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MALAYSIA

# Overcoming the epidemic of fear: Why both clinic and community matter, and why the social context in which people living with HIV live and love matters most of all

## Introduction

Today the world is at a tipping point in the response to AIDS. In the past five years, compelling scientific evidence has demonstrated that successful treatment has an important role to play in preventing the spread of HIV and the onset of AIDS. Viral load suppression through medication can keep individuals at high risk of infection from getting HIV,<sup>1</sup> and treatment has so far been similarly effective in preventing HIV transmission in both vaginal and anal sex.<sup>2,3</sup>

Yet alongside these tremendous gains, the realities of stigma and discrimination against people living with HIV remain stark. In my part of the world – the Asia Pacific region – even where treatment is available, there are many people who are still afraid to test for HIV. For them, scientific progress has had limited effect on their daily lives.

1. World Health Organization (2014), Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. Available at: <http://www.who.int/hiv/pub/guidelines/keypopulations/en/>

2. Cohen, M.S., McCauley, M., Gamble, T.R. (2012), 'HIV treatment as prevention and HPTN 052', *Current Opinion in HIV and AIDS* 7(2): 99–105.

3. Rodger, A. et al. for the PARTNER Study Group (2014), *HIV transmission risk through condomless sex if HIV+ partner on suppressive ART: PARTNER study*, Boston, MA: IAS-USA.





For too many people in the world, AIDS continues to be more than just an epidemic with physical manifestations.

In the words of Jonathan Mann, it remains a deeply challenging “epidemic of social reaction and response”.<sup>4</sup>

The test for activists in this new era of a science-driven AIDS response will be to address the unintended consequences of a biomedical approach. There are growing fears that in the race to reach more people with treatment, the biomedical approach – the ‘clinic’, as it were, that offers pills and machines, and the benefits of ‘modernity’ – might very well displace the ‘community’. There are very real questions about what happens to people living with HIV in a biomedicalised race for efficiency and delivery.

As the current Millennium Development Goal paradigm draws to a close, and given that community mobilization has been established as a critical enabler in the AIDS response,<sup>5</sup> this essay explores the raging debate about whether the best place for HIV treatment is the community or the clinic. By looking at the life stories of people living with HIV and AIDS in the Asia Pacific region, as well as my own history as a gay positive man, I explore whether activists should continue to place our efforts in strengthening health systems for more effective service delivery, or whether we should concentrate on strengthening community systems, empowering ourselves to advocate for better environments within which HIV services can and should be delivered.

## Defining health and community systems

When people are asked what it means to be healthy, they often say that it means feeling good. This instinctive response is in line with the World Health Organization (WHO)’s definition, that health is a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.<sup>6</sup>

When we speak of health systems, most of us have an idea of what this means too. We are familiar with the roles of doctors and nurses. We accept health tests and take medications, even though we may not completely understand medical instruments or how medicines work. We are also familiar with going to pharmacies, hospitals and clinics to get our care. In all likelihood, when we think of health systems we see how these components work together to look after our health. In this vein, WHO defines health systems as the “sum total of all the organizations, institutions and resources whose primary purpose is to improve health”.<sup>7</sup>

However, it is much more difficult to define the concept of ‘community systems’. The Global Fund to Fight AIDS TB and Malaria (Global Fund), which has been instrumental in championing the concept, defines community systems as “community-led structures and mechanisms used by communities through which community members and community-based organizations and groups interact, coordinate and deliver their responses to the challenges and needs affecting their communities. Many community systems are small-scale or informal.”<sup>8</sup>

4. Mann, J.M. (1988), ‘Statement at an informal briefing on AIDS to the 42nd session of the United Nations General Assembly’, *Journal of the Royal Statistical Society Series A (Statistics in Society)* 151: 131–6.

5. Schwartländer, B. et al. (2011), ‘Towards an improved investment approach for an effective response to HIV/AIDS’, *Lancet* 377(9782): 2031–41.

6. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

7. World Health Organization (9 November 2005), What is a health system? Online Q&A. Available at <http://www.who.int/features/qa/28/en/>

8. Global Fund (2014), Community Systems Strengthening Framework. Available at: <http://www.theglobalfund.org/en/civilsociety/reports/>





But what, really, is a community? The Global Fund admits that there is “no single or fixed definition”.<sup>9</sup> It goes on to suggest that “communities are formed by people who are connected to each other in distinct and varied ways ... connected by living in the same area or by shared experiences, health and other challenges, living situations, culture, religion, identity or values.”<sup>10</sup>

In essence, then, the idea of communities as places in which people are connected to one another generates an infinite number of relationships between people and institutions in as many different contexts. The social sciences have long recognised the looseness of community membership. For the purposes of academic and activist research, the organic and rich sets of relationships within communities, indeed the very ‘fuzziness’ of the notion of community, provides the basis for important analysis. But public health systems have had a less easy time accepting the vagaries of the term and the behaviours of its actors.

Thus, in the fight against AIDS, the term ‘communities’ at times reflects a public health approach: groups of people are defined as a community based by their risk behaviours. However, for activists the term reflects the political identities that are forged when people are discriminated against. It captures how they find kinship through the experience of being kept at the margins of society, through being ostracised.

While it may have been epidemiologically expedient to identify people by their HIV risk categorisation in the early days of AIDS campaigning, there are real problems with this approach. The term ‘most-at-risk populations’ can be seen as stigmatising. It labels groups of people by what they do and defines them in this sense as an imagined community. The term holds within it the moralistic residue of an era in which certain groups of people were ‘to blame’ in disproportionate ways for driving the epidemic.

The term ‘community’ also defines a sense of identification and belonging rather than simply speaking to a commonly held goal.

| If health is your goal, then what do identification and belonging have to do with anything?

Surely you can achieve it alone, through your own actions, through vigilance and self-monitoring? This is, of course, a trick question, but it is an important one. Particularly where the stigma of AIDS is debilitating, the health of people living with HIV cannot be delinked from a sense of belonging. Belonging in a legal sense confers rights, but it also allows people living with HIV to feel confident and capable of claiming their rights to health and healthy sexuality, to kinship and respect.

Disparate groups of people consigned to the margins of society often define themselves as belonging to the same community precisely because they share a common experience of discrimination and vulnerability, even though in other ways they might not fit together. Being ‘put in the same box’ strengthens their voices. As the AIDS movement has shown over the last few decades, the idea of being part of a community can also turn people who previously lived on the margins of society into experts and representatives of life-worlds that people in mainstream society know little about.

Across Asia, Africa and the Middle East, at conferences and meetings, people who use drugs, sex workers, men who have sex with men, transgender people, and

9. Global Fund (2014), Community Systems Strengthening Framework. Available at: <http://www.theglobalfund.org/en/civilsociety/reports/>  
10. Global Fund (2014), Community Systems Strengthening Framework. Available at: <http://www.theglobalfund.org/en/civilsociety/reports/>





people living with HIV are sharing the lives of their communities. It is alternative voices like these that are helping to gain better and more comprehensive access to HIV prevention and treatment services. Today, they constitute an important community.

Yet in discussions about what happens next, about where the post-Millennium Development Goal framework takes the world, there have been few efforts to engage effectively with the people who actually use the community and health systems that currently exist.

### Role delineation: who should do what for whom?

Yet there is rich experience within these groups. The circumstances in which many of these communities live are dire, filled with stigma and abuse. Over the years, many people living with HIV have come to accept that they will get poor or mediocre services at their local clinics or hospitals. Some people living with HIV simply refuse to access formal services because of the humiliation they face from some healthcare workers, or the stigma they encounter from members of the public who can guess why they are in the queue because of the way health systems are set up.

Around the world, people living with HIV who have refused to accept sub-standard or discriminatory services have developed powerful ways of ensuring that they get the help and support that is their right. In some places, the most effective short-term route has been to establish parallel health systems. Special clinics that cater to sex workers, men who have sex with men, or transgender people have proliferated. So too have special days or rooms set aside within existing facilities, where doctors, nurses and healthcare workers sensitive to their needs will provide HIV testing, diagnosis and treatment, and attend to their questions and concerns.

Health activists living with HIV have built up considerable community networks, knocking on doors, providing home-based care and spiritual ministry. They have carried out workshops on everything from how to use the female condom or explaining the importance of lubricants during anal sex, to talking about the science of HIV and attending the court cases of community members victimised by the police and other state officials. In some cases, they have extended this 'community' across borders, as the case of Maura from Papua New Guinea illustrates:

*After I left Max he continued to drink heavily, his health declined rapidly and he died in 2006. His family blamed me and beat me up. I lost control of the drop-in centre and it closed. In September 2007 I developed resistance to my first-line ARVs and I was really scared that I might die. But I had contacts outside the country and I was relying heavily on them. That was something that made me feel strong inside, that I'm not doing this alone and that there is this positive community that I can fall back on. Friends helped me to receive second-line ARV medication and now the PNG [Papua New Guinea] government is working on getting second-line ARV drugs.<sup>11</sup>*

Maura's story highlights how the importance of a community stems from how it responds under duress. Although it wasn't physically proximate to her, Maura's community helped her to circumvent the reality of being an HIV-positive woman in a poor country. The immediate solution – to get her drugs – was of course a short-term fix. But it led to the provision of second-line drugs through the public

11. Paxton, S. (2009), *Diamonds: stories of women from the Asia Pacific Network of People Living with HIV*, Bangkok: APN+ and UNIFEM





health system, so that other women like Maura do not have to rely solely on the community response that she was able to muster.

As inspiring as stories like Maura's may be, there has also been a backlash against the activism of this kind of community. The AIDS movement, in part because of its visibility, is often perceived as being larger and better resourced than it is. The community systems for care are criticised; seen as duplicating rather than extending.

Globally, there has been a backlash against the activists who have championed a response to AIDS with such tenacity. While it has its merits, the move towards strengthening health systems so they are better able to cater to the needs of everyone, regardless of their HIV status, can be seen as part of this backlash. With better health systems, the theory goes, community systems would then be used to reach key populations, to help them to come forward to receive health services. So, for example, in areas with high levels of injecting drug use, community groups would help to get people who use drugs to the clinic and into treatment. In this model, more clients are reached and the disease burden is diminished. The community system is used in an instrumental way to achieve a set of clearly defined health goals.

In the long term, then, the vision of health system strengthening advocates is that the 'parallel' systems and activities of community groups running actual services would become unnecessary – and indeed, some of the referral efforts might eventually become unnecessary too. However, there are real questions about whether this is a vision that people living with HIV (itself a heterogeneous group) collectively share.

The question is who in this longer-term vision defines these health goals? As APN+ has noted in its studies on treatment access,<sup>12</sup> the obsession with quantification might lead to a corresponding de-emphasis on concerns about quality that are often so crucial to people living with HIV. As such, if the community system is seen as subordinate to the health system, then surely the goals that communities of people living with HIV have for themselves, the vision they sketch out for their health, also become subordinate.

In my experience, even where established methods of integrated community and health systems help communities to build capacity in service delivery, they do not always help to attend to the overarching social determinants of health that drive exclusion and inequity.<sup>13</sup> These are the most important challenges that community activists are required to address in the longer term.

As we move past the Millennium Development Goal era, there must be a way to go beyond the standard technical approaches to community systems towards more political, and therefore more structural, approaches to tipping the scales against AIDS. There is a real danger that we are approaching health systems as the primary focus on global health programmes, and community systems as existing to service these larger objectives. This perspective will diminish the contribution that these systems make to the way that health is understood and experienced by people living with HIV.

In part, this is not helped by the fact that community system contributions are harder to quantify. The work of legal advocacy, accompaniment and emotional support is equally difficult to quantify. So health systems get the glory, counting the

12. APN+ (2012), *Access to HIV treatment and services for HIV positive MSM in 4 Chinese cities: an APN+ study*. APN+ (2010), *Treatment access for positive MSM in the Asia Pacific*. APN+ (2009), *Access to HIV-related health services in positive women, men who have sex with men (MSM), transgender (TG) and injecting drug users (IDU): research finding highlights*. Available at: [www.apnplus.org](http://www.apnplus.org).

13. Parker, R. and Aggleton, P. (2003), 'HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action', *Social Science & Medicine* 57(1): 13–24.





number of people they treat as a measurable success. Community systems cannot point quite so easily to the number of people they directly or indirectly deliver to the doorsteps of the clinic. In a new AIDS programming landscape, where numbers rule, this is a big disadvantage for proponents of more robust and better-funded community systems.

In order to make the case for community systems, we must embrace the social response to AIDS.

The stories of people living with HIV must be told, their complexities understood and their journeys accompanied.

### A personal and political journey

As I was sourcing material for this article, I came across an interview I conducted in 2009 with a person who injected drugs. At the end of the interview, with the tape still recording, he asked, “What do you think of people like me?” My response was:

*We all have principles. You said [during the interview] you picked the wrong road [in using drugs]. I can understand that, I have also picked a wrong road in the past. I cannot say I am better or worse than you. If we share a common understanding, we can rely on one another so that we can both become better people.*

As I reflect on what I said then, I realise that coming to terms with HIV has stripped away a lot of the prejudices I once had. I am not sure I could have said what I did to him if it hadn't been for HIV. It has certainly helped me to discover a common humanity. It has made me part of a community that crosses geographic boundaries and issues like drug use or non-drug use, sexuality, gender and race.

Only those of us intimately affected by HIV can readily appreciate the social processes that structure the stigma and discrimination people living with HIV face. HIV (or any disease with moral connotations) changes us somehow. Writing of my experience with HIV in 2006, a few years after diagnosis and as I was coming to terms with treatment, I noted that:

*Treatment and the social experience of illness ... become a constant process of negotiation—between my self and my body, on one hand, and the conflated effect of social interactions, on the other. When I am asked about my ‘condition’ what can I answer except by referral to such indicators as my CD4 count and my viral load? What if, as is so often the case, I feel sick but the indicators say that I am well? Such is the conundrum of illness at the juncture of the medical and the social. That is, of course, if the social is aware of my ‘condition’. Up until now, I have kept my story mostly to myself, with the exception of a few close friends and people whom I think will understand.<sup>14</sup>*

I can still sense the desolation I felt then.





At the time, I had described my relationship with HIV as being like “one who watches in the darkness of night a mounting invasion it feels but cannot see”.<sup>15</sup>

Looking back, I realise I have come a long way, and my well-being is testimony to the community support I have received.

As Maura’s story teaches us, it is not uncommon for people living with HIV to experience catastrophic events, when everything in their lives seems to fall apart. Community systems are important at all stages, but in moments of need they are critical. And these moments can be often and long. As APN+ has explored in its research over the years, these critical moments are experienced as ‘biographical disruptions’,<sup>16</sup> traumatic moments when the stories we tell about ourselves shift so drastically that identities have to be formed anew.<sup>17</sup> It is at these times that community systems help when no one else could or would.

### Context matters

In some ways the difference between the community system and the health system is that the community system is concerned with the context in which the person’s health is lived. It is concerned with the emotional and spiritual well-being of the person who may or may not be sick. The health system may look at parts of the person requiring emotional and spiritual support, but these are ancillary. The physical realm is the primary concern of the medical system. Even when doctors, nurses and public health officials recognise the importance of context, they often do not have the capacity to address the contexts in which their clients are living.

The community system, on the other hand, has the ability to become that context – to take over, prop up, hold hands with, entertain, pray with, feed and clothe, even if this is only temporary. No hospital or clinic, however well equipped, can do this.

One might argue that these are still only palliative, aimed at getting someone treated. What it takes to beat AIDS is something different, something more political, something to do with inner strength, with the ability to resist and fight and challenge. At their best, in the process of addressing immediate needs, community systems also embody and pass on a strong sense of worthiness. They remind community members that they are rights holders: that they are deserving of attention and pills and roads to transport them to hospital. Communities that can foster genuine belonging are those that can address the underlying determinants of health. These communities restructure power, and in so doing help the health system to function better, aim higher and prioritise differently.<sup>18</sup>

In plotting a way forward, community activists must take stock of how we can help more people to live fulfilled lives despite their HIV status. There is no doubt that using some community resources to facilitate treatment expansion is important. However, we must not forget that we are most effective when we take the time to understand and nurture one other, creating enabling environments that will change

15. Choo, M. (unpublished), *When normal isn't normal enough: my relationship with HIV – a regimen contested*.

16. Bury, M. (1982), ‘Chronic illness as biographical disruption’, *Sociology of Health & Illness* 4(2): 167–82.

17. Frank, A. (1995), *The wounded storyteller: body, illness, and ethics*, London: University of Chicago Press.

18. Braveman, P. and Gruskin, S. (2003), ‘Defining equity in health’, *Journal of Epidemiology in Community Health* 57(4): 254–8.





the social determinants that prevent people from getting tested and treated. We are most effective when we demonstrate solidarity and wage battles for our rights, including our rights to life, health and love.

## Conclusion

In some ways, the debate about whether to invest more vigorously in health systems or in community systems is a misguided one. Communities have been crucial in mobilising a demand for health services and delivering services to those at the fringes of society who otherwise would not be reached by conventional health systems. Yet it is also important to note that the fringes of society are as much geopolitical as they are geographical – that they are structured. Community systems play an important role in reconfiguring these transnational boundaries that make health iniquitous and stigmatising.<sup>19</sup>

Communities, especially those representing people living with HIV, play a crucial role in supporting those who are criminalised.<sup>20</sup> Legal support to get people out of jail, time spent educating community members about their rights, efforts aimed at changing laws so that needle exchange and condom distribution programmes can function; all of these are time consuming, expensive and dramatically increase the chances of vulnerable people accessing health services to prevent or treat HIV.<sup>21</sup>

Yet there is little evidence of health systems seeking to quantify the costs of lobbying, advocacy and solidarity work. Indeed, I have yet to hear a serious conversation about community systems that asks what the costs would be to health systems and to society at large – especially for marginalised people like sex workers, young people, those who use drugs and transgender women and men – if there were no community systems at all.<sup>22</sup>

With less money to fight AIDS, and with a heavier focus on a biomedical approach, we risk many, many millions of people being unable to benefit from the scientific dividend. Why? Because the vibrant community systems that have carried the AIDS response this far – that were, in fact, crucial to the investments in science that we see today – are over stretched and under attack.<sup>23,24</sup>

Worse yet, as we approach the fourth decade of the pandemic, stigma and discrimination remain as pernicious as ever.<sup>25</sup> Instead of establishing an oppositional relationship between traditional health systems and the community systems that provide support to people living with HIV and populations vulnerable to infection, we must accept that both are important.

There must be a radical shift towards accepting this in the new development framework.

19. Greenall, M., Metheny, N., Raff, N., Beck, J., Ayala, G. (2013), *Community systems strengthening and key populations: a policy discussion paper*, The Global Forum on MSM & HIV.

20. Spicer, N. et al. (2011), 'Circus monkeys or change agents? Civil society advocacy for HIV/AIDS in adverse policy environments', *Social Science & Medicine* 73(12): 1748–55.

21. Rodriguez-Garcia, R., Bonnel, R., Wilson, D., N'Jie, N.D. (2013), *Investing in communities achieves results: findings from an evaluation of community responses to HIV and AIDS*, Washington DC: International Bank for Reconstruction and Development/World Bank.

22. Asthana, S. and Oostvogels, R. (1996), 'Community participation in HIV prevention: problems and prospects for community-based strategies among female sex workers in Madras', *Social Science & Medicine* 43(2): 133–48.

23. Rodriguez-Garcia, R., Bonnel, R., Wilson, D., N'Jie, N.D. (2013), *Investing in communities achieves results: findings from an evaluation of community responses to HIV and AIDS*, Washington DC: International Bank for Reconstruction and Development/World Bank.

24. Halmshaw, C. and Hawkins, K. (2004), 'Capitalising on global HIV/AIDS funding: the challenge for civil society and government', *Reproductive Health Matters* 12(24): 35–41.

25. Parker, R. and Aggleton, P. (2003), 'HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action', *Social Science & Medicine* 57(1): 13–24.







Health systems are meaningless without community systems pushing them to be better and more effective; and community systems alone cannot meet the needs of the 35 million people living with HIV across the planet.

Both are deserving of bold, ambitious, long-term funding. With the right resources in place, and with a nuanced understanding of how community systems fight the social epidemic of stigma, we can prevent HIV transmission, we can treat AIDS, and we can tackle the social factors that are so critical to determining community health.



#### BIOGRAPHY

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