in responding to the self as risk-taker in the era of AIDS.<sup>13</sup> Culture, at its most basic, is jointly produced by humans in a continuous dialogue about a way

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<sup>10</sup> Justified by low estimates of HIV prevalence in MSM from newly acquired and unpublished UNAIDS data. The same study had not returned any HIV prevalence in transgender women.

<sup>11</sup> Douglas, M. (2004). Chapter Four: Traditional Culture – Let’s Hear No More About It. In *Culture and Public Action*. Rao V. and Walton, M. (Eds.). Stanford, CA.: Stanford University Press: pp.85-109.

<sup>12</sup> Douglas, M. (2004), op. cit: p.91; also Verweij, M. (2004). Chapter 5: Appendix to Douglas: Cultural Theory and Development Studies; same volume: pp.110-114.

<sup>13</sup> Douglas, M. (1992). The Self as Risk-Taker: A cultural theory of contagion in relation to AIDS. In *Risk and Blame: Essays in Cultural Theory*. London: Routledge: pp.102-121.

to live together;<sup>14</sup> which results in a system of values that generates social norms, a worldview that justifies them, as well as rules and sanctions to deter transgressing.<sup>15</sup> Culture mobilizes people into communities with shared values and norms, and gives them reasons to be constrained in configuration.<sup>16</sup> The cultural process that configures social organization is the interaction between four opposing tendencies, or cultural biases, in social relations: individualism, hierarchy, egalitarianism, and fatalism.<sup>17</sup> Cultural theory highlights the importance of preserving the distinct voices of each cultural bias to avoid widespread fatalism in any society.<sup>18</sup>

Using the cultural lens, the report will explore the cultural values and norms of MSM and transgender communities, the civil society organizations steering the HIV response in these communities, as well as the available cultural spaces for PLHIV in the municipal response. This will provide a cultural perspective of social relations from an egalitarian cultural bias that often gets drowned out of deliberations on municipal HIV responses by social organizations with a hierarchical cultural bias (such as government AIDS programmes), and individualistic cultural bias (such as international donors).

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<sup>14</sup> Douglas, M. (2004), op. cit.: p.107

<sup>15</sup> Ibid: pp.92-93.

<sup>16</sup> Ibid: pp.92, 93, 106, 107.

<sup>17</sup> See Douglas, M. (1992, 2004) for full explanation of the cultural theory; also, Verweij, M. (2004), op. cit.

<sup>18</sup> Verweij, M. (2004), op. cit.: p.112.

Finally, this report proposes that the community of MSM and transgender women living with HIV, who have been, or are at imminent threat of ostracism from their respective reference peer groups, may be displaying the tendency of fatalism. If this proposition is accurate, it will require urgent action from all parties including PLHIV to strategize ways of inclusion, and avoid widespread fatalism in the urban cultures of these South Asian cities. This report therefore brings their voices to the fore in the chapter the culture of HIV municipal response in South Asian cities, with fervent hope that these potential isolates may also participate in the ongoing deliberations on municipal HIV responses in their region.

### *Distinctive gender norms*

According to the Naz Foundation International, which has pioneered research and services on MSM sexual health in the region, there are strict cultural requirements for biological males to attain the gender identity of manhood in Indian cultures. Its cornerstones are the duty of marriage and the responsibility of producing children (particularly males).<sup>19</sup> Importantly, males who do not conform to these gender norms are not considered as men, either by their male sexual partners, or as is often the case, by themselves.<sup>20</sup>

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<sup>19</sup> See Pappas, G. et al. (2001). *Men who have sex with men and HIV/AIDS in India: The Hidden Epidemic*, retrieved from [www.nfi.net](http://www.nfi.net); also Khan, S. (2004). *MSM and HIV/AIDS in India*, retrieved from [www.nfi.net](http://www.nfi.net).

<sup>20</sup> Khan, S. (2004), op. cit.: p.3.

There are overt cultural identification markers for men and non-men, mainly through linguistic markers (*panthi*, *giryā*, double-decker, *danga*); which can denote hierarchies of masculinity; indicated mainly by expressing dominant forms of masculinity, the willingness of taking on passive sexual roles, and displays of aggression.<sup>21</sup> Thus the hierarchical cultural norms of masculinity entail social pressures and can yield adverse effects. A recent study on gender, masculinity and male sexual health in South Asia summarized its findings as follows.

Expected cultural norms of masculine behaviour deny them the space to express fears and anxieties since such behaviour is seen as feminine... Health problems such as severe depression, addiction, mental illness and at times impotency among men are perceived by them to be linked to the pressure of having to conform...<sup>22</sup>

Effeminized men, called *kothis* in Bangladesh and India, *metis* in Nepal, and *zenanas* in Pakistan, are also at risk of gender-based violence, including rape, social exclusion, marginalization and isolation.<sup>23</sup> Transgender women are known generally as the *hijra* across South Asia, although country-specific variations also exist.<sup>24</sup>

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<sup>21</sup> See Asthana, S. & Oostvogels, R. (2001). The social construction of male 'homosexuality' in India: implications for HIV transmission and prevention. In *Social Science & Medicine* 52: pp.707-721. For variations in Bangladesh, see Bondyopadhyay, A. & Ahmed, S. (2010). *Same-Sex Love in a Difficult Climate: A Study into the Life Situation of Sexual Minority (Lesbian, Gay, Bisexual, Kothi, and Transgender) Persons in Bangladesh*. Dhaka: BSWs. For variations in Pakistan, see Abid, S. (2012). *Enculturing Masculinity: Young Boys Learning Gender Performativity: Research Report*, retrieved from <http://www.engagingmen.net/files/resources/2012>.

<sup>22</sup> IPPF. (2013). *Gender, masculinities, and male sexual health in South Asia*. New Delhi: IPPF South Asia Regional Office: p.18. Qualitative and quantitative study conducted in Bangladesh (Jamalpur; n=365), India (Gwalior; n=383), Nepal (Sunsari; n=374) and Pakistan (Faisalabad; n=353). Total 1475 married men (aged 15-54) were interviewed by household sampling.

<sup>23</sup> For India, see Chakrapani, V. (2014). *HIV and STI Prevalence, Vulnerability and Sexual Risk among Hijras and other Male-to-Female Transgender women People in India: A Research Synthesis and Meta-Analysis*. New Delhi: UNDP. For Bangladesh, see Bondyopadhyay, A. & Ahmed, S. (2010), op. cit. For a general guidance on South Asia, see NFI. (n.d.). *Taking Care of Ourselves: Guidelines for MSM living with HIV in South Asia*, retrieved from

### Locating enabling environments

On 26<sup>th</sup> September 2014, the UN Human Rights Council passed a landmark resolution on human rights violations based on sexual orientation and gender identity.<sup>25</sup> Of the South Asian states voting on the resolution, Pakistan had voted against it while India had abstained.<sup>26</sup>

Given the potential for social exclusion and isolation from marginalization among (non-dominant) MSM and transgender women in South Asian society, and though which the potential for economic and social underachievement, destitution and poverty,<sup>27</sup> this report focuses on locating enabling environments for MSM and transgender women, including PLHIV, in this assessment of South Asian cities.

To provide an overview of the global indicators of enabling environment that impact on gender identities and expressions, the Human Development Index of countries

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<http://www.msmpoz.com/Taking-care-of-ourselves.pdf>

<sup>24</sup> In Bangladesh, *hijras* are distinct for their desire for macho men. In Pakistan, *hijras* are an umbrella term used to refer to the *Khusras* (hermaphrodites), *Zananas* (transgender women), and *Narbans* (eunuchs or castrated men). For definitive guidance, see Nanda, S. (2014). *Gender Diversity: Crosscultural Variations*, 2<sup>nd</sup> ed. Long Grove, IL: Waveland Press; Abdullah M. A. et al. (2012). Is social exclusion pushing the Pakistani Hijras (Transgenders) towards commercial sex work? A qualitative study. In *BMC International Health and Human Rights* 12(32), retrieved from <http://www.biomedcentral.com/1472-698X/12/32>; Khan, S. (2004), op. cit.

<sup>25</sup> For a complete review of violations, see UN General Assembly. (2011, November 17). *Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity: Report of the United Nations High Commissioner for Human Rights*. Retrieved from [http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.41\\_English.pdf](http://www2.ohchr.org/english/bodies/hrcouncil/docs/19session/A.HRC.19.41_English.pdf).

<sup>26</sup> HRW. (2014, September 26). *UN: Landmark Resolution on Anti-Gay Bias Condemns Violence, Bias Based on Sexual Orientation, Gender Identity*, retrieved from <https://www.hrw.org/news/2014/09/26/un-landmark-resolution-anti-gay-bias>

<sup>27</sup> See Douglas, M. (2004), op. cit.: p.102. Citing the theory of poverty by Sen, A. (1985a; 1999).

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included in this report is shown with selected indicators from the Index,<sup>28</sup> to contextualize the “infrastructure of human lives,”<sup>29</sup> in relation to the legal situation of transgender women,<sup>30</sup> and the mortality of trans and gender-diverse people in the region (Table 1).<sup>31</sup>

**Table 1. Select global indicators of the South Asian environment affecting gender identities and expressions.**

Country	HDI 2014 <sup>a</sup>	Adult Literacy <sup>a</sup> (%)	Physicians <sup>a</sup> (per 10,000 people)	Population in Multidimensional Poverty <sup>a</sup> (%)	Transgender Legal Rights <sup>b</sup>	Mortality of Trans/Gender Diverse Persons 2008-2014 <sup>c</sup>
Bangladesh	0.570	58.5	6.8	47.8	Since 2013	2
India	0.609	62.8	7.0	51.1	Since 2014	48
Nepal	0.548	57.4	3.6	47.4	Since 2007	1
Pakistan	0.538	54.7	2.1	52.0	Since 2009	22
Sri Lanka	0.757	91.2	8.3	-	None	-

Note. <sup>a</sup> UNDP Human Development Index 2015 indicators. <sup>b</sup> See Health Policy Project et al. (2015), footnote 11. <sup>c</sup> Trans Murder Monitoring Results IDAHOT 2015 Update, only includes reported cases.

Of the five South Asian countries, only Sri Lanka achieves a high HDI score in 2014; followed by India and Bangladesh with medium HDI scores, and Nepal, and Pakistan with low HDI scores. In countries with medium and low human development, adult literacy is exceedingly low, ranging from 55% to 63% of the adult population. In low

<sup>28</sup> The HDI has been developed by UNDP “to emphasize that people and their capabilities should be the ultimate criteria for assessing the development of a country, not economic growth alone.” Retrieved from <http://hdr.undp.org/en/content/human-development-index-hdi>.

<sup>29</sup> Douglas, M. (2004), op. cit.: p.103

<sup>30</sup> Health Policy Project et al. (2015). *Blueprint for the Provision of Comprehensive Care for Trans People and Trans Communities*. Washington, DC: Futures Group, Health Policy Project.

<sup>31</sup> TvT research project. (2015). *Trans Murder Monitoring results: TMM IDAHOT 2015 Update, Transrespect versus Transphobia Worldwide (TvT) project*, retrieved from <http://www.transrespect-transphobia.org/en/tvt-project/tmm-results/idahot-2015.htm>.

human development countries, trained physicians are also difficult to access, with only 2 to 4 physicians per 10,000 of the population. This translates to high-levels of multidimensional poverty, which include contributions from health, education and living standards, affecting approximately half of the population in countries with low and medium human development. However, societies with high human development do not necessarily equate to better social environments for gender diversity. In Sri Lanka, even with its high human development, transgender women do not have any legal protection as compared to the other countries at medium and lower human development; in fact, statistics and facts on transgender women are difficult to obtain. It is also the only country in the region that actively persecutes transgender women on charges of impersonation.<sup>32</sup> Nonetheless, the situation for transgender women does not necessarily improve even when countries offer them legal recognition under the law.<sup>33</sup> Besides Nepal, which is the first country in Asia to recognize and protect sexual and gender diversity in its new constitution,<sup>34</sup> there is minimal legal recognition or protection for MSM in South Asia. Between 2008 and 2014, 73 trans and gender-diverse people lost their lives regionally.

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<sup>32</sup> WSG. (2011). 'Not gonna take it lying down': Experiences of Violence and Discrimination as Told by LBT Persons in Sri Lanka. In *VIOLENCE: Through the Lens of Lesbians, Bisexual Women and Trans People in Asia*. New York: IGLHRC: pp.201-235.

<sup>33</sup> Balzer, C. et al. (2012). *Transrespect versus Transphobia WorldWide: a comparative review of the human-rights situation of Gender-variant/Trans people*. In *TvT Publication Series 6*, Balzer, C. & Hutta, J. S. (eds.). Berlin: Transgender Europe. Retrieved from [http://www.transrespect-transphobia.org/uploads/downloads/Publications/TvT\\_research-report.pdf](http://www.transrespect-transphobia.org/uploads/downloads/Publications/TvT_research-report.pdf)

<sup>34</sup> HRC. (2015, September 17). The new constitution of Nepal and LGBT human rights, retrieved from <http://hrc-assets.s3-website-us-east-1.amazonaws.com/files/documents/NepalConstitution-LGBTRights.pdf>

### *Leaving no one behind*

The lack of enabling environments for MSM and transgender women in South Asian countries indicates even greater vulnerability for MSM and transgender women living with HIV. To ensure that their voices are included in this report, the assessment follows the principle of Greater involvement of People Living with HIV (GIPA).<sup>35</sup> The interventions that are recommended in this report also follow closely the advice provided in the practical guidance for collaborative MSM interventions,<sup>36</sup> and the blueprint for comprehensive care for trans communities in the Asia Pacific.<sup>37</sup> These measures have been put in place to ensure that HTS are leaving no one behind.

### *Limitations of this report*

The rapid assessment underlying this report is, by definition, an explorative study of a highly complex culture, difficult circumstances, and an exceptional disease. Thus, the brevity of time of three-days allotted in each city for site visits, key informant interviews, and focus groups discussions, compounded existing pressures to gain a clear picture of community-initiated HTS in these cities. The assessments have therefore relied heavily on post-assessment desk research to fill in the gaps, as well as analytical methods to generate the insights necessary to provide the best possible assessments under these constraints; and should be read with these caveats in mind.

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<sup>35</sup> UNAIDS. (2007). UNAIDS Policy Brief: The Greater Involvement of People Living with HIV (GIPA), retrieved from [http://data.unaids.org/pub/BriefingNote/2007/jc1299\\_policy\\_brief\\_gipa.pdf](http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf).

<sup>36</sup> UNFPA et al. (2015). Implementing comprehensive HIV and STI programmes with men who have sex with men: practical guidance for collaborative interventions. New York (NY): UNFPA.

<sup>37</sup> Health Policy Project et al. (2015), op. cit.

## Navigating this report

This report has been written for serial reading – that is, from cover-to-cover; as well as modular information retrieval – its chapters can be read out of sequence. In serial reading, the report builds a case study of community-initiated HTS for MSM and transgender women in South Asian cities, which unfolds as follows:

- The report begins with a background that contextualizes the work and summarizes key concepts; provides an overview of community-initiated HTS assessed in the work, and highlights key emerging issues; it relays, in narrative format, the assessments of MSM and transgender women communities in five South Asian cities, which include either an assessment of existing community-initiated HTS, or an ideal HTS wished for by local communities.
- Subsequently, the report analyzes the available data using a cultural lens, and focuses on the question of creating enabling municipal environments in the region.
- The final chapter offers five outlines of programmatic recommendations at the structural level, which are based on the evidence collected and insights gleaned from the assessments. The report is annotated in detail throughout for easy reference.

For modular information retrieval, the report offers the following as possible standalone pieces:<sup>38</sup>

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<sup>38</sup> To be more effective, it is recommended that footnotes be converted into endnotes and placed at the end of each chapter.

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- Assessment of community-initiated HTS in Mumbai, Lahore and Dhaka;
- Assessment of HIV response in Mumbai, India; Shakti Clinic (ICTC);
- Assessment of HIV response in Lahore, Pakistan; DMHS and KSS services;
- Assessment of HIV response in Dhaka, Bangladesh; BSWs-AAS service;
- Assessment of HIV response in Kathmandu, Nepal; an ideal HTS;
- Assessment of HIV response in Colombo, Sri Lanka; an ideal HTS;
- Assessment of the culture of municipal responses in South Asian cities;
- Guidance for enabling municipal environments;
- Programmatic recommendations for group-level structural interventions.

## Methodology

### Guiding questions for the assessment

The rapid assessment in each South Asian city is guided by the following questions:

- What is the likelihood for the (sustained) provision of community-initiated HTS for MSM and transgender women in this South Asian city?
- What kinds of responses and expectations can implementers expect (or have observed) from MSM and transgender women on community-initiated HTS?
- How local socio-political, cultural, and structural contexts may influence the operations of community-initiated HTS for MSM and transgender women?

### Data collection procedures

Materials and instruments to be used in the rapid assessment were conceptualized and developed. These included oral informed consent scripts for key informant interviews (Appendix A), and focus group discussion participants (Appendix B), semi-structured interview schedule (Appendix C), and focus group discussion guide (Appendix D) to assess available or potential community-initiated HTS; the instruments were designed to explore the development of these services with key individuals and from the perspectives of MSM and transgender women that included PLHIV.

To streamline the rapid assessments in five cities, an assessment model had been developed from an established community-initiated HTS strategy that was familiar to

investigators. The model was used as a heuristic device to critically assess available community-initiated HTS in the cities (see Figure 1 below).

A local coordinator, who is living with or affected by HIV and fluent in both English and their national language, had been recruited in each city from a shortlist of candidates provided by Country SRs. APN+ Ethics Committee clearance on the rapid assessment protocol had been obtained prior to data collection.

Country SRs had identified 3-6 key informants who had influenced, or could influence, the development of MSM and transgender women community-initiated HTS in their respective cities. The local coordinator invited selected individuals to participate in in-depth interviews. The interviews were audio recorded and reviewed for key domains that moderated the availability of (or potential for) community-initiated HTS.

Local coordinators then organized and facilitated focus group discussions with at least one group of MSM and transgender women respectively in each city, and had to include PLHIV (Table 2).

**Table 2: Composition of focus group discussion participants by city, as ordered in the narrative.**

City	MSM	Transgender Women	PLHIV
Mumbai	5	5	4
Lahore	5	5	5
Dhaka	5	10	10
Kathmandu	5*	5	10
Colombo	N/A	N/A	N/A

Note. \* Three individuals considered themselves as gay and one individual did not consider himself either as MSM or gay. N/A Not available.

All participants were asked to provide oral informed consent. Participation was voluntary and participants were compensated for their time. Discussions were audio recorded with prior consent and later transcribed and translated for analysis.

Audio-recorded interviews were reviewed and key information extracted and transcribed in verbatim. Audio-recorded focus group discussions were transcribed and translated into English by the local coordinator. Two coders independently coded the transcripts, and inter-coder discrepancies were resolved through discussions. Coding identified factors that influenced the success (or potential founding) of community-initiated HTS for MSM and transgender women in each city.

### Rapid assessment model

The rapid assessment model (Figure 1 below) was based by the Kios Atma Jaya strategy for people who inject drugs (PWID) in Indonesia.<sup>39</sup> The programme had made an important inroad in providing care to PWID, including needle and syringe exchange, ‘test for triage’ HIV testing using rapid diagnostic tests (RDTs), and linking PWID found to be HIV positive for confirmatory testing in a healthcare facility.<sup>40</sup> This model was a heuristic device that assisted in the critical assessment of community-initiated HTS in South Asia with the assumption that MSM and

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<sup>39</sup> The adoption of the Kios Atmajaya strategy was not meant to convey that PWID shared substantive HIV-related characteristics with MSM and/or transgender women communities; nor did it assume that Indonesia and South Asia had similar or comparable situations.

<sup>40</sup> Sihombing, L. (2007). Impact of sterile needle services in strengthening the utilization of medical and psychosocial services in the Kios Atma Jaya Jakarta at *4th IAS Conference on HIV Pathogenesis, Treatment and Prevention*: Abstract no. CDB450

transgender women in this region would benefit from ‘test for triage’ HIV testing as it did for PWID in Indonesia, and for MSM and transgender women in communities elsewhere.<sup>41</sup>

### Core functions of HTS

Central to the model was the proposition that community-initiated HTS for MSM and transgender women included three basic components, or core functions:

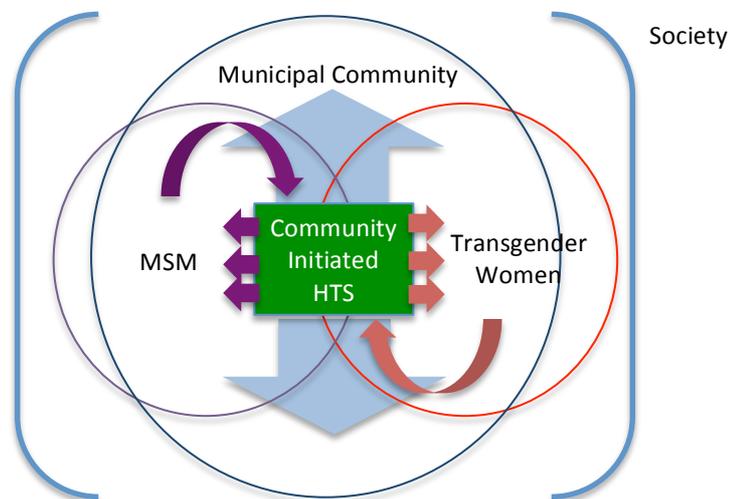


Figure 1. Rapid assessment model

- Community outreach and satellite recruitment would be performed by preferably certified community healthcare workers who are members of local MSM and transgender women (red and purple arrows);<sup>42</sup>

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<sup>41</sup> See e.g. McPherson, P. et al. (2011) for comparison between HIV testing in a healthcare facility and through community outreach; Bailey, A.C. et al. (2009) for MSM specific results; and Schulden, J.D. et al. (2008) for transgender women specific results.

<sup>42</sup> Prasad, B. M. & Muraleedharan, V. R. (2007, October). *Community Health Workers: a review of concepts, practice and policy concerns*. London: International Consortium for Research on Equitable Health Systems (CREHS).

- Distribution of HIV prevention materials including condoms, behaviour change communication (BCC), and demand generation for HIV testing would be offered during outreach;<sup>43</sup> mobile HTS using RDTs could also be offered as a ‘test for triage’ strategy to ensure PLHIV are followed up;<sup>44</sup>
- Linkage into the municipal healthcare system (blue arrows) of HIV services including ARVs will be provided; should ARV provision not be feasible, a referral system that tracks PLHIV to ensure linkage to care is critical.<sup>45</sup>

These components ensured that the benefits derived from community mobilization, a key feature of community systems, would translate into dividends across the treatment cascade; from HIV diagnosis, to risk reduction, to treatment initiation, to retention in care. Thus by mobilizing community towards ensuring better linkages to care, this model would be strengthening the key feature of community systems and linking this success to strengthening local health systems.

### *Factors moderating HTS*

Factors moderating HTS in fulfilling its core functions had been derived iteratively from interviews with key informants, and were divided into four domains and broadly defined. These were communal power, municipal response, societal rules, and decisive conditions (Table 3 below).

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<sup>43</sup> WHO. (2013, June), op. cit.

<sup>44</sup> WHO. (2015, July), op. cit. In ‘test for triage’, only one RDT is required, with positive test results referred for confirmatory ELISA test.

<sup>45</sup> Ibid.

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**Table 3. Factors influencing the success or failure of community-initiated HTS for MSM and transgender women groups as defined by domains and identified with key indicators.**

Domains	Definitions	Key Indicators
<b>Societal rules</b>	The shared rules of behaviour among aggregate communities of people living in a country or region.	<ul style="list-style-type: none"> <li>• Custom</li> <li>• Legal rights</li> <li>• Religiosity</li> </ul>
<b>Municipal response</b>	Responses from the people who live and work in the city, which includes staff of municipal healthcare facilities.	<ul style="list-style-type: none"> <li>• Social practices</li> <li>• Communal attitudes</li> </ul>
<b>Communal power</b>	The potency of individuals to unite and work together to achieve particular objectives and in the common interest.	<ul style="list-style-type: none"> <li>• Group solidarity</li> <li>• Skills and knowledge</li> </ul>
<b>Decisive conditions</b>	Circumstances that can produce game-changing outcomes that is not within the control of individuals in civil society.	<ul style="list-style-type: none"> <li>• Political will</li> <li>• Healthcare access</li> <li>• Enabling environment</li> </ul>

Key indicators that influenced each domain were identified first from key informant interviews and subsequently confirmed with details from focus group discussions in the five cities with MSM and transgender women that included PLHIV. Briefly, the key indicators were defined as follows:

- Group solidarity referred to collective behaviours toward commonly held interests or goals;
- Skills and knowledge were applicable expertise that included HIV knowledge and treatment literacy, but also broad skills such as mobilizing for advocacy;
- Custom referred to traditional and widely accepted ways of behaviour;
- Legal rights were the legal statutes that protected the rights of communities, sanctioned misbehaviour, and included policies that regulated civic life;
- Religiosity was the intensity of impact on civic life from religious doctrines, pronouncements, beliefs, and the severity of punishments for transgressions;
- Social practices encompassed localized behaviour, usually normative;
- Communal attitudes were shared ways of thinking or feeling about people;

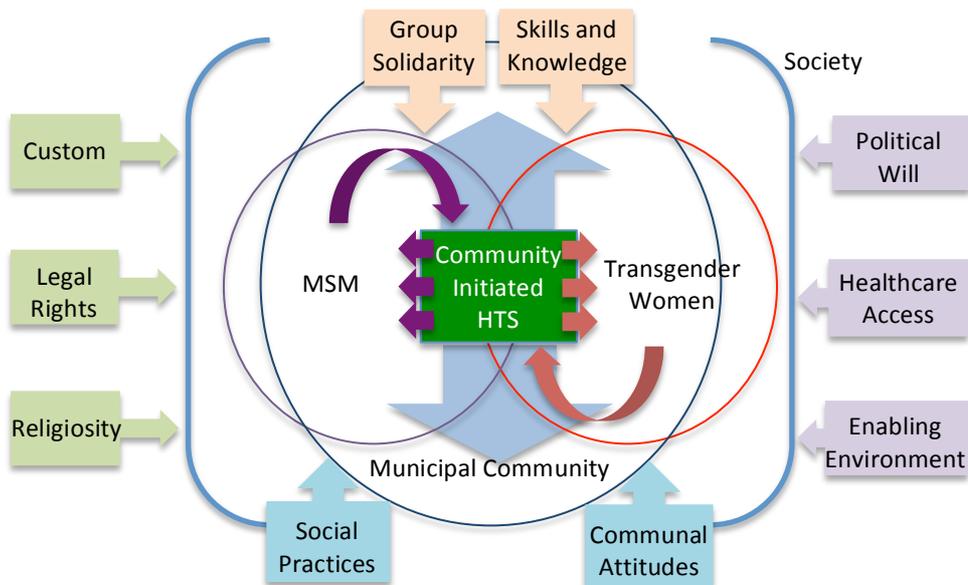
- Political will referred to the impetus by governments and politicians in championing particular issues, despite opposition or poor chances of success;
- Healthcare access included accessibility, adequacy, and acceptability of HIV treatment specifically, but also healthcare services in general; and
- Enabling environment indicated socio-political situations that empowered individuals toward self-fulfillment.

### Plan of analysis

The analysis began by placing the factors moderating the fulfillment of core functions of HTS into the rapid assessment model for a nuanced model. The resulting model provided ten key indicators to evaluate when assessing the potential founding or sustainability of these endeavours in South Asia (Figure 2 below). In view of the insights generated by the nuanced model, an overview of existing community-initiated HTS for MSM and transgender women was carried out and focused on issues of sustainability, effectiveness, programmatic gaps, and key concerns.

Next, contextual narratives on the lives of MSM and transgender women in the five cities had been produced to describe the local cultures in which community-initiated HTS had been operating, or would operate. The narratives were derived from focus group discussions with MSM and transgender women, including PLHIV, in each city. The narratives were preceded by an overview of the city and country on aspects of population sizes, legality, the situation of MSM and transgender women, and HIV prevalence with regards to MSM and transgender women from a desk review of secondary data sources. Secondary data sources also supplemented and contextualized

focus group discussion results. Each narrative ended with an assessment of the community-initiated HTS programmes that had been included in the assessment, or an ideal type of community-initiated HTS wished for by focus group participants.<sup>46</sup>



**Figure 2. Rapid assessment model with indicators of moderating factors**

In the following section, the culture of municipal responses to HIV in South Asia is derived using cultural theory. This entailed adapting a typology of social organizations developed by Douglas, an anthropologist.<sup>47</sup> HIV responses from the 5 cities were distilled with a cultural lens according to the four cultural tendencies of social organizations: hierarchical, individualistic, dissenting enclaves, and isolate. The objective of the analysis is to understand the cultural process of isolation and social

<sup>46</sup> Except for the case study of Colombo, where focus group discussion results had been of poor quality. In this case, two secondary resources, the Stigma Index and a study of PLHIV by the AIDS Foundation Lanka, had been used to contextualize the lives of MSM and transgender women.

<sup>47</sup> Douglas, M. (1992), op. cit.

exclusion of PLHIV in MSM and transgender women communities, which has been a common feature in both communities.

The analysis ended with guidance on the prerequisites of enabling environment for community-initiated HTS for MSM and transgender women in South Asia, and programmatic recommendations of interventions at cultural, structural, community-levels had been designed as group interventions to address the key issues highlighted in the assessment and based on principles developed in the global HIV collaborative intervention tool for MSM, and blueprint for the comprehensive care of trans people and communities in the Asia Pacific.<sup>48</sup>

### Community endorsement

The draft report was submitted for community endorsement from MSM and transgender women who had participated in the rapid assessment in their respective cities, as well as the Country SRs who had organized the study locally. This ensured that the descriptions and analyses on each city and key population had been accurately portrayed. Comments and recommendations from the endorsement would be addressed prior to submission of the final report.

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<sup>48</sup> See UNFPA et al. (2015); and Health Policy Project et al. (2015).

## A Critical View of Community-Initiated HTS

### Existing services for MSM and transgender women

The rapid assessment returns well-established community-initiated HTS for MSM and transgender women in three South Asian cities,<sup>49</sup> and assesses the HTS provided by Humsafar Trust in Mumbai, Naz Male Health Alliance (NMHA) in Lahore, and Bandhu Social Welfare Society (BSWS) in Dhaka. An overview in the form of a heat map summarizes the assessment of three community-initiated HTS (Table 4 below).

### *Assessment heat map*<sup>50</sup>

The three existing community-initiated HTS in South Asian cities being assessed were the Shakti Clinic (ICTC) in Mumbai, India; the Dostana Male Health Society (DMHS) and Khawaja-Sara Society (KSS) services in Lahore, Pakistan; and the BSWS – Ashar Alo Society (AAS) service in Dhaka, Bangladesh.

Depending on how it is read, the heat map shows overviews of existing features in the HTS being assessed (when read column-wise), or the situation of moderating factors contextualizing HTS in the region (when read row-wise).

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<sup>49</sup> This list is not definitive as the rapid assessment depended on the expertise of local coordinators to identify active community-initiated HTS for MSM and transgender women groups in their respective cities. Small-scale programmes may not be included.

<sup>50</sup> The heat map is interpreted like a traffic light and depending on the context of the indicator, either points to restrictive conditions or magnitude; where red is indicative of critically restrictive conditions, or critically low magnitudes; yellow is indicative of moderately restrictive conditions, or moderate magnitude; and green is indicative of low or non-restrictive conditions, or high magnitude.

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**Table 4. Heat map on rapid assessments of existing community-initiated HTS services in Mumbai, Lahore, and Dhaka focusing on core functions and moderating factors.**

Assessments	Shakti Clinic Mumbai	DMHS and KSS Lahore	BSWS – AAS Dhaka
<i>Core Functions</i>			
Outreach			
Prevention and demand creation			
Linkage to care			
<i>Moderating Factors</i>			
Group solidarity			
Skills and knowledge			
Custom			
Legal rights			
Religiosity			
Social practices			
Communal attitudes			
Political will			
Enabling environment			

### Summary of HTS assessments

Of the three community-initiated HTS assessed in this report, only the BSWS-AAS service managed to fulfill its core functions. The Shakti Clinic in Mumbai did not manage to obtain sufficient new clients for its services after the substantial increase in government targets, while DMHS and KSS services in Lahore faced compounding issues that hampered the fulfillment of its core functions, these were: fearing to be labeled as HIV positive in the MSM community affecting outreach; inter-clan rivalries of *hijra* affecting prevention material distribution in the *hijra* communities; high levels of stigma affecting demand creation; and attrition of clients after testing means the majority do not get their HIV test results hampering linkages to care. As a caveat, DMHS and KSS services in Lahore have been operating under critically restrictive conditions on six of ten moderating factors being assessed. An in-depth

assessment of each HTS is provided at the end of city-specific analyses in the following chapters.

### *Summary of moderating factors*

It should be noted that the three South Asian cities assessed, each have an agglomeration upwards of ten million people. Population density puts a strain on the municipal healthcare infrastructure, and increases problems of overcrowding and equitable access to municipal resources. Although none of the three major cities included in the heat map performed remarkably well, Mumbai offered comparatively better circumstances for community-initiated HTS in South Asia than Dhaka and Lahore.

Collectively the indicators of custom, social practices and communal attitudes broadly refer to the contours of South Asian culture. The critical value of these indicators gives the image of highly restrictive socio-cultural conditions that MSM, transgender women, and PLHIV have to face daily in these cities; and the region in general.

The critical condition on group solidarity among MSM and transgender women communities is based on the persecution and social exclusion of their peers who test positive for HIV in Dhaka and Lahore. In Lahore, elements of extreme religiosity in Pakistani culture has led to a restrictive and disabling environment for MSM and even transgender women, despite legal of recognition of their rights.

### *Overview of current HTS strategies*

The current initiatives share a similar goal-attainment supply strategy that relies on the mobilization capabilities inherent in communities. This involves strengthening the community mobilization aspect of community systems by increasing the number of community outreach workers, providing outreach training on recognizing and approaching community members as potential service clients, setting targets for community members who are effectively provided with services, and incentivizing these targets.

The interaction between members of the community for the majority of services is as follows: mobilize MSM and transgender women outreach workers to selected hotspots in the city known to be places where their respective communities meet for sexual encounters. Often outreach workers will bring with them HIV prevention materials to distribute, such as condoms, lubricants and safer sex information leaflets. At these hotspots, outreach workers will look out for other members of their community, approach them with HIV prevention supplies, and gain their trust sufficiently to engage in conversation about HIV, HIV prevention, and HIV testing.

### *Reciprocating without trust*

A demand creating strategy of building reciprocal relationships with potential HTS clients is performed by providing potential clients with services and informal help as an exchange for their support of the CBO's activities, which include HIV testing. The strategy involves building rapport and trust, nurturing understanding and fairness between outreach worker and potential HTS client, and creating a symbiotic

relationship that aims to satisfy mutual needs. In principle, reciprocal relationships that are properly nurtured should generate buy-in to the idea of HIV testing among potential clients, which could eventually translate into completed HIV testing procedures, and yield HIV testing outcomes.

However, the reciprocal relationship strategy commonly relied upon to generate demand among MSM and transgender women is a programme implementation strategy that is incompatible with the goal attainment strategy used to evaluate the effectiveness of HTS programmes; often by setting year-on-year incremental targets on rates of HIV testing and HIV detection. The main point of contention between reciprocal relationship and goal attainment strategies is the length of time it can take to build sufficiently robust reciprocal relationships that will concretize with actual testing and receipt of testing outcomes.<sup>51</sup> The reality that reciprocal relationships usually take a long time to cultivate and nurture, is a challenge for community outreach workers who have to wait a long time to see the fruits of their labour.

From the perspective of goal attainment, the reciprocal relationship strategy is an ineffective use of scarce resources: reciprocal strategies cultivate individual interpersonal relationships with potential HTS clients, attend to client interactions sequentially, requires the investment of unknown quantities of effort before the client gets tested for HIV, and must rely on the goodwill of clients to reciprocate by

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<sup>51</sup> The community-initiated HTS programmes in this assessment experience high rates of attrition between HIV testing and receiving test results. In general, this is a problem in South Asia, with a report that only 10.8% of people returning to receive their HIV test result in India.

undergoing testing, with little or no control over when testing events will actually take place. Given the uncertainty of effort that is required to produce a single HIV test, the effort and resources invested can be exponential in relation to actual tests completed, and the rates of HIV detection achieved. Low rates of people returning to receive their HIV test results also reduce opportunities for linkage to treatment and care among those who test positive for HIV.

### Justifying required effort

In addition, the level of uncertainty with regards to the effort required per HIV test, and per HIV positive result, will be problematic in decision-making on the optimum levels of effort and resources required, and mobilizing these effectively to reach given targets. Furthermore, reciprocal relationships may not be able to address the complex needs of potential HTS clients especially when the rapport building process becomes compressed and truncated due to time and resource constraints, and the pressure to meet targets. This can result in rushed and poorer quality services provided, reverse the benefits accrued from prior rapport building, and negate the primacy of engaging potential HTS clients in a reciprocal relationship.

Crucially, the popular targeting of hotspots of sexual activity among MSM and transgender women, and mobilizing community outreach workers there to create demand for HIV testing is flawed. With the high HIV associated stigma and discriminatory practices documented in these communities, the current strategy may have the opposite of its intended effect on demand creation for community-initiated

HTS. Research has found that people who hold stigmatizing beliefs and attitudes about PLHIV were less likely to test for HIV.<sup>52</sup>

A further complication arises when the strategy is applied among transgender women. The gurus of transgender women belong different *gharanas* (clans), which can have well-established rivalries, fluid competing interests, and complex contentious histories. Thus, a transgender woman outreach worker may find that she is refused access to a *dera* (a pseudo-household) if she is from a *gharana* that at that moment rivals, competes or contends with the *gharana* of the potential HTS client she intends to meet, or when delivering prevention intervention materials to a particular community. These complications can become critical problems if it affects the health and wellbeing of transgender women, and would affect any strategy that requires interpersonal relationships to generate demand for HTS.

### Reaching communities at risk of HIV

Finally, this assessment finds that the current reciprocal strategy to generate demand for community-initiated HTS is unlikely to penetrate deep into MSM and transgender women's networks to reach individuals at highest risk of HIV. Given the overwhelming fear of HIV already existing in the MSM and transgender women communities, and the stigmatization and discrimination of its members found to be infected with HIV, and the use of HIV status and other intimate details as means of

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<sup>52</sup> See e.g. S. C. Kalichman & L. C. Simbayi (2003) on attitudes to HIV testing in South Africa; Liu, H. et al. (2005) on sexual risk-taking and HIV associated stigma in China.

disrupting the lives of others in their communities, it is rational to assume that high-risk members in these communities would be motivated to keep their risk behaviours and HIV status both private and strictly confidential. This would generally entail limiting the number of people who are privy to the risk behaviour of the community member concerned, in particular other community members and people directly associated with the community.

In view of this underlying motive for secrecy, it seems unlikely that MSM and transgender women at high risk of HIV acquisition would consider community outreach workers as safe conduits for HIV testing given the reciprocal relationships outreach workers have to build with other community members as part of the demand creation strategy. Outreach workers' repeated and close contacts with the same communities from whom individuals may wish to hide their personal details yields disproportionate risk for a breach of privacy;<sup>53</sup> including the possibility of unintentional disclosure of HIV status, risk behaviours, and personal identities to other community members.

Although the lengths at which individuals would go to protect their privacy can vary, an APN+ study had found that MSM living with HIV in India were willing to travel long distances to access HIV treatment in different towns to effectively minimize the

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<sup>53</sup> Although it is arguable that robust confidentiality protocols and intensive training of community outreach workers can effectively reduce the risk for a breach of privacy, with the high levels of stigma and discrimination observed in South Asian communities, even rumours and perceptions of wrongdoing can setback prior programme efforts, and potentially derail the meeting of HTS goals.

risk of meeting somebody they knew.<sup>54</sup> This behaviour may indicate the extent and willingness of certain groups of South Asians to trade convenience and ease of access to services for anonymity and privacy even if it costs more and requires more effort. Community-initiated HTS programmes in South Asia for MSM and transgender women must factor in these tacit priorities in their service delivery models, programmatic characteristics, and logistical arrangements if they wished to tap the demand for their services from these hidden communities.

### Sustaining existing services

The Global Fund under its MSA HIV programme has funded entirely or substantially the community-initiated HTS for MSM and transgender women assessed in this report. Currently being implemented by UNDP, the programme is scheduled to end in 2016. The situation is precarious as alternative funding streams have yet to be identified, and it is unlikely that the respective South Asian governments will take on the responsibility of fully funding these services.

From key informant interviews, it appears that the HTS dedicated to serving MSM and transgender women communities are returning lower than expected HIV positive test results in these key populations, and reporting high rates of attrition between HIV testing and receiving test results; taken together this indicates that the services are not

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<sup>54</sup> Choo, M. (n.d.) Treatment Access for Positive MSM in the Asia Pacific: An APN+ Analytical Report on Data from 6 Countries. Bangkok: APN+. Retrieved from <http://www.apnplus.org>

effectively detecting latent HIV in their communities, and thus not appropriately linking HIV positive individuals into treatment and care.

Given the conservative outlook on future funding, the effectiveness of services is becoming crucial points of contention in advocating for their sustainability. The MSA HIV Programme should therefore capitalize on the availability of final-year funds to engage more effective and evidence-based interventions that are culturally sensitive and targeted, to obtain and present better outcomes in 2016.

### Requiring to stand in front

It is challenging for MSM and transgender women to stand at the forefront of a society that perpetrates the double stigma on their sexuality and their likely HIV status, which in some cases, have been known to end in violence. Yet standing at the front of the line, with their heads over the parapet, is precisely that which is required for community-initiated HTS to succeed. To belabor the point, programme implementers need to appreciate that standing at the forefront of an HIV response will be difficult to achieve without adequate community and social support available to bolster each individual's efforts from behind, and even more so in hierarchical cultures. The following quotation from a potential HTS client reminds us:

There are many people who have not done testing yet. I met one person, I asked him whether [he] will go for testing but he hesitate[d], that by accessing services he will open himself and also fears that he should not be seen by others... There is this constant thing [he] thinks if he is positive then what people will think about him? (MSM outreach worker, Mumbai).

In the culture of South Asia, MSM and transgender women have to feel sufficiently safe and confident to both initiate and partake in HTS in the municipalities of their childhoods, families, neighbourhoods, and peer groups; in short, the agglomeration of groups, each with its own values and aspirations exacting a particular hold on each individual; we tend to forget how complex the endeavor can be when abbreviated as community and culture.

## Municipal Responses in Mumbai, India

### Overview

Mumbai, in the state of Maharashtra, is one of the world's most populous cities with a population that exceeds 18 million people.<sup>55</sup> With humble beginnings as a fishing colony on a rocky outcrop of islands, Mumbai today is the financial centre that drives the Indian economy. It is the most globalized of South Asian megacities; yet lags behind on public infrastructure such as health systems.<sup>56</sup>

An estimate of MSM in Mumbai returns 19,000 individuals,<sup>57</sup> and a non-desegregated estimate of both MSM and transgender places the figure at 27,000.<sup>58</sup> The official count of the third gender in the 2014 census returns 488,000 transgender women.<sup>59</sup> In December 2013, India's Supreme Court re-criminalized consensual same sex between adults only four years after the Delhi High Court had decriminalized it. Four months later, in April 2014, India's highest court recognizes transgender women as a distinct

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<sup>55</sup> UNAIDS. (2014). *The Cities Report*. Geneva: UNAIDS.

<sup>56</sup> Clark, G. & Moonen, T. (2014) *Mumbai: India's global city: A case study for the Global Cities Initiative: A joint project of Brookings and JPMorgan Chase*. Retrieved from [https://www.jpmorganchase.com/corporate/Corporate-Responsibility/document/gci\\_mumbai\\_02.pdf](https://www.jpmorganchase.com/corporate/Corporate-Responsibility/document/gci_mumbai_02.pdf)

<sup>57</sup> Roy, S. D. (2014, November 29). Dip in HIV cases among gay men. *Times of India*, retrieved from <http://www.timesofindia.indiatimes.com>.

<sup>58</sup> India Health Action Trust. (2010). *HIV/AIDS Situation and Response in Mumbai City and Suburban Districts: Epidemiological Appraisal Using Data Triangulation*. Bangalore: IHAT, retrieved from <http://www.ihat.in>.

<sup>59</sup> Nagarajan, R. (2014, May 30). First count of third gender in census: 4.9 lakh, retrieved from <http://timesofindia.indiatimes.com/india/First-count-of-third-gender-in-census-4-9-lakh/articleshow/35741613.cms>

gender.<sup>60</sup> The population of MSM is an estimated 3.5 million individuals, of whom 427,000 individuals are categorized as high-risk of HIV; the population of transgender women is an estimated 60,000 individuals.<sup>61</sup>

Both MSM and transgender women are vulnerable to HIV in India. National HIV prevalence is estimated at 0.36% in 2013, and there are between 2.0 and 3.1 million Indians living with HIV. The estimates are: HIV prevalence of 4.4% in MSM,<sup>62</sup> and 8.8% in transgender women.<sup>63</sup> A 2013 meta-analysis of the risk of HIV infection in India between 2000 and 2011 found that transgender women had 208 times the odds of HIV infection when compared to productive adults between the ages of 15 and 49; the prevalence of HIV in transgender women is 43.7%.<sup>64</sup> A 2011 estimate of HIV prevalence in transgender women in Maharashtra state returns the prevalence of 18.8%.<sup>65</sup> Mumbai is one of UNAIDS' fast-track cities that aims to end AIDS epidemic in cities by 2030.<sup>66</sup> The HIV epidemic in Mumbai is concentrated in key populations of PWID, FSW and MSM.<sup>67</sup>

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<sup>60</sup> Health Policy Project et al. (2015), op. cit.: p.66.

<sup>61</sup> NACO. (2011). *Strategic Approach for Targeted Intervention among MSM*. New Delhi: NACO.

<sup>62</sup> NACO. (2013) *Global AIDS Response Progress Reporting: India*. New Delhi: NACO, retrieved from <http://www.aidsinfoonline.org>.

<sup>63</sup> NACO. (2014) *Annual Report 2013-14*. New Delhi: NACO.

<sup>64</sup> Baral, S. D. et al. (2013). Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *Lancet Infectious Diseases* 13: 217

<sup>65</sup> Chakrapani, V. (2014), op. cit.

<sup>66</sup> UNAIDS. (2014), op. cit.

<sup>67</sup> India Health Action Trust. (2010, May). HIV/AIDS Situation and Response in Mumbai City and Suburban Districts: Epidemiological Appraisal Using Data Triangulation. Retrieved from <http://www.ihat.in/Annual%20report%20IHAT/Data%20Triangulation/Maharashtra%20all%20District%20Inner%20Pages/Mumbai%20Report%20Final%2057pgs.pdf>

## Navigating the unending discrimination

Discrimination of MSM and transgender women is common in Mumbai, and includes institutionalized discrimination in government-run municipal health centres, which deters these communities from accessing healthcare, including HIV testing.

...government people don't behave the way they are expected to behave, they behave rudely with MSM. They discriminate me as I am effeminate then why should I go? (MSM).

Occasionally the community does protest at the injustice, but usually the harm is already done.

I remember when I went for the [HIV] testing (sic) lab technician refused to draw blood sample for [the] test. She insisted other technician to come and draw the blood. When I asked technician the reason she ignored me by not replying. I created a scene, asking, are we not humans? After the huge quarrel, [the person] in charge intervened and my testing was done. But this bitterness has created a place in my heart, thus [I] would not like to visit those government hospitals (transgender woman).

For MSM communities, individuals who can conform to socially preferred gender norms would generally prefer to do so rather than face (more) discrimination, which means not associating with a community-based gay organizations, “they didn't want to be associated with a community-based gay organization which may lead to the disclosure of their sexuality to others” (MSM). This unfortunately dampens the ability of MSM to unite.

## Engendering new ways to be in the world

MSM whose gender expression is effeminate will always be made aware of his gender identity of not-man. “Since we are not like straight guys, we think how they will behave with us and how they will react seeing us...” They are watchful and pre-emptive at possible overtures of discrimination, which can result in self-stigma.

Compared to MSM, transgender women do not share similar opportunities to disguise as gender normative in Indian society. Most transgender women self-organize by leaving their families when they are young to live with a guru, who cultivates their gender identities and socializes their gender expressions. In most cases, socialization also includes facing the economic reality that there are few options for income that are open to the transgender women besides sex work and begging.

Obedience to the guru is paramount in transgender women custom. It is fortunate when

Gurus are sensible. They are not stopping their *chelas* (disciple) from getting associate[d] with NGOs, as our gurus are also concerned about our health” (transgender woman).

In this respect, and with reference to their newly acquired legal status as a distinct gender, transgender women should have less to fear when asserting their rights to health than do MSM in India.<sup>68</sup>

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<sup>68</sup> Comment from the community review: Although fear may be less, the doctors/health care providers are not trained on issues (such as castration/hormones) central to transgender women’s sexual health. In addition, the lack of an enabling environment at the hospitals is a barrier to health seeking behavior.

Furthermore, discrimination also occurs within MSM and transgender women communities. This is most keenly felt by PLHIV, who are discriminated against and ostracized by their peers. “People in India are not dying of Aids (sic), they are dying of hunger, stigma and rejection... No one wants to live with HIV.” An HIV positive test result for MSM and transgender women means having to live at the bottom of the communal social hierarchy.<sup>69</sup> At times like these, “seeing the (HIV) positive counselor, he will get inspiration to live” (MSM).

### Responding to HIV positive test results

This double stigma and its potential for social isolation compound the fear of HIV testing. It is more keenly felt for MSM in Mumbai, who do not have the well-established social support networks of transgender women communities. According to an MSM outreach worker, “they (MSM) fear of testing, if they get positive [result] then what will happen next? The[y] fear ostracism and discrimination.” Testing for HIV, MSM come face-to-face with the possibility that a positive diagnosis may sever a prized connection; the sense of belonging in a community whose membership they keep hidden, and at times denied. An HIV positive result can be a sense of guilt and loss.

A positive diagnosis can also mean worrying about the future. “They think its better to not get tested [than] have the tension of being positive. They want to be happy and

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<sup>69</sup> Gaikwad, T. (2011, June 8) Living with HIV in Mumbai, India. *The Guardian*, retrieved from [www.theguardian.com](http://www.theguardian.com).

tension free without being tested” (transgender outreach worker). However, individuals who can accept the circumstances leading to a positive diagnosis, testing offers the realization of the risks they have taken and exacting a price.

It is not so easy to accept by any individual to learn about his HIV positive report, but the fact remain[s] [the] same that we know how and why we risk[ed] our life (sic). We risk it for bread [and] butter, it takes some time for us to accept our HIV positive report, and this directly affects our job (as a sex worker). But slow and steady we accept the fact (transgender woman).

HIV testing and a positive diagnosis in instances such as this can be a sense of resolution; HIV exacting the terms of one’s recognition.<sup>70</sup>

### Shakti Clinic (ICTC), Humsafar Trust

Humsafar Trust is a pioneer in providing community-initiated HTS for MSM and transgender women in India. “The organization started with a group of gay men in 1996, then the *hijra* started coming...the clinic was setup in 1999 and we had two doctors coming in from Sion Hospital (to provide support for clinical activities),” recalls its Executive Director, Vivek Anand.<sup>71</sup> Shakti Clinic (ICTC) is now part of the municipal government’s network of integrated counselling and testing centres, under MDACS and NACO, which offers free HIV and STI testing, and counselling, with a resident doctor, professionally accredited counselor, and a laboratory technician.

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<sup>70</sup> See Appadurai, A. (2004). Chapter 3: The Capacity to Aspire: Culture and the Terms of Recognition. In *Culture and Public Action*. Rao V. and Walton, M. (Eds.). Stanford, CA.: Stanford University Press: pp.59-84

<sup>71</sup> In-depth interview. (2015, September 11). Vivek Anand (Executive Director), Anees (Peer Counsellor), and Urmi (TG Outreach Worker) at Humsafar Trust office, Mumbai. Details for this assessment draws from in-depth interviews conducted separately with each candidate.

Entrance to the clinic is kept distinctly separate from the entrance to Humsafar Trust's office, which ensures the privacy of potential HTS clients. Humsafar Trust implements HIV targeted interventions across six sites in Mumbai. The outreach worker from these sites refer their clients to the Shakti Clinic at Humsafar Trust's main office for HIV and STI services. Those who get tested positive for HIV and/or STIs are linked with the health facilitators for treatment and care and support services within the municipal public health system; as well as generate demand for HTS and distribute BCC and IEC materials.

The clinic mobilizes teams of MSM and transgender women as community outreach workers to link individual community members to treatment and care within the municipal public health system; as well as generate demand for HTS and distribute BCC and IEC materials.

### *A family model*

Shakti Clinic is based on the Humsafar Model, a family model. Anand elaborates.

When you came to Humsafar, you did not come just for an HIV test. You also spoke about your being homosexual, your identity...When people came here and saw that everybody was gay and the doctors were comfortable...when you initiate community based testing you play a larger role than just HIV testing...there is a social network that is happening. At Humsafar...when someone tests positive, at that point in time, [he] needs a hand to hold, not just [being] linked to treatment.

The model is however under threat since the government started providing programmatic oversight of the clinic in 2006. Rather than spending its effort on clients with the highest risk that is Humsafar's preferred way to address HIV testing,

the government wanted the HTS under its purview to provide services to all clients who were MSM and transgender women, similar to the testing services currently provided for brothel-based sex workers. Humsafar maintains that unlike sex workers, MSM are a mobile community that may not stay long at one outreach site before gravitating to another. Providing services to all available clients without prioritizing their risk may therefore duplicate efforts and reduce the programme's effectiveness in reaching MSM who do not yet know their status.

### *Targeted intervention*

For MSM and transgender women, the current national guidelines for HIV testing focused on targeted intervention (TI) programmes that consisted of condom use promotion, peer educators and outreach workers sharing IEC materials, and offering the treatment of STIs. The guidelines specified that “intensified detection of HIV” will continue to play “a pivotal role in HIV prevention and control,”<sup>72</sup> and its NACP-IV strategy (2012-2017) aims to reduce new infections by 50% (based on 2007 NACP-III baseline values), and provide comprehensive care and support for PLHIV. Among the strategy's key priorities are “preventing new infections by sustaining the reach of current interventions,” and “focusing on BCC strategies in high risk groups, awareness among [the] general population, and demand generation for HIV services.”<sup>73</sup>

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<sup>72</sup> NACO. (2015, July). *National Guidelines for HIV Testing*. New Delhi: NACO.

<sup>73</sup> NACO. (n.d.). *National AIDS Control Programme – Phase IV (2012-2017): Strategy Document*. New Delhi: NACO: p.9.

### *Generating required demand*

To generate demand the required demand for its HTS, Humsafar conducts scheduled MSM outreach to a total of 72 sites identified through extensive mapping of hotspots of known cruising grounds and places of sexual contact, such as railway public lavatories on particular platforms, municipal parks and video arcades of (heterosexual) pornography in the greater Mumbai area. The outreach is part of an elaborate community mobilization, which keeps Humsafar connected to MSM and transgender women who live in greater Mumbai. This network of local communities include transgender women sex workers, and small community-based organizations that deliver HIV services to MSM, transgender SW, and MSW that work around Mumbai's two ports; which are also satellite sites for HIV prevention services.

### *Constraining targets*

Although these activities commensurate with the government's NACP-IV strategy, demand generation in this manner may no longer be sustainable given the activities do not account for its high cost, and tightly held government targets. This tension had already been foretold at the start of NACP-IV: Although the strategy recognizes that reaching 64% of MSM populations through TI programmes as part of NACP-III has seen the reduction of HIV prevalence in MSM from 7.41% in 2007 to 4.43% in 2011,<sup>74</sup> it also acknowledges that NACP-III has been delivered with only 10% of domestic funding; no longer feasible in the current economic climate of shrinking

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<sup>74</sup> NACO. (n.d.). National AIDS Control Programme Phase-IV (2012-2017): Strategy Document. New Delhi: NACO: pp.5-6. Retrieved from <http://www.naco.gov.in/upload/NACP%20-%20IV/NACP-IV%20Strategy%20Document%20.pdf>

international funding.<sup>75</sup> Therefore, it is expected that NACP-IV will soon face a dilemma of funding its “core prevention strategy” on 99% of the population that is HIV-negative with IEC, and its ambitious plan to reach 90% of high-risk groups through TIs provided by CBOs such as the Humsafar Trust.<sup>76</sup> The strategy intends to put this challenging prevention effort in place with activities, such as “saturating quality HIV prevention services to all [high-risk] groups, based on emerging behaviour patterns and evidence;” and by “reaching out to MSM and transgender communities.”<sup>77</sup>

### *Overstretched, under-reached*

Outreach to communities has been the core strength of Humsafar. To initiate the community on HIV testing, Humsafar organizes weekly community activities on Friday at its main DIC located next to the Shakti Clinic, which provides a safe space for local MSM and transgender women groups to get together and socialize. Besides the entertainment that is a big attraction for these groups, Humsafar also takes the opportunity to provide talks on HIV-related topics including sexual orientation and gender identities (SOGI), intimate partner violence, and sexual diversity. These are its efforts to strengthen local community systems through knowledge sharing; a model Humsafar had since expanded into cyberspace, with Yaariyan, an online safe space

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<sup>75</sup> Ibid: p.6.

<sup>76</sup> See Craig, A. P. et al. (2014) for the divergence in cost-effectiveness between the two objectives. Craig and colleagues recommends targeting resources at populations at highest risk of HIV until saturation before investing in general un-targeted interventions to achieve the highest epidemiologic impact and cost-effectiveness.

<sup>77</sup> NACO. (n.d.), op. cit.: p.11.

for youth, “with more than 3,000 members to-date,” acknowledges Anand. Humsafar is seeking new ways to reach its constituents via social media and social networking applications on the internet and smartphones. According to Anand, “We have started direct internet outreach. We are on more than 90+ groups and apps. A lot of people from Yaariyan and the internet outreach have been coming to the clinic.” This extra demand for HTS is, nonetheless, not sufficiently large to fulfill the coverage targets of the government; which Anand says, has increased by 100% this year.<sup>78</sup> A quick survey of current scientific evidence provided below detects possible discrepancies between the NACP-IV strategy, and Humsafar’s current programmes in community outreach and generating demand for HTS.

### *Maximizing epidemiologic impact*

In South Asia, where the estimated proportion of MSM who are married range between 22% and 41%,<sup>79</sup> Hemmige and colleagues found that current HIV testing efforts in India have not targeted insertive MSM and may have been better at targeting unmarried MSM rather than those who were married.<sup>80</sup> Although being married did increase the likelihood of previous HIV testing, missed opportunities of testing insertive MSM might not be wise given that this group of MSM were more

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<sup>78</sup> Cumulative targets for ICTCs were 22,400,000 (2013-14), 23,660,000 (2014-15; 5.6% increase year-on-year), and 26,460,000 (2015-16; 11.8% increase year-on-year). Retrieved from [https://naco.gov.in/NACO/NACP-IV2/NACP\\_IV\\_Targets](https://naco.gov.in/NACO/NACP-IV2/NACP_IV_Targets).

<sup>79</sup> Carceras, C. F. et al. (2008). Epidemiology of male same-sex behaviour and associated sexual health indicators in low- and middle-income countries: 2003–2007 estimates. *Sexually Transmitted Infections* 84(Suppl 1): pp.i49 - i56. DOI: 10.1136/sti.2008.030569.

<sup>80</sup> Hemmige, V. et al. (2011). Sex Position, Marital Status, and HIV Risk Among Indian Men who have sex with men: Clues to Optimizing Prevention Approaches. *AIDS Patient Care and STDs* 25(12): pp.725-734. DOI: 10.1089/apc.2011.0079

likely to have engaged in unprotected anal intercourse (UAI), had lower rates of previous HIV testing and higher likelihood than receptive MSM of being married. As HIV seroprevalence, previous HIV testing and UAI were strongly correlated with sexual position rather than marital status, the authors' suggested refocusing current testing efforts on behaviours at risk of HIV.<sup>81</sup> NACO should also revisit a critical review of its transition from NACP-II to NACP-III, which points out the need to transfer more intervention ownership to communities if it wants to reach its ambitious targets.<sup>82</sup>

### *Uncertain future*

Presently, Shakti Clinic faces an uncertain future. The government funding to run the clinic this year had not materialized by the time of this assessment in September. Outreach staff had not been paid for four months, which had impacted the effectiveness of outreach activities, and compounded its existing problem of not meeting its targets. Despite the overwhelming odds, Anand vows to continue fighting: "This clinic cannot close...it was here before the government programme, and it is community-driven...it has huge community ownership." However, with pressing priorities, Anand may need to recall a maxim by which he steered the organization:

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<sup>81</sup> Ibid: pp.730 & 732. Although the study also found insertive MSM to have the lowest HIV prevalence among MSM, HIV testing and counselling could moderate their sexual risk behaviour. The study was conducted in Hyderabad and Secunderabad. HIV seroprevalence exceeded 20%.

<sup>82</sup> See Claeson, M. & Alexander, A. (2008). Tackling HIV In India: Evidence-Based Priority Setting And Programming. *Health Affairs* 27(4): pp.1091-1102. DOI: 10.1377/hlthaff.27.4.1091

Humsafar is a community-based organization. We are a model of trial and error...we do not have professionals working here...we come with limitations. If today you come to me and say, "I know five things that can help you improve," I will do it. We will listen.

### *Serving non-family*

The MSM is unlike gay men of the clinic, seeing its first clients in 1999. Today, by Anand's own account, the MSM sees outreach workers as a hindrance rather than comfort. MSMs are likely not motivated by the gay identity,<sup>83</sup> and may not want to be part of the Humsafar family, which is itself a gay identity:

No, this is not easy because many of them don't come to see us. [They think] as [we] are from Humsafar so [we] just want [them] to get tested and take [their] blood. Seeing us they run away, some of them say, "we come for sex and fuck, we don't come here for all these [other] things. Just give us condom[s] and go." Then lots of time get waste[d] to change their behaviour, only few people listen to us... we try to keep convincing them (MSM outreach worker, Humsafar Trust, Mumbai).

Diversifying the service delivery strategy of the Humsafar Model to provide services to non-family as well as family may be required to tap the demand of men outside its current reach. Just as Humsafar had done when it pioneered gay community-initiated HTS in 1999, it should compel itself once again to consider how to provide accessible HTS to its MSM clients in a way that they considered feasible and acceptable; and by doing so, lead the Indian HIV response by improving HIV detection among MSM and transgender women.

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<sup>83</sup> See Kumta, S. et al. (2010, February 1). Incidentally this is a publication on the VCT clients who are MSM at Humsafar Trust. The article concludes, "the present study documented that men in Mumbai who had sex with men but did not identify as gay already had an HIV prevalence more than 10-fold greater than the general population" (p.6).

*Bottom line*

Beyond meeting the national targets,<sup>84</sup> HIV testing should effectively prioritize reaching individuals at highest risk of HIV in Mumbai, testing individuals with their consent, and linking them into care as required. Humsafar should consider ‘test for triage’ recommended by the WHO,<sup>85</sup> to prioritize its resources while substantially increasing testing coverage, and may reduce and even eliminate the attrition that is occurring in the process of conducting outreach, demand creation, HIV testing, quality counselling, and providing HIV results.<sup>86</sup> A study of the London MSM epidemic when HIV prevalence doubled within a 5-year period gives a pause for thought. Researchers found that just 10 clusters totaling 400 men were all it took to double the HIV burden in MSM in a city with half the population of Mumbai.<sup>87</sup> While contexts are dissimilar, there is an important lesson. The current lack of HIV prevalence data on insertive MSM in India who would most likely engage in UAI should be as concerning as it is disconcerting.

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<sup>84</sup> Of interest, the NACP-IV HIV testing target is “number of vulnerable population accessing ICTC services /annum.” Reported targets have not been set for HIV detection, or the number of HIV positive individuals linked to care. It does have targets of “PLHIV provided free ART” but this will not include pre-ART. Retrieved from [https://naco.gov.in/NACO/NACP-IV2/NACP\\_IV\\_Targets](https://naco.gov.in/NACO/NACP-IV2/NACP_IV_Targets).

<sup>85</sup> WHO. (2015), op. cit.

<sup>86</sup> For examples from a different context but applicable, see: European Centre for Disease Prevention and Control. (2010). *HIV testing: Increasing uptake and effectiveness in the European Union*. Stockholm: ECDC.

<sup>87</sup> Lewis, F. et al. (2008). Episodic Sexual Transmission of HIV Revealed by Molecular Phylogenetics. *Plos Medicine* 5(3): pp.392-402.

## Municipal Responses in Lahore, Pakistan

### Overview

Pakistan is estimated to have 180 million people,<sup>88</sup> and in the northern state of Punjab, Lahore has a greater agglomeration of more than 10 million people.<sup>89</sup> Lahore is the cultural centre of significance in South Asia and can trace its municipality through the history of six empires to the 11<sup>th</sup> century.<sup>90</sup> Today it is located on an important heroin trade route between Pakistan, Afghanistan, and Iran called the Golden Crescent.<sup>91</sup>

Pakistan has low literacy rates, with only 58% of men and 46% of women reported to be literate.<sup>92</sup> The legal system in Pakistan is classified as highly repressive for MSM and transgender women by two UN legal reviews.<sup>93</sup> Under Islamic Law, sex other than between husband and wife is strictly forbidden. According to the Pakistan Penal Code (Section 377) and the Hudood Ordinance, someone who is caught engaging in same-sex behaviour can be punished with up to 100 lashes, imprisoned for up to 10 years, or stoned to death. However, the Supreme Court ruled in 2009 that transgender

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<sup>88</sup> NACP. (2015), op. cit.: p.10; citing the *2012 Economic Survey of Pakistan* conducted by the Ministry of Finance.

<sup>89</sup> *Demographia World Urban Areas*. (2015, January). Retrieved from [www.demographia.com/db-worldua.pdf](http://www.demographia.com/db-worldua.pdf).

<sup>90</sup> Students' Academy. (2011). *Lahore-The Cultural Capital of Pakistan*. Retrieved from [www.lulu.com](http://www.lulu.com).

<sup>91</sup> Chandran, D. S. (1998). Drug trafficking and the security of the state: A case study of Pakistan. *Strategic Analysis*: pp.903-922. DOI: 10.1080/09700169808458862

<sup>92</sup> NACP. (2015), op. cit.: p.10; citing the Pakistan Bureau of Statistics in 2012.

<sup>93</sup> See Godwin, J. et al. (2010) and Cáceres, C F. et al. (2008) for the UN legal reviews.

women or *hijra* should have equal rights, which will entitle them to vote and access to social support services.<sup>94</sup> However, it will take time for these rights to materialize as social wellbeing in a community that has been systematically discriminated since the British Raj.<sup>95</sup> The British Home Office, in summarizing its policy guidance on asylum and humanitarian requests from Pakistanis reports,

Widespread and systematic discrimination against LGBT persons in Pakistan does, however, persist, including harassment and violence. This treatment may, in individual cases, amount to persecution. No effective protection is provided by the authorities.<sup>96</sup>

MSM and transgender women face substantial mortal risk in Pakistani society. In May 2015, two men on a motorcycle shot at a group of transgender women standing at a street corner in Rawalpindi, northwest of Lahore. Three transgender women were killed, and four others – two transgender women and two feminized men – were injured in the attack.<sup>97</sup> Between March and April 2014, a serial killer in Lahore had murdered three gay men he had contacted through an online dating website, after having sex with them. Sentenced to death, the father of two had said, “They are spreading evil and transmitting diseases. They cannot control themselves.”<sup>98</sup>

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<sup>94</sup> NACP. (2010). *UNGASS Country Progress Report: Pakistan*. Islamabad: Ministry of Health Services, Regulation and Coordination.

<sup>95</sup> For example, see Babar, M. & Synovitz, R. (2015, December 31). Despite Gains, Pakistan's Transgender Community Under Attack. *RFE/RL*, retrieved from <http://www.rferl.org/content/pakistan-transgender-eunuchs/25148690.html>.

<sup>96</sup> Home Office. (2014, July 14). *Country Information and Guidance: Pakistan: Sexual orientation and gender identity*. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/331641/Pakistan\\_CIG.SOGI.2014.07.16.v1.0.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/331641/Pakistan_CIG.SOGI.2014.07.16.v1.0.pdf).

<sup>97</sup> Asghar, M. (2015, May 11). Three transgenders killed in armed attack. *Dawn*, retrieved from <http://www.dawn.com/news/1181248>.

<sup>98</sup> AFP. (2014, April 28). Lahore serial killer ‘wanted to teach gays a lesson’. *The Express Tribune*, retrieved from <http://tribune.com.pk/story/701322>.

Subsequently, two months later in June, three more gay men were murdered in Faisalabad, 118km west of Lahore; these murders had not been publicized.<sup>99</sup>

Extrapolating available data, UNDP and APCOM estimate that there are 2,285,500 MSM in Pakistan.<sup>100</sup> In contrast, Asian Epidemic Modelling (AEM) provides a more conservative population estimate of 150,000 adult MSM, or 0.3% of the total male adult population.<sup>101</sup> Spectrum estimates a population of 50,598 transgender women.<sup>102</sup> Previous mapping in Lahore<sup>103</sup> estimates a municipal population of 38,000 MSM.<sup>104</sup>

Pakistan has a concentrated HIV epidemic in PWID but the largest contributions to new infections over time is from MSM and transgender women.<sup>105</sup> By analyzing the HIV gene sequences in blood samples obtained from PWID, MSM, the wife and children of MSM, of whom all were living with HIV, researchers have found evidence of HIV bridging between these populations; with MSM injecting drugs by

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<sup>99</sup> Erasing 76 Crimes. (2014, June 9). *Update: LGBTI Pakistanis mourn 6 serial killer victims*. Retrieved from <http://76crimes.com/2014/06/09>. Information from NMHA.

<sup>100</sup> UNDP. (2012). *Country Snapshots: Pakistan: HIV and Men who have sex with men*. Bangkok: UNDP.

<sup>101</sup> NACP. (2015) *Global AIDS Response Progress Reporting: Country Progress Report Pakistan*. Islamabad: Ministry of National Health Services, Regulation and Coordination: p.14

<sup>102</sup> NACP. (2015), op. cit.: p.13. Transgender women population estimate is based on the 2014 Spectrum modelling of *hijra* sex workers.

<sup>103</sup> Khan, S. & Khilji, T. (2002). *Pakistan enhanced HIV/AIDS program: social assessment and mapping of men who have sex with men (MSM) in Lahore, Pakistan*. Lucknow: Naz Foundation International.

<sup>104</sup> World Bank. (2015, June). *HIV/AIDS in Pakistan*, retrieved from <http://siteresources.worldbank.org/INTPAKISTAN/Resources>. MSM used here refers to a heterogeneous community that could have included *hijras* (transgender women), *zenanas* (transvestites) and masseurs.

<sup>105</sup> NACP. (2015), op. cit.: p.8.

sharing injecting equipment implicated as the likely source of the bridge.<sup>106</sup> Injecting drug use has also been reported in among transgender women population, albeit the practice is not widespread; 3% of a respondent driven sample of 200 *hijra* in Lahore reported injecting drugs in the past year.<sup>107</sup>

There are currently no official baseline estimates of HIV prevalence in MSM and transgender women in Pakistan. However, as a proxy for national HIV prevalence in MSM using data from an epidemiological survey conducted in 2010 provides an estimate of 10.9%;<sup>108</sup> and in 2014 UNAIDS reported a lower estimate of 3.5%.<sup>109</sup> Among transgender women sex workers, Pakistan's 2011 HIV surveillance estimated prevalence at 7.2%,<sup>110</sup> while a 2013 meta-analysis on transgender women specifically provided an estimate of 2.2%. The meta-analysis also found that between 2000 and 2011, transgender women in Pakistan had 21.9 times the odds of being at risk of HIV infection as compared to the general population between the ages of 15 and 49 years.<sup>111</sup> A study of the hierarchical power dynamics of transgender women culture in Lahore found that gurus, as heads of *deras* (a pseudo-family), was an important focal

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<sup>106</sup> Khanani, M. R. et al. (2011). The Spread of HIV in Pakistan: Bridging of the Epidemic between Populations. *Plos One* 6(7): e22449. DOI:10.1371/journal.pone.0022449.

<sup>107</sup> Rehan, N. et al. (2009, June) Socio-sexual Behaviour of Hijras of Lahore. *Journal of Pakistan Medical Association* 59(6): pp.380-384. Retrieved from <http://jpma.org.pk/PdfDownload/1719.pdf>.

<sup>108</sup> UNDP. (2012), op. cit. In the absence of an official reported figure, an epidemiological survey of 396 MSM from Karachi (69.19 percent), Sangar (18.18 percent) and Larkana (12.62 percent) was used.

<sup>109</sup> UNAIDS. (2014) *Global AIDS Response Progress Reporting data*, retrieved from <http://www.aidsonline.org>.

<sup>110</sup> NACP. (2011). *HIV Second Generation Surveillance in Pakistan, National Report Round IV 2011*. Retrieved from <http://www.aidsdatahub.org>.

<sup>111</sup> Baral, S. D. et al. (2013), op. cit.: p.217.

point in the provision of HIV services and raising HIV awareness among transgender women.<sup>112</sup>

There is an estimated 91,340 PLHIV in Pakistan.<sup>113</sup> In 2009, the PLHIV Stigma Index reported that of the 883 individuals surveyed, one in three (33%) of PLHIV had been denied health services, and 26.8% had faced discrimination from other PLHIV.<sup>114</sup> In the same year, a study of 200 healthcare providers (HCPs) in Lahore revealed a health system that was unprepared for HIV.<sup>115</sup>

### Institutionalizing the stigma of HIV

HIV acquisition is highly stigmatized in Pakistan. Given that non-conjugal and non-heteronormative sex is strictly forbidden, and there are repressive punishments for same-sex behaviour, stigma from sexually acquiring HIV among MSM and transgender women has become institutionalized,<sup>116</sup> which includes the public health system. In a case involving MSM, health centre staff had requested that his parents

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<sup>112</sup> Bangash, O. (2012). Unfolding power: the *Hijra* hierarchical system in Pakistan and HIV/AIDS interventions. At the *International AIDS Conference*, Washington D.C. Retrieved from <http://pag.aids2012.org/EPosterHandler.axd?aid=11703>.

<sup>113</sup> NACP. (2015), op. cit.: p.8.

<sup>114</sup> APLHIV. (2009-10). *People Living with HIV Stigma Index-Pakistan*. Islamabad: APLHIV. Revised 2014.

<sup>115</sup> Khan, M. S. et al. (2009). *Knowledge, attitudes and practices regarding Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome and sexually transmitted infections among health care providers in Lahore, Pakistan*. Retrieved from <http://ayubmed.edu.pk>. Results show that less than half (45%) of HCPs had correct knowledge about HIV the transmission and prevention; and although one in five (21%) HCPs had seen at least one patient with advanced HIV infection but only two HCPs were trained to manage these cases.

<sup>116</sup> See Home Office. (2014, July 14), op. cit.

receive counselling before he could be treated with antiretroviral therapy (ART), which eventually returned him to health but had created a problem with his family.<sup>117</sup>

Now even though he is taking his ARVs and he is gaining stability in his life but his father hates him. The poor guy tells us that everything is going well in his life but his father hates him and he can't live in his house (A1, MSM).

It is therefore not uncommon to hear of people failing to turn up to collect their HIV test result, or disappear after getting their confirmatory test reports.

The moralizing of HIV among HCPs is a commonly reported experience:

Then I was summoned to meet a senior doctor who told me why do you want to do unjust to women when your own activities are wrong and why do you want to marry with a negative? You should marry someone who is positive...It was a long lecture on the Muslim culture. So this was purely discrimination (Y3, MSM).

Given that it is the practice of HCPs to share their case notes, this can also increase the stigma of patients by increasing the number of HCPs privy to their HIV status. Furthermore, a recent study on male sexual health in South Asia reported that service providers interviewed in Pakistan were more likely to perceive that “HIV positive people don't really have a right to confidentiality about their infection,”<sup>118</sup> which contravenes ethical guidelines.<sup>119</sup> In a country with a poorly funded and over-

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<sup>117</sup> NACP. (2013, December). *Pakistan Country Strategy: HIV Testing and Counselling: based on Situation and Response Analysis*, retrieved from <http://www.nacp.gov.pk/library/reports>. This is not standard practice, and reflects on poor training of counsellors and/or HCPs. See note 6 (p.44).

<sup>118</sup> IPPF. (2013), op. cit.: p.22.

<sup>119</sup> NACP & WHO. (2004, October). *Guidelines on ethical issues for HIV/AIDS related research and service delivery in Pakistan: Draft version*. Retrieved from [http://www.nacp.gov.pk/policies\\_and\\_guidelines/treatment\\_and\\_care/nacp-ethical-guidelines.pdf](http://www.nacp.gov.pk/policies_and_guidelines/treatment_and_care/nacp-ethical-guidelines.pdf).

extended health system with lax oversight in medical ethics,<sup>120</sup> doctors' moral stance can develop into discriminatory practices.

I know 1-2 examples where minor accidental surgeries were refused by doctors, and in the very same hospital the transgender woman was diagnosed positive by [the] doctor's friend, who told him about her status (M1, transgender woman).

According to an MSM participant, "if they find out that you are positive then they hate you, they don't want to come close to us." Social exclusion can take many forms; including removing physical contact to the extent that, "they ask us to hold the cotton with our hands while injecting us," recalls the same participant. At the very least, there is an increase in waiting time before being seen by a doctor. A PLHIV relates the one time he made a complaint.

As human you do realize you've wasted your 4 hours then they tell us "in future you cannot say this, we know what we have to do, do you know the amount of money being spent on you?" It felt as if they were paying for my treatment (X2, MSM).

In societies where resources are allocated hierarchically, the poor quality and delayed treatment of MSM and transgender women could be indicative of non-compliance with treatment resources being allocated to groups perceived to be hierarchically undeserving.

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<sup>120</sup> See Jafree, S. R. et al. (2015). Ethical violations in the clinical setting: the hidden curriculum learning experience of Pakistani nurses. *BMC Medical Ethics* 16: 16. DOI: 10.1186/s12910-015-0011-2. See also, the thought provoking article by Shiwani, M. H. & Gadit, A. A. M. (2011). Medical negligence: A growing problem in Pakistan. *Journal of Pakistan Medical Association* 61(6): pp.610-611. Retrieved from <http://jpma.org.pk/PdfDownload/2837.pdf>.

## Accessing healthcare with dignity

However, there are positive experiences in the healthcare services too.

Initially when I went to the treatment centre I was nervous and confused. Now there are more people in lines and I don't have any tension any more. Now I have become shameless (N5, transgender woman).

The better treatment is due in large part to the community-based organization advocating directly with the hospital.

We have established good links with [a government hospital] and we refer our positive clients there and also do follow-ups if they are on proper treatment or not (M1, transgender woman).

This has brought about surprising results.

Once the expectations of poor treatment and the uncertainty of visiting the place for the first time subsided, a pleasant experience at a municipal hospital emerged.

The initial fears are how they would treat us, and what would they say to us. But my overall experience was very nice (B3, transgender woman).

However, this success is by no means commonplace in Lahore, and not every member of the community has been able to experience it, especially if they lived far away. In a rare moment of reflection, a PLHIV acknowledged that people must recognize that they have a role to play in perpetuating the stigma of HIV.

We have ourselves stigmatized the disease, so how is it possible to reverse the effects without awareness? Unless we provide proper awareness to [the] general population then no one would come forward for testing and get counselling. Because unless we get proper counselling, then we would get to hear from government centre officials that you can't marry, you [can't] bare (sic) children and you can never have sex (Y3, MSM).

## Fearing confirmation of HIV diagnosis

Stigma also leads to the delay in seeking treatment, and not always because community members anticipate stigma at the treatment centre. It is also the fear that their own communities may find out about their status.

Only 30-35 percent of community go (sic) to treatment centres. The rest refuse to go to treatment centres. This is because they think that until now only the few people in [the] organization know about [their] status but what if their status gets confirmed and spread out amongst the community members? At least [until] this stage they have a chance to say its not confirmed yet [with the] third test and they fear the news will spread if they go to a hospital (M1, transgender woman).

Knowledge of someone else's status gives the person an unfair advantage.

...it is also common that the community degrade each other. If someone finds out about someone else[s] status then they [would] spread it. All *moorats* (transgender women) residing in *Heera Mandi* area know about each other's status. And they use this information by retaining each other's [sex work] clients (I2, MSM).<sup>121</sup>

To the extent that community members are willing to spread lies about another.

Some people even make up false information about HIV status. They have insecurities, just like M1 said because of competition. Insecurities can also be about money, that who has how much (J4, transgender woman).

These intra-communal rivalries have exacerbated stigma, discrimination and caused disunity within the transgender women community.

I think one of the problems is that we are not united. The transgender on [the] lower floor will tell that [the] trans[gender] on [the] upper floor are doing [sex] work, to police.

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<sup>121</sup> Information obtained from focus group discussion with MSM at DMHS, confirms information provided during key informant interview with transgender woman living with HIV.

Trans[gender] on [the] upper floor will say the same thing about the lower floor residents...(B3, transgender woman).

In the end, the participant summarizes, it becomes detrimental for the whole community when “transgender women get arrested from [both] upper [and] lower floor[s].”

### DMHS and KSS services, Naz Male Health Alliance

Naz Male Health Alliance (NMHA) is the first technical support provider in the region on male and transgender sexual health, and is recognized by the government as an important collaborator in HIV healthcare. NMHA is responsible for the significant increase in the registration of MSM and transgender women in the public health system.<sup>122</sup> Under MSA HIV Programme, it is supporting six community-initiated HTS throughout Pakistan. It is unlikely that these HTS will be able to continue operating once the current grant ends.<sup>123</sup>

### Safe spaces

The Dostana Male Health Society (DMHS) and Khawaja Sara Society (KSS) are the two service delivery centres in Lahore for MSM and transgender women respectively.<sup>124</sup> DMHS is located in a conservative part of town and housed in a

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<sup>122</sup> Cited from Health Policy Project et al. (2015), op. cit.: p.40.

<sup>123</sup> NACP. (2013, December), op. cit. It is Objective 2 of the proposed strategy to expand HIV testing to vulnerable populations through CBOs, so there is an opportunity for targeted advocacy with NACP.

<sup>124</sup> NACP & WHO. (2004, October), op. cit.: p.17. Both DMHS and KSS facilities followed guidelines on VCT and service delivery to high-risk populations.

building with reinforced steel doors and shutters, whereas KSS is located near the junction of two important highways that crisscross Lahore. Both these centres are located near known MSM and transgender women hotspots, where community outreach runs on weekly schedules. The distribution of condoms and lubricant, and BCC are provided during outreach, as well as efforts to create demand for HTS in local MSM and transgender women networks. Besides HTS, the services also offer free diagnostic and treatment for STIs, as well as safe spaces for respective MSM and transgender women communities to network and socialize as part of its DIC facilities.

### *Dedicated services*

KSS offers dedicated community-initiated HTS for transgender women and *hijra* populations in Lahore, and is the only transgender women's only HTS assessed in this report. Besides usual outreach at hotspots in its vicinity, KSS also provides outreach services to *deras* (pseudo-households) around Lahore; where many transgender women are engaged in sex work. For *hijra* that engage in begging, the free STI diagnostic and treatment services offered at KSS have saved these women needing to look for appropriate HCPs away from begging sites to safeguard their dignity.

A transgender woman who has STI...cannot go to her area[']s] doctor for treatment because of degradation. First there is a degradation factor and then they would not go begging in that area because they would not want the doctor to know about it (Z2, transgender woman).

### *Counterfactuals misinform*

HIV knowledge in the *hijra* communities is relatively poor, and transgender women often rely on lay perceptions and deductions to fill in missing gaps in their

understanding of HIV transmission and infection. These knowledge gaps have given rise to counterfactuals derived from misinformation circulating in transgender women communities, which KSS staff addresses on an ad-hoc basis.

During the assessment, the misinformation had been about the efficacy of condoms in protecting the community from HIV infection. Deducing the reverse, a counterfactual emerged from transgender women having observed that HIV had not existed prior to their use of condoms.

...only a few days ago a transgender women friend of mine who is also well educated she also held the same belief that we've had sex all our lives...no one used condoms... now that people have started using condoms that's when HIV has started to spread (M1, transgender woman).

These misinformation have led some individuals also accuse NGOs for spreading diseases among transgender women.

They also have the concept that ever since NGOs have started working there diseases have increased (Z2, transgender woman).

Unfortunately, these counterfactuals and misinformation have had a direct impact on increasing the effort of KSS in demand creation for its services. Outreach workers find that they need to correct misconceptions prior to providing services, which increases the time it takes in engaging potential clients.

### *Systematic abuse*

Their demand creation for HTS is further hampered by the social exclusion and attacks of transgender women living with HIV. These individuals have to bear the

brunt of ill will directed at them among their peers, even from members of the same *gharanas* (clans) and *deras* (pseudo-households).

Everyone would start hating them. No one would let them use their things. No one would eat with them... Well guru does not say anything to us even though she knows we have the disease... The *chelas* (disciples) and *guru-bhai* (sisters of the same guru) taunt us... Like they have to keep their distance and hate us (B3 and N5, transgender women).

These traumatic experiences and the expectation of more abuse cause many transgender women to isolate themselves, impacting their ability to access required HIV services.

I have even stopped going out...I just don't like it, hearing hateful things... Things like, "I've heard you are sick", you have this disease... So I don't go out which prevents people from asking (N5, transgender woman).

And in obtaining social support to help them through their HIV diagnoses; even relatives have been known to disown transgender women living with HIV.

...the relatives refused to care for her instantly... even her guru left after 2-3 days saying she could not take her responsibility (J4, transgender woman).

The social policing of possible infection in the community is systematic and relentless:

People obviously find out. For example see how many of us are sitting together. So someone will tell this to someone. People talk. When this problem starts, it does not stay hidden. It automatically spreads out. The community acts differently [in] your face and later speaks sarcastically against us (N5, transgender woman).

The social exclusion and isolation impact the ability of transgender women engaged in sex work to sustain a living.

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Firstly if a transgender women is involved in sex work then she would never want people to find out about her status...even in her own trans-family her status would be shared with the clients the she is positive and people make a distance from her (Z4, transgender woman).

And, also impacts their sociability in communities and local networks.

In Larkana the *moorat* (transgender women) and MSMs have devised a sign for HIV. They make a hand sign to each other to tell them not to have sex with [a] person close to them. It's a AIDS sign. I've seen community using this sign language to tell each other and also *giryas* (penetrative male sex partner) (Z2, transgender woman).

These systematic abuse and exclusionary practices amounts to persecutions of PLHIV, and describes the process of community ostracism for transgender women living with HIV.

### *Abandoned by peers*

The potential HTS clients' fear of testing HIV positive and being judged negatively by their community and peers are therefore well founded. Transgender women have been reported leaving the city when they test positive for HIV, preferring to choose self-exile to escape from community ostracism. Although such systematic persecution had not been reported among the MSM community, one participant had feared for his safety when the person he had protected sex with had subsequently found out about his status.

...the person I had sex with a few days ago was told about my HIV status...I started receiving calls and messages that they'd hand me over to FIA (the police) since I was spreading HIV even though I had protected sex...So how do you suppose people would come forward when someone who is on treatment gets discriminated so much? Why would they come forward for testing [and] counselling? (Y3, MSM).

Not only do these events impact on demand for community-initiated HTS, it is also indicative of high-levels of stigma in the populations of MSM and transgender women in Lahore, as well as low-levels of HIV knowledge. Taken together, it is therefore not at all surprising that many MSM and transgender women who test for HIV at DMHS and KSS do not return to collect their results; inevitably impacting the linkage of PLHIV into appropriate care, and the operationalizing of treatment as prevention in these communities.

### *Added privacy*

Given the sensitivity of HIV positive testing outcomes, the setup of HIV testing facilities at both DMHS and KSS centres is exemplary. Both centres have with dedicated spaces for doctors and counselors, in clean and conducive environments. In both locations, potential HTS clients can access HIV testing without going through the centre, giving them an added measure of anonymity.

### *Interrupted funding*

Respondents at both sites remember past interruptions in funding, and are concerned that these programmes will discontinue at the end of 2016 when the Global Fund grant comes to an end. Transgender women clients of KSS deliberate the issue:

B3: God is almighty, if these services close, what else would we do?

J4: If they close this platform then we would lose a safe space and enabling environment. This space can even be a *dera* (a pseudo-household), but there needs to be a place where community can mobilize and move further on together. This does not need to be office but a safe and enabling environment where we have

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surety and then many more would come afterwards...gradually happen, not in a few seconds. Change takes time.

Z2: From the looks of it, the... community would only want to continue begging and dance [at] functions to generate income by any means.... very few people [will] think forward. If [only] we [are] united, and [will] talk about our rights [to] health...

B3: I think people can be saved from this disease.

These transgender women see the upcoming challenge in funding with candid honesty and a will to survive. Having been through at least one funding crisis, they are cognizant of having few options when funding stops.

The MSM community at DMHS has deliberated similar questions. Unlike the *hijra* community who has legal recognition,<sup>125</sup> rights, and access to government welfare funding, the MSM community remains sidelined.

Y3: The KPK (provincial) government is not involved in the project from the start...

A1: The government does not have any interest in this project because it is an MSM-focused project. NMHA through its advocacy has at least gotten the government to accept that MSM exist in Pakistan...

I2: It would cause a lot of harm to the community...

A1: The work that we have carried out for 5-years would go to waste...

I2: The community does not have sufficient unity (to get HIV testing done on its own).

Y3: For that we need to establish groups, develop leaders, and select people. Everyone has a group; they should select someone who can take them...

I2: But in our community everyone wants to be a leader...

Y3: They should have sufficient awareness and should be able to provide awareness to others as well.

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<sup>125</sup> See Babar, M. & Synovitz, R. (2015, December 31), op. cit. It will likely take time to translate legal gains into improved social status and actual rights.

A1: Apart from awareness people should have a sense of responsibility, we don't have the required educational level. If some people sit in a group then their category will be different, their understanding would be different.

These excerpts of their discussion shows that the seeds of an HIV response among MSM and transgender women in Lahore are clearly present, and that participants can grasp the main issues affecting their community. There is however the urgent need for capacity building to germinate and develop present ideas into community-initiated responses that are both sustainable and pragmatic to maintain the present momentum.

### *Hostile elements*

The DMHS and KSS services operate in dangerous circumstances and situations, which is a tribute to the courage of the MSM and transgender women who run these facilities. They are at the forefront of the AIDS response with little structural support behind them, and under threat from the risk of mortal danger. It is an inhospitable environment that these centres must be a refuge for communities as for the staff. It is commendable work; building an enabling environment with hostile elements at the doorstep. The services' targets, goals and aims must seriously consider challenging contexts, and expectations set to the longer term rather than on immediate returns.

## Municipal Responses in Dhaka, Bangladesh

### Overview

Dhaka is the capital of Bangladesh. It is a city of 15.7 million people on the banks of the Buriganga River, and one of South Asia's megacities.<sup>126</sup> In contrast with its historical fame as regional capital of the Mughal Empire's Bengal Province in the 17<sup>th</sup> century,<sup>127</sup> Dhaka city today is described as a rural megacity for its lack of civic spaces, poorly maintained infrastructure, and high rates of poverty.<sup>128</sup>

A 2010 key population estimate of Bangladeshi returned 110,581 MSM and 8,882 transgender women.<sup>129</sup> MSM are highly stigmatized in Bangladesh, which has section 377 of the penal code that criminalizes anal sex and homosexual acts. Although rarely enforced, the law has been used to harass MSM.<sup>130</sup> A community-based study of 102 MSM in Bangladesh reported that almost half (47%) had considered suicide at least

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<sup>126</sup> *Demographia World Urban Areas*. (2015, January), op. cit.

<sup>127</sup> Ring, T. et al. (1996). *International Dictionary of Historic Places: Asia and Oceania*. Abingdon: Routledge.

<sup>128</sup> Hossain, S. (2006) Social characteristics of a megacity: a case of Dhaka City, Bangladesh. *The Australian Sociological Association 2006 Conference Proceedings*. Crawley: UWA: p.6.

<sup>129</sup> *Country Progress Report: Bangladesh*. (2014, May 2): p.51. Retrieved from <http://www.unaids.org/sites/default/files/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries>.

<sup>130</sup> UNDP. (2012, December). *Country Snapshots: Bangladesh: HIV and men who have sex with men*. Bangkok: UNDP.

once.<sup>131</sup> In contrast, transgender women, or *hijras* have been recognised as a third gender in 2013, and will be prioritized for education and other rights.<sup>132</sup>

In a seminal study on individuals with proclivities for same-sex love conducted in Dhaka,<sup>133</sup> Bondyopadhyay and Ahmed described Bangladeshi society as traditional and “clannish” with priorities in kinship duties and familial obligations above individuals needs. It is a place where “individual emancipation is often very hard, if not impossible.”<sup>134</sup> Individuals are defined by their family connections and social circles, and in fulfilling society’s expectations. Gender norms favour masculine expressions and frown on feminization. The authors called Bangladesh a “homonormative”<sup>135</sup> society that accepted public and private displays of same-sex affection, but not anything sexually explicit. It is a dangerous society for visibly feminized men (*kothis*) and transgender women, with violence commonly perpetrated by members of society as chastisement for gender normative transgressions; often carried out by total strangers as a proxy for dishonouring their families.<sup>136</sup> Sexual assault and rape of *kothis*, bisexual men, and transgender women are also common.<sup>137</sup> A study of stigma among *kothis* found that they had inadvertently employed stigma management

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<sup>131</sup> BSWS. (2014). *Bandhu Social Welfare Society Annual Report 2014*. Dhaka: BSWS: p.17.

<sup>132</sup> Health Policy Project et al. (2015), op. cit: p.65.

<sup>133</sup> Bondyopadhyay, A. & Ahmed, S. (2010), op. cit.

<sup>134</sup> Ibid: p.22.

<sup>135</sup> Ibid: p.vii.

<sup>136</sup> Ibid: p.23.

<sup>137</sup> Ibid: p.22.

strategies to minimize their discreditable social identities, which included passing as gender normative whenever possible.<sup>138</sup>

Bangladesh has a low prevalence HIV epidemic that is concentrated among people who use drugs (PWUD), male sex workers (MSW), female sex workers (FSW), MSM and transgender women or *hijra*. A 2013 estimate of HIV prevalence in the city of Dhaka returned a prevalence of 0.7% in MSM, and 0.5% in transgender and *hijra*.<sup>139</sup> There are currently approximately 8,900 PLHIV in Bangladesh.<sup>140</sup> According to UNAIDS, 1,287 PLHIV (approximately 14%) were on ART by 2014.<sup>141</sup> Results from a retrospective study on the predictors of deaths in hospitalized HIV-infected patients is sobering: the deaths were indicative of AIDS progression that were likely caused by testing and presenting too late into healthcare. The novel finding was that there were no medical surprises; these deaths had been both predictable and avoidable.<sup>142</sup> This finding resonates with the current reality of PLHIV:

We only find HIV patients when they become weak and are continuously suffering from diseases and infections...a fair and supportive environment should be ensured at all levels of society (Habiba Akter, Executive Director of Ashar Alo Society).<sup>143</sup>

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<sup>138</sup> Ferdoush, M. A. (2013). Living with Stigma and Managing Sexual Identity: A Case Study on the Kotis in Dhaka. *Sociology Mind* 3(4): pp.257-263. DOI: 10.4236/sm.2013.34034.

<sup>139</sup> Country Progress Report: Bangladesh. (2014, May 2), op. cit.: p.39.

<sup>140</sup> UNAIDS. (2015, November). *Data Sheets: Bangladesh: HIV prevalence and epidemiology*, retrieved from <http://www.aidsdatahub.org/Data-Sheets>

<sup>141</sup> UNAIDS. (2015, November), op. cit.

<sup>142</sup> Shahrin, L. et al. (2014). Characteristics and Predictors of Death among Hospitalized HIV-Infected Patients in a Low HIV Prevalence Country: Bangladesh. *Plos One*. DOI: 10.1371/journal.pone.01113095

<sup>143</sup> Azad, A. (2014, December 1). Foreign donors to stop funding for AIDS patients in Bangladesh. *Dhaka Tribune*, retrieved at: <http://www.dhakatribune.com/bangladesh/2014/dec/01>.

Of the 238 PLHIV surveyed in the 2009 PLHIV Stigma Index, only one in three (33.6%) PLHIV had volunteered for HIV testing, more than a quarter (26.9%) had been tested due to work requirements, and one in five (21.8%) had tested because significant others were found to be HIV positive.<sup>144</sup> The 2014 surveillance data showed that although almost half (46.5%) of MSM in Dhaka knew where to seek confidential HIV testing, only half (50.6%) of whom had ever been tested; in comparison, more than four fifth (84%) of transgender women in Bangladesh knew where to seek confidential HIV testing, and three in five (60%) of whom had ever been tested.<sup>145</sup>

### Seeking HTS that fulfill community needs

Currently, the majority of HTS in Bangladesh are vertical programmes operated by NGOs.<sup>146</sup> Nonetheless, given the choices available, the majority of MSM in Dhaka and transgender women in Bangladesh (both around 68%) had accessed HTS at particular CBOs rather than NGOs; with MSM preferring Bandhu Social Welfare Society (BSWS), while transgender women preferred the FHI 360 clinic (USAID funded service that ceased operations in 2014), followed by BSWS (30.8%).<sup>147</sup> Without the FHI 360 clinic as an option, the major preference of both communities

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<sup>144</sup> Draft Report on “People living with HIV Stigma Index” study in Bangladesh. (2009), retrieved from <http://www.stigmaindex.org>.

<sup>145</sup> Reza, M. M. et al. (2014), op. cit.

<sup>146</sup> Ahmed, S. M. et al. (2015). *Bangladesh Health System Review: Health Systems in Transition*. Manila: WHO.

<sup>147</sup> Reza, M. M. et al. (2014), op. cit.

for their HTS needs is from BSWs. Currently, BSWs is exploring other modalities in providing counselling services to MSM and transgender women living with HIV.<sup>148</sup>

However, of interest, MSM and transgender women living with HIV have unanimously underscored that neither of their communities is ready to initiate HTS with existing issues on confidentiality:

We, who are from the MSM community, we are not consistent in our words and deeds.

We religiously say that we won't tell it to anybody, but we express secrets to others very easily. If we have a tension with a person, we don't keep it close, we disclose people's HIV status to others (MSM).

Similarly, in transgender women communities:

We are leaking our own information...I said to one of my friends that I am HIV positive, he is telling this to our other friends. (all: many of them do it) (transgender woman).

Thus, seeking community-centred HTS is more important to these communities than initiating HTS by themselves.

### Providing safe spaces under inhospitable conditions

A 2014 surveillance study of 487 MSM in Dhaka, almost one in five (18.4%) reported being beaten or raped in the last year, although this had declined over time. Among the 533 transgender women across Bangladesh who had participated, less than one in three (31%) transgender women reported being beaten, of whom the majority (58.6%) had said that the perpetrators were other *hijra*. Transgender women working in sex

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<sup>148</sup> In-depth interview. (2015, October 21). Shale Ahmed, Executive Director of BSWs at his office, Dhaka city. The BSWs HIV testing service is partially by referral to Ashar Alo Society (AAS), as the latter is a PLHIV CBO that is under contract to provide ARVs to PLHIV. Thus HTS by AAS is assured linkage to care.

work were significantly more likely to report being raped in the last year than non-sex workers (33.6% vs. 5.6% respectively).<sup>149</sup>

In this context of violence, seeking HTS from the community's perspective is beset with potential problems caused by the double stigma of gender normativity and HIV, and the need to side-step potential sources of discrimination. For the MSM, the need to talk about the same-sex behaviour that defines their identities can be perplexing.

It's on our physical relationship... the actions that we mostly enjoy during physical relationship. That means we can express our mental desire [at] Bandhu (BSWS) (MSM).

Services that provide safe spaces for MSM and transgender women will provides moments of being unencumbered, free from the constraints of social norms, etiquette, and rules.

They have a separate place for us so that we can wait. When people from our community go there, we sit together, discuss together, we don't face any problem. We can talk freely (MSM).

These safe spaces create environments conducive to health seeking and HTS delivery.

"They feel comfortable and secure at our DICs," reports Anisuzzaman, Programme Manager at BSWS.<sup>150</sup> Its DIC-based HTS currently reached between 200-300 MSM and transgender women a month across Bangladesh. However, the current coverage is only an estimated 24% to 30% of the respective populations. BSWS plans to increase

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<sup>149</sup> Reza, M. M. et al. (2014). *A survey of risk behaviours among males having sex with males, male sex workers and hijra: Global Fund Rolling Continuation Channel Project of icddr,b*. Dhaka: icddr,b.

<sup>150</sup> In-depth interview. (2015, October 21). Anisuzzaman, HTS programme manager and VCT specialist at BSWS Executive Director's office, Dhaka city. BSWS has 6 DICs offering HTS in Dhaka.

its service coverage to between 36% and 50% in 2016, and think that the best way to expand is by locating DICs closer to MSM and transgender women in rural Bangladesh so they have less distance to travel to receive care and support.<sup>151</sup>

However, findings from focus group discussions with both MSM and transgender women living with HIV do not support this view. Although many participants agreed that locating services in areas where they lived would make it more convenient to access services, the potential for the lack of anonymity and being stigmatized were key concerns. The fear of being “despised” and looked upon in “disdain” and “marked as HIV positives” by their local communities would make it less likely, at least among PLHIV from communities of MSM<sup>152</sup> and transgender women,<sup>153</sup> to access care and support services in their neighbourhoods.<sup>154</sup> It is a point of view that BSWs may want to explore in greater detail before it expands its HTS as planned.

### Providing accurate official information about HIV dispels myths

The low level of knowledge about HIV even among doctors, with one doctor reported to have called it a non-communicable disease, indicates how little the general public may know about HIV: “Many people do not know about the reason for this disease. They don’t understand it” (MSM). The lack of reliable formal channels of accurate

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<sup>151</sup> Ibid.

<sup>152</sup> MSM living with HIV (2015, October 20). Focus group discussion, BSWs, Dhaka city.

<sup>153</sup> Transgender women living with HIV (2015, October 19). Focus group discussion, BSWs, Dhaka city.

<sup>154</sup> See Bondyopadhyay, A. & Ahmed, S. (2010). Study participants from rural areas in Bangladesh were more likely to report violence as a result of their feminized behaviour.

information about HIV leaves the public ignorant and creates uncertainty among communities of MSM and transgender women.

Now, there are many HIV positives in our community. But, they do not know about their status, what are the services they need, where to go, what are the services available for them...since they are afraid, they do not come in front of others. They are not willing to face it (transgender woman).

The fear of HIV, and the process of working out where the appropriate services are located, can be time consuming, and unnecessarily delay HIV testing and accessing care.

Furthermore ignorance and uncertainty about HIV can compound negative reactions to MSM behaviour that many in Bangladesh currently think of as aberrant:

Our problems are different. I told my uncle and aunt that I got this disease. But they don't think I have got it after having sex with a male...they don't understand the MSM matter... they don't think this is natural (MSM).

Not being understood, especially by one's family, can be isolating, and adds to the fear of taking an HIV test. The juxtaposition of instances when families have provided the necessary care and support is indicative of the centrality of families in encouraging more HTS.

When I felt the problem, my wife and elder brother took me to Jagori (HTS at Dhaka Hospital by iccdr,b). They counseled them... I am getting same treatment as before... I don't have any problem disclosing it to [others] since my family is with me (MSM).

It should also be noted that good outcomes usually involved HTS that is performed well, and as such it is with good reason that, "for the community, counselling is the most important (HIV) service" (transgender woman).

### BSWS-AAS collaborative HTS, Bandhu Social Welfare Society

Founded in 1996, BSWS is the oldest and largest social welfare society for MSM and transgender women in Bangladesh. It has 37 field health centers in 22 districts, and collaborates with 23 partner CBOs, to offer services to MSM and transgender women communities across Bangladesh.<sup>155</sup> This programme will be under threat when the current Global Fund grant ends in 2016.

### *Synergistic collaboration*

In Dhaka, the community-initiated BSWS-AAS collaborative HTS synergizes the expertise of Bandhu Social Welfare Society (BSWS) and Ashar Alo Society (AAS) to offer MSM and transgender women in Dhaka the HIV testing services that have been carefully tailored to their needs. The collaboration was founded on the community mobilization capacity of BSWS for MSM and transgender women throughout the country, and that AAS was the sole point of entry for HIV treatment in Bangladesh at the time, recalled Shale Ahmed, Executive Director of BSWS.<sup>156</sup> The synergetic collaboration meant that BSWS was assured that MSM and transgender women testing positive for HIV would be in the best place for linkage to treatment and the continuum of care.

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<sup>155</sup> BSWS. (2014), op. cit.: p.12.

<sup>156</sup> In-depth interview. (2015, October 21), op. cit.

BSWS outreach teams had effectively reached 15,842 MSM and 2,638 transgender women in 2014.<sup>157</sup> The BSWS-AAS collaborative HTS uses the social networking capacity of BSWS to conduct outreach and create demand for HTS, which is conducted at AAS' three facilities in Dhaka city. The HTS facilities are located in the same building as the AAS office, at the Dhaka Medical College and Hospital (DMCH), and at the Bangabandhu Sheikh Mujib Medical University (BSMMU), which is locally known as PG hospital. In the two hospitals, AAS is contracted by the government to provide peer counselling services and HIV diagnostics, which means that the counsellors and lab technicians are AAS staff. This arrangement ensures the privacy and confidentiality of HIV test results, and the quality of services is maintained throughout the testing process, even though it is within a government facility.

### *Effective HIV detection*

HIV testing at the AAS is both effective and comprehensive, according to Habiba Akter, Executive Director of AAS.

In the last three months, [AAS] did 304 (HIV) tests, and 45 were HIV positive (14.8% effective rate)...we do less testing but get effective results. Other (non-CBO) HTS do thousands of tests a year but only one or two PLHIV are identified...it shows [that] we maintained confidentiality and people rely on that.<sup>158</sup>

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<sup>157</sup> Ibid: p.15.

<sup>158</sup> In-depth interview. (2015, October 20). Habiba Akter, Executive Director of AAS at her office in Dhaka city.

AAS does not stop at HIV testing, however, as it aims to provide the best level of care for PLHIV in Dhaka.

We don't just provide testing, we also provide HIV positive counselling, a form of psychosocial support counselling, and also health improvement activities as well as treatment support and referrals as necessary. That's why people are comfortable here; they are getting everything in one place...<sup>159</sup>

### *Adding value*

A quick comparison with the basic HTS that are inconvenient and poorly managed government-run services underlines the comfort that people feel with the accessible and value-added HTS they can get at AAS.

Sometimes in government centres, they give misinformation when people are tested positive for HIV, not positive living information, or other colleagues in the centres disclose the HIV status of patients...even to family members without their consent. That's why people are not comfortable at government centres...government centres also open from 9am to 2pm but our centres open from 9am to 5pm. We also provide support (via) a helpline, [that connects to] one of our counsellors... When someone tests positive, they are offered membership (to our society), and we offer (free) OI testing and treatment, and HIV treatment...monthly education sessions such as living positively, adherence information, [and] care giver training to family and friends of PLHIV.<sup>160</sup>

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<sup>159</sup> Ibid.

<sup>160</sup> Ibid. Although the shift in funding mechanisms in April 2015 requires AAS to pay for services out of pocket, which can cost the CBO up to USD100,000 every quarter until it is reimbursed by the funding agency. This meant that AAS has had to utilize operational funds to pay for services, and the need to prioritise and reduce non-essential services to save cost. The utilization of operational funds entails staff not getting paid until the funding agency reimburses these funds.

### *Community needs*

For MSM and transgender women, adapting its HTS to a service that is sensitive to their needs took considerable effort, and time.

These communities need special counselling and have special requirements. For the TG (transgender women) and MSM, there are [different] needs. (Interviewer: What is special about them?) MSM and TG are not comfortable with other communities...they are [only] comfortable and relax[ed] with MSM and *hijra* peer groups.<sup>161</sup> This can be difficult to manage. So for example, we now jointly facilitate monthly meetings (among MSM and transgender women living with HIV) with BSWS by having some of their staff facilitate sessions at our centre [for] MSM and TG [that] are on a separate day.<sup>162</sup>

The forming of the synergistic collaboration with BSWS evolved slowly, as AAS began to understand that the services MSM and transgender women would need differed from the HTS it was then providing to other communities of PLHIV.

### *Grasping the problem*

To comprehend what was required, AAS began by responding to areas it perceived as crucial for the comprehensive service it intended to provide to MSM and transgender women communities, and soon found a necessary partner in BSWS.

[Initially] our outreach workers are PLHIV but not MSM or TG... it can be difficult for us around adherence issues. If they come to our centre then we have information, but other than that there is no contact, home visits for example. With *hijra* and MSM, sometimes there is no address... they don't give, or there is a lost of address or loss of

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<sup>161</sup> According to Ahmed, these communities' concerns and interests are remarkably unique to the MSM and transgender communities given the stigma and discrimination, social exclusion and violence it has endured in Bangladeshi society.

<sup>162</sup> Akter, H. (2015, October 20), op. cit.

(phone) numbers...so we reach out to BSWS and through their outreach workers we are in contact with them.<sup>163</sup>

In the end, a suitable community-centred response was found; one that catered to the intrinsic needs of MSM and transgender women communities in Dhaka city.

They are very happy coming to our centre, they need special care, treatment, and [on personal] issues. Sometimes they are not comfortable to share their feelings...now we hire our outreach workers and peer counsellors from these communities, that's the better way to manage.<sup>164</sup>

### *Counselling well*

Shale Ahmed, the Executive Director of BSWS, agrees.<sup>165</sup> He sees counselling as the cornerstone of HTS, as do many MSM and transgender women who participated in this assessment, and has been lamenting the poor counselling skills in the public health system of Bangladesh. Ahmed is doubtful that current services is able to effectively deal with the complex problems of sexuality and gender identities at the intersection of stigma, discrimination, social exclusion and violence, that defined MSM and transgender women's experiences in Bangladesh.<sup>166</sup> After her recent experience with MSM and transgender women living with HIV at the AAS, Akter too, concurs; and wishes for sufficient resources to train doctors to offer community-centred healthcare, at public health facilities and at AAS.<sup>167</sup>

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<sup>163</sup> Ibid.

<sup>164</sup> Ibid.

<sup>165</sup> Ahmed, S. (2015, October 21), op. cit.

<sup>166</sup> See Khosla, N. (2009). HIV/AIDS Interventions in Bangladesh: What Can Application of a Social Exclusion Framework Tell Us? *Journal on Health, Population and Nutrition* 27(4): pp. 587-597.

<sup>167</sup> Akter, H. (2015, October 20), op. cit.

### *Challenging times*

Change is, however, looming on the horizon. The government is deliberating on a new strategy for HIV that may seek to remove the current prioritizations of CBOs to operate the vertical programmes for HIV services currently in place and placing these services on open tenders; a move that will be detrimental to CBOs such as AAS and BSWs. The AAS is lobbying the government relentlessly, including staging protest marches with PLHIV on Dhaka city streets.

We are saying to the government that community-initiated HIV testing is effective. Almost 70% of HIV detected comes from the [PLHIV] community.<sup>168</sup> Without the community, it will be very difficult. We are the ones who go door-to-door. If it is the government, they will just open the shop and give information. It is their approach and their attitude.<sup>169</sup>

### *Sense of ownership*

AAS tries to explain to the government that it is the shared experience of living with HIV that makes its HIV services successful; there is common ownership, and a common interest in getting services right for PLHIV.

We have ownership, and [same] feelings with the community that it is the psychological issues. They need the mental support because if anybody suspected it is HIV, to survive one night can be difficult for these people. But the government people, doctors, service

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<sup>168</sup> Akter, H. (2014) Community based HIV testing: challenges and opportunities in Bangladesh at the 20<sup>th</sup> International AIDS Conference in Melbourne, Australia. Abstract: MOPE361. The HTS at AAS had diagnosed 39% of all newly diagnosed PLHIV in Bangladesh in 2010, 29% in 2011, and 44% in 2012. The AAS has conducted a total of 6,058 HIV tests between 2006 and 2013, yielding 773 HIV positive results and an effective test rate of 12.8%.

<sup>169</sup> Akter, H. (2015, October 20), op. cit.

providers, they don't understand the mental stress. That is the main difference between the [PLHIV] community's feelings and other people's feelings.<sup>170</sup>

PLHIV from both MSM and transgender women communities who were participating in the assessment had unanimously endorsed this HTS; a reliable measure of success.

### *Exemplary service*

The BSWs-AAS service is exemplary in the way it undertook a painstaking process to ensure that it leaves no one behind. Driven by PLHIV, MSM and transgender women communities, it is able to capitalize on the expertise and insider peer group knowledge of all three communities to find pragmatic solutions to community-specific issues; which are highly contextual and often based on historical pain as well as present-day afflictions. The fact that the BSWs-AAS service delivers quantifiable results that contribute directly to the country's HIV response shows that community-initiated responses can make a real difference in the unfolding HIV epidemic. These are the factors that make it the best example of a community-initiated HTS for MSM and transgender women in this assessment.

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<sup>170</sup> Ibid.

## Municipal Responses in Kathmandu, Nepal

### Overview

Kathmandu is the capital of Nepal, with a population of 1,744,240 people.<sup>171</sup> Located in the foothills of the Himalayas, Kathmandu is the gateway to the world's highest mountains of which eight in ten, including Mount Everest, are located in Nepal. Tourism is the country's main industry, attracting almost 800,000 people annually before the 2015 Kathmandu earthquake, which had flattened many tourist sites.<sup>172</sup>

Blue Diamond Society (BDS) reports that the official figure of MSM and transgender people in Nepal is estimated at 128,500 individuals, with a confidence interval of 64,000-193,000.<sup>173</sup> In 2015, UNAIDS Data Hub triangulates available figures in Nepal's GARPR to provide updated population estimation figures of 196,270 MSM and 9,474 transgender individuals.<sup>174</sup> In 2007, the Supreme Court decided in favour of Sunil Babu Pant, a director of BDS and member of the constituent assembly at the time, who brought a case against the Nepalese government on transgender recognition. A third gender category was created but it took another six years before it was

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<sup>171</sup> Central Bureau of Statistics. (2014). *Statistical Pocketbook Nepal 2014*, retrieved from <http://www.cbs.com.np>; population figure is from the 2011 census.

<sup>172</sup> Ibid, tourism figure is from the Nepal Tourism Statistics 2013, Ministry of Culture, Tourism and Civil Aviation.

<sup>173</sup> BDS. (2014) *Blue Diamond Society Annual Report 2014*. Kathmandu: BDS: p.14, retrieved from <http://bds.org.np/wp-content/uploads/2014/09/Annual-report-11.pdf>; BDS estimates that the actual figure is closer to 500,000 because estimation techniques used could not possibly reach hidden populations of MSM and transgender individuals.

<sup>174</sup> Personal communication from UNAIDS RST.

reflected in Nepal's Citizenship Certificate in 2013, and another two years before it appeared in Passports in 2015.<sup>175</sup> However, with the ratification of its new constitution, Nepal becomes one of the few nations in the world that explicitly mentions the human rights of lesbian, gay, bisexual and transgender (LGBT) people, and is the only country in Asia that enshrines their protection and rights.<sup>176</sup>

Nepal has a concentrated epidemic among key populations including MSM and transgender. There are approximately 39,249 PLHIV in Nepal,<sup>177</sup> of which, an estimated 8% (or 3,140) PLHIV are MSM and transgender individuals.<sup>178</sup> Estimated HIV prevalence in MSM and transgender is 2.4%.<sup>179</sup> The Nepal PLHIV Stigma Index reported that 53% of MSM had experienced stigma and discrimination, while 100% of transgender individuals had experienced self-stigma and 56% also had suicidal feelings.<sup>180</sup>

### Stigmatizing transgender despite legislation

It is concerning when more than one half of transgender PLHIV experienced suicidal tendencies in a society with pioneering legislation for transgender people. Yet, it is

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<sup>175</sup> Health Policy Project et al. (2015), op. cit.: p.65.

<sup>176</sup> HRC. (2015, September 17), op cit.

<sup>177</sup> NSASC. (2015). *Factsheet 2015*. Retrieved from [http://ncasc.gov.np/uploaded/facts\\_n\\_figure/Factsheet-2015/HIV-Factsheets-2015-Infographs.pdf](http://ncasc.gov.np/uploaded/facts_n_figure/Factsheet-2015/HIV-Factsheets-2015-Infographs.pdf)

<sup>178</sup> Ibid.

<sup>179</sup> Ibid.

<sup>180</sup> FPAN. (2011). *The People Living with HIV Stigma Index*. Kathmandu: FPAN: viii. See also Amiya, R. M. et al. (2014) on suicide ideation and depression in PLHIV is found to be associated with perceived family support.

only when taking the perspective of transgender people, does the gravity of their situation become apparent. They now live in a society with legislation that recognizes them;<sup>181</sup> the rest of society is only coming to do so remarkably slowly, as is evident with their identity documentation and passports.

Even in the medical establishment, and among well-educated medical practitioners, the stigmatization and discrimination experienced by the transgender, especially transgender women who cannot easily hide their gender identities, is deplorable.

Our confidentiality is degrading... the doctor immediately called a group of students...and show (sic) them about me and tell (sic) them openly that I'm such type, in front of all the people there...he explained to the students that I am transgender and has gonorrhoea otherwise I wouldn't have come there. He flashed everything (R6, transgender woman, Kathmandu).

Such treatment can be considered inhumane; in which case, it would contravene the Nepal Medical Council (NMC) Code of Ethics on at least two points: 1) that doctors respect the secrets confided by patients, and 2) the health of the patient will be the first consideration.<sup>182</sup> Both points are part of the declaration doctors agree to at their conferment as medical practitioners in Nepal. Furthermore, as a member of World Medical Association (WMA), the NMC should heed the association's new guidelines on the care of transgender patients that,

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<sup>181</sup> Health Policy Project et al. (2015), op. cit.: p.65; the legislation still does not provide redress for their wish to be free of the binary sex categories that bind them at birth. Transgender women cannot select to be identified as women in the current legislation, unlike 2014 Indian Supreme Court ruling.

<sup>182</sup> NMC. (2015). *NMC – Code of Ethics*, retrieved from <http://www.nmc.org.np/information/nmc-code-of-ethics.html>.

Condemn all forms of discrimination, stigmatisation and violence against transgender people and want to see appropriate legal measures to protect their equal civil rights. And as role models, physicians should use their medical knowledge to combat prejudice in this respect (WMA President, Sir Michael Marmot).<sup>183</sup>

Given that the situation points to a high degree of pervasive, intransigent institutional stigma that is ingrained in the medical establishment, the NMC should consider WMA's instruction for "national medical associations to take action to identify and combat barriers to care."<sup>184</sup> A good starting point is in reviewing healthcare access in Nepalese public health facilities. Despite the Supreme Court ruling of a third gender in 2007, transgender individuals still face confusion and uncertainty when accessing healthcare in 2015, more than half a decade after the ruling:

When we go to the hospital. We stand on the male line they say go to female line. When we stand in female line they say go to male line. So where to go? (R4, transgender woman).

This ambiguity can create problematic situations that put transgender individuals through discomfort and shame; such as when they have to undress for medical examination, use the bathroom, are warded, require hormonal treatment, or when they have to undergo invasive medical procedures. Given that the requirement of medical and social support usually occurs when individuals are at their most vulnerable, the lack of thought about their treatment can compound existing feelings of isolation; clearly evident during the Kathmandu earthquake relief efforts:

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<sup>183</sup> WMA (2015, October 18) *New Guidelines for Physicians on Transgender Healthcare*, retrieved from [http://www.wma.net/en/40news/20archives/2015/2015\\_36](http://www.wma.net/en/40news/20archives/2015/2015_36).

<sup>184</sup> Ibid.

The quake cast many transgender people out into the streets, as their homes crumbled...When relief camps were quickly set up, people without families were segregated into male and female camps. Where did that leave the third gender? (BDS and APTN Press release, 3<sup>rd</sup> June 2015).<sup>185</sup>

### Recognizing and attending to the needs of hidden MSM

Although under the new 2015 constitution MSM is legally recognized and have had their rights safeguarded, it is not known how this far-reaching development will change the behaviours of MSM in the near future. Previously, their main defense is the cloak of secrecy that protects their sexual inclinations from public scrutiny and social jibes, which have become ubiquitous in the social experience of transgender women: “people like looking, laughing when seeing the transgender, and calling, teasing” (R8, transgender woman).

But as gay people they are hidden in the society, they are not exposed themselves as gay in family and society because they had a lot of problem for the pressure from peer circle, from family and they are getting married with female. And they are surviving [by leading a] double life with [a] wife and many other gay partners. And they have a lot of mental health problems...like depression and anxiety (R10, MSM).<sup>186</sup>

What had started as self-defense, soon became an isolating position, and they soon found it difficult to extricate themselves from the double life. So they coped,

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<sup>185</sup> Health Policy Project et al. (2015), op. cit.: p.63.

<sup>186</sup> Deuba, K. et al. (2013). Psychosocial Health Problems Associated with Increased HIV Risk Behavior among Men Who Have Sex with Men in Nepal: A Cross-Sectional Survey. *Plos One*. DOI: 10.1371/journal.pone.0058099

“enjoying with a lot of alcohol, with some drugs. Because of that they are at risk and they [become] vulnerable [to] HIV and [other] STIs.”

Thus, the need to remain hidden presents its own problems in accessing treatment.

MSM and gay people, they cannot expose their sexuality. As a gay they cannot go for medical treatment in hospital as well as ART services, that’s the main problem; and if gay people have another problem, they hide themselves (R3, MSM).

Gay men and MSM hide from healthcare providers for a reason:

As we go as male there is no discrimination...we [get] discriminated [when] we disclose our sexual orientation and we say we are doing anal sex, oral sex, it’s happening to me and when we share this thing we get discriminated from there, they can talk with their colleagues (R8, MSM).

It leaves MSM in an impossible situation: the disclosure of their sexuality invites the stigmatization and discrimination they wish to avoid, yet without disclosing they cannot get the treatment and care they need. The outcome for many is to avoid going to the hospital and suffers the consequences of their decision, which on one occasion proves fatal from the missed diagnosis of anal cancer.

### Seeking treatment for PLHIV in a discriminatory system

In a public healthcare system that is known for its discriminatory practices against MSM and transgender, the situation for PLHIV can be surprisingly straightforward if PLHIV have a regular income, and do not require surgery. The majority of PLHIV in the Stigma Index had been working, albeit in agriculture/animal husbandry among

males (30%) and females (47%), or the services industry among the transgender (33%); 17% had been unemployed.<sup>187</sup> For those PLHIV without an income, access to healthcare can become major economic and logistical challenges in the mountainous terrain of Nepal, where relatively inexpensive public transportation can be prohibitive.

In general, many of us are [from the] grassroots...we don't have money. Not everyone have [the] capability to pay for the micro and bike. Some don't even have pocket money...it is difficult (R7, MSM).

For PLHIV who can overcome the economic and logistical barriers to treatment access, the challenge is in navigating the Nepalese public healthcare system. Having said that, PLHIV participating in the Stigma Index study had reported low levels of access denials to healthcare,<sup>188</sup> and the majority were either on ART (66%), or had been confident of its availability and accessibility (67%).<sup>189</sup> ART access requires doctors to monitor CD4 count,<sup>190</sup> PLHIV will have to make their way to the appropriate hospital on the appropriate day to have it assessed: “CD4 [count] is available in many places, but...not available all seven days of the week...maybe four days a week” (R9, MSM).

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<sup>187</sup> Ibid: p.vi.

<sup>188</sup> FPAN. (2011), op. cit.: p.viii; denial of health services by health workers include dental care (7%), family planning (3%) and sexual and reproductive health (2%).

<sup>189</sup> Ibid: p.x.

<sup>190</sup> WHO. (2014, March). Supplement to Chapter 7- Antiretroviral therapy. In *WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (pp.32-68). Geneva: WHO

For PLHIV who are stable on ART and only treatment monitoring is required, current WHO guidelines recommend viral load testing as the preferred method, instead of CD4.<sup>191</sup> However, the viral load testing facility in Nepal has not been set up for this purpose,<sup>192</sup> thus treatment monitoring will have to rely on CD4 count in the interim.<sup>193</sup> Understandably, as more PLHIV initiate and become stable on ART, it will place increasing strain on the demand for CD4 counts: “people [will just] have to wait” (R9, MSM).

For PLHIV needing surgery, getting a doctor willing to perform the procedure is itself a challenge. Doctors have been known to avoid performing surgery on PLHIV by finding a reason to refer them to another physician:

Doctor was referring another place to another place...so that patient [is] already dead  
(R1, MSM).

A participant agrees, saying that some people have died because of delays to their biopsies and surgeries. Thus, for MSM and transgender women living with HIV who are unemployed, or in need of surgery, the reality can be daunting and with little opportunity to influence potential outcomes.

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<sup>191</sup> Ibid. It is the best method to detect treatment failure in PLHIV who are stable on ART.

<sup>192</sup> At Sukraraj Tropical & Infectious Disease Hospital in Teku, Kathmandu. Given the complexity of viral load testing, a central viral load testing facility is the current WHO recommendation until new technologies or better logistic arrangements are available.

<sup>193</sup> Ibid: p.59. “CD4 count and clinical monitoring should be used to diagnose treatment failure, with targeted viral load testing to confirm virological failure where possible.”

### Ideal community-initiated HTS<sup>194</sup>

A comprehensive community-based HTS that offers treatment and care besides HIV testing and counselling would be an ideal HTS for a group of MSM and transgender women in Kathmandu. Linkage to care is particularly important for PLHIV in this group as they have experienced practical difficulties of accessing care in Kathmandu. The group therefore proposes that treatment should include ARVs and OIs, as well as medication for side effects from taking ARVs. In terms of care, the group seeks basic social welfare protection for the economically destitute such as transportation allowances to access healthcare, and social housing for the isolated and infirm.

The group also feels that MSM and transgender women communities should have their respective HTS that is located in environments accepting of gender diversity to encourage service access, citing the example of BDS.

Finally, the group recommends that the HTS be government-funded under its annual budget allocations for health. Deliberations on funding prioritized stability and permanence, hence the lack of enthusiasm for a donor-funded scheme.

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<sup>194</sup> From the community review: BDS is currently implementing community-initiated HTS under the Save the Children Global Fund supported project. However, the lack of National Guidelines on lay testers for HIV entailed the need to bring along a Lab Assistant to the field for phlebotomy. Clear National Guidelines on community-initiated HTS is required for a fully community-based HTS.

## Municipal Responses in Colombo, Sri Lanka

### Overview

Colombo, with a metropolitan population of 5.65 million inhabitants,<sup>195</sup> is the capital city of Sri Lanka that has an estimated population of 20.64 million people in 2014.<sup>196</sup> The government of Sri Lanka had just concluded a 30-year civil war against the Liberation Tigers of Tamil Eelam (LTTE) in May 2009, with an estimated loss of life of 70,000 Sri Lankans.<sup>197</sup>

The city of Colombo produces almost half (45%) of the nation's gross domestic product (GDP) in 2010,<sup>198</sup> and has been called a city of extremes. In striking contrast with a well-serviced urban population, are the poorly serviced urban shacks and shantytowns, in which more than half of its population lived.<sup>199</sup>

The National STD/AIDS Control Programme (NSACP) of the Ministry of Health conducted a size estimation study of MSM in 2014 that reported there were 7,551 MSM in Sri Lanka across 1,438 hotspots, of whom 3,991 MSM were in Colombo.<sup>200</sup>

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<sup>195</sup> The Brookings Institution. (2013). *Colombo: The 10 Traits of Globally Fluent Metro Areas*. Retrieved from [www.brookings.edu/~media/Multimedia/Interactives/2013/tentraits/Colombo.pdf](http://www.brookings.edu/~media/Multimedia/Interactives/2013/tentraits/Colombo.pdf)

<sup>196</sup> World Bank. (2015). *Population, total*, retrieved from <http://data.worldbank.org/indicator>

<sup>197</sup> WSG. (2011), op. cit.

<sup>198</sup> The Brookings Institution. (2013), op. cit.

<sup>199</sup> Horen, B. v. (2002). City Profile: Colombo. *Cities* 19(3): pp217-227. DOI: 10.1016/S0264-2751(02)00011-2

<sup>200</sup> NSACP. (2015, March). *Integrated Biological and Behavioural Surveillance (IBBS) Survey among*

The national MSM population estimation figure is much lower than previous estimates of between 24,000-37,000 MSM.<sup>201</sup> There are no reported estimates of transgender women. Sri Lanka's has two repressive laws against gender non-conformity. Besides the law on gross indecency (Section 365a), there is Section 399 of the Penal Code on "cheat by personation."

A person is said to "cheat by personation" if he cheats by pretending to be some other person or by knowingly substituting one person for another, or representing that he or any other person is a person other than he or such other person (Section 399, Penal Code of Sri Lanka, 1833).<sup>202</sup>

This law has reportedly been used to discriminate against transgender people.<sup>203</sup>

Sri Lanka has a low level HIV epidemic with an estimated 3,300 PLHIV at the end of 2014, of whom almost seven in ten (69%) PLHIV were men.<sup>204</sup> The NSACP reported in 2013 that a quarter (25%) of PLHIV were in the advanced stage of AIDS.<sup>205</sup> UNAIDS data hub figures show that 644 of PLHIV (an estimated 19%) are on ART. Up to November 2015, the HIV prevalence in MSM is estimated at 0.6%; HIV testing coverage among MSM is low, with only an estimated 14.1% having been tested for

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*Key Populations at Higher Risk of HIV in Sri Lanka, 2014 - Report.* Colombo: NSACP, Management Frontiers and KIT: p.20

<sup>201</sup> NSACP. (2010, March) *UNGASS country progress report – Sri Lanka: January 2008 - December 2009.* Colombo: NSACP.

<sup>202</sup> *Country Profile on Universal Access to Sexual and Reproductive Rights: Sri Lanka.* (2015, December 4). wmcslanka: p.11. Retrieved from <http://www.scribd.com/doc/292133568>

<sup>203</sup> WSG. (2011), op. cit.: p.226.

<sup>204</sup> NSACP. (2015), *National STD/AIDS Control Programme Annual Report 2014: Sri Lanka.* Colombo: NSACP: p.44.

<sup>205</sup> NSACP. (2013). *Annual Report 2013, National STD/AIDS Control Programme: Sri Lanka.* Colombo: NSACP: p.15.

HIV and received the results.<sup>206</sup> However, only a quarter (26%) of MSM or 1,983 individuals had tested for HIV in a government clinic in 2014, of which approximately three in five (63%) MSM had collected their test results.<sup>207</sup>

In Colombo, of the population of 3,991 MSM estimated in the 2014 IBBS survey, estimated rates of HIV testing and HIV prevalence were 19.6%, and 1.2% respectively. The study also found high levels of stigma, including in the families of MSM, and as a consequence MSM tended not to present for testing in government clinics as well as access health services.<sup>208</sup>

### Living with HIV in two separate worlds

The PLHIV Stigma Index study conducted in 2010 had interviewed a total of 15 PLHIV.<sup>209</sup> In contrast, the NSACP had reported 1,317 cumulative cases of HIV infection by the fourth quarter of same year.<sup>210</sup> In a subsequent study by the AIDS Foundation of Lanka and funded by WHO SEARO, a team of researchers had interviewed 100 consecutive PLHIV and the family member accompanying them (making a total sample of 200) as they presented for treatment at the NSACP clinic in

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<sup>206</sup> UNAIDS. (2015, November). *Data Sheets: Sri Lanka: HIV prevalence and epidemiology*, retrieved from <http://www.aidsdatahub.org/Data-Sheets>

<sup>207</sup> Ibid: p.60.

<sup>208</sup> NSACP. (2015, March), op. cit.: pp.331 & 337

<sup>209</sup> *The People Living with HIV Stigma Index: Sri Lanka*. (2010, November). Colombo: UNAIDS, Family Planning Association Sri Lanka and Partners.

<sup>210</sup> NSACP (2011, January 12) *Update 4<sup>th</sup> Quarter 2010: Reported HIV/AIDS cases National STD/AIDS Control Programme 2010*. Retrieved from [http://www.aidscontrol.gov.lk/web/images/pdf/quarterly\\_reports](http://www.aidscontrol.gov.lk/web/images/pdf/quarterly_reports).

Colombo and the Infectious Disease Hospital in Angoda.<sup>211</sup> The low number of respondents in the Stigma Index study in comparison with the number of reported HIV cases in the country at the time (approximately 1.1%), and the 100 PLHIV recruited subsequently to the AIDS Foundation Lanka study, is a stark difference.<sup>212</sup>

The Stigma Index had underscored PLHIV's need to maintain the secrecy of their HIV status despite the social isolation it engendered, and said that non-disclosure extended to their families, and even their spouses. PLHIV researchers also alluded to the occurrence of domestic abuse in these families, which had been justified for the shame HIV brought to the family.<sup>213</sup> The Stigma Index then concluded:

In Sri Lanka the **main obstacle** to effecting change is the **fear of disclosure** and related fears of stigma and discrimination. People are not willing to come forward and be identified as HIV positive... Do HIV positive people who belong to higher socio-economic groups exist? (...) The research team speaks of how these individuals have avoided interaction with the networks (author's emphasis).<sup>214</sup>

In an article written after the Stigma Index, the author had clarified his conclusion by explaining that PLHIV had been “drawn largely from the (PLHIV) networks, were

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<sup>211</sup> Perera, M. J. S. et al. (n.d.). *Exploratory study on the impact of HIV positivity on psycho-social aspects of People Living with Human Immunodeficiency Virus infection (PLHIV) and their family members (FMs) in Sri Lanka*. Colombo: AIDS Foundation Lanka.

<sup>212</sup> The study provides important insights on the state of the PLHIV community in Sri Lanka from the perspectives of the three PLHIV who had conducted the study. The views of the research team recorded in the text have been verified by triangulating them with available documentary sources.

<sup>213</sup> The People Living with HIV Stigma Index: Sri Lanka. (2010, November), op. cit.: pp.17&18.

<sup>214</sup> Ibid: p.31.

poor and uneducated. Life before HIV was limited. Why shouldn't life after HIV still be limiting?"<sup>215</sup>

In the AIDS Foundation study, slightly more than half (51%) of PLHIV had disclosed their HIV status to their spouse, and half (50%) had disclosed to a family member, all of whom said that they had received some form of support. One in five (20%) PLHIV had not disclosed their HIV status, mainly from the fear of stigma and discrimination.<sup>216</sup> HIV disclosure had in fact returned overwhelming support from spouses, families and friends, with no evidence of punitive retaliation.<sup>217</sup> Although this finding had led the second study to evince "the strong family bonds of the Sri Lankan culture",<sup>218</sup> it also reported that the majority of family members too had fears about HIV stigma. The authors had concluded that, "a significant proportion of PLHIVs had adopted potentially harmful behaviours such as smoking, drinking alcohol, other forms of substance abuse and social withdrawal, in trying to deal with the psycho-social distress."<sup>219</sup> Neither of these results coincided with findings from the Stigma Index.

The juxtaposition of these two findings is interesting because it paints two different pictures of Sri Lankan society with the same brush of HIV stigma: although the fear

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<sup>215</sup> Billimoria, H. (2011). *Living with HIV in Sri Lanka: Reflections from ICAAP10 in Busan, Korea*. Retrieved from <http://groundviews.org/2011/09/07/living-with-hiv-in-sri-lanka-reflections-from-icaap10-in-busan-korea/>

<sup>216</sup> Perera, M. J. S. et al. (n.d.), op. cit.: p.12.

<sup>217</sup> Ibid: pp.14 & 21.

<sup>218</sup> Ibid: p.24.

<sup>219</sup> Ibid: pp.29-30.

of stigma and discrimination had driven non-disclosure behaviours in both the studies, the HIV disclosure behaviours and the outcomes PLHIV did obtain from HIV disclosure appeared diametrically opposed. It seemed unlikely that both studies were describing PLHIV from the same networks.

### Dividing PLHIV by socio-economic class

Thus, to explore further the possibility that they may indeed be describing two different networks of PLHIV, the socio-demographic characteristics of the two samples were compared using a statistical test (Table 5).

**Table 5: Selected socio-demographic characteristics of PLHIV cohorts in the Stigma Index and AIDS Foundation studies with p-values from chi-square tests comparing cohorts on each characteristic.**

Characteristics	Stigma Index	AIDS Foundation	p-value
Education level			
Primary or lower	9 (61%)	20 (20%)	0.0023*
Some secondary and higher	6 (39%)	80 (80%)	
Employment after diagnosis			
Some employment	12 (78%)	63 (63%)	0.2533
Unemployed	3 (22%)	37 (37%) <sup>a</sup>	
Has a partner <sup>b</sup>			
Yes	8 (56%)	56 (56%)	1.0000
No	7 (44%)	44 (44%)	

Note. \* Statistically significant at  $p < 0.005$ . <sup>a</sup> AIDS Foundation cohort includes 18 individuals who were unemployed before diagnosis. <sup>b</sup> Partner includes spouses, cohabiting partners and individuals in a relationship but were not cohabiting.

The majority of PLHIV in the Stigma Index were aged between 30 and 49 years, while in the AIDS Foundation they were between 22 and 41 years. Although the AIDS Foundation cohort was younger, these characteristics could have been the

artifact of sampling rather than actual demographic differences.<sup>220</sup> The results showed that as compared to the AIDS Foundation cohort, PLHIV in the Stigma Index cohort were significantly more likely to be less educated, indicating that the samples could have been drawn from different networks; although the proportion in employment after diagnosis was not significantly different, and both cohorts had the same proportion of having a partner.

On balance, it is likely that PLHIV in the Stigma Index had been from lower socio-economic class as indicated by their level of education; and PLHIV in the AIDS Foundation study who had supportive families could be the corollary of PLHIV from higher economic classes, whose existence the Stigma Index author had questioned. However, even though both studies may be describing PLHIV in different socio-economic classes, in reality both cohorts of PLHIV fell into a similar rhythm of inaction; paralyzed by the fear of disclosure on the one hand, and coping with an HIV positive reality through forms of escapism on the other.

### Getting to zero discrimination will need a united PLHIV

The inability of PLHIV from the current networks to connect with PLHIV from higher social economic classes and therefore could not include them in the Stigma Index may therefore point to class divisions in PLHIV, and the lack of motivation from PLHIV in higher economic classes to join their PLHIV networks. If this is true,

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<sup>220</sup> Differences in class categorisations between the two studies did not allow for statistical testing to evaluate the comparison.

the non-significant difference observed in employment after diagnosis in the two studies offers a pause for thought; that HIV could have deleterious effects on employment regardless of socio-economic class.<sup>221</sup> Even though people of higher socio-economic classes may have more resources at their disposal to ameliorate the effects of HIV, to operationalize these resources could require the disclosure of their HIV status beyond the family and in places where PLHIV stigma may currently reside.

Before concluding their article, the authors of the AIDS Foundation study had provided the following epilogue:

The study also reconfirmed that there is a considerable amount of stigma and discrimination associated with the disease in Sri Lanka... and call for new approaches in which the resistance of stigmatised individuals and communities is utilised as a resource for social change.<sup>222</sup>

The new approaches that the authors were alluding to that were beyond “individualistic modes of stigma alleviation”<sup>223</sup> could only occur if PLHIV from as many sides of the socio-economic divide were to unite. Without a united PLHIV, and given that lack of education and poverty currently describe PLHIV networks, it might not be possible to eradicate PLHIV stigma in institutions that had produced experiences such as this:

I have an experience through a diabetic clinic I was told to check my sight, so I went [to] check...due [to] HIV...I was rejected by the opticians – they don’t want me to use

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<sup>221</sup> This comparison does not account for social and economic resources such as personal savings and social connections that members of higher socio-economic classes could call upon to ameliorate the effects of HIV diagnosis and living with HIV in the longer term.

<sup>222</sup> Ibid: p.29.

<sup>223</sup> Ibid: p.29.

the same machine, what others use. Then the following year, I did the eye test without informing them [about my HIV status]. Then later on he told to the doctor, [the] doctor [had] called all [the] staff and informed them [of] what [had] happened...in front of everyone I bow[ed] down and stood as though a criminal, I was just neglected (MSM).

Current PLHIV networks are disempowered, feeling that “they have no power to influence any decision related to the community, and prefer to remain silent,”<sup>224</sup> and broken by economic inequities that saw two of the fifteen respondents in the Stigma Index going “hungry for up to 10 days in the month before they answered the questionnaire.”<sup>225</sup> Invariably the lack of support and participation from PLHIV in upper levels of Sri Lankan society in current PLHIV networks may be the result of stigma, as it “feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality”<sup>226</sup> among PLHIV. It is incredibly difficult for the most marginalized of PLHIV to challenge the burden of stigma that has been placed on them; it is a task made immeasurably harder without the support of less marginalized PLHIV, and the fact that marginalization by definition excludes these PLHIV from the very opportunities and circumstances that are the impetus of social change.

### Ideal community-initiated HTS

The ideal community-initiated HTS is one that does not require local PLHIV community effort. MSM living with HIV in this assessment wished for a community-

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<sup>224</sup> The People Living with HIV Stigma Index: Sri Lanka. (2010, November), op. cit.: p.31.

<sup>225</sup> Ibid: p.13.

<sup>226</sup> Perera, M. J. S. et al. (n.d.), op. cit.: p.29.

friendly HTS, which is attached to a community-based clinic and have access to a comprehensive 24-hour primary healthcare facility; and service delivery models throughout the scheme welcoming gender diversity, and have HIV desensitized staff. At the community-based clinic, ARVs and OI medication shall be provided free. Access to other medical services, such as diagnostic and treatment for STIs, and mental healthcare, shall be offered if possible; or referrals made to access care at the comprehensive primary healthcare facility linked to the clinic. Surgical procedures should also be made accessible to disenfranchised communities. The ideal would be to offer stigma-free medical care in one place, and accessible at anytime.

## The Culture of Municipal Responses to HIV

The following is a perspective on the cultural project of municipal responses to HIV in five South Asian cities: Colombo, Sri Lanka; Dhaka, Bangladesh; Kathmandu, Nepal; Lahore, Pakistan; and Mumbai, India. Douglas reminds us that culture is the “ardently debated, flexibly responding, system of values”<sup>227</sup> that is jointly produced by people who are bound together in social interaction; which, in this case, are the institutions and communities involved in the municipal response to HIV.

### Looking through a cultural lens

The cultural lens of this perspective is fashioned from the cultural typology presented by Douglas in her essays on risk and blame, in particular the municipal response of a city during the AIDS epidemic.<sup>228</sup> This perspective aims to dissect the system of values underlying social organizations of the cities’ response to HIV by employing cultural theory. The objectives are to establish the cultural process that isolates community constituents in municipal responses (Figure 3 below), and explore the loss of their contribution and its effects on the overall response.

The central community, in the current context, includes the municipal political regime and its mechanisms, families and communities of the political and cultural elite who

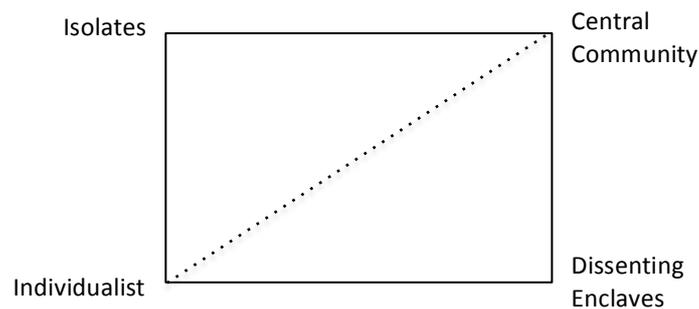
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<sup>227</sup> Douglas, M. (2004), op. cit.: p.106.

<sup>228</sup> Douglas, M. (1992), op. cit.

COMMUNITY-INITIATED HIV TESTING SERVICES IN SOUTH ASIAN CITIES FOR  
MEN WHO HAVE SEX WITH MEN AND TRANSGENDER WOMEN

derive their authority for stewardship from government policy, bureaucratic office, state and municipal conferred legitimacy, social rules, and traditional norms.<sup>229</sup> Social organizations in the central community include the ministries of health and social welfare, the medical establishment, healthcare providers (HCPs), and state and municipal AIDS control programmes.



**Figure 3. The social organization of municipal HIV response in South Asian cities.**

The individualist refers to a system of coordination dependent on displays of power;<sup>230</sup> in the present context of municipal response in South Asian cities, power follows access to finance, direct influence on grant making, and as arbiters of technical knowledge and skills. Social organizations include supranational and multilateral funding and donor agencies such as the Global Fund, the United States Agency for International Development (USAID), Bill & Melinda Gates Foundation (BMGF), and international NGOs. In these municipal communities, the central community and individualists constitute a major line of command and control in

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<sup>229</sup> Douglas, M. (2004), op. cit.: p.92.

<sup>230</sup> Douglas, M. (1992), op. cit.: p.93.

society;<sup>231</sup> diametrically opposed, the central community aims to augment and protect its stewardship and value systems in the cities, while individualists encourage competition, diversity, meritocracy, opportunities, and have independent systems of incentives from the state.<sup>232</sup>

Dissenting enclaves are the pockets of civil society representing municipal communities affected by HIV in seeking social justice and more equitable distribution of resources. Their sustained appearance in the municipal response is the result of interventions by funding agencies, which have empowered them to seek a revision on their “terms of engagement” in civil society, particularly with the central community in municipalities. Dissenting enclaves in the South Asian cities comprise MSM and transgender women CBOs such as Humsafar Trust in Mumbai, NMHA in Lahore, BSWs in Dhaka, and BDS in Kathmandu; informal but stable social networks of MSM and transgender women, and associations of PLHIV such as AAS in Dhaka, and Lanka Plus in Colombo; most of whom would have gained their political voices and stripes as the result of individualistic cultural bias in hierarchical cultures.

### *Engendering mutual accountability*

To differentiate an individual perspective from a cultural perspective, cultural theory begins with the assumption of mutual accountability between persons in a culture;<sup>233</sup>

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<sup>231</sup> Ibid: p.93.

<sup>232</sup> Ibid: p.93.

<sup>233</sup> Douglas, M. (1992a). Risk and Justice. In *Risk and Blame: Essays in Cultural Theory* (pp.22-37). London: Routledge: p.31.

being part of a culture construes a tacit agreement between parties on their responsibility for each to be held accountable, and “fraught with the political implications of mutual accountability.”<sup>234</sup>

Writing in the first decade of epidemic, when there was little knowledge about the disease, Douglas made the following observations at the end of her paper:

The way that the citizen who is a member of the central community responds to the epidemic is very threatening for the other citizens... The bigger the gap between rich and poor in income distribution and wealth, the less contact between them and the more the poor appear to be an alien sub-culture. The more unequal the ratio of numbers of wealthy to numbers of poor, the more the poor will seem a threat.<sup>235</sup>

For South Asian cities, with wide disparities and unequal distribution of income,<sup>236</sup> her observations are prescient. The economic iniquities of the urban population compound the social exclusion experienced by “non-men”<sup>237</sup> and transgender women communities due to a strict gender normative culture, further disenfranchising them.

### *Visibility and the politics of recognition*

The process of relentless marginalization can render populations invisible.<sup>238</sup> Visibility is especially crucial when the political implications of mutual accountability are negotiated between stakeholders and the value of responsibilities is weighed,

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<sup>234</sup> Ibid.

<sup>235</sup> Ibid: p.119.

<sup>236</sup> With the exception of Sri Lanka.

<sup>237</sup> See e.g. Khan, S. (2004), op. cit.

<sup>238</sup> See Pappas, G. et al. (2001), and Khan, S. (2004).

which usually entails the earmarking and securing of necessary resources. However, besides missing out on the allocation of material resources, the invisibility of a community also diminishes its cultural value; first, by diminishing its voice hampers its ability to create cultural products through collective expressions; second, by eroding its cultural capability to contend in the “politics of recognition,”<sup>239</sup> and third, its diminished voice and cultural capability further yields poorer “terms of recognition” even among its constituents, causing the community to lose out on an essential step in collectively establishing its legitimacy as community. Thus, the systematic process of marginalization that results in invisibility can be deleterious to both culture, and community.<sup>240</sup>

A poignant example is the absence of transgender women in Sri Lankan culture. Their non-presence in government statistics and policies has been remarked upon, albeit to no avail.<sup>241</sup> Unlike the transgender women in other cities, who have successfully gained legal recognition (see Table 1), transgender women in Colombo do not have sufficient cultural resource and collectivity to seek formal recognition of their existence.<sup>242</sup> According to Equal Ground, an LGBT organization,

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<sup>239</sup> See Appadurai, A. (2004), op. cit.: pp.59-84; drawing from the work of Charles Taylor.

<sup>240</sup> The problem of mutual accountability has largely been overcome for MSM and transgender women communities in South Asia, with the exception of Sri Lanka, through the efforts of Naz Foundation International.

<sup>241</sup> *Country Profile on Universal Access to Sexual and Reproductive Rights: Sri Lanka*. (2015, December 4), op. cit.

<sup>242</sup> Recent advocacy by the Sri Lanka Family Planning Association resulting from the Global Fund MSA HIV Programme with the police and judiciary may be changing the situation for transgender women. There have reportedly been fewer cases of police harassment and the judiciary seems to be open to the idea of legal recognition.

Transgender individuals often face extreme difficulties... They experience harassment, discrimination, sexual abuse, ostracisation (sic) from their families, violence, bullying, threat, harassment by police and rape... issues of legality and confrontations with police...they meet prejudice. They have problems finding housing... It is difficult for them just to live.<sup>243</sup>

Citing Douglas, “if the existence of the minority is not acknowledged, even the scale of its problems is not assessable: the figures are not there.”<sup>244</sup> It is therefore hopeful that this community’s situation may change with dedicated and targeted advocacy from this and other CBOs, as well as regional MSM and transgender networks.

### Growing the “freedom to choose”

Amartya Sen contends that poverty is also about the “freedom to choose”,<sup>245</sup> and the number of quality exchanges that is available to communities: “if there are few options for interaction, the quality of the exchanges is low, high if the choices are many and free.”<sup>246</sup> Thus, should the negative scenario prevail, Douglas recommends,

The best protection...will be a community that already has taken social justice to heart...a community can have enough solidarity to protect its members...The central community’s attitude to expenditure on research and health and medical treatment for the sick is conditioned for each disease by its expectation of getting the disease.<sup>247</sup>

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<sup>243</sup> Lamplough, A. (2015, July). Transgender Support: Interview with Rosanna Flamer-Caldera. *Life Times Sri Lanka*, retrieved from <http://www.lt.lk/2015/07>.

<sup>244</sup> Ibid: p.35.

<sup>245</sup> See Sen, A. (1981, 1985, 1999; Nussbaum & Sen 1993) on the development and elucidation of the theory of poverty.

<sup>246</sup> Douglas, M. (2004), op. cit.: p.102.

<sup>247</sup> Douglas, M. (1992), op. cit.: p.119.

Her advice is especially salient as the HIV epidemic in all five cities is concentrated in specific key populations, who are generally materially and socially removed from the central community as a result of economic deprivation and social exclusion.<sup>248</sup> But what if the communities do not have enough solidarity to protect their members?

### *Culture of fear*

The five municipalities included in the assessment have hierarchical cultures, which are based on kinship bonds and prioritize familial obligations and duties over the fulfillment of individual needs.<sup>249</sup> Arranged marriages are common in these cultures, and marriage resulting in progeny is a gender-defining characteristic of men.<sup>250</sup> The position of men at the apex of the gender hierarchy in relation to other males is vigorously guarded by civil society; which devalues males with linguistic labels that signify non-men, as well as threats and actual violence perpetrated against MSM and transgender women, as they do not meet the normative gender preferred by culture.<sup>251</sup> The use of aggression as a socially acceptable instrument to relay gender dominance and kinship honour in the social hierarchy creates a culture of fear in these municipalities, especially in the communities where perpetration of violence has positive cultural value. The level of fear communities' display towards law enforcement is directly related to the institutionalization of violence in the organs of

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<sup>248</sup> See e.g. Khosla, N. (2009); Chakrapani, V. (2014)

<sup>249</sup> See e.g. Bondyopadhyay, A. & Ahmed, S. (2010), op. cit.

<sup>250</sup> See e.g. Pappas, G. et al. (2001); Khan, S. (2004); Bondyopadhyay, A. & Ahmed, S. (2010).

<sup>251</sup> Ibid.

the municipality and the state: “There is a lot of fear at that time. When we see them (the police) we become automatically silent” (transgender woman, Lahore).

In this respect, gay lifestyle has cultural cache in South Asian municipalities. According to a study in Dhaka, had the gay lifestyle been accessible to *kothis*, it might have entailed better life situations for them.<sup>252</sup> The capability of acting ‘straight’ in the repertoire of gay culture allows gay men to conform to the normative masculine gender image preferred in South Asia; possibly minimizing possible threats and acts of violence against them. The study had reported no police harassment and substantially fewer incidences of sexual assault and rape amongst gay men, as compared to the greater magnitudes of both events amongst the *kothis* and *hijras*.<sup>253</sup>

### *Culture of discrimination*

For MSM and transgender women living with HIV, access to equitable healthcare is an essential urban commodity. Nonetheless, it is not a guaranteed resource that is freely accessible in South Asian cities. In all the cities included in this assessment, both gender-related and HIV stigma have been institutionalized in its public health system, and deeply entrenched in the professional hierarchy of HCPs. These results in a culture of discrimination against non-normative gender expressions, and against PLHIV in accessing HIV services, which are delayed, are of poorer quality, or withheld altogether. These discriminatory practices can be seen as relational

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<sup>252</sup> Bondyopadhyay, A. & Ahmed, S. (2010), op. cit.: p.34.

<sup>253</sup> Ibid: p.22.

expressions of status, pulling rank in the social hierarchy, to signify cultural value.<sup>254</sup>

At receiving end, the recourse to action for these MSM and transgender women are restricted by their accessibility to cultural, social and material resources. The reported cases of an MSM living with HIV in Colombo, and a transgender woman in Kathmandu, being paraded in front of HCPs or their students as specimens are indicative of the cultural value of gender minorities and PLHIV in the respective municipal responses to HIV. The viability of voicing dissatisfaction would depend on the level of self-stigma suppressing a rejoinder, and exiting the scene could be left as the only available action; which is hardly freedom to choose.

The worst reports of HCP discrimination have come from Lahore and Kathmandu, involving senior physicians despite anti-discrimination clauses in healthcare ethical guidelines and strategies;<sup>255</sup> as well as making it the vision of its national AIDS programme, as in the case of Nepal.<sup>256</sup> Incidentally, these countries had the lowest HDI in South Asia. Given that hierarchy is relational, it would be more effective to acculturate the spirit of these guidelines, strategies and mission in the institution of medicine and between HCPs. As expedient signifiers of cultural value, it is therefore expected that these discriminatory healthcare practices would remain in place unless there is a change in the value preference constituting the hierarchy of local institutions

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<sup>254</sup> They would occur less frequently, and with less severity, among middle class MSM.

<sup>255</sup> For Pakistan, see NACP & WHO. (2004, October), op. cit.; for Nepal, see NCASC. (2011). *National HIV/AIDS Strategy 2011-2016*. Kathmandu: NCASC.

<sup>256</sup> It is the NCASC's vision that "Nepal will become a place where new HIV infection are rare and when they do occur, every person will have access to high quality, life extending care without any form of discrimination."

of medicine and among HCPs, respectively. For example, an increase in the relational value of professionalism to levels above the value of discrimination as a signifier of cultural value could entail HCPs providing professional, non-discriminatory services as a status symbol to signify their cultural value.

### *Culture of misinformation*

There is also a culture of misinformation about HIV and AIDS in some cities, which exacerbates poor public understanding about the disease, its cause, and routes of transmission; as well as the availability and access of HIV services. In South Asian cities, this culture of misinformation is brought to the fore by having no collectively accepted hierarchy of trustworthy information on HIV and AIDS, the lack of credible sources of information, and the propagation of lay perceptions within MSM and transgender communities. In cities where this culture is prevalent, late diagnosis and treatment of HIV consequentially prevail; it places substantive and symbolic limitations on communities' freedom to choose, causes deaths that could have been averted,<sup>257</sup> and jeopardizes the effectiveness of the collective municipal HIV response.

Citing Douglas on hierarchical cultures in relation to knowledge offers insight:

Hierarchy, both as a system of governance and a type of culture, assumes that the world is up to a point knowable, and that itself, the hierarchy is organized according to the principles which run the universe. Consequently, the consensus that upholds the political system upholds the authority of facts. Its self-protective political effort goes

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<sup>257</sup> Shahrin, L. et al. (2014), op. cit.

into protecting the system of knowledge with which it is identified. Confidence in its old knowledge is its hallmark.<sup>258</sup>

Thus, the lack of municipal government urgency to secure HIV and AIDS information by controlling the transmission of these information and prioritizing its interpretation of facts could be indicative of not identifying with this particular knowledge content,<sup>259</sup> or not valuing its municipal constituents who may (unknowingly) be infected with HIV. Given that these constituents are generally low in the social hierarchy with epidemics concentrated in key populations, it is not surprising and could be part of the social exclusionary practices currently in place.<sup>260</sup> Hence, in the prevailing culture of misinformation in South Asian municipal responses, the freedom to choose quality choices through the consumption of HIV information and services may not always be easily accessible, and if available, may come at too high a price. PLHIV seeking biopsies and surgeries in Kathmandu are cases in point: they are entered into a loop of endless referrals, for which they are insufficiently informed to protest or desist, and which inevitably delayed the medical procedures that could have saved some of their lives.

### *Culture of weaponizing HIV*

It would be a mistake to presume that individualistic competition is absent in hierarchical cultures. In fact, when they do occur, there are not the usual legal and

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<sup>258</sup> Douglas, M. (1992a), op. cit.: p.32.

<sup>259</sup> India is the only country in this assessment with a well-established system of information sharing on HIV and AIDS. See, NACO. (2015), op. cit.

<sup>260</sup> See e.g. Chakrapani, V. et al. (2014), op. cit.; and Khosla, N. et al. (2009), op. cit.

cultural restraints built into the civic cultures of South Indian municipalities to prevent the worst excesses. Among transgender women who perform sex work in Lahore, there is a vibrant rivalry in seeking to minimize competition and equalize earnings from sex work between constituents. Rivalry in one area of Lahore has become so pronounced that even the weaponizing of HIV becomes acceptable to steal each other's clients, and denigrate the community's star performers.

To minimize the competition they spread out the rumours. If a client specially likes certain transgender women then others tell him that she has disease and they don't want to have sex with him. This is how the rumours are spread and it gradually spreads throughout the circle and everyone gets to know about it (transgender woman, Lahore).

In a culture such as this, the freedom underlying choices on testing for HIV, getting HIV test results, and seeking HIV treatment, are restricted by the risk of status disclosure at any point in the continuum of counselling, testing, obtaining test results and accessing care.

Transgender women in Dhaka related their experience of a defunct CBO, which had weaponized HIV by systematically disclosing the status of transgender women who had been under their care when the community had stopped partaking in the CBO's HIV services. More benign, the culture of weaponizing HIV has also been detected within MSM and transgender women communities, where constituents use it as ammunition in arguments between friends. As a result, especially among the transgender women community, there is a perceptible weariness for HIV testing to be conducted by transgender women CBOs. In this municipal culture, developing a culture of trust with a particular HIV testing programme becomes paramount in discerning communities' freedom to choose.

## Cultivating social justice

With the prevailing cultures jostling for dominance within the hierarchical cultures of South Asia, cultivating a culture of social justice has become an important strategy in the municipal response to HIV. Given the traditionalist standpoints of hierarchical cultures that value status-quo and are unlikely to instill the required cultural change of their own accord, this unenviable task that is fraught with implications of political legitimacy is often left to social organizations with individualistic cultural tendencies in these hierarchies; albeit, only social organizations with sufficient clout can reliably function as counterbalance in these hierarchical cultures.

## Counterbalancing hierarchies

In the South Asian municipalities included in this assessment, counterbalancing hierarchies inevitably become the task of international donors and funding agencies such as the Global Fund. It is a task, which the fund navigates through programmatic policies such as by empowering communities, promoting gender diversity, creating mechanisms for social justice; examples include grant-making on community systems strengthening (CSS),<sup>261</sup> a strategy promoting sexual orientation and gender identities (SOGI),<sup>262</sup> and a new channel for whistleblowing through the Office of the Inspector General that bypassed the hierarchy to aid the reporting of human rights violations occurring in its programmes with the New Funding Model.<sup>263</sup> These measures had

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<sup>261</sup> Global Fund. (2014, March), op. cit.

<sup>262</sup> Global Fund. (2009). *The Global Fund Strategy in Relation to Sexual Orientation and Gender Identities*. Geneva: Global Fund.

<sup>263</sup> Global Fund. (2015). *Thirty-Third Board Meeting: Community, Rights and Gender Report: Annex 1*.

built the organizational capacities of CBOs such as Humsafar Trust in Mumbai and BSWs in Dhaka,<sup>264</sup> introduced new information on sexual and gender-diversity that had not been available in prevailing cultures, and provided realistic channels for social justice to transpire in these hierarchies; which were all necessary for the survival of MSM and transgender women communities in these municipal responses.

### *Disrupting local cultures*

However, interventions by supranational organizations such as the Global Fund could be contributing to the disruption of local cultures through the fragmentation and discontent among MSM and transgender women communities as groups breakaway in competition for grants; disrupting the value systems of the community, which used to allocate resources relationally based on the hierarchy of groups and intimate knowledge of members' capabilities.<sup>265</sup> Acknowledging that these remain contentious issues, there is nonetheless a nascent culture of social justice in the hierarchical cultures of South Asian cities as a result of these interventions.

### *Improving the "terms of recognition"*

Through strategic donor investment in community, four of the five cities now legally recognize transgender women; although the cultural value of the *hijra* may take time

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Geneva: Global Fund: p.27.

<sup>264</sup> Information provided by respective Executive Directors during key informant interviews.

<sup>265</sup> See Douglas, M. (2004), op. cit.

to recover from its fall in the social hierarchy,<sup>266</sup> and more needs to be done for the social exclusionary measures deployed by society against them to come to an end. For the MSM, legal recognition may not be forthcoming, but the adoption of MSM terminology within public health has provided males who do not conform to gender norms, and do not or cannot adopt gay culture and identity, a political identity and cultural space to congregate as collectives. It has improved their “terms of recognition”<sup>267</sup> with governments and civil society, within their communities, and with themselves. These interventions have given “non-men”<sup>268</sup> and transgender women cultural competency, currency, and value; and improving their visibility and facilitating their quest for social justice in their respective societies.

Along similar lines, UN agencies such as The World Bank and the WHO have been displaying individualistic cultural tendencies in their responses to HIV; uncharacteristic of hierarchical governing systems. Pertinent examples, which South Asian cities can emulate, include; The World Bank funding case studies on cultural and media interventions to reduce HIV stigma in South Asia,<sup>269</sup> and convening a bank-led collaboration with anthropologists and social scientists on the intersection between poverty, social justice and development, which is outside the bank’s usual

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<sup>266</sup> In the Mughal Empire, the *hijras* or *Khawaja Saras* had high social status as keepers of the Sultan’s harems and other stations of substance.

<sup>267</sup> See Appadurai, A. (2004), op. cit.: p.70.

<sup>268</sup> See Pappas, G. et al (2001), op. cit.; Khan, S. (2004), op. cit.

<sup>269</sup> Stangl, A. et al. (2010). *Tackling HIV-Related Stigma and Discrimination in South Asia*. Washington DC: The World Bank.

remit of economic development financing;<sup>270</sup> and the WHO including community voices in their HIV testing, treatment and services guidelines,<sup>271</sup> and with more transparency in considering lay knowledge and addressing PLHIV concerns;<sup>272</sup> although initially these were uncommon practices for medical professionals and the medical fraternity, the measures have improved the “terms of recognition”<sup>273</sup> of PLHIV.

### *Increasing cultural value*

These efforts have led to the discovery of new knowledge on aspiration as a cultural capability to help communities navigate out of poverty, set new standards of community participation according to the principle of GIPA, and more coherent strategies to integrate lay and professional knowledge; which have democratized the knowledge marketplace and decision-making on medical standards and procedures. These HIV responses and outcomes reflect the trendsetting characteristic more commonly found in individualism cultures than in hierarchies, have improved the cultural value of MSM, transgender women and PLHIV communities globally; and from which South Asian municipal communities can draw in their response to HIV. However, the lack of solidarity in MSM and transgender women communities means that these increases in cultural value are only slowly recognized and adopted:

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<sup>270</sup> Rao V. and Walton, M. (Eds.). (2004). *Culture and Public Action*. Stanford, CA.: Stanford University Press.

<sup>271</sup> Declaration: An author of this paper (MC) sat on two 2015 WHO Guidelines Development Groups as community representative.

<sup>272</sup> See, WHO. (2013, 2015), op. cit.

<sup>273</sup> Appadurai, A. (2004), op. cit.: p.70.

But only few people think forward. If [only] we [are] united and talk about our rights [to] health [but] then that rarely happens (transgender woman, Lahore).

### Promoting the equality of agency

By viewing economics through a cultural lens, Rao and Walton saw inequality arising as a result of unequal “terms of engagement.”<sup>274</sup> This meant that inequality not only arose from the lack of affiliation in groups with access to resources as suggested by the individual principle of “equality of opportunity”, but was also dependent upon the relatedness between members in a group, and between the group and other groups, which they had termed the group-based principle of “equality of agency.” They concluded,

“Equality of agency” [accounts for] the impact of the relationality of individuals, the social and cultural contexts within which they operate, and the impact of these processes on inequality and poverty.<sup>275</sup>

MSM in Lahore who are a fragmented community of many leaders but insufficient stewards see the value of equality of agency in collectively increasing the strength of their voices: “If we form a group and jointly raise a voice then no one would get suppressed, not in front of media, not anywhere.” It is also the same principle that is leading dissenting enclaves to appear in the municipal response culture, having lived through inequality as a result of relationality and experienced its contribution to economic deprivation, as they have done. According to Douglas, the role of dissenting

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<sup>274</sup> Rao V. & Walton, M. (2004). Culture and Public Action: Relationality, Equality of Agency, and Development. In *Culture and Public Action*. Rao V. and Walton, M. (Eds.) (pp.3-36). Stanford, CA: Stanford University Press: p.29.

<sup>275</sup> Ibid: p.30.

enclaves is important because it draws attention to the socially defined fissures that divide the MSM and transgender women communities, and bring forth a “community conscience”<sup>276</sup> in the municipal response.

### *Acculturating “community conscience”*

Successful dissension requires that these MSM and transgender women CBOs, social networks and associations to equally represent all voices of their constituent communities based on the principle of “equality of agency.”<sup>277</sup> Thus, understanding the process through which community constituents become culturally isolated and socially excluded is crucial in the process of acculturating “community conscience”<sup>278</sup> in their respective communities particularly, and in the municipal response more generally. From the perspective of community MSM and transgender women constituents, community conscience is important because these communities, in many cases, represent their most authentic gender identities, and thus a relational social identity of great important in the psyche of individuals. From the insight of Douglas,

A general trait of human society [is] that fear of danger tends to strengthen the lines of division in a community. If that is so, the response to a major crisis digs more deeply the cleavages that have been there all the time.<sup>279</sup>

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<sup>276</sup> Douglas, M. (1992), op. cit.: p.93.

<sup>277</sup> Rao V. & Walton, M. (2004), op. cit.: p.30.

<sup>278</sup> Douglas, M. (1992), op. cit.: p.93.

<sup>279</sup> Douglas, M. (1992a), op. cit.: p.34.

Based on the HIV response in South Asian cities available in this report, in particular the response of MSM and transgender women communities, a common dividing line that stratifies both communities is HIV infection.

### *Persecuting PLHIV within communities*

There is a culture of persecution in South Asian cities of MSM and transgender women living with HIV,<sup>280</sup> by their own respective communities: “They treat [a] HIV positive person like a criminal” says an MSM in Lahore who had been persecuted by a sex partner for not disclosing his HIV status despite having protected sexual intercourse and a non-detectable viral load from being stable on HIV treatment; a key informant living with HIV in India had called it “inhumane” behaviour to be thrown out of the house in the middle of the night upon disclosing his HIV status to his partner;<sup>281</sup> transgender women in Dhaka have been known to lose their livelihoods, beaten by other transgender women in their households, and turfed out of their household altogether when their HIV status become known; and transgender women in Lahore leave the city upon finding out their HIV status, choosing self-exile instead of facing persecution and social exclusion by their peers.

Studying AIDS in the first decade of the AIDS epidemic, Douglas found that communities have two views of protection against AIDS; the biological protection of

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<sup>280</sup> This characteristic is not strong in the MSM community of Sri Lanka, where social class appeared as a stronger dividing line. However, this could be because the MSM community is fragmented to the extent that it may be difficult to locate a community of MSM as such.

<sup>281</sup> In-depth interview. (2015, October 9). Key informant is an MSM living with HIV and working for MSF. He is currently living with his partner who is seronegative, finally succeeding in holding on to a HIV negative partner after many adverse experiences.

the skin that protected the body against the infection diseases, and a social protection offered by communities that closed ranks and identified threats within itself through moral and social policing of constituents.<sup>282</sup> Drawing from the insight of Douglas, the South Asian municipal response that included localized cultures of fear, discrimination, misinformation, and particularly that of weaponizing HIV, constituted the second skin of municipal communities, and underlie the value system that saw the persecution of PLHIV; in isolating and socially excluding PLHIV from MSM and transgender communities, it was meant as a protectionist communal strategy. Even so, this protectionist strategy could be alienating the most vulnerable constituents in communities, and painting them into corners of society where there are few options left open to them; thus, eroding their “freedom to choose.”<sup>283</sup>

### *Safeguarding against apathy*

Acculturating community conscience and safeguarding against the development of a culture of apathy in the municipalities of South Asia are of particular importance for the development of a socially just HIV response. The looming culture of apathy on the horizon needs to be addressed urgently. Douglas called it “the biggest cultural problem,” and borrowing the terminology of Sen, had defined it thus: “the culture of apathy develops when freedom to choose has been eliminated.”<sup>284</sup> For MSM and transgender women living with HIV who have to live in these municipalities, facing the present grinding cultures within municipalities is inequality at its most socially

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<sup>282</sup> Douglas, M. (1992), op. cit.

<sup>283</sup> See Sen, A. (1981, 1985, 1999), op. cit.

<sup>284</sup> Douglas, M. (2004), op. cit.: p.107.

unjust. Imagine this; living in constant fear for their livelihoods and their lives; facing discrimination when they wish to access healthcare because of their gender expression and also their HIV status; living in societies with poor or inaccurate information about HIV and AIDS; having to rely on informal sources of information on where to find the services most suited to their needs; and when they have found these services, being able to access services equitably; and finally suffering the injustice of having their affliction be used as a weapon to inflict more pain.

The current cultures ebb the freedom to choose of MSM and transgender women living with HIV, and will arguably drive anyone except the strongest and most able of them to the edge of despair, and towards relational oblivion and dismal cultural value. Thus, unless something is done to improve these PLHIV's "terms of engagement", it is very likely that these individuals will become isolates in South Asian municipalities, without "equality of agency", bereft of community, alone, and apathetic.

## Enabling the Municipal Environment

Ensuring that municipalities have enabling environments is key to MSM and transgender women living with HIV have the “freedom to choose”<sup>285</sup> and social justice, and safeguard from the development of a “culture of apathy.”<sup>286</sup> Furthermore, enabling municipal environments is in line with the Paris Declaration to end the AIDS epidemic by 2030.<sup>287</sup> Thus, the following guidance elucidates the necessary conditions for an enabling environment as distilled from municipal responses.

### *Addressing institutionalized stigma in municipalities*

Providing equitable access to PLHIV at all municipal services including the police, healthcare facilities and HTS in Colombo, Dhaka, Kathmandu, Lahore and Mumbai, needs urgent attention. It may be that legislating against the occurrence of stigma based on gender expression and HIV status in municipal services may be required to address the pervasive institutionalization of these types of stigma in current services, and especially among HCPs.

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<sup>285</sup> See Douglas, M. (2004), op. cit.

<sup>286</sup> See Douglas, M. (1992), op. cit.

<sup>287</sup> See UNAIDS. (2014), op. cit.

### *Instilling cultural value in HCP professionalism*

Should there be more cultural value in professionalism it could incentivize HCPs with social status to provide better quality services and at professional levels, in lieu of engaging in discriminatory practices towards their clients who may be MSM and transgender women. This will also likely build a culture of trust among the public in government HCP, and contribute towards increasing the social and cultural capital of municipalities.

### *Instituting GIPA in municipal HIV services*

Involving PLHIV, including communities of MSM and transgender women, in municipal HIV services' decision-making and programming will ensure that services are sensitive to community needs. This will likely increase the demand for, and effectiveness of, municipal HIV services; which will increase the social prestige and authority of municipal AIDS programmes, and municipal hierarchies more generally.

### *Intervening in the municipality at the structural level*

A concerted effort towards the betterment of municipality at the social, political and cultural environments for PLHIV, particularly in communities of MSM and transgender women, will likely require structural interventions that are contextually specific and sensitively implemented.<sup>288</sup> This report recommends group-level

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<sup>288</sup> Gupta, G. R. et al. (2008, August). Structural approaches to HIV prevention. *The Lancet*. DOI: 10.1016/S0140-6736(08)60887-9.

interventions to promote “equality of agency”<sup>289</sup> to be conducted in culture, within civic infrastructures, using the mass media, among urban communities, and intervening at a key service delivery component of HIV services.

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<sup>289</sup> Rao, V. & Walton, M. (2004), op. cit.: p.30.

## Programmatic Recommendations

The five interventions proposed in this chapter are outline sketches of ideas in germination that require further extensive elaboration before they can be put into practice. These interventions have been included as programmatic recommendations because of their capacity as game-changers; their effects will likely have lasting impact beyond the key populations of MSM and transgender women, to bring about measurable change in the municipal response to HIV for all PLHIV.

All the interventions proposed are structural, group-level interventions, which means they seek to influence the social, economic, political, or environmental factors determining HIV risk and vulnerability, and have been specially designed according to the contextual analyses of the municipal; provided in this report.<sup>290</sup> The intervention would require implementation in groups, and their outcome measures should likewise be group measures.

### *1. Acculturating the “capacity to aspire” in communities of MSM and transgender women living with HIV in South Asian municipalities.*

Drawing from the cultural insights and successful social intervention on poverty in Mumbai’s slums, Appadurai focuses on culture as a receptacle of human ideas, and contends that within culture the ideas of the past, as well as the future, are “embedded

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<sup>290</sup> See Gupta, G. R. et al. (2008, August), op. cit.

and nurtured.”<sup>291</sup> Thus, cultural capacity can carry with it aspiration as a capability.<sup>292</sup> Opposite of beliefs and norms, which are historical capacities of ideas and practices in communities, the “capacity to aspire”<sup>293</sup> is forward looking by focusing on what the community can become in the future. According to Appadurai, the capacity to aspire is a navigational capacity,<sup>294</sup> which allows community constituents to navigate towards the circumstances that can bring about the things being aspired.

Along the same lines, acculturate the capacity to aspire in MSM and transgender women living with HIV by focusing on issues that have intrinsic value to communities, such as beauty and sensuality. This could germinate in the form of a beauty pageant organized in collaboration with the communities, and including a category of competition in the pageant for PLHIV. The objective of this is four-fold: first, it will increase the visibility of PLHIV in MSM and transgender communities; second, it may show to HIV-negative MSM and transgender women that HIV positive members of their constituents aspire for the same things as they do; third, it portrays a positive self-image of PLHIV as a point of reference for both HIV positive and negative constituents; and fourth, it provides a space and outlet for healthy competition in the community in lieu of the destructive competitiveness that is occurring among transgender women communities particularly in Lahore.

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<sup>291</sup> For details of the novel intervention on poverty, see Appadurai, A. (2004), op. cit.: p.59.

<sup>292</sup> Ibid: p.62. He draws from the works of Sen (1984, 1985, 1999), whose insights on social welfare as ‘capabilities’ and “placing matters of freedom, dignity, and moral well-being at the heart of welfare and its economics” (p.63).

<sup>293</sup> Ibid: p.64.

<sup>294</sup> Ibid: p.69.

If conducted well, and with sufficient community buy-in, it could change the “terms of recognition”<sup>295</sup> of PLHIV in these communities as social outcasts; and ameliorate the self-stigma and self-esteem of PLHIV as well. These positive “terms of engagement”<sup>296</sup> may mean a great deal to PLHIV when they face abject inequality in society, and help them to navigate through these realities with aspirational hope in the future, than sink in seeming desperation and despair of present moments.

*2. Showcasing PLHIV in the mass media as lives well-lived and living well, with MSM and transgender women issues included as elements of stories.*

Similar to the cultural intervention in the Maharashtra mass media to reduce PLHIV stigma in the municipal communities by getting PLHIV journalists to share intimate details on life stories as part as parcel of living with HIV,<sup>297</sup> showcasing PLHIV as lives well-lived and who are living well may instill positive cultural values for PLHIV, and begin altering its poor terms of engagement within the municipal community. The intervention affects municipal culture by instilling a sense of hope for members of the municipality who are motivating themselves to test for HIV, or have just found out their HIV positive status, that they are not alone.

Additionally, showcasing PLHIV in productive lifestyles will help municipal communities see that there could be life after HIV diagnosis, as well as the possibility

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<sup>295</sup> Ibid: p.70.

<sup>296</sup> Rao. V. & Walton, M. (2004), op. cit.: p.29.

<sup>297</sup> See Stangl, A. et al. (2010), op. cit.: 77-84. Chapter 10: Celebrating Those Who Care: A Radio Program by HIV-Positive Journalists in Maharashtra.

of normality; which will undoubtedly contribute towards normalizing PLHIV in communities, and embedding the notion of HIV testing as a regular health screen, something of cultural value in society. Furthermore, by showcasing PLHIV as lives well-lived, provides living with HIV the cultural cache of surmounting difficult circumstances and finally overcoming personal challenges; a heroic occasion.

Taken together, these positive cultural contributions should contribute to changing the “politics of recognition”<sup>298</sup> of PLHIV in the municipal community, and more importantly, ebb discriminatory practices currently occurring in South Asian municipalities. These politics and practices have been derived from the belief that HIV is a mark of shame, and one that conveys to society that PLHIV is of poor relational value in communities.

Finally, the inclusion of MSM and transgender women elements in the stories have been designed to keep socially critical ideas of gender in the public psyche as embellishments in order to draw the municipal community’s attention away from engaging its built-in hierarchically imposed gender value system. This strategy is aimed at desensitizing the municipal community of MSM and transgender women by instigating conversations rather than debates about gender appropriateness as people reflect on these stories.

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<sup>298</sup> Drawing from the work of Charles Taylor, see Appadurai, A. (2004), op. cit.: p.62.

*3. Rapidly scaling up the UNDP intervention with HCPs on sexual health  
desensitization with PLHIV partnership.*

Evidence from the assessment supports the scaling up of the UNDP intervention towards equitable access and standards of care on sexual health, STIs and HIV.<sup>299</sup> Discrimination in healthcare facilities is a singular concern repeated by participants in all five cities included in this assessment, and its effects include self-stigmatizing HIV acquisition and gender expression, refraining further access to services including HIV testing, losing of privacy and confidentiality on HIV status, being moralized about marriage choice, and barring access to required healthcare services including biopsies and surgery.

Although these discriminatory practices affect all MSM and transgender women due to their deployment along gender normative lines, MSM and transgender women living with HIV, who need consistent access to HIV services through public healthcare facilities, disproportionately bear the brunt of these practices because their freedom to choose is constrained by the certainty of mortality should services remain withheld continuously. Thus, these practices inflict on PLHIV an additional emotional burden and psychological stress that HIV uninfected members of their communities may not readily grasp, or even if they do, may not fully comprehend. Furthermore, as the assessments have revealed, there are contextual differences in each South Asian municipality that is not generalizable. Thus, it is of paramount importance that the scaling up of this intervention be carried out in partnership with PLHIV from both

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<sup>299</sup> UNDP & WHO. (2014), op. cit. Retrieved from <http://www.timehascome.org>.

MSM and transgender women communities in each municipality. PLHIV can bring to the training sessions not only a human face, but actual stories of discrimination, details of discriminatory practices, and relate the loss of other PLHIV, which can be indelibly pinned to the discriminatory practices of HCPs.

The success of this intervention is directly related to the capacity to achieve critical mass of HCPs trained under its training-of-trainers (TOT) scheme. Unless this critical mass is achieved in a sufficiently truncated duration of 5-7 TOT cycles, the intervention is unlikely to show results in the short or medium term. Critical mass is defined as the perceptible (and measurable) difference in HCP attitude to gender diversity, STI and HIV at a healthcare, such that it influences other HCPs not involved in the scheme to reconsider their attitudes and behaviours in line with their superiors and juniors in the HCP hierarchy. Due to the relational hierarchies of healthcare facilities, a key ingredient to attain critical mass is to ensure that within 5-7 TOT cycles, there is an HCP trained in the scheme at every distinct level of the HCP; from the management at the top of the hierarchy right through to services delivery and down to auxiliary and support staff at the bottom of the hierarchy. Unless this occurs, the chance of linking the scheme through the HCP hierarchy, in an acceptable timeframe, is likely to be remote.

*4. Facilitating a regional advisory council on the rights to health of transgender women consisting of the Gurus at the head of each Gharana.*

India, Pakistan, and Bangladesh share similarities on the problem of getting required HIV services and care to transgender communities due to the continuous friction and

rivalries between *Gharanas* (clans) of transgender women. The worst cases of friction have come from Lahore, Pakistan; where rivalries involve using HIV status as socially acceptable ammunition to discredit transgender women. Such practices have also been detected in Mumbai and Dhaka, but to a much lesser extent, and with less vehemence when it does occur.

This intervention proposes building on the efforts of BSWS in Dhaka to form a regional advisory council of *Gurus* who head each of the seven *Gharanas* in their respective states. *Gurus* will deliberate on issues concerning transgender women health in these three South Asian countries.<sup>300</sup> Given that the *Hijra* have attained legal recognition in all three states, the facilitated advisory council can therefore provide oversight on transgender women's rights to health, and see to it that the existing gender gap on access to healthcare, services and welfare will eventually cease.

To ensure minimal disruption to proceedings, preempt relational hierarchies between *Gharanas* and among *Gurus*, and ensure the correct protocols are in place, it is highly recommended that prior research on the *Gharanas* be carried out prior to setting up and facilitation of the regional council.<sup>301</sup> Research areas should include social

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<sup>300</sup> See, BSWS. (2014), op. cit.: p.18. In March 2014, BSWS had organized a national consultation and coordination meeting with hijra gurus from different parts of the country with the objective to identify, understand, discuss roles and responsibilities and think of innovative ways to enhance effective service delivery for the *hijra* community. BSWS has also taken steps to form a national *hijra* platform to raise voice on their human and constitutional rights in the wake of third gender recognition by the government in 2013. According to BSWS, “the gurus also requested BSWS to design appropriate campaign to move further with this very welcoming outcome in terms of mass sensitization for their social acceptability.”

<sup>301</sup> See Nanda, S. (2014), op. cit; also Bangash, O. (2012), op. cit.

hierarchies and status symbols, distinctions and displays of power, and the history of rivalries between *Gharanas*.

*5. Improving the morale of outreach staff with career plans and the option of accreditation as a public health certified Community Health Worker (CHW).*

Outreach staff is the key to viable HIV prevention services for MSM and transgender women in South Asian municipalities. Their work is often fraught with existential challenges as they are the forefront of the community HIV response in these cities, and as such can become targets of gender-based violence and abuse from municipal communities as they go about their duties. Furthermore, the career plans of these outreach workers are often informal, and unstructured. This leaves them with few incentives to shoulder the burden of the HIV response, especially when funding crises occur, or threats of violence take place.<sup>302</sup> It is also highly recommended that, where possible, PLHIV peers from MSM and transgender women communities be employed in the role of outreach workers to enhance rapport building between PLHIV and non-HIV positive outreach workers, as well as to gain the trust of PLHIV in communities.<sup>303</sup>

This intervention proposes providing each outreach worker with a well-defined career plan, and the further option of training towards public health certification as a

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<sup>302</sup> Based on focus group discussions (2015, October) with MSM and transgender women outreach workers in Mumbai and Lahore.

<sup>303</sup> UNFPA et al. (2015), op cit.; and, Health Policy Project et al. (2015), op. cit.

community health worker (CHW) that is a transferrable skill set. In India, CHW is the backbone of its extensive public health system. A review of the services of CHW found that their effectiveness depended on key factors, including nature of employment, incentives and career prospects, training, and feedback, monitoring mechanisms and community participation.<sup>304</sup>

This intervention should preempt these factors by ensuring the CHWs are properly trained (at least a 3-month course), which entail a marketable certification to authenticate their skills, and build into the system a feedback and monitoring mechanism that included obtaining feedback from the communities they served. Interestingly, the review found that if CHWs get good feedback from rewards from the community, these contributed more significantly to their overall motivation and performance of CHWs than other factors.<sup>305</sup> These improvements in motivation and performance also meant fewer requirements for handholding, and overall supervisory needs. Should this intervention be put in place, it is expected that the professionalism of outreach staff will markedly improve, and their performance in locating and delivering HIV services to constituents most vulnerable to HIV will show measurable improvements.

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<sup>304</sup> Prasad, B. M. & Muraleedharan, V. R. (2007, October), op. cit.: p.6.

<sup>305</sup> Ibid: p.7.

## Appendix A: Oral Informed Consent Script for Key Informant Interviews

Hello, I am \_\_\_\_\_ from the Asia Pacific Network of People Living with HIV (APN+). APN+ is a Regional sub-recipient of the Global Fund's multi-country South Asia (MSA) DIVA program. APN+ is conducting a regional study to identify the likelihood for community-initiated HIV testing and counseling among men who have sex with men and transgender communities, and explore how to encourage this practice in South Asia. This study aims to provide a foundational response on the feasibility of MSM and TG community-initiated HIV testing and counseling (HTC) service provision in five South Asian cities. These are Colombo, Dhaka, Kathmandu, Lahore, and Mumbai. I am looking for input from civil society on the needs of these communities, and how to overcome existing barriers. The interview will take at most 90 minutes and we will reimburse you [insert local currency] for your time and opinions. Your participation would help us understand what people in society think about HIV testing and counseling services that is community-centered.

I would like to get permission from you before we begin the interview. Talking to us is completely your choice and you can stop participating at any time and for any reason. If you don't want to answer a question I ask, you are free to not answer, or to stop the discussion entirely if you feel uncomfortable talking any more. If you feel uncomfortable about how the discussion is going, please let us know.

You will not directly benefit from this study. However, the information gained from this study will help us learn more about community HIV services in South Asia, which may help design better HIV services for other communities in the future.

We will be recording your voices during the discussion for research purposes. These recordings will be destroyed once transcription is complete. To protect your identity, we won't be using your real name during the interview. Please choose any name you wish to be called during the interview. Only the people working on this study will have access to the recordings and transcripts of this interview. There is a very small risk that the recording or transcript of our conversation will accidentally become available to other people, but we will be very careful to keep this interview private.

If you have any questions about this study, this participant information sheet [hand out contact information sheets] include the name and contact information of someone locally who can reach me and information about how to reach the people overseeing my study as well.

Do you have any questions about this study or about participating in this interview?

[Once any questions are resolved] May I begin the interview?

## Appendix B: Oral Informed Consent Script for Focus Group Participants

### **To the focus group:**

Hello, I am \_\_\_\_\_ from \_\_\_\_\_. I am working with the Asia Pacific Network of People Living with HIV (APN+), which is a Regional sub-recipient of the Global Fund's multi-country South Asia (MSA) DIVA program. APN+ is conducting a regional study to identify the likelihood for community-initiated HIV testing and counseling among men who have sex with men and transgender communities, and explore how to encourage this practice in South Asia. This study aims to provide a foundational response on the feasibility of MSM and TG community-initiated HIV testing and counseling (HTC) service provision in five South Asian cities. These are Colombo, Dhaka, Kathmandu, Lahore, and Mumbai. I am looking for input from civil society on the needs of these communities, and how to overcome existing barriers. The discussion will take at most 90 minutes and we will reimburse you [insert local currency] for your time and opinions. Your participation would help us understand what the communities think about HIV testing and counseling services that is community-centered.

I would like to get permission from each of you before we begin the discussion. Talking to us is completely your choice and you can stop participating at any time and for any reason. If you don't want to answer a question I ask, you are free to not answer, or to stop the discussion entirely if you feel uncomfortable talking any more. If you feel uncomfortable about how the discussion is going, please let us know.

You will not directly benefit from this study. However, the information gained from this study will help us learn more about community HIV services in South Asia, which may help design better HIV services for your communities in the future.

I will be recording your voices during the discussion for research purposes. These recordings will be destroyed once transcription is complete. To protect your identity, we won't be using your real names during the discussion. Please choose any name you wish during the discussion, and call each other by that name. Only the people working on this study will have access to the recordings and transcripts of our discussion. There is a very small risk that the recording or transcript of our conversation will accidentally become available to other people, but we will be very careful to keep this discussion private.

If you have any questions about this study, this participant information sheet [hand out contact information sheets] include the name and contact information of someone locally who can reach me and information about how to reach the people overseeing my study as well.

### **To each potential participant:**

Do you have any questions about this study or about participating in this discussion?  
[Once any questions are resolved] May I begin the discussion?

## Appendix C: Key Informant Interview Schedule

- 1) Assessing existing and available HIV testing and counseling services (HTC) in relation to men who have sex with men (MSM) and transgender (TG) communities' needs
  - a. Available HTC services
    - i. What kinds of HTC services are available for your communities in this city?

*Probe: Fee based service? Free service? Provider initiated HTC? VCT? Homebased HTC services?*
    - ii. When do these HTC services operate?
      - *Probe: Office hours? After office hours? Weekends?*
    - iii. Where are these HTC services located?
      - *Probe: City center? Near public transportation? Where a lot of community members live?*
    - iv. Who are the providers of these HTC services?
      - *Probe: Government? Non-government? Global Fund? External funding agency?*
    - v. What needs do MSM and TG communities have for HTC services?
      - *Probe: Confidentiality? Feeling safe? Non-stigmatising attitude from staff? Understanding sexuality related issues? Same day results? Free service? Convenience?*
  - b. Addressing community needs
    - i. How well do existing services cater to the needs of MSM/TG communities?

*Probes: How well do these services protect the confidentiality on HIV status and sexuality-related issues? How accessible are these HTC services for MSM/TG communities?*
    - ii. How satisfied do you think MSM/TG communities are with existing HTC services?

*Probes: How comfortable are community members when accessing services? How convenient are these services for community members?*
    - iii. What would you change about these services to better serve MSM/TG communities' needs?

*Probes: What are the gaps in current services? How*

*differently might you operate these services?*

2) Exploring the idea of a community-initiated HTC service for MSM/TG communities

a. Aspects of a community-initiated service

- i. If MSM/TG communities could set up an HTC service that only served their respective communities, what do you think it will be like?

- **Probes:** *Where will it be? Who will work there? When will it operate? How realistic is this idea?*

- ii. How different would these community-initiated HTC service be as compared with existing services?

- **Probes:** *What do you expect will be done differently from existing HTC services? How important would it be for the community to have its own HTC service?*

- iii. How likely would social, political, religious, and cultural contexts influence the operations of these services?

- **Probes:** *How accepting is the general population of this city regarding MSM/TG? How open can MSM/TG communities be regarding their sexualities in this city?*

b. Community capacity

- i. How would you rate between 1 and 10 of the MSM/TG communities' capacity in setting up a community-initiated HTC service for this city (where 1 is a complete lack of capacity, and 10 is having the required capacity)?

- **Probes:** *What made you decide to give this rating? Which communities are you referring to? What gaps in community capacity will you be expecting?*

- ii. What would MSM/TG communities need to set up a community-initiated HTC service in this city?

- **Probes:** *Money? Land? Building? Financial support? Social and network support? Technical assistance?*

- iii. How well MSM/TG communities support a community-initiated HTC service for MSM/TG in this city?

- **Probes:** *What objections will you expect from community members about this service? What expectations will you expect from community members about this service?*

3) Expected structural barriers for a community-initiated HTC service for MSM/TG communities

a. Internal

- i. What will affect how much ownership communities will have about this service?

***Don't Probe***

- ii. What will it take for your communities to be enthusiastic about this service?

***Don't Probe***

- iii. In your opinion, how likely will your communities be able to initiate such a service?

***Don't Probe***

b. External

- i. What social factors do you think will affect the success of this community-initiated HTC service?

ii. ***Don't Probe***

- iii. What political influence will you expect on this community-initiated HTC service?

***Don't Probe***

- iv. What religious influence will you expect on this community-initiated HTC service?

***Don't Probe***

- v. What cultural factors do you think will affect the success of this community-initiated HTC service?

***Don't Probe***

## Appendix D: Focus Group Discussion Guide

- 1) Assessing existing and available HIV testing and counseling services (HTC) in relation to men who have sex with men (MSM) and transgender (TG) communities' needs
  - a. Available HTC services
    - i. What kinds of HTC services are available for your communities in this city?

**Probe:** *Fee based service? Free service? Provider initiated HTC? VCT? Homebased HTC services?*
    - ii. When do these HTC services operate?
      - **Probe:** *Office hours? After office hours? Weekends?*
    - iii. Where are these HTC services located?
      - **Probe:** *City center? Near public transportation? Where a lot of community members live?*
    - iv. Who are the providers of these HTC services?
      - **Probe:** *Government? Non-government? Global Fund? External funding agency?*
    - v. What needs does your communities have on HTC services?
      - **Probe:** *Confidentiality? Feeling safe? Non-stigmatising attitude from staff? Understanding sexuality related issues? Same day results? Free service? Convenience?*
  - b. Addressing community needs
    - i. How well do services cater to the needs of your communities?

**Probes:** *How well do these services protect the confidentiality on HIV status and sexuality-related issues? How accessible are these HTC services for your communities?*
    - ii. How satisfied are members of your communities with existing HTC services?

**Probes:** *How comfortable are community members when accessing services? How convenient are these services for community members?*
    - iii. What would you change about these services to better serve your communities' needs?

**Probes:** *What are the gaps in current services? How differently might you operate these services?*

2) Exploring the idea of a community-initiated HTC service for MSM/TG communities

a. Aspects of a community-initiated service

i. If your communities could set up an HTC service that only served MSM/TG, what would it look like?

- **Probes:** *Where will it be? Who will work there? When will it operate? How realistic is this idea?*

ii. How different would these community-initiated HTC service be as compared with existing services?

- **Probes:** *What would you do differently from existing HTC services? How important would it be for the community to have its own HTC service?*

iii. How likely would social, political, religious, and cultural contexts influence the operations of these services?

- **Probes:** *How accepting is the general population of this city regarding MSM/TG? How open can MSM/TG communities be regarding their sexualities in this city?*

b. Community capacity

i. How would you rate between 1 and 10 your community's capacity in setting up a community-initiated HTC service for MSM/TG in this city (where 1 is a complete lack of capacity, and 10 is having the required capacity)?

- **Probes:** *What made you decide to give this rating? Which communities do you represent? What gaps in community capacity will you be expecting?*

ii. What would your communities need to set up a community-initiated HTC service for MSM/TG in this city?

- **Probes:** *Money? Land? Building? Financial support? Social and network support? Technical assistance?*

iii. How well will your communities support a community-initiated HTC service for MSM/TG in this city?

- **Probes:** *What objections will you expect from community members about this service? What expectations will you expect from community members about this service?*

3) Expected structural barriers for a community-initiated HTC service for MSM/TG communities

a. Internal

i. What will affect how much ownership communities will have

about this service?

***Don't Probe***

- ii. What will it take for your communities to be enthusiastic about this service?

***Don't Probe***

- iii. In your opinion, how likely will your communities be able to initiate such a service?

***Don't Probe***

b. External

- i. What social factors do you think will affect the success of this community-initiated HTC service?

ii. ***Don't Probe***

- iii. What political influence will you expect on this community-initiated HTC service?

***Don't Probe***

- iv. What religious influence will you expect on this community-initiated HTC service?

***Don't Probe***

- v. What cultural factors do you think will affect the success of this community-initiated HTC service?

***Don't Probe***